

# A Complete and Joined up Ecosystem of Support

Submission to the NDIS Review



AUSTRALIAN  
Autism Alliance

and

lived experience focus group



Supporter

We welcome the opportunity to discuss and elaborate further. Please contact:

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## About the Lived Experience Focus Group

A number of neurodivergent people from a range of backgrounds, were consulted in the preparation of this paper, capturing knowledge that was also involved in submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission' — or 'DRC'), the Senate Select Committee on Autism.

This group are also some of the community, professional, and research group members from the National Autism Strategy Oversight Council and are not only disability representatives and advocates but also individuals who are passionate about the well-being and the equitable treatment of disabled people.

## About the Australian Autism Alliance

[www.australianautismalliance.org.au](http://www.australianautismalliance.org.au)

The Australian Autism Alliance (Alliance) aims to provide 'A United Voice for Autism'. The Alliance was established in 2016 and aims to improve the life chances of Autistic people and facilitate collaboration within the autism community. The Alliance is a national network of diverse autism organisations with two co-chairs, that brings together key autism organisations representing and led by Autistic people, advocacy groups, peak bodies, service providers, educators, and researchers. Most importantly, our work is informed by Autistic people and their families and carers.

We:

- are Australia's first diverse collaborative network of autism organisations bringing together a range of autism interests.
- reach well over half a million people through our communication channels.
- provide support to Autistic people across the lifespan from early childhood to adulthood.
- have significant national and international linkages for advocacy, research and service delivery.
- worked with government to secure commitment for the National Autism Strategy and National Health and Mental Health Roadmap.
- continue to support government through being active in various roles including the NDIA Autism Advisory Group, the NDIA DRCO Co-Design Advisory and Reform groups, NDIS Commission Disability Sector Consultative group, National Autism Strategy Oversight Council member, and National Health and Mental Health Roadmap for Autistic people member.
- have been a witness at a number of inquiries including the Senate Inquiry into Autism and the NDIS Capability and Culture of the NDIA.  
commissioned the largest and most comprehensive community consultation survey of Autistic people and their families and carers in Australia to inform the Senate Inquiry into Autism with over 3,800 responses received.

## Key Information

### Acknowledgement

The Australian Autism Alliance acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past, present and recognise those whose ongoing effort to protect and promote Aboriginal and Torres Strait Islander cultures will leave a lasting legacy for future Elders and leaders.

The Autism Alliance recognises and thank emphatically all the Autistic and disabled people who contributed to this submission. The authors acknowledge the individual and collective expertise of those with a living or lived experience of mental ill-health and recovery.

### Copyright

Copyright in this written paper is vested in the author pursuant to the *Copyright Act 1968* (Cth). Unless permitted by the *Copyright Act 1968* (Cth), no part may be reproduced by any process, or used for any commercial purposes, without the written permission of the authors.

### Language

A mix of person-first language (e.g. '*person with disability*' / '*person with ADHD*' / '*person with ASD*') and identity-first language (e.g. '*disabled person*' / '*ADHDeR*' / '*Autistic person*') has been used throughout this written paper to reflect the diversity of preference in the disability community so as to acknowledge lived experience and neurodiversity.

### Authors and Contributors

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## Overview of Defining a Problem to Enduring Solutions

The following submission is in response to the NDIS Review question regarding Part B – Priority areas for improvement. **No 2. A complete and joined up ecosystem of support:**

“We have observed that support for Australians with disability is not planned, funded or governed as a whole ecosystem.”

While it is recognised that a NAS is under development with the National Autism Strategy Oversight Council (‘NASOC’) guiding the development and the implementation of the NAS, this submission outlines what solutions are required in the broader ecosystem to enable an effective National Autism Strategy (‘NAS’). When considering reforms resulting from the current Review of the NDIS, it must be recognised that the success of the NAS, in parallel with the NDIS is critical to improved outcomes for Autistic people, their families and the broader disability community - including the many Autistic Australians who may not be eligible for the NDIS.

In the current environment, the NAS would sit in a similar position to the NDIS - as an island without an effective broader ecosystem to ensure its success as it does not have state commitment, unlike the Australian Disability Strategy. While it is understood that government policy seeks NOT to differentiate the separate disability cohorts and indeed there are many aspects of this submission that applies and benefits all disability cohorts particularly given the significant level of co-occurring conditions that exist (refer background section) – it is also time to agree that autism is different and the “whole of disability” strategies are not and will not achieve equitable outcomes. As recognised in the Senate Select Committee on Autism <sup>1</sup>with outcomes manifestly worse for Autistic people than for people with disability more generally, urgent and dedicated action is needed. The NDIS must acknowledge this fact and actively accommodate the separate and distinct difference in approaches and practice that are necessary. Without this change there can be no alignment across the NAS, that addresses the broader ecosystem, and the NDIS.

The following legislative and policy recommendations would underpin the National Autism Strategy (NAS), provide for longevity of a broad vision for government and society to follow and address the accountability gaps that currently exist in the ecosystem. Other recommendations will further support the operationalisation of the NAS. These recommendations also provide the opportunity for the NDIA to be demonstrably the exemplar organisation (and for all government

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<sup>1</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [v].

agencies to follow their lead) for autism inclusion practice through investment in organisation-wide knowledge, skills and confidence in engaging with and including autistic individuals, their families and carers. The majority of the 81 recommendations in the Senate Select Committee on Autism report <sup>2</sup>found that the biggest barrier to inclusion is lack of autism knowledge, skills and confidence. The array of systems at all levels in the ecosystem undoubtedly are willing to do better – but do not know how.

Furthermore, the power of respectful accurate acknowledgement, as outlined in Recommendation 1.1, goes a long way for disability communities, and in particular Autistic Australians who have been the invisible disability for such a long time.

## Models of Disability

**Recommendation 1.1:** That the Australian Government takes urgent steps to ensure that all policies, strategies, programs, and interventions — including the National Autism Strategy ('NAS') and the National Disability Insurance Scheme ('NDIS') — for and affecting disabled Australians (including Autistic Australians) are:

- explicitly **human rights-based** and aligned with a **Social and Human Rights Model of Disability** and ensure effective protection from disability discrimination (including disability vilification);
- aligned with Australia's commitments under the United Nations' *Convention on the Rights of Persons with Disabilities* ('CRPD') in order to ensure that disabled Australians (including Autistic Australians) can participate in **decision-making**;
- espouse **intersectionality** and principles of **disability justice**, centering the leadership of the most impacted (including those of First Nations communities, LGBTQIA+ communities, and intersecting identities at large);
- are informed by an **equity** framing to autism, as opposed to merely a **medical** or **biopsychosocial** framing of autism;
- aligned with **affirmative care practices** that are not only **neurodiversity-affirmative**, **culturally responsive**, and strengths-based but also **accessible** and **inclusive**; and
- **person-centred** and **trauma-informed** in not only service design but also service delivery.

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<sup>2</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [vi-vii]

**Recommendation 1.2:** That the Australian Government continue to work towards ensuring that all further policies, strategies, programs, interventions, and research relating to Autistic Australians — including the materials relating to the National Autism Strategy (‘NAS’) and the National Disability Insurance Scheme (‘NDIS’) — be **co-developed** and **co-delivered** by and for Autistic people.

## Governance and Accountability Frameworks

**Recommendation 2.1:** That the Australian Government support the National Autism Strategy by implementing accountability measures including:

- **clear** and **measurable** actions, targets and milestones;
- an **implementation plan** with clearly defined responsibilities;
- **continuous monitoring** and **annual reporting requirements**; and
- **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**.
- **built in timelines** for **review** and **renewal** of the strategy (every 5 years), based on the aforementioned monitoring and re-engagement process, and with the support of a majority-led Autistic and autism community oversight council.

**Recommendation 2.2:** That the Australian Government implement these accountability measures by:

- Mandating **effective governance** and **frequent monitoring** through the introduction of **legislation** — modelled after the *Autism Act (Northern Ireland) 2011* (NI) or the *Autism Act 2009* (UK) — that builds **timelines for regular review** and **development** of the NAS. Noting the Act being considered is not required to be an extensive document but modelled on focussing on capturing these recommendations.
- Empowering a **dedicated, independent, Autistic-led taskforce** to oversee progress on **implementation KPIs** on the local, state/territory, and national level by granting them access to the **Disability Reform Ministers**.

**Recommendation 2.3:** That the Australian Government support the Autistic-led taskforce by granting the **Autistic-led taskforce** with governance and oversight over **independent auditors**,

which shall by legislation have the power to independently investigate **cross-jurisdictional complaints** and **accountability gaps** — including lack of progress on implementation KPIs.

## Interaction with Local, State, & Commonwealth Services

**Recommendation 3.1:** That the Australian Government support the National Autism Strategy by having the **development and implementation** of an Autism Strategy **at each of the State and Territory** levels of Government, and in turn, at **each Local Council** aligned with the National Autism Strategy **supported through legislation**. (The commitment by Victoria and South Australia to a State based Autism Strategy is recognised).

**Recommendation 3.2:** That a **Federal Assistant Minister, Premier and Cabinet**, ideally for autism, be appointed **to ensure the operationalisation of a co-ordinated and integrated whole of government and whole of life approach**. Refer Figure 1.

**Recommendation 3.3:** That Autism strategy at any government level is viewed **alongside** any other policy initiatives and **supported by adequate, ongoing funding models**.

**Recommendation 3.4:** **Co-production** with Autistic people is critical. Reflecting the principle of “nothing about us without us,” this would need to be co-developed from end to end with Autistic people and their families/carers.

**Recommendation 3.4:** That any policy regarding Autistic Australians must be co-developed and co-delivered by Autistic Australians. Reflecting the principle of “nothing about us without us,” this would need to be **co-produced from end to end** with autistic people and their families/carers.

**Recommendation 3.5:** That the Australian Government support the National Autism Strategy by implementing a **national autism core capabilities framework** to identify key capabilities for those working with and for supporting Autistic people including:

- **values and behaviours** that underpin all the capabilities in the framework.
- **evaluation methodology:**
  - individual assessment of knowledge and/or competence



- impact on practice
- impact on quality of service (e.g. measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
- continuous monitoring and annual reporting requirements.
- built in timelines for review of the framework (every 3 years).

**Recommendation 3.6:** That the Australian Government **prioritise support** for and consultation with the following demographics of Autistic Australians:

- First Nations people;
- Women and girls;
- LGBTQIA+ communities;
- Culturally and Linguistically Diverse ('CALD') communities;
- People in regional and remote areas;
- Individuals in the child protection and justice systems;
- Senior (50+ years) people;
- People in supported independent living;
- Students in various education settings; and
- People with complex needs.

## Any Other Related Matter

**Recommendation 3.7:** That a question be framed in the 2026 National ABS Census as follows:

- Do you have a neurodevelopmental condition? Tick all that apply:
  - Autism or Autism Spectrum Condition, including Autism Spectrum Disorder
  - ADHD (to be written in full)
  - Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, or a Specific Learning Disorder (SPDs)
  - Another neurodevelopmental condition

## Background

### Autistic people in Australia

Autism is a lifelong neurodevelopmental difference. Every Autistic person is different, and the support needs for each person differs, and this may change over time, particularly around big

life transitions. Autism is highly prevalent and affects people from all walks of life and across the lifespan. It is among the biggest disability groups in Australia.

Improved recognition of autism and the reclassification of Asperger's Syndrome has contributed to a dramatic increase (217%) of people diagnosed with autism in Australia over the last decade. In 2018 the ABS reported that 1.3% of males, 0.4% of females and 3.2% of children aged 5–14 years have an autism diagnosis. Based on childhood diagnosis rates, actual prevalence in the community is likely to be 2–3%, which means that the majority of Autistic adults are yet to be formally diagnosed.

**While we wait for the next ABS data to be released, there is evidence that the prevalence rate in Australia is very consistent with the prevalence rate with the Centre for Disease Control <sup>3</sup>(USA) and the UK<sup>4</sup>.**

A recent study<sup>56</sup> screening 13,511 children in Victoria, returned a prevalence rate of 1 in 50 (2%) between 11 and 30 months of age and 1 in 31 (3.3%) between 11 and 42 months of age, based on data collected over 6 years. This was a very tightly controlled, rigorous study with thorough diagnostic assessments to confirm diagnosis, and the use of advanced statistical methods to infer missing data. Therefore, the most current Australian data would indicate that the prevalence is approx. 1 in 31 or 3.3% of the Australian population (approximately 867,000 of Australian's based on current population numbers - 26,268,359 - from ABS December 2022 data)<sup>7</sup>.

However, it is important to recognise that this is likely an underestimation as there is likely children who do not present with traits clear enough to be identified until school age. More broadly speaking, the burgeoning of research and clinical understanding of autism over the past decade or so has also left many clinicians without the current knowledge to recognise more subtle or 'internalised' presentations of autism, as well as presentations outside of the "white, western" presentation that our current criteria are based upon. This is particularly apparent for

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<sup>3</sup> Maenner MJ, Warren Z, Williams AR, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. *MMWR Surveill Summ* 2023;72(No. SS-2):1–14. DOI: <http://dx.doi.org/10.15585/mmwr.ss7202a1>

<sup>4</sup> [https://www.thelancet.com/journals/lanepi/article/PIIS2666-7762\(23\)00045-5/fulltext](https://www.thelancet.com/journals/lanepi/article/PIIS2666-7762(23)00045-5/fulltext)

<sup>5</sup> Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010–2012. *The Medical Journal of Australia*, 202(6), 317–320.

<https://doi.org/10.5694/mja14.00328>

<sup>6</sup> Barbaro, J., Sadka, N., Gilbert, M., Beattie, E., Li, X., Ridgway, L., Lawson, L., & Dissanayake, C. (2022). Diagnostic accuracy of the Social Attention and Communication Surveillance-Revised with Preschool tool for early autism detection in very young children. *JAMA Network Open*, 5(3), e2146415.

<https://doi.org/10.1001/jamanetworkopen.2021.46415>

<sup>7</sup> <https://www.abs.gov.au/statistics/people/population>

populations of women and girls, First Nations people, and those with Culturally and Linguistically Diverse (CALD) backgrounds. It is also recognised that the diagnosis pathway is often expensive, and many do not have access to appropriate services to seek identification, especially in regional and remote areas of Australia. Together this may in part account for the lower diagnostic rates in the broader Australian population.

Other important information:

- 95% of Autistic people have other co-occurring conditions such as ADHD or intellectual disability, specific learning disabilities such as dyslexia or dyspraxia, and/or mental health issues such as depression and anxiety.
- Autism is the largest primary disability group in the NDIS (31%).
- Autism requires a spectrum of solutions as there is no one size fits all.
- Some Autistic people may never require the NDIS if appropriate supports exist in mainstream settings and in the community.

A historical and ongoing lack of appropriate supports in mainstream settings<sup>8</sup> and in the community, however, has led to many Autistic people needing significant and often ongoing supports.

While our focus is on Autistic people it is emphasised that the recommendations in this paper will benefit other disabilities.

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<sup>8</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [viii].

<sup>9</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [v].

## Defining a Problem

The NDIS review asked the question in Part B – Priority areas for improvement. No 2. A complete and joined up ecosystem of support:

*We have observed that support for Australians with disability is not planned, funded or governed as a whole ecosystem. There is not enough support for people with disability outside the NDIS. This is unfair and is undermining the sustainability of the NDIS. Which results in people falling through the cracks and missing out on much needed support.*

Our solution is in the context of this review question. The Senate Select Committee on Autism report<sup>9</sup> identified that the “life outcomes for autistic Australians are unacceptably poor”. We know that hundreds of thousands of autistic people in Australia continue to experience much poorer life outcomes in education, health, employment, mental health, and participation in society than other Australians, including other major disability types.

It is based on these poorer outcomes that it was recommended that a National Autism Strategy (NAS) was required as generic disability approaches have failed to address the discrete challenges and enablers of Autistic people.

While it is recognised that a NAS is under development with the National Autism Strategy Oversight Council (‘NASOC’) guiding the development and the implementation of the NAS, this submission outlines what solutions are required in the broader ecosystem to enable an effective National Autism Strategy (‘NAS’). When considering reforms resulting from the current Review of the NDIS, it must be recognised that the success of the NAS, in parallel with the NDIS is critical to improved outcomes for Autistic people, their families and the broader disability community - including the many Autistic Australians who may not be eligible for the NDIS.

In the current environment, the NAS would sit in a similar position to the NDIS - as an island without an effective broader ecosystem to ensure its success as it does not have state commitment, unlike the Australian Disability Strategy. While it is understood that government policy seeks NOT to differentiate the separate disability cohorts and indeed there are many aspects of this submission that applies and benefits all disability cohorts particularly given the significant level of co-occurring conditions that exist (refer background section) – it is also time to agree that autism is different and the “whole of disability” strategies are not and will not

achieve equitable outcomes. As recognised in the Senate Select Committee on Autism <sup>10</sup>with outcomes manifestly worse for Autistic people than for people with disability more generally, urgent and dedicated action is needed. The NDIS must acknowledge this fact and actively accommodate the separate and distinct difference in approaches and practice that are necessary. Without this change there can be no alignment across the NAS, that addresses the broader ecosystem, and the NDIS.

The following legislative and policy recommendations would underpin the National Autism Strategy (NAS), provide for longevity of a broad vision for government and society to follow and address the accountability gaps that currently exist in the ecosystem. Other recommendations will further support the operationalisation of the NAS. These recommendations also provide the opportunity for the NDIA to be demonstrably the exemplar organisation (and for all government agencies to follow their lead) for autism inclusion practice through investment in organisation-wide knowledge, skills and confidence in engaging with and including autistic individuals, their families and carers. The majority of the 81 recommendations in the Senate Select Committee on Autism report <sup>11</sup>found that the biggest barrier to inclusion is lack of autism knowledge, skills and confidence. The array of systems at all levels in the ecosystem undoubtedly are willing to do better – but do not know how.

Furthermore, the power of respectful accurate acknowledgement, as outlined in Recommendation 1.1, goes a long way for disability communities, and in particular Autistic Australians who have been the invisible disability for such a long time.

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<sup>10</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [v].

<sup>11</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [vi-vii]

<sup>12</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [3.2].

<sup>13</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [3.17].

<sup>14</sup> ‘Public hearing 21: The experience of people with disability engaging with Disability Employment Services’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Web Page, 25 February 2022) <<https://disability.royalcommission.gov.au/public-hearings/public-hearing-21>>.

# Enduring Solutions: The National Autism Strategy and the NDIS Review

## I. Models of Disability

1. Any discussion regarding the interaction between the NAS and the NDIS, as well as any discussion regarding potential solutions to address the gaps and result in improved outcomes for Autistic people, must acknowledge the adverse life outcomes for Autistic Australians, which — as the bipartisan report of the Senate Select Committee on Autism — can, inter alia, include:
  - 1.1. Autistic people have a life expectancy **20–36 years** shorter than the general population, with over two times the mortality rate;
  - 1.2. **75%** of autistic people do not complete education beyond Year 12;
  - 1.3. the unemployment rate for autistic people is **almost eight times** the rate of people without disability;
  - 1.4. **50–70%** of autistic people experience co-existing mental health conditions;
  - 1.5. **51%** of autistic people and their families feel socially isolated; and
  - 1.6. **39%** feel unable to leave the house due to concerns about negative behaviours.<sup>12</sup>
2. There is particular concern with the poor mental health outcomes faced by Autistic people. The Senate report underscores that in one Australian study of Autistic people without intellectual disability, 66% reported suicidal ideation and 35% reported suicide plans or attempts – about five times higher than the general population.<sup>13</sup> Similar reports of adverse outcomes for Autistic Australians have been noted at the Disability Royal Commission. For example, public hearings of the DRC have illustrated the mistreatment of Autistic employees — when interacting with the Disability Employment Services — and the abrogation of their rights,<sup>14</sup> which is contributing to poorer mental health and adverse life outcomes for Autistic people.<sup>15</sup>

3. As a signatory to the United Nations *Convention on the Rights of Persons with Disabilities* ('*CRPD*'), Australia has a treaty obligation to protect the rights of disabled people at large — including Autistic Australians — to liberty, equality, and personal integrity,<sup>16</sup> including the right to protection from discrimination.<sup>17</sup> For example, Article 29 of the *CRPD* guarantees 'the right of persons with disabilities to work, on an equal basis with others'.<sup>18</sup> The right of disabled people to socioeconomic participation without discrimination is further guaranteed in Article 5, which requires Australia and other state parties to 'prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds'.<sup>19</sup>
4. Moreover, Article 24 requires that signatory states such as Australia 'enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community',<sup>20</sup> as well as 'ensur[ing] persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others'.<sup>21</sup> As the Disability Royal Commission notes, the extent to which the *CRPD* has been implemented for the outcomes of disabled people is relevant for not only discussions of service provisions but also the efficacy of service design in general.<sup>22</sup>
5. Therefore, the recommendation from the Senate Select Committee on Autism is reaffirmed — that all policies relating to Autistic people are not only 'human rights-based... [but also] are aligned with Australia's commitments under the United Nations *Convention on the Rights of People with Disabilities*'.<sup>23</sup> Any policy, strategy, or framework regarding Autistic Australians — including the NAS — must be explicitly **human rights-based** and **aligned with a Social and Human Rights Model of Disability** as well as the *CRPD* in order to ensure that Autistic Australians can participate in **decision-making**.<sup>24</sup>

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<sup>15</sup> Ibid. See also Ye In Jane Hwang et al, 'Mortality and cause of death of Australians on the autism spectrum' (2019) 12(5) *Autism Research* 806, 806-807.

<sup>16</sup> *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) ('*CRPD*').

<sup>17</sup> Ibid arts 4(3), 5, and 33.

<sup>18</sup> Ibid art 27.

<sup>19</sup> Ibid art 5.

<sup>20</sup> Ibid art 24

<sup>21</sup> Ibid art 24(5).

<sup>22</sup> Ron McCallum, 'The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance' (Research Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 8 October 2020), 8-9.

<sup>23</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) 366.

6. Moreover, the Disability Royal Commission notes that structural ableism which is concomitant with other forms of structural marginalisation, such as systemic racism and sexism, is creating disproportionately adverse life outcomes for people with disability from diverse backgrounds.<sup>25</sup> For example, First Nations people with disability who experience discrimination which resides at the intersection of racism and ableism must pursue separate claims under the *Racial Discrimination Act 1975* (Cth) and the *Disability Discrimination Act 1992* (Cth), which contributes to inequitable access to justice.<sup>26</sup> Furthermore, 46% of the LGBTQIA+ victim-survivors had a disability according to one DRC submission, indicating a critical need to espouse an intersectional approach to disability and to autism.<sup>27</sup>
7. Therefore, we reaffirm the recommendation — from the Disability Royal Commission — that policies relating to people with disability, including Autistic Australians, must espouse **intersectionality** and principles of **disability justice**.<sup>28</sup> We note that a disability justice approach, by centering the leadership of the most impacted, would implement a rights-based framework which enriches intersectionality and racial justice, which is required for cultural safety.<sup>29</sup>
8. This framing of autism would be particularly impactful for BIPOC — the acronym for ‘*black, indigenous, and other people of colour*’ — communities insofar it would apply an **equity** framing to autism, as opposed to merely a **medical** or biopsychosocial framing, and ensure that any policies or strategies deliver outcomes of social justice.<sup>30</sup> , and in

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<sup>24</sup> Ibid. See also Disability Discrimination Legal Service, Submission No 153 to Senate Select Committee on Autism, Parliament of Australia, *Inquiry into Services, Support and Life Outcomes for Autistic Australians* 21.

<sup>25</sup> Ron McCallum, ‘The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia’s Level of Compliance’ (n 11), 23-24.

<sup>26</sup> Ibid. See also The Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Second and Third Combined Reports of Australia*, 22nd sess, UN Doc CRPD/C/AUS/CO/2-3, 15 October 2019 [12](b).

<sup>27</sup> William Leonard and Rosemary Mann, ‘The everyday experience of lesbian, gay, bisexual, transgender and intersex (LGBTI) people living with disability’ (Research Paper No.111, GLHV@ARCSHS, La Trobe University, July 2018); ‘Alarming rates of family, domestic and sexual violence of women and girls with disability to be examined in hearing’, *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (Web Page, 12 October 2021).

<sup>28</sup> Ibid. See also Ilias Bantekas, ‘Article 7 Children With Disabilities’, in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 198.

<sup>29</sup> See, eg, Catherine Jampel, ‘Intersections of disability justice, racial justice and environmental justice’ (2017) 4(1) *Environmental Sociology* 122; Lissa Ramirez-Stapleton et al, ‘Disability Justice, Race, and Education’ (2020) 6(1) *Journal Committed to Social Change on Race and Ethnicity* 29; Hailey Love & Margaret Beneke, ‘Pursuing Justice-Driven Inclusive Education Research: Disability Critical Race Theory (DisCrit) in Early Childhood’ (2021) 41(1) *Topics in Early Childhood Special Education* 31; Deloitte, ‘Options to improve service availability and accessibility for First Nations people with disability’, (Report prepared for the Royal Commission into Violence, Abuse, Neglect, and Exploitation of People with Disability, Deloitte, June 2023) 91 <<https://disability.royalcommission.gov.au/system/files/2023-06/Research%20Report%20-%20Options%20to%20improve%20service%20availability%20and%20accessibility%20for%20First%20Nations%20people%20with%20disability.pdf>>.



particular pertaining to Autistic Australians (including the NAS) as a population that is often overlooked. Furthermore, we reiterate the recommendation that any policies, strategies, and programs regarding Autistic Australians must be **developed, designed, and delivered by and for** Autistic people.<sup>31</sup> For example, service provisions for Autistic people can — and should — arise from co-production with Autistic people,<sup>32</sup> who are often otherwise at risk of being omitted, misunderstood, and disregarded.<sup>33</sup>

9. Finally, we recommend that all policies, strategies, and programs for Autistic Australians — including the NAS and the NDIS — implement a model of disability which is **affirmative of neurodiversity**.<sup>34</sup> Neurodiversity Affirming care practices, especially for Autistic people from the LGBTQIA+ community,<sup>35</sup> respect the individual's inherent dignity and hence are not only lifesaving but ethical insofar as they can collaborate with communities rather than seeking to 'correct' them.<sup>36</sup>
10. Neurodiversity-affirmative — or **neuro-affirmative** — approaches are not only **strengths-based, accessible, inclusive** but also eschews perpetuating stigma and shame,<sup>37</sup> which is reported as a barrier in both health settings and workplaces.<sup>38</sup> Moreover, these supports must be both **person-centred** and **trauma-informed** in order to avoid further alienating the lived experience of trauma within the Autistic community.<sup>39</sup>

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<sup>30</sup> See generally Adrienne Asch, 'Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity', in Elizabeth Emens (ed), *Disability and Equality Law* (Routledge, 2017) 138; Matthew Bennett & Emma Gooddall, *Addressing Underserved Populations in Autism Spectrum Research: An Intersectional Approach* (Emerald Publishing Limited, 2022) 4.

<sup>31</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) 366.

<sup>32</sup> See also Jill Ashburner et al, 'Co-Design and Co-Production of a Goal Setting Tool for Autistic Adolescents and Adults' (2023) 5(1) *Autism in Adulthood* 37.

<sup>33</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [5.41].

<sup>34</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) 362.

<sup>35</sup> See Ada Cheung et al, 'Sociodemographic and Clinical Characteristics of Transgender Adults in Australia' (2018) 3(1) *Transgender Health* 229.

<sup>36</sup> See, eg, Aaron Dallman, Kathryn Williams, & Lauren Villa, 'Neurodiversity-Affirming Practices are a Moral Imperative for Occupational Therapy' (2022) 10(2) *The Open Journal of Occupational Therapy* 1; Sebastian Shaw et al, 'Towards a Neurodiversity-Affirmative Approach for an Over-Represented and Under-Recognised Population: Autistic Adults in Outpatient Psychiatry' (2022) 52 *Journal of Autism and Developmental Disorders* 4200; David Call, Mamatha Challa, & Cynthia Telingator, 'Providing Affirmative Care to Transgender and Gender Diverse Youth: Disparities, Interventions, and Outcomes' (2021) 23(6) *Current Psychiatry Reports* 33; Ann Genovese et al, 'Gender Diverse Autistic Young Adults: A Mental Health Perspective' (2023) 52(3) *Archives of Sexual Behavior* 1339.

<sup>37</sup> See generally Sebastian Shaw et al, 'The experiences of autistic doctors: a cross-sectional study' (2023) 14(July) *Frontiers in Psychiatry* 1; Steven Kapp (ed), *Autistic Community and the Neurodiversity Movement* (Palgrave Macmillan, 2020) 4; Sebastian Shaw et al, 'Autistic role modelling in medical education' (2022) 33(2) *Education for Primary Care* 128.

<sup>38</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [13.9].

<sup>39</sup> See, eg, Teal Benevides et al, 'Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project' (2020) 24(4) *Autism* 822; Freya Rumball, Francesca Happé, & Nick Grey,

11. Therefore, we recommend:

- **Recommendation 1.1:** That the Australian Government takes urgent steps to ensure that all policies, strategies, programs, and interventions — including the National Autism Strategy (**'NAS'**) and the National Disability Insurance Scheme (**'NDIS'**) — for and affecting disabled Australians (including Autistic Australians) are:
  - explicitly **human rights-based** and aligned with a **Social and Human Rights Model of Disability** and ensure effective protection from disability discrimination (including disability vilification);
  - aligned with Australia's commitments under the United Nations' *Convention on the Rights of Persons with Disabilities* (**'CRPD'**) in order to ensure that disabled Australians (including Autistic Australians) can participate in **decision-making**;
  - espouse **intersectionality** and principles of **disability justice**, centering the leadership of the most impacted (including those of First Nations communities, LGBTQIA+ communities, and intersecting identities at large);
  - are informed by an **equity** framing to autism, as opposed to merely a **medical** or **biopsychosocial** framing of autism;
  - aligned with **affirmative care practices** that are not only **neurodiversity-affirmative, culturally responsive**, and strengths-based but also **accessible** and **inclusive**; and
  - **person-centred** and **trauma-informed** in not only service design but also service delivery.
  
- **Recommendation 1.2:** That the Australian Government continue to work towards ensuring that all further policies, strategies, programs, interventions, and research relating to Autistic Australians — including the materials relating to the National Autism Strategy (**'NAS'**) and the National Disability Insurance Scheme (**'NDIS'**) — be **co-developed**<sup>40</sup>, and **co-delivered** *by and for* Autistic people.

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'Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events' (2020) 13(23) *Autism Research* 2122; Nirit Haruvi-Lamdan, Danny Horesh, & Ofer Golan, 'PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms' (2018) 10(3) *Psychological Trauma Theory Research Practice and Policy* 290; Nirit Haruvi-Lamdan et al, 'Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions' (2020) 24(4) *Autism* 884.

<sup>40</sup> chrome-extension://efaidnbmnnnibpcajpcgiclfefndmkaj/https://www.autismcrc.com.au/access/sites/default/files/resources/Participatory\_and\_Inclusive\_Autism\_Research\_Practice\_Guides.pdf

## II. Governance & Accountability Frameworks

12. We also note that for the policies and strategies regarding Autistic Australians, including the NAS and the NDIS, to succeed, these policies and strategic plans must be undergirded by robust governance and accountability frameworks.
13. Firstly, strategic documents and policy frameworks may not effectuate tangible outcomes in terms of implementation due to an accountability gap. Because decentralised monitoring can lead to privatisation of auditing, the absence of a panoptical system for audit and assessment can raise concerns about the accountability of public services.<sup>41</sup> A strategic document targeting autism which does not embed monitoring into its implementation plan would therefore fail to address the accountability gap, as reflected by the recommendations by Scotland's Cross-Party Group on Autism that an Autism Commissioner be established to close the accountability gap at a local level.<sup>42</sup>
14. Indeed, Northern Ireland and Scotland have both elucidated the need for **effective governance** and **frequent monitoring** with inbuilt **timelines for review**.<sup>43</sup> Without the obligation upon the government to undertake not only a regular review of a strategy but also an **implementation/action plan** with legislated accountabilities such as **implementation KPIs**, the odds of improving life outcomes dwindle.<sup>44</sup> Without **supporting legislation** to mandate the review, monitoring, and implementation of the NAS, the systemic barriers leading to poorer outcomes for Autistic people within mainstream education, employment, and health systems and broader community access will continue, thereby placing further strain on the NDIS.<sup>45</sup>

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<sup>41</sup> Peter Eckersley, Laurence Ferry, & Zamzulaila Zakaria, 'A 'panoptical' or 'synoptical' approach to monitoring performance? Local public services in England and the widening accountability gap' (2014) 24(6) *Critical Perspectives on Accounting* 529.

<sup>42</sup> National Autistic Society Scotland, 'The Accountability Gap: A Review of the Scottish Strategy for Autism', (Report prepared for the Joint Secretariat to the Cross-Party Group (CPG) on Autism, National Autistic Society Scotland, October 2020) 91 <[https://www.scottishautism.org/sites/default/files/cpg\\_on\\_autism\\_report\\_-\\_the\\_accountability\\_gap\\_06.10.2020.pdf](https://www.scottishautism.org/sites/default/files/cpg_on_autism_report_-_the_accountability_gap_06.10.2020.pdf)>.

<sup>43</sup> Ibid. See also Karola Dillenburger, Lyn McKerr, & Julie-Ann Jordan, 'Lost in Translation: Public Policies, Evidence-based Practice, and Autism Spectrum Disorder' (2014) 61(2) *International Journal of Disability, Development and Education* 134.

<sup>44</sup> Ibid. See also Leanne Connolly, 'Key Policies and Legislation Underpinning Post-School Transition Practices for People with Disabilities in the Republic of Ireland' (2023) 2(1) *International Journal of Educational and Life Transitions* 18.

<sup>45</sup> See, eg, Karola Dillenburger, Lyn McKerr, & Julie-Ann Jordan, 'Lost in Translation: Public Policies, Evidence-based Practice, and Autism Spectrum Disorder' (2014) 61(2) *International Journal of Disability, Development and Education* 134; Leanne Connolly, 'Key Policies and Legislation Underpinning Post-School Transition Practices for People with Disabilities in the Republic of Ireland' (2023) 2(1) *International Journal of Educational and Life Transitions* 18.

15. Systemic barriers leading to poorer life outcomes for Autistic people — systemic barriers that are essentially worsening the functional impairments and further disabling Autistic people — must be dismantled within mainstream supports such as health, education, and employment,<sup>46</sup> as segregating Autistic people to rely upon the NDIS will incur indirect economic costs that may affect the sustainability of the Scheme.<sup>47</sup>
16. Therefore, we reaffirm the recommendation — from the Senate Select Committee on Autism — to implement accountability measures which include:
- 16.1.1. **clear and measurable** actions, targets and milestones;
  - 16.1.2. **an implementation plan** with clearly defined responsibilities;
  - 16.1.3. **ongoing monitoring and reporting requirements**; and
  - 16.1.4. **built in timelines for review and renewal** of the strategy.<sup>48</sup>
17. Moreover, we reiterate that a **dedicated, independent taskforce** — steered *by and for* Autistic Australians — should oversee the ongoing monitoring and reporting requirements.<sup>49</sup> We recommend that this taskforce be given not only access to meetings of the **Disability Reform Ministers** but also governance and oversight over **independent auditors**, which by legislation will have the power to independently investigate cross-jurisdictional complaints and accountability gaps — including lack of progress on implementation KPIs.<sup>50</sup>
18. We reaffirm the importance of introducing **legislation** to not only build in timelines for review but also empower an independent, Autistic-led taskforce — with governance over independent auditors, situated in Premier and Cabinet, who will monitor and investigate progress on the KPIs on implementation/action plans. Otherwise, a risk that such policies may ‘sit on a shelf’ exists.<sup>51</sup> Moreover, legislation would eliminate any undermining of progress due to a change-in-government.<sup>52</sup>

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<sup>46</sup> Ye In Jane Hwang et al, ‘Mortality and cause of death of Australians on the autism spectrum’ (2019) 12(5) *Autism Research* 806. See also Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [13.83].

<sup>47</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [4.15].

<sup>48</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [5.69].

<sup>49</sup> Amaze Australia, Submission No 47 to Senate Select Committee on Autism, Parliament of Australia, *Inquiry into Services, Support and Life Outcomes for Autistic Australians* 6.

<sup>50</sup> ND Australia, Submission No 97 to Senate Select Committee on Autism, Parliament of Australia, *Inquiry into Services, Support and Life Outcomes for Autistic Australians* 2. See also National Autistic Society Scotland, ‘The Accountability Gap: A Review of the Scottish Strategy for Autism’, (Report prepared for the Joint Secretariat to the Cross-Party Group (CPG) on Autism, National Autistic Society Scotland, October 2020) 91 <[https://www.scottishautism.org/sites/default/files/cpg\\_on\\_autism\\_report\\_-\\_the\\_accountability\\_gap\\_06.10.2020.pdf](https://www.scottishautism.org/sites/default/files/cpg_on_autism_report_-_the_accountability_gap_06.10.2020.pdf)>.

<sup>51</sup> Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [548].

19. Therefore, we recommend:

- **Recommendation 2.1:** That the Australian Government support the National Autism Strategy by implementing accountability measures including:
  - **clear and measurable** actions, targets and milestones;
  - an **implementation plan** with clearly defined responsibilities;
  - **continuous monitoring** and **annual reporting requirements**; and
  - **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**.
  - **built in timelines** for **review** and **renewal** of the strategy (every 5 years) based on the aforementioned monitoring and re-engagement process, and with the support of a majority-led Autistic and autism community oversight council.
  
- **Recommendation 2.2:** That the Australian Government implement these accountability measures by:
  - Mandating **effective governance** and **frequent monitoring** through the introduction of **legislation** — modelled after the *Autism Act (Northern Ireland) 2011* (NI) or the *Autism Act 2009* (UK) — that builds **timelines for regular review** and **development** of the NAS. Noting the Act being considered is not required to be an extensive document but modelled on focussing on capturing these recommendations.
  - Empowering a **dedicated, independent, Autistic-led taskforce** to oversee progress on **implementation KPIs** on the local, state/territory, and national level by granting them access to the **Disability Reform Ministers**. Refer Figure 1.
  
- **Recommendation 2.3:** That the Australian Government support the Autistic-led taskforce by:
  - Granting the **Autistic-led taskforce** with governance and oversight over **independent auditors**, which shall by legislation have the power to independently investigate **cross-jurisdictional complaints** and **accountability gaps** — including lack of progress on implementation KPIs.

*“There has been significant progress. Awareness of autism has increased hugely. Every council now has an adult autism diagnosis pathway, whereas fewer than half did before the Autism Act. Today, all but a*

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<sup>52</sup> See, eg, Simon Jarrett, ‘The British Journal of Learning Disabilities: A History’ (2022) 50(2) *British Journal of Learning Disabilities* 122; s

*very few councils have a lead commissioner for autism. Autism is also a cross-party priority” UK*

*Parliamentary review of ten years of the Autism Act*

### III. Interaction with Local, State, & Commonwealth Services

20. **Three-tier, legislation approach.** There must be state/territory and local government strategies which are aligned and policed for the effective implementation of a National Autism Strategy.
21. It was recognised in the Australian Disability Strategy (‘**ADS**’) that there are Australian, state, territory, and local governments (commonly known as local councils) all play a part in delivering services that help people with disability.
22. The NDIS Applied Principles and Tables of Support provides further information and outlines the responsibilities between the NDIS and other service systems that deliver supports to people with disability. These were last updated in 2015.
23. Agreements between the Australian government and state and territory governments are in place to allow the shared responsibility of services, systems, funding and governance of programs and policies that affect people with disabilities.
24. The Outcomes Framework is a key initiative under Australia’s Disability Strategy 2021–2031 to measure, track, and report on outcomes for people with disability over the life of the Strategy. Annual reporting against the measures in the Outcomes Framework will show what progress is being made on outcomes for people with disability. The Outcomes Framework has 85 measures across the 7 outcome areas of the Strategy and 3 types of measure - system measures, population measures and community attitude measures. While there were some [favourable trends before baseline](#) in the areas of inclusive homes and communities, safety rights and justice, and education and learning, there were also unfavourable trends in employment and financial security, safety rights and justice in the areas of domestic and family violence and also health and wellbeing.
25. Despite the intention that in most cases one level of government has the main responsibility for delivering the system, as more than one government is involved in funding or delivering a service system, the interfacing is poor. The current significant reviews and reforms occurring in Australia in parallel indicates that principles and

policies alone are not sufficient. Specifically, to autism, as reported through the Senate Select Committee report on Autism, Autistic Australians were experiencing such significantly poorer outcomes that the life expectancy for Autistic Australians was listed as **20-36** years shorter than that of the general population, with over two times the mortality rate.<sup>53</sup>

26. Even where the Australian Government provides a number of disability services nationally, with the intention that the same service is received no matter which state or territory the person is in has not been effective.
27. A **whole-of-government** and **whole-of-life** approach which coordinates and integrates Commonwealth, State, and local government services is necessary to provide comprehensive support.
28. The NAS does not have this support at a state level, although it is recognised that two states have committed to a State Autism Strategy. As identified earlier, a key recommendation of Scotland's Cross-Party Group on Autism to "seek to solve the accountability gap" is the establishment of an independent auditor – such as a taskforce to not only uphold the rights of Autistic people but also ensure that effective policy and laws are implemented appropriately at a local level.
29. Further to this, we reiterate that the Australian Government must ensure a **whole-of-government approach**, an **Assistant Minister** to the Prime Minister (on a Federal level) be to ensure the operationalisation of a co-ordinated and integrated whole-of-government and whole-of-life approach.
30. It is reiterated that strategies such as the NAS which target Autistic Australians – at any government level – is viewed alongside any other policy initiatives and linked to funded strategies.
31. Disability, and particularly for autism with significant co-occurring conditions also, as a factor of intersectionality makes individuals more vulnerable and requires an independent, disability specific approach also to education and training. While a strengths perspective is endorsed to reinforce that all with disability are not inherently vulnerable, cultural attitudes and beliefs of the community towards people with disability to remove onus on people with disability to keep themselves safe or to find the right service to contact must be reformed<sup>54</sup>. As an example, with the establishment of the NDIS Quality and Safeguard Commissioner (NDIS QSC) there has been significant

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<sup>53</sup> Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [3.2].

<sup>54</sup> DACCSA, Interface of Systems with Disability, 2020 [8]

policy change in recent years which has changed the jurisdictions of existing statutory bodies and the way they triage and respond to disability abuse. Organisations have found these changes have brought about immense ambiguity and confusion on a systems level to understand who is responsible for matters of disability abuse. This disadvantages the individual who is ‘handballed’ from system to system and often given misinformation. The NDIS QSC is unable to provide tangible safeguarding responses where a person with disability is not on the NDIS, or where incidents have not been reported. This introduces the interface issue of system design and scope. The result is burdensome systems and processes for people with disability as they’re vested with the responsibility to right entry point, provide information, fill out forms and seek external support. Other frameworks are also limited such as the Office of Public Advocate, Community Visitors Scheme and Health and Community Services Complaints Commission.

32. The scope of each statutory body is nuanced and navigation of these processes for the individual is disempowering, cumbersome and overwhelming. Existing frameworks are unable to reach and protect people with disability who can’t be accommodated by the limited scope of multiple systems and mechanisms for complaints and reporting. The increase in matters relating to abuse, neglect and violence and disability service complaints can in part, be attributed to the degree to which these reporting mechanisms have become inaccessible. Government systems access points need to better understand each other and communicate effectively to carry out consistent triaging and warm referral of people with disability.
33. Furthermore, the systems that are in place to support people have their rights met such as the Australian Human Rights Commission (‘**AHRC**’) do not result in effective outcomes as their role is as mediators. The significant research<sup>55</sup> and literature on school refusal within the Autistic community (reframed to “school can’t<sup>56</sup>” withing a neurodiversity affirming framework) supports this, as Autistic students are often bullied, excluded, forced to change school, is home, schooled, or become completely disengaged from school altogether.
34. High quality information and training is a key enabler for implementation. Training requirements and quality accreditation of training (as a response to missed quality) are common. An example is the UK have developed a national autism core capabilities framework<sup>57</sup> to identify key capabilities for those working with and for supporting Autistic

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<sup>55</sup> <https://link.springer.com/article/10.1186/s13034-020-00325-7>

<sup>56</sup> <https://www.livingonthespectrum.com/education/school-refusal-school-cant/>



people. A tiered approach is used: Tier 1 for those who require a general understanding of autism but may not regularly work for autistic people; Tier 2 for those who provide care and support for Autistic people but are not autism specialists; Tier 3 for those who work intensively with Autistic people.

35. Based on the above, to enable a whole of government approach (or in the words of the NDIS Review “governed as a whole ecosystem”, therefore we recommend:

- **Recommendation 3.1:** That the Australian Government support the National Autism Strategy by having the **development and implementation** of an Autism Strategy at **each of the State and Territory** levels of Government, and in turn, at **each Local Council** aligned with the National Autism Strategy **supported through legislation**. (The commitment by Victoria and South Australia to a State based Autism Strategy is recognised).
- **Recommendation 3.2:** That a **Federal Assistant Minister, Premier and Cabinet**, ideally for autism, be appointed **to ensure the operationalisation of a co-ordinated and integrated whole of government and whole of life approach**. Refer Figure 1.
- **Recommendation 3.3:** That Autism strategy at any government level is viewed **alongside** any other policy initiatives and **supported by adequate, ongoing funding models**.
- **Recommendation 3.4:** That any policy regarding Autistic Australians must be co-developed and co-delivered by Autistic Australians. Reflecting the principle of “nothing about us without us,” this would need to be **co-produced from end to end** with autistic people and their families/carers.
- **Recommendation 3.5:** That the Australian Government support the National Autism Strategy by implementing a **national autism core capabilities framework** to identify key capabilities for those working with and for supporting Autistic people including:
  - **values and behaviours** that underpin all the capabilities in the framework.
  - **evaluation methodology:**
    - individual assessment of knowledge and/or competence

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<sup>57</sup> [https://www.autismhampshire.org.uk/assets/uploads/Autism\\_Capabilities\\_Framework\\_Oct\\_2019\\_1.pdf](https://www.autismhampshire.org.uk/assets/uploads/Autism_Capabilities_Framework_Oct_2019_1.pdf)

- impact on practice
  - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
  - continuous monitoring and annual reporting requirements.
  - built in timelines for review of the framework (every 3 years).
- **Recommendation 3.6:** That the Australian Government **prioritise support** for and consultation with the following demographics of Autistic Australians:
    - First Nations people;
    - Women and girls;
    - LGBTQIA+ communities;
    - Culturally and Linguistically Diverse ('CALD') communities;
    - People in regional and remote areas;
    - Individuals in the child protection and justice systems;
    - Senior (50+ years) people;
    - People in supported independent living;
    - Students in various education settings; and
    - People with complex needs.

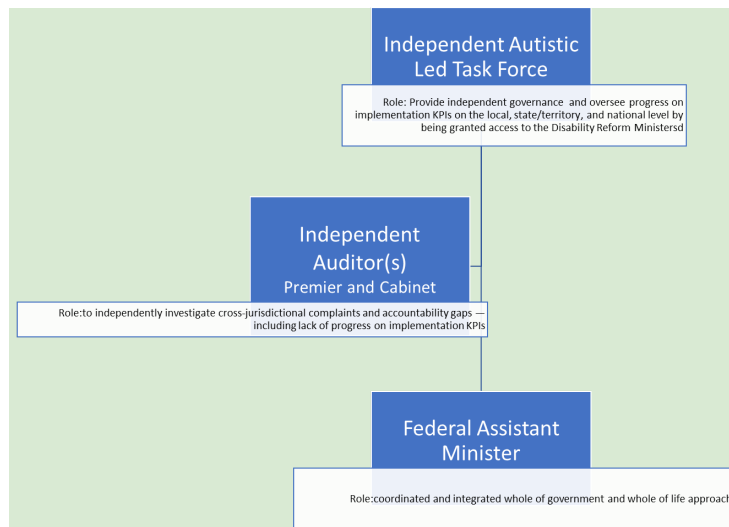


Figure 1: Governance Model

## V. Any Other Related Matters

36. There are continual conversations regarding the number of Autistic Australians. To support planning in the future it is proposed that the question in the 2026 National ABS Census be expanded to capture the number of neurodivergent people in Australia.

37. Therefore, we recommend:

- **Recommendation 3.7:** That a question be framed in the 2026 National ABS Census as follows:
  - Do you have a neurodevelopmental condition? Tick all that apply:
    - Autism or Autism Spectrum Condition, including Autism Spectrum Disorder
    - ADHD (to be written in full)
    - Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, or a Specific Learning Disorder (SPDs)
    - Another neurodevelopmental condition

## Conclusion

Thank you for the opportunity to contribute to the NDIS Review. We appreciate the opportunity to uplift and amplify the voices of Autistic and autism community stakeholders in this consultation.

We trust that the insights and recommendations presented in this submission, based on expertise and academic research, will inform the development of policies and practices that prioritise the well-being and success of Autistic Australians.

We commend the current consultations and recommend further consultations with stakeholders from intersecting backgrounds, in order to best ensure that their experiences and perspectives are reflected within disability service design and specifically autism service design.

We encourage the Australian Government to remain open to addressing any additional related matters that may arise during the course of investigation. The landscape of autism assessments and support services is continuously evolving, with emerging research and evolving practices shaping the field.

We welcome any invitation to speak further with the NDIS Review, although we would prefer a private session for the sake of maintaining confidentiality due to the sensitivity of some of the potential topics.