

Australian Autism Alliance

Submission to Draft National Autism Strategy Consultation

Thriving in an Inclusive and Accountable Society

31 May 2024
c/o AutismPolicy@dss.gov.au

About the Australian Autism Alliance

www.australianautismalliance.org.au

The Australian Autism Alliance (Alliance) aims to provide 'One 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. Operating as a cohesive network of organisations with a diverse focus on autism, we have a national reach that brings together key autism organisations representing and led by autistic people, advocacy groups, peak bodies, service providers, and researchers. We reach over half a million people through our communication channels and provide support to people with autism across the lifespan. Most importantly, our work is informed by autistic people and their families and carers.



Acknowledgement:

We acknowledge the First Nations and Traditional Owners of the land, sea and waterways and pay respects to Elders past, and 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.

We acknowledge the individual and collective expertise of those with a living or lived experience of disability, as well as the lived experience of people who have been carers. We recognise their vital contribution at all levels and value the courage of those who share their unique perspective for the purpose of learning and growing together to achieve better outcomes for all.

1. Executive Summary

The following submission is in response to the Draft National Autism Strategy paper. This should be read in conjunction with our submission to the National Autism Strategy discussion paper “An Integrated and Inclusive Safe Society – 30 October 2023” for further detail on the relevant topics outlined below.

As recognised in the Senate Select Committee on Autism¹ with outcomes manifestly worse for Autistic people than for people with disability more generally, urgent, and dedicated action is needed. 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.

The Alliance celebrates the Australian Government on its commitment to the National Autism Strategy and strongly supports all that it is intended to represent. We commend the extensive consultation and investment of all those who have contributed to the development of this draft Strategy to date including the National Autism Strategy Oversight Council, the Working Groups, the special consultant groups, the Department of Social Services staff and most importantly the dedication and persistence of Autistic people, their families, and the autism community.

The Alliance is excited to see the progress towards the shaping of a strategy to address the significant gaps that exist between Autistic people and other Australians, including other disabilities. It is acknowledged that the intention of the National Autism Strategy is that it is a working document with ongoing review and evaluation and that it will be difficult to capture all issues in detail, as the experience of autism is diverse, and a one-size-fits all solution approach will not be sufficient. Notwithstanding, the following recommendations are considered important elements that are captured in this inaugural National Autism Strategy.

Summary of Recommendations:

General Improvements

- **Recommendation 1:** The feedback from the extensive consultation undertaken on issues relating to States and Territories be captured in a formal document that is referenced in the National Autism Strategy.
- **Recommendation 2:** The National Autism Strategy is not finalised in its drafting until after there has been opportunity for the National Autism Strategy Oversight Committee and working groups to recognise the government’s response to the DRC Recommendations and NDIS Review (particularly Foundational Supports) and consider anything relevant in the Strategy.
- **Recommendation 3:** The National Autism Strategy alternates between the use of identity-first language and person-first language so that a wider range of the community feels equally represented.

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

Summary of Recommendations:

General Improvements

- **Recommendation 4:** A statement be included in the Statement on Language that some people identify with being neurodivergent and others do not. A statement or definition also be included recognising the diversity in the meaning of inclusion/ participation and recognition that there is a spectrum of solutions and/or supports needed in context for the individual. A check needs to be done in general that the National Autism Strategy has adequately captured the diversity of the Autistic population.
- **Recommendation 5:** The statement on neurodiversity is contained to neurodevelopmental neurodivergence and shifted to the glossary, and there is acknowledgement where language that is not neuro-affirming is necessary.
- **Recommendation 6:** The diversity of the autism population is to be better reflected throughout the strategy including the Preamble, Vision, Goal, Guiding Principles.
- **Recommendation 7:** Capture in the glossary a definition of Autistic people with high dependency needs (as distinct from Autistic people with complex needs).
- **Recommendation 8:** Review the drafting of the Commitments to capture the end goal to better enable the commitment to be measurable against the three action plans. Capture in the glossary a definition of Autistic people with high dependency needs (as distinct from Autistic people with complex needs).

Strategy Overview – Vision, Goal and Guiding Principles

- **Recommendation 9:** That the Vision be reviewed to be more ambitious, recognise the need for an accessible society and the need for the right individualised supports. An example may be “...for a safe, accessible and inclusive society where all Autistic people are empowered with the right individual supports to thrive in all aspects of life, in line with international human rights.”
- **Recommendation 10:** The Goal be reviewed to capture the sentiment for Autistic people to have the rights, choices, and experiences in life that every other Australian enjoys. An example may be: “...to improve life experiences and outcomes for all Autistic people across the life span, where social justice, equality and choice exist and there are no gaps with other Australians.”
- **Recommendation 11:** Principle 1 be amended to:
 - refer to only “In Partnership” as the headliner with the slogan as part of the detail.
 - capture an additional statement that activities of co-design, co-produce, co-review, and co-delivery will involve representatives from and reflect the diversity within the Autistic and autism community.
- **Recommendation 12:** A section regarding communications is captured in the National Autism Strategy similar to the Statement on Language and a co-design protocol and communication framework be developed as part of the strategy to support the diversity, rights, and autonomy of ALL Autistic people. This is to include the range of communication devices and methods that Autistic people use.

Commitments – Social Inclusion

- **Recommendation 13:** Review Commitment 1a) under Social Inclusion so that it better reflects that a better understanding of autism is not specifically called out only for workplaces (as it currently reads) and that a better understanding of autism includes the elements detailed under section 4.1.a. Recommendation 13.
- **Recommendation 14:** For Social Inclusion Commitment 1d to be expanded to include Autistic people, their families and support networks.
- **Recommendation 15:** For Social Inclusion Commitment 3 to be expanded to include for the Australian government to be demonstrably the exemplar organisation for autism inclusion practice through:
 - investment in mandatory training capturing organisation-wide knowledge, skills, and confidence in engaging with and including Autistic people, their families, and carers.

Summary of Recommendations:

Commitments – Social Inclusion

- **Recommendation 16:** Ensure that all Australian Government policies, strategies, programs, and interventions at an operational level— for and affecting Autistic Australians include a range of elements as outlined in the detail of Section 4.1a. Recommendation 16.
- **Recommendation 17:** For Social Inclusion Commitment 4 to be expanded to reflect that the Australian Government ensures that all existing and future policies, strategies, programs, interventions, and research relating to Autistic people occurring in government have an “autism-lens” applied, the National Autism Strategy is referenced where relevant and appropriate representation of Autistic people, their families and autism community, as relevant, on reference groups.
- **Recommendation 18:** For Social Inclusion Commitment 5 to be expanded to reflect that the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation should not rely on the Autistic person, their families and support networks to enable this to have effect but there are independent mechanisms to safeguard the effective operation.
- **Recommendation 19:** For a specific commitment to be introduced for National Standards for Autism Friendly Environments and Services Across Government Business and Community Organisations.
- **Recommendation 20:** The Australian Government continue to work in partnership with the States and Territory to achieve whole of government support and integrated local Autism Strategy plans (The commitment by Victoria, South Australia and ACT to a State based Autism/Neurodiversity Strategy is recognised).

Commitments – Economic Inclusion

- **Recommendation 21:** Create a separate commitment that develops a National Autism Employment Framework (possibly relabelled as a National Autism Economic Framework) and includes economic inclusion options for Autistic people who may never be in a position to be gainfully employed and protection/ safeguard mechanisms or significantly disadvantage due to intersectionality issues. This may include a sustainable disability support pension, Medicare to be expanded in coverage for age and the reduction in payment gaps and the ability to loan/lease/sell back equipment and communication devices.
- **Recommendation 22:** Expand Economic Inclusion Commitment 6 to include career pathways and better school transition supports and that pathways capture Autistic people who need to reengage.
- **Recommendation 23:** Expand Economic Inclusion Commitment 10 to capture specifically “accommodations and communications” and make reference to capture high dependency needs and vulnerable intersectional students.
- **Recommendation 24:** Introduce a specific Tertiary Education commitment that addresses a Tertiary Education roadmap inclusive of the safety and well-being of Autistic Tertiary students.
- **Recommendation 25:** Expand Economic Inclusion Commitment to include a restoration channel and strategy to close the gap for those students who have disengaged, past and present.
- **Recommendation 26:** Introduce a specific commitment for the review of the Disability Standards for Education with an autism lens in the short-term action plan.
- **Recommendation 27:** Include Fund Peer and Mentoring Support to improve student outcomes.

Summary of Recommendations:

Commitments – Diagnosis, Services and Supports

- **Recommendation 28:** Commitments 12 and 13 make specific reference to vulnerable intersectional cohorts.
- **Recommendation 29:** 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 (refer detail in Section 4.3.2 for what this includes)
- **Recommendation 30:** Professionals to provide targeted supports to parents during the pre-and post-natal period to support Autistic parents in developing necessary skills.
- **Recommendation 31:** Remove the age limit and remove (or as a minimum reduce) the rebate restriction on diagnostic assessments under the Medicare Benefits Schedule.
- **Recommendation 32:** Create and publish information tailored to the needs of Autistic people and their families with a particular focus on addressing various intersectionality issues, communication formats and channels, supported decision-making, dignity of risk and substitute decision-making.

Commitments – Governance

- **Recommendation 33:** is that Commitment 21 captures the following detail in Section 4.4.1 for clarity and consistency:

Commitments –Research

- **Recommendation 34:** Commitment 22 is amended to capture the following:
 - As well as Develop, “Design and Implement” autism research that can best be fostered and applied to policy and service delivery.
 - underpinned by the Strategy’s Guiding Principles, and
 - this research is linked to the National Autism Strategy Commitments, Evidence Framework and Evaluation and Reporting.
- **Recommendation 35:** Commit to developing a National Autism Research Framework as recommended in the Senate Select Committee on Autism Recommendation 26. The Framework should commit to best practice approaches to ensure the involvement of the diversity of the Autistic and autism community, including often overlooked cohorts and Autistic researchers.

Commitments – Evidence Framework

- **Recommendation 36:** Commitment 23 is amended to capture the elements identified under Section 6.4.3.
- **Recommendation 37:** Commit to undertake a review and incorporate as relevant the Senate Select Committee on Autism’s Recommendations regarding data collection, including for a National Autism Register (Recommendations 27 and 28).

Commitments – Evaluation and Reporting

- **Recommendation 38:** Commitment 24 is amended to capture the following:
 - a. “and underpinned by the Strategy’s Guiding Principles”
 - b. inclusion of family and carers, Autistic community
 - c. that is representative of the diversity within the Autistic and autism community
- **Recommendation 39:** A definition of co-led is added to the Glossary.

Strategy Gaps - Housing

- **Recommendation 40:** Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to support Autistic People to have choice and control of Affordable, Accessible and Safe Housing Options. This includes Supported Independent Living, Homelessness, Effective Emergency Accommodation and transitioning from service or institutional settings as a priority for Autistic people in alignment with any National Strategies.

Summary of Recommendations:

Strategy Gaps - Justice System including first responders, correctional services, and child protection

- **Recommendation 41:** Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Arrest the Overrepresentation of Autistic people dealing with the Justice System and Child Protection issues and Achieve Effective Informed Interactions. This includes:
 - a. Autism Training for the Justice System Workforce including first responders, correctional services, and child protection
 - b. Prison-to-community transitions
 - c. Improvement of Child Protection processes
 - d. Medicare benefit scheme access remains active while incarcerated
 - e. NDIS Plans reactivation before release from incarceration

Strategy Gaps – Transportation and Accessible Supports

- **Recommendation 42:** Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Address Transport Accessibility, Availability and Affordability Challenges.

Strategy Gaps – Carer Economy

- **Recommendation 43:** Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Build a Sustainable Carer Economy including access to peer parent networks, parenting support needs, respite and succession plans for the care of their Autistic children.

Strategy Gaps – Autism Specific Independent Advocacy

- **Recommendation 44:** Include a Commitment in the National Autism Strategy to Develop a model and Fund Independent Specialised Autism Advocacy delivered locally in the changing environment.

Strategy Gaps – Workforce, Productivity and Innovation

- **Recommendation 45:** Include a Commitment in the National Autism Strategy to Develop and Implement a Workforce and Innovation Strategy that results in a productive, skilled, resilient, value-based workforce and optimises the human capability of Autistic people.

Strategy Gaps – Ageing

- **Recommendation 46:** Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy for elderly Autistic people.

Strategy Gaps – Early Investment (Intervention)

- **Recommendation 47:** A further commitment be added to Diagnosis, Services and Supports that captures the development of a strategy regarding Early Investment (Intervention) and how this will interface with the NDIS Review regarding foundational supports and the Federal Early Years strategy to ensure the needs of Autistic people and their families are met.

2. General Improvements

This section responds to the question “Is there anything you want to say about how the Draft National Autism Strategy could be improved?” and applies to the entire Strategy.

2.1 Policy and Reforms

2.1a Feedback on issues relating to States and Territories

The Alliance acknowledges the statement that feedback from the community on issues relating to states and territories has been shared with state and territory governments. Recognising that this is an Australian Government strategy and relates to areas of Commonwealth responsibility to improve life outcomes for Autistic people, the Alliance supports for the feedback from the extensive consultation undertaken on issues relating to States and Territories be captured in a formal document that is referenced in the National Autism Strategy so that the rich and insightful information from Autistic people, their families, and the autism community.

Recommendation 1: *The feedback from the extensive consultation undertaken on issues relating to States and Territories be captured in a formal document that is referenced in the National Autism Strategy.*

2.1b Government Response to DRC Recommendations

The Alliance recognises the timing issues associated with the government’s response to the Disability Royal Commission (DRC) Recommendations. Many of the DRC Recommendations are supported but of the 222 recommendations it was identified that there is a lack of autism-specific findings and recommendations. This reinforced the need for any initiatives, strategies, legislation, or policies to have an autism lens applied to them and have a specialised component or stream relating to autism, so the specific needs of Autistic people and their families are recognised and met. It is recommended that the National Autism Strategy is not finalised in its drafting until after there has been opportunity for the National Autism Strategy Oversight Committee and working groups to recognise the government’s response and consider anything relevant in the Strategy. This will also give effect to the Principle: Aligned and Accountable Outcomes that identifies that the National Autism Strategy and actions will align with other key government strategies. The same is applicable to the NDIS Review.

Please also refer to the Alliance’s submission to the DSS National Autism Strategy discussion paper Appendix 1 Comments regarding Disability Royal Commission (DRC) Recommendations.

Recommendation 2: *The National Autism Strategy is not finalised in its drafting until after there has been opportunity for the National Autism Strategy Oversight Committee and working groups to recognise the government’s response to the DRC Recommendations and NDIS Review (particularly Foundational Supports) and consider anything relevant in the Strategy.*

2.2 Context

2.2.1 Statement on Language

The Autistic population is divergent and divergent views need to be recognised.

Feedback has been heard from the community that:

- It would be preferred that the National Autism Strategy alternates between identity-first language and person-first language so that a wider range of the community feels equally represented.
- A statement be included that “some people identify with being neurodivergent and others do not”.
- A statement recognising that Autistic people with high dependency needs face unique life experiences including communication methods, safeguarding needs, disadvantage, isolation, and life outcomes.

There is reference in the National Autism Strategy and society in general regarding inclusion and participation. This has different connotations for different Autistic people and their families based on their choice and opportunity. For instance, inclusion may be social inclusion and to be part of mainstream community events. For others inclusion may mean that they would like “inclusion/ participation” in a segregated environment.

Recommendation 3: *The National Autism Strategy alternates between the use of identity-first language and person-first language so that a wider range of the community feels equally represented.*

Recommendation 4: *A statement be included in the Statement on Language that some people identify with being neurodivergent and others do not. A statement or definition also be included recognising the diversity in the meaning of inclusion/ participation and recognition that there is a spectrum of solutions and/or supports needed in context for the individual. A check needs to be done in general that the National Autism Strategy has adequately captured the diversity of the Autistic population.*

2.2.2 Statement on Neurodiversity

Feedback has been heard from the community that the significant statement upfront in the National Autism Strategy is detracting and confusing as to who the strategy is meant to cover.

It has been highlighted that:

- a) as a minimum that reference to “neurodiversity” should be contained to neurodevelopmental neurodivergence” so that it refers to autism and ADHD
- b) ideally, this is removed from having such a prominent place in the strategy and that it be contained in the glossary
- c) there are instances where to elicit an appropriate timely response language that is not neuro-affirming is necessary. For instance, when an Autistic person is in danger and an emergency response is needed.

It has also been identified that the use of the terminology relating to “level of functioning” is offensive and subject to misinterpretation. This is a very important aspect to be captured as we move towards shaping a new narrative.

Recommendation 5: *The statement on neurodiversity is contained to neurodevelopmental neurodivergence and shifted to the glossary, and there is acknowledgement where language that is not neuro-affirming is necessary.*

2.3 Diversity of the Autism Population

Feedback has been heard that there needs to be a more prominent reflection on representing the diversity of the spectrum by reflecting throughout the strategy including the Preamble, Vision, Goal, Guiding Principles, Commitments, Actions and Glossary:

- Autistic people with high dependency needs (also referred to as profound needs), which is distinct from having complex needs. This includes capturing various ways of communication than just “the voice”. Note that Autistic people with complex needs may not necessarily have high dependency needs. This differentiation needs to be captured in the glossary.
- Parent and Carers – currently terminology only referencing Autistic people or Lived Experience is being interpreted as excluding Autistic people who are less able to advocate for themselves. Often Autistic people require the support of their families and carers. This important role needs to be reflected in the strategy where the parent/carers is supporting an Autistic person to be represented or is representing on their behalf.
- Vulnerable Intersectional Cohorts such as First Nations, Culturally and Linguistically Diverse, Children in Child Protection etc as captured on page 18 of the draft National Autism Strategy.

Also refer to responses to Sections 3, 4 and 5 below.

Recommendation 6: *The diversity of the autism population is to be better reflected throughout the strategy including the Preamble, Vision, Goal, Guiding Principles, Commitments Actions and Glossary particularly a) Autistic people with high dependency needs - aka profound autism b) parents/carers and c) vulnerable intersectional cohorts as outlined on page 18 of the draft National Autism Strategy. To enable this the National Autism Strategy Oversight Council and Working groups need to focus on these areas and co-develop, co-produce and test appropriate elements of the National Autism Strategy with targeted reference groups.*

Recommendation 7: *Capture in the glossary a definition of Autistic people with high dependency needs (referred to by some as profound and as distinct from Autistic people with complex needs).*

2.4 Drafting of Commitments

Given the Commitments are enduring throughout the life of the National Autism Strategy, as currently written they do not accurately articulate the end goal or result, noting there will be three action plans – short-term, medium-term, and longer-term. It is recommended that the Commitments are rewritten with the end goal in mind, so they are more absolute and measurable against progress. This will also support the effectiveness of the commitments covered by Governance, Research, Evidence and Evaluation and Reporting.

For example:

~~Improve~~ Achieve understanding of, and change attitudes towards, Autistic people across all of society.

~~Increase representation~~ of Autistic people in senior and board positions to promote people as visible role models.

Recommendation 8: Review the drafting of the Commitments to capture the end goal to better enable the commitment to be measurable against the three action plans. Capture in the glossary a definition of Autistic people with high dependency needs (as distinct from Autistic people with complex needs).

3. Section 1: Strategy Overview – Vision, Goal and Principles

This section responds to the question of how ‘appropriate’ we think the Vision, Goal and Principles are for the Strategy. It is recognised that the Vision, Goal and Guiding Principles are crafted with the intention to speak to the experience of autism which is diverse.

Feedback and recommendations are as follows:

3.1 Vision

Feedback provided is that Autistic people, their families and supports would like to see:

- something more ambitious in the Vision encapsulating words such as “thrive”
- recognition of an accessible society; and
- the need for the right individualised supports

Recommendation 9: That the Vision be reviewed to be more ambitious, recognise the need for an accessible society and the need for the right individualised supports. An example may be “....for a safe, **accessible and** inclusive society where all Autistic people are empowered **with the right individual supports** to ~~fully participate~~ **thrive** in all aspects of life, in line with international human rights.”

3.2 Goal

The goal in the draft National Autism Strategy reads as follows:

“...to improve life outcomes for all Autistic people.”

In the National Autism Strategy Discussion paper consultation, the question was asked “What outcomes would you most like to see from a National Autism Strategy?”

The Alliance’s response was:

- a. That Autistic people and their parents, families, carers, and the autism community:
 1. are no longer falling behind the outcomes of other Australians;
 2. are integrated in all aspects of society;
 3. are part of policy and legislation shaping and considered an important priority cohort;

- b. There is a vertically integrated society that understands, accepts, and actively includes autism at all levels –Federal, State, Local, Community, Organisations and Individual
- c. Those government agencies, systems, and organisations that exist to support people with disability, including autism are accountable for the outcomes and the onus is no longer on Autistic people and their parents, families, and carers to educate and/or demonstrate their rights including the right not to be discriminated, abused, exploited, or vilified. A stakeholder mapping exercise of current government systems resulted in identifying that every tier of government relies on the individual needing to navigate the systems, educate, and facilitate the interfaces and gaps.

Refer to the Alliance submission to the National Autism Strategy discussion paper for further details.

Hence it is recommended that the goal in the draft National Autism strategy be reviewed to capture the above.

Recommendation 10: The Goal be reviewed to capture the sentiment for Autistic people to have the rights, choices, and experiences in life that every other Australian enjoys. An example may be: “....to improve life experiences and outcomes for all Autistic people across the life span, where social justice, equality and choice exist and there are no gaps with other Australians.”

3.3 Guiding Principles

3.3.1 Principle: In Partnership – Nothing about us, without us

Feedback received from the community is as follows:

- While the “In Partnership” is embraced, there is concern that “nothing about us, without us” has certain well-known connotations in the disability sector which may be a risk of excluding Autistic people with high dependency needs who are less able to advocate for themselves and require alternative communication means such as letter boards, supported decision making and/or substitute decision making.

Wikipedia identified that “**Nothing about us without us**” (*Latin: Nihil de nobis, sine nobis*) is a slogan used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy.

While it is recognised that it is stated underneath the slogan in the draft National Autism Strategy that:

“This Strategy will be co-designed, co-produced, co-reviewed and co-delivered with Autistic people, and their families and carers and support networks”.

it is important that:

- It is recognised that autism requires a spectrum of solutions as there is no one-size-fits-all. This includes for communications.

- As a divergent population with divergent needs and views to be addressed this means no one should be silenced by one group over another but supported through the principles of:
 - self-determination and choice and control
 - inclusion where the environment is safe and conducive to achieving the outcomes of the individual
 - respect and dignity and to be free of abuse, discrimination, and vilification
 - equality
 - a need for a range of supports, irrespective of their diagnosis or diagnosis level

to enable all voices to be heard, so that codesign, co-production, co-review and co-delivery occur with and for authentic voices of the respective cohort, including recognising the intersectionality of the Autistic community there should be a commitment to a codesign protocol and communications framework included as part of the strategy. This should also include the range of communication methods that could be used and about decision making.

Further to support the above, due to ableist attitudes, a lack of understanding of and support for Autistic people and social structures that are designed for the neurotypical experience, Autistic individuals are routinely denied the ability to speak for themselves, make their own choices or be involved in decision-making processes about policies and programs that impact them.

While the right to be involved in decision-making processes about one's own life is a fundamental human right that is enshrined in a number of international human rights conventions to which Australia is signatory, including the International Covenant on Civil and Political Rights² and the Convention on the Rights of Persons with Disabilities,³ legislation and support structures in Australia are not conducive to the full and meaningful participation of Autistic people.

At the systemic level, while it is broadly agreed that effective policies, supports and services should be co-designed and implemented alongside the communities they impact, national co-design and consultation processes in Australia to date, have rarely acknowledged or been inclusive of the diverse needs of the Autistic community.

For example, while the recently developed National Disability Strategy (NDS) 2021–2031 involved some consultation with the Autistic community,⁴ many advocates in the Autism sector have argued that the NDS, in its broad focus on disability generally, does not represent the specific views or needs of the Autistic community.

At an individual level, arguments against the full and unhindered autonomy of Autistic people, include evidence that many Autistic people require support with everyday living, including, but not limited to tasks such as shopping, travelling, or socialising.⁵ This need for support is often linked to 'functioning levels,' according to medicalised assessments.

² International Covenant on Civil and Political Rights 1966 ([1980] ATS 23)

³ Convention on the Rights of Persons with Disabilities 2006 [2008, ATS 12]

⁴ Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra.

⁵ Späth, E.M.A and Jongsma, K. R (2020) 'Autism, autonomy, and authenticity,' *Medicine, Health Care and Philosophy*, vol. 23, p. 74.

In the current guidelines for diagnosis, assessors are required and advised to specify the 'severity' of symptoms as Level 1, 2 or 3.

In turn these prescribed levels are used by government agencies like the National Disability Insurance Scheme (NDIS) as well as community members to ascertain the needs of the individual. However, while these levels can assist individuals and families to access systems of support, there is significant anecdotal evidence to suggest that functioning levels or labels (for example 'high functioning' or 'low functioning' do not allow for the nuance required to understand that one Autistic person may have exceptional capability in one area but need support in another. Additionally, there is some concern that these labels can be counterproductive to the autonomy and choices available to the individual by inaccurately painting a picture of a person's ability to take control of their lives.

Under the guise of functioning levels for example, adult Autistic people can be forced into legally binding guardianship orders and/ or other substitute decision-making arrangements which allow another person to make their decisions about everything including their relationships, medical treatments and living conditions; when it is possible for the individual to make their own decisions with the support of accessible information and assistance.

The likelihood of being placed into guardianship or other substitute decision-making arrangements is further increased for Autistic people who experience intersectional discrimination based on co-occurring disability, gender, age, or race. In the disability sector broadly, it is well recognised that the impacts of ableist, sexist and racist discrimination all contribute to assumptions about decision-making ability. In a report on the agency and decision making of women and girls with disability for instance, Women With Disabilities Australia (WWDA) describes how ableist attitudes about the (in)ability of women with disability to parent has often resulted in disabled and Autistic women and gender diverse being denied the ability to make choices about their sexual and reproductive health and subject to long-acting forms of contraception or sterilisation against their will by guardians, caregivers or medical professionals.⁶ Similarly, it has been well documented that due to the intersection of racism, ableism and society built on white, colonial values, First Nations people with disability experience disproportionate rates of child removals, are grossly overrepresented among people under guardianship orders, experience unacceptably high rates of incarceration and are rarely included in decisions about services or interventions that are forced upon them.⁷

Recommendation 11: Principle 1 be amended to:

- 1. refer to only "In Partnership" as the headliner with the slogan as part of the detail.*
- 2. capture an additional statement that activities of co-design, co-produce, co-review, and co-delivery will involve representatives from and reflect the diversity within the Autistic and autism community,*

Recommendation 12: A section regarding communications is captured in the National Autism Strategy similar to the Statement on Language and a co-design protocol and communication framework be developed as part of the strategy to support the diversity,

⁶ Women With Disabilities Australia (WWDA) (2016) 'WWDA Position Statement 2: The Right to Decision-Making'. WWDA, Hobart, Tasmania, p.7.

⁷ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) 'The experience of First Nations people with disability in Australia,' Australian Government. <<https://disability.royalcommission.gov.au/publications/experience-first-nations-people-disability-australia>>

rights, and autonomy of ALL Autistic people. This is to include the range of communication devices and methods that Autistic people use and about decision making.

4. Section 2: Commitments

This section responds to whether there is any feedback about the Commitments for Social Inclusion. The Alliance welcomes the commitments identified and provides the following recommendations to capture either refinements to existing commitments or additional commitments, including to address some of the issues raised in Section 2.

4.1 Social Inclusion

4.1a Improving Understanding of Autism Population Groups

Furthermore, in the Alliance's response to the National Autism Strategy discussion paper we responded with a number of recommendations to the questions:

"What might help to improve people's understanding of Autism population groups?" and "What are your priorities for a National Autism Strategy".

This included:

1. a vision for a vertically integrated society with understanding, acceptance, and actively including autism at all levels was to be achieved through various education campaigns starting with a public campaign to be delivered nationally to both increase understanding of autism and inform the community how to better support Autistic people. A vertically integrated society will help us achieve equal citizenship. We know that the true measure of success is when people with disability are taking their rightful place as full and equal members of Australian society. There are also many tangible ways to integrate an understanding of autism into society including Autism Inclusion and Access Plans, Diversity and Inclusion plans in organisations specifically referencing autism, the Australian Curriculum to include disability and neurodiversity as a subject and for there to be communication boards at all parks. Please refer to the Alliance's submission to the National Autism Strategy discussion paper for more detail.
2. To change the narrative. Autistic people and parents are often required to repeatedly justify and advocate for their support needs. This process can be demeaning and hurtful to the self-respect and identity of the Autistic person.
3. For the Federal government to be demonstrably the exemplar organisation 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 found that the biggest barrier to inclusion is a lack of autism knowledge, skills, and confidence. The array of government systems at all levels in the ecosystem undoubtedly are willing to do better – but do not know how. But that's not all - a key skill is the ability to ask the right questions. We have so many of the community comment that they are not being listened to, and not being respected.

The relevant recommendations extracted from this prior Alliance submission (to the National Autism Strategy discussion paper) are:

Recommendation 13: Review Commitment 1a) under Social Inclusion so that it better reflects that a better understanding of autism is not specifically called out only for workplaces (as it currently reads) and that a better understanding of autism includes:

- the impact social isolation from the community has including adversely impacting mental health, education, social and economic outcomes;
- the range of barriers that prevent Autistic people from full and equal participation in the community and society;
- unaccommodating built environments and the low levels of supported independent living.⁸;
- the lack of services designed specifically to cater for Autistic people with Autistic people often having to 'make do' with generic services or services designed for people with intellectual and cognitive disabilities.⁹;
- the experience of intersectional discrimination and high dependency needs;
- how to support Autistic people.

Recommendation 14: For Social Inclusion Commitment 1d to be expanded to include Autistic people, their families and support networks.

Recommendation 15: For Social Inclusion Commitment 3 to be expanded to include for the Australian government to be demonstrably the exemplar organisation for autism inclusion practice through:

- a) investment in mandatory training capturing organisation-wide knowledge, skills, and confidence in engaging with and including Autistic people, their families, and carers.
- b) a competency framework with the right behaviour-driven performance KPIs, performance management and accountability exercised.

Recommendation 16: Ensure that all Australian Government policies, strategies, programs, and interventions at an operational level— for and affecting 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') to ensure that disabled Australians can participate in decision-making;
- espouse intersectionality and principles of disability justice, centring 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;
- aligned with affirmative care practices that are not only neurodiversity-affirmative, culturally responsive, and strengths-based but also accessible, available, affordable, and inclusive; and
- person-centred and trauma-informed in not only service design but also service delivery.

This way it is not a foreign language when Autistic people and their families raise the above. A great example in principle is the Disability Royal Commission's Recommendation 11.5 Complaint Handling and Investigative Practice Guidelines.

⁸ Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, pp. 34.

⁹ Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, p 92.

Recommendation 17: *For Social Inclusion Commitment 4 to be expanded to reflect that the Australian Government ensures that all existing and future policies, strategies, programs, interventions, and research relating to Autistic people occurring in government have an “autism-lens” applied, the National Autism Strategy is referenced where relevant and appropriate representation of Autistic people, their families and autism community, as relevant, on reference groups.*

Recommendation 18: *For Social Inclusion Commitment 5 to be expanded to reflect that the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation should not rely on the Autistic person, their families and support networks to enable this to have effect but there are independent mechanisms to safeguard the effective operation.*

Refer to Recommendation 27 below regarding mitigating the reliance on Autistic people. Their families and support networks.

4.1b National Standards for Autism-Friendly Environments and Services

It was suggested to the Senate Inquiry for the introduction of National Standards for Autism Friendly Environment and Services. Such standards could sit alongside the National Autism Strategy and act as a complementary guideline for how the Disability (Access to Premises – Buildings) Standards 2010 can be implemented in a way that meets the specific requirements of Autistic people.

Recommendation 19: *For a specific commitment to be introduced for National Standards for Autism Friendly Environments and Services Across Government Business and Community Organisations.*

4.1c Government Partnering for an Effective Ecosystem

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 and complex to navigate. 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.¹⁰ This would also assist the government in more effective and efficient government services operations and allocation of resources.

Recommendation 20: *The Australian Government continue to work in partnership with the States and Territory to achieve whole of government support and integrated local Autism Strategy plans (The commitment by Victoria, South Australia and ACT to a State based Autism/Neurodiversity Strategy is recognised).*

Please refer to the Alliance submission to the National Autism Strategy discussion paper for more detail regarding the above.

¹⁰ Senate Select Committee on Autism, Parliament of Australia, Services, support, and life outcomes for autistic Australians (2022) [3.2].

4.2 Economic Inclusion

This section responds to whether there is any feedback about the Commitments for Economic Inclusion.

4.2.1 Economic Viability

As outlined in Section 2 there is a need to capture specific actions for vulnerable intersectional cohorts and Autistic people with high dependency needs that often face more barriers to achieving economic inclusion.

For Autistic people who are women, gender diverse, LGBTIQ+, First Nations, CaLD, ageing or from migrant or refugee backgrounds, there are a number of further barriers to obtaining and maintaining meaningful and stable employment. For example, due to racist attitudes in the workforce, First Nations and CaLD people often have difficulty obtaining and maintaining employment.¹¹ VISA restrictions mean that many temporary residents are only able to work a certain number of hours and in specific areas of employment.¹² Older Autistic people experience high rates of age discrimination when searching for work¹³ and Autistic women, gender diverse and LGBTIQ+ people are more likely to experience various forms of gendered and sexual violence, abuse and harassment in the workplace¹⁴ as well as to have caring responsibilities which impact their ability to work.¹⁵

While there is limited data on the specific employment rates of each sub-group of the Autistic community, there is evidence to suggest that the workforce participation of the Autistic community goes down with each layer of intersectional disadvantage. For example, available data shows that:

- The labour force participation rate for First Nations people with disability is less than half of that of First Nations people without disability;¹⁶
- Job seekers from CALD backgrounds make up almost one-fifth of the total job-seeking population;¹⁷
- 51 per cent of women with disability are employed, compared to 56 per cent of men with disability, or 80 per cent of women without disability;¹⁸

¹¹ See for example: Farhart, C (2020) 'More than half of Indigenous Australians are experiencing racism in the workplace,' *SBS News*, Viewed 08 June 2023 <<https://www.sbs.com.au/news/article/more-than-half-of-indigenous-australians-are-experiencing-racism-in-the-workplace/3e0wwoyif>>.

¹² Department of Home Affairs (2020) 'Immigration and Citizenship: Work Restrictions,' Australian Government, Viewed 08 June 2023 <<https://immi.homeaffairs.gov.au/visas/working-in-australia/work-rights-and-exploitation/work-restrictions>>.

¹³ Australian Human Rights Commission (2023) 'Ageism keeping older people out of the workforce,' *Australian Human Rights Commission*, Viewed 08 June 2023 <<https://humanrights.gov.au/about/news/media-releases/ageism-keeping-older-people-out-workforce>>.

¹⁴ See for example Smith, P (2019) 'Women four times more likely to experience sexual assault at work,' *The Conversation*, Viewed 08 June 2023 <<https://theconversation.com/women-four-times-more-likely-to-experience-sexual-assault-at-work-108380>>; LGBTIQ+ Health Australia (no date) 'Response to the Royal Commission into Violence, Abuse Neglect and Exploitation of People With Disability' <<https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00652.PDF>>.

¹⁵ Department of Prime Minister and Cabinet (2023) 'National Strategy to Achieve Gender Equality - Discussion Paper: Women Bear the Burden of Care,' Australian Government, Canberra <<https://www.pmc.gov.au/resources/national-strategy-achieve-gender-equality-discussion-paper/current-state/burden-care>>.

¹⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2021) 'Overview of responses to the Employment Issues paper,' p. 4 <<https://disability.royalcommission.gov.au/system/files/2022-03/Overview%20of%20responses%20to%20the%20Employment%20Issues%20paper.pdf>>.

¹⁷ FECCA (2016) 'Employment services and outcomes for CALD people with disability' <<https://fecca.org.au/wp-content/uploads/2016/01/Employment-participation-of-CALD-people-with-a-disability.pdf>>.

¹⁸ Australian Institute of Health and Welfare (2022) 'People with Disability in Australia' <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/labour-force-participation>>.

- the percentage of unemployed LGBTIQ+ people is more than double the national rate;¹⁹
- Youth (aged 15–24) with disability (25 per cent) are more likely than those aged 25–64 (7.9 per cent) to be unemployed.²⁰

Hence there needs to be a specific economic inclusion commitment that covers ALL Autistic people including those who may never be in a position to be gainfully employed such as highly dependent Autistic people. This may include a sustainable disability support pension, Medicare to be expanded in coverage for age and the reduction in payment gaps and the ability to loan/lease/sell back equipment and communication devices.

It is also noted that the Senate Select Committee on Autism reported under Recommendation 58 that a National Autism Employment Framework be developed under a National Autism Strategy. This would be welcomed to ensure the diverse range of Autistic people are captured in a structured, well-governed, innovative, and measurable way. It will also provide for longevity with strategies across the lifespan as parent/ carers find themselves no longer available to continue to support their children.

The above commitment would be welcomed by Autistic people and their families, particularly for those with high dependency needs or vulnerable intersectional cohorts to provide protections and safeguards. Protections and safeguards extend to individuals who have financial security but are at high risk of exploitation, particularly those without a close network.

Recommendation 21: *Create a separate commitment that develops a National Autism Employment Framework (possibly relabelled as a National Autism Economic Framework) and includes economic inclusion options for Autistic people who may never be in a position to be gainfully employed and protection/ safeguard mechanisms or significantly disadvantage due to intersectionality issues. This may include a sustainable disability support pension, Medicare to be expanded in coverage for age and the reduction in payment gaps and the ability to loan/lease/sell back equipment and communication devices.*

4.2.2 Career Pathways and Better School Transitions Supports

Lack of support in making the transition from secondary school to further study and employment is a common experience for Autistic students. Autistic school students rarely participate in work experience, which severely impacts opportunities for vocational exploration, and to build aspiration and networks.²¹

Pathways need to be created early for Autistic students so that they can build life skills and careers. The current Australian curriculum needs to be modified to take an approach similar to STEM which starts in primary and early secondary school years supporting students to have the exposure to and therefore opportunity to identify early where they may channel their interests. A range of pathways should be built besides traditional pathways including skills towards trades, and micro-social enterprises.

¹⁹ Meridian Community Health Action, A Gender Agenda, Hands Cross Canberra and Collective Action (no date) 'Removing barriers to employment for LGBTIQ+ people: Understanding the role of employment services,' p. 3
<https://docs.google.com/document/d/1zaxTC4rvi7WvEMg674HeJVDmRV97BX8szn5j76kj_Xw/edit>.

²⁰ Australian Institute of Health and Welfare (2022) 'People with Disability in Australia'
<<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/labour-force-participation>>.

²¹ Australian Autism Alliance (2020) 'The Autism Dividend: Unleashing the skills, talent and opportunity of Australia's autistic community,' p. 31.

It is unclear in the commitments where the bridge is between education to employment. Hence it is recommended that career pathways and better school transition supports are captured under Economic Inclusion Commitment 6.

Recommendation 22: *Expand Economic Inclusion Commitment 6 to include career pathways and better school transition supports and that pathways capture Autistic people who need to reengage.*

4.2.3 Inclusive Accommodations and Communication

When it comes to academic participation, research suggests that there are similarly a range of factors which challenge the full and equal participation of students with Autism. Except for some schools across Australia that have made a distinctive effort to provide an inclusive education, the majority of schools and educators provide very few accommodations for Autistic students, even when there is a clear benefit.²² For example, while many Autistic students experience auditory processing delays, are non-verbal or experience difficulties with communication; classroom communication is mostly verbal and instructions or information on topics is rarely provided in alternative visual formats.

Furthermore, for Autistic students who face intersectional disadvantages, the schooling and education system can present an array of additional disadvantages. For example, First Nations and CaLD Autistic students face added disadvantages associated with language and cultural barriers,²³ the education system curriculum being centred around a white colonial history²⁴ and a risk of experiencing racism from their educators and peers.²⁵ LGBTIQ+ students often have to navigate, at best a lack of understanding of their experiences, and at worst, blatant discrimination and school expulsion based on their gender or sexual identification.²⁶ Autistic students living in rural or remote areas or who experience socio-economic disadvantage are more likely to attend public, under-resourced schools with even more limited ability to offer support and accommodations;²⁷ and Autistic women and girls are less likely to even receive recognition of their support requirements, due to barriers to diagnosis and pressures around compliance and social assimilation.²⁸ And this is just some of the intersectionality issues.

²² Australian Autism Alliance (2020) 'The Autism Dividend: Unleashing the skills, talent and opportunity of Australia's autistic community,' p. 31.

²³ See for example: Foundation House and Multicultural Youth Advocacy Network (2021) *National Education Roundtable. Briefing Paper: Education and students from refugee and migrant backgrounds*, Viewed 8 June 2023, p. 6 <https://myan.org.au/wp-content/uploads/2020/11/education_issue_05.pdf>; Prior, M (2013) 'Language and Literacy Challenges for Indigenous Children in Australia,' *Australian Journal of Learning Difficulties*, Vol. 18, no. 2, pp. 123-137 <<https://eric.ed.gov/?id=EJ1024454>>.

²⁴ See for example Moore, R (2017) 'History textbooks still imply that Australians are white,' *The Conversation*, Viewed 8 June 2023 <<https://theconversation.com/history-textbooks-still-imply-that-australians-are-white-72796>>.

²⁵ See for example Pirest, N and Biddle, N (2015) 'Racism hits Indigenous students' attendance and grades,' *Australian National University*, Viewed 8 June 2023 <<https://www.anu.edu.au/news/all-news/racism-hits-indigenous-students-attendance-and-grades>>;

²⁶ See for example: Elphick, L (2023) 'Religious schools can still expel LGBTQ kids. That needs to change,' *Sydney Morning Herald*, Viewed 8 June 2023 <<https://www.smh.com.au/national/religious-schools-can-still-expel-lgbtq-kids-that-needs-to-change-20230221-p5cm5l.html>>.

²⁷ See for example: Cobbold, T (2020) 'Low SES Schools Have Far Less Resources than High SES Schools,' *Save Our Schools Australia*, Viewed 8 June 2023 <<https://saveourschools.com.au/equity-in-education/low-ses-schools-have-far-less-resources-than-high-ses-schools/>>.

²⁸ See for example: Yellow Lady Bugs and the Department of Education and Training Victoria (2008) 'Spotlight on Girls with Autism,' <<https://yellowladybugs.com.au/School/Download>>.

Recommendation 23: *Expand Economic Inclusion Commitment 10 to capture specifically “accommodations and communications” and make reference to capture high dependency needs and vulnerable intersectional students.*

4.2.4 Tertiary Education

Although most research about the barriers that face Autistic students is focused on primary and sometimes high school, there is evidence that these barriers persist and often worsen throughout all levels of education, including at universities and TAFEs.²⁹

Given Tertiary education is covered by the Federal government and is a significant stepping stone to achieving employment, particularly to enable graduate entry to Australian Public Service roles a specific stand-alone Commitment regarding Tertiary Education should exist that addresses a Tertiary Education Roadmap inclusive of the safety and wellbeing of Autistic Tertiary students.

Recommendation 24: *Introduce a specific Tertiary Education commitment that addresses a Tertiary Education roadmap inclusive of the safety and well-being of Autistic Tertiary students.*

4.2.5 Reengagement Channel to Address Disengaged Students

Economic Inclusion Commitment 11 makes specific reference to improving the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation to specifically focus on Autistic students at all levels of education. This commitment should also have a restoration channel and strategy to close the gap for those students who have school refusal, and/or have been unfairly victimised so as to re-engage disengaged students, past and present.

Recommendation 25: *Expand Economic Inclusion Commitment to include a restoration channel and strategy to close the gap for those students who have disengaged, past and present.*

4.2.6 Disability Standards for Education (DSE)

Economic Inclusion Commitment 11 makes specific reference to improving the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation to specifically focus on Autistic students at all levels of education.

While the Disability Standards for Education (DSE) specify a number of obligations for educational providers to prevent discrimination against disabled and Autistic students, evidence suggests that disability discrimination is still rife across all levels of education.³⁰

²⁹ Ibid.

³⁰ Jenkins, K and Young, E (2019) “Not acceptable”: Calls for disability act reform after report reveals discrimination still rife, SBS News, Viewed 8 June 2023 <<https://www.sbs.com.au/news/article/not-acceptable-calls-for-disability-act-reform-after-report-reveals-discrimination-still-rife/fhkxekz1k>>.

According to statistics from the Australian Human Rights Commission, the majority (38 per cent) of all complaints are lodged under the protections of the Disability Discrimination Act, with approximately 8-10 per cent of those complaints being specific to education.³¹

While national data on complaints from or on behalf of Autistic individuals is limited, a number of Autistic community organisations have heard anecdotally and through membership surveys that many Autistic students experience discrimination in the form of being denied enrolment in mainstream settings or refused required and necessary supports.³² Despite this evidence, however, there is little that can be done to change to improve school protections due to a lack of accountability mechanisms.

Among a number of other recommendations related to the provision of support for Autistic students and training for educators, the need to strengthen accountability mechanisms for education providers was specifically recommended in the yet-to-be-implemented final report on the 2020 review of the DSE.³³

As per the Alliance's National Autism Strategy discussion paper submission, it is recommended that there is a specific commitment for the Disability Standards for Education to be reviewed with an autism lens in the short-term action plan.

Recommendation 26: *Introduce a specific commitment for the review of the Disability Standards for Education with an autism lens in the short-term action plan.*

4.2.6 Peer and Mentoring Support

The government should provide funding for outcome-based commercial models for peer-support programs for Autistic individuals, which have proved successful in improving a range of outcomes for Autistic individuals and can do so pre and post-school age. Peer support plays an important role in strengthening participant capabilities to exercise their choice and control. Mentoring programs (5–22-year-olds) have been shown as represented by Australian Catholic University, to increase young people's positive Autistic identity and belonging.

Recommendation 27: *Include Fund Peer and Mentoring Support to improve student outcomes.*

4.3 Diagnosis, Services and Supports

This section responds to whether there is any feedback about the Commitments for Diagnosis, Services and Supports.

³¹ Australian Human Rights Commission (2014) 'Complaint Statistics,' Viewed 8 June 2023 <<https://humanrights.gov.au/our-work/appendix-3-complaint-statistics>>.

³² See for example Amaze report; Australian Autism Alliance (2020) 'The Autism Dividend: Unleashing the skills, talent and opportunity of Australia's autistic community,' p. 30.

³³ See for example: Saggars, B. et al., (2018) 'Australian Autism Educational Needs Analysis: What are the needs of schools, parents and students on the autism spectrum?' Autism CRC. <<https://www.autismcrc.com.au/sites/default/files/inline-files/Educational%20Needs%20Analysis%20-%20Final%20report%20Version%202.pdf>>.

4.3.1 Diagnosis Complexities Due to Intersectionality

While it is also common for Autistic people to have psychosocial disabilities as co-occurring conditions, biases in assessment processes mean that Autistic women and gender-diverse people in particular often experience misdiagnoses which create further barriers to being diagnosed Autistic. While it is impossible to identify the exact number of misdiagnoses that occur, estimates suggest that approximately 80 per cent of Autistic women are misdiagnosed – often with conditions such as borderline personality disorder (BPD) eating disorders, bipolar disorder, and anxiety.³⁴

Recommendation 28: Commitments 12 and 13 make specific reference to vulnerable intersectional cohorts.

4.3.2 National Autism Core Capabilities Framework

It is recognised that there are a number of commitments under this section that reflect developing standardised tools, best practice resources and training etc for diagnosticians, service and support providers.

In the Alliance's submission to the National Autism Strategy discussion paper was a reference to the need for implementing a National Autism Core Capabilities Framework.

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 the onus on people with disability to keep themselves safe or to find the right service to contact must be reformed³⁵. As an example, with the establishment of the NDIS Quality and Safeguard Commissioner (NDIS QSC) there has been significant 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.

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.

³⁴ See for example Gesi, C et al. (2021) 'Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability,' *Brain Sci*, Vol. 11, no. 7, p. 912
<<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8306851/>>; Rudra, A (2022) 'Why many women with autism and ADHD aren't diagnosed until adulthood – and what to do if you think you're one of them,' *The Conversation*, Viewed 13 June 2023
<<https://theconversation.com/why-many-women-with-autism-and-adhd-arent-diagnosed-until-adulthood-and-what-to-do-if-you-think-youre-one-of-them-179970>>

³⁵ DACCSA, *Interface of Systems with Disability*, 2020 [8]

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.

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 research³⁶ and literature on school refusal within the Autistic community (reframed to "school can't"³⁷ within 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.

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 has developed a national autism core capabilities framework.³⁸ to identify key capabilities for those working with and for supporting Autistic 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.

Based on the above, to enable a whole of government and ecosystem approach it is recommended that:

Recommendation 29: *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).

This commitment would also apply to:

- a) professional bodies hence supporting current issues highlighted regarding diagnosis, behaviour support practitioners and other existing and emerging roles due to the NDIS and DRC Review.
- b) Building capability in universal service platforms, particularly maternal and child health services and General Practitioners to detect warning signs and refer young children for assessment.

4.3.2 Targeted support for parents in the pre-and post-natal period

Post-birth and into parenting, Autistic mothers and parents of Autistic children also report experiencing higher rates of depression, social isolation, selective mutism, and prolonged stress about the various responsibilities associated with caregiving. While there is some support available in the form of postnatal midwifery, child health centres, playgroups and early childhood education centres, these options are often inaccessible for Autistic children and parents due to heightened sensory sensitivities, communication difficulties and a

³⁶ <https://link.springer.com/article/10.1186/s13034-020-00325-7>

³⁷ <https://www.livingonthespectrum.com/education/school-refusal-school-cant/>

³⁸ https://www.autismhampshire.org.uk/assets/uploads/Autism_Capabilities_Framework_Oct_2019_1.pdf

workforce that is not aware of the Autistic experience. Additionally, many disabled and Autistic parents avoid seeking formal support due to a fear of the involvement of child protection. As was cited in the Senate Select Committee Inquiry on Autism, there is evidence that many Autistic mothers have had their children removed for 'no other reason than their disability';³⁹ an issue which is even more common for Autistic women who are First Nations or have had prior contact with the justice system.

Recommendation 30: Professionals to provide targeted supports to parents during the pre- and post-natal period to support Autistic parents in developing necessary skills.

4.3.2 Medicare Benefits (to access Diagnosis Assessments)

The Alliance welcomes Commitment 14 which references the Medicare Benefits Schedule (MBS) to improve access to primary care to explore ways to make Autism diagnosis and assessment processes timelier and more accessible. A key driver is affordability. Rebates for autism assessments and diagnosis under the Medicare Benefits Schedule (MBS) are only available for children and adults under 25 years of age and do not cover the total cost of the assessments. Given the evidence that Autism is often not identified among particular cohorts (such as women and gender-diverse people) until adulthood and that Autistic people are more likely than the general population to experience economic disadvantage, the MBS rebate restrictions mean that many individuals simply cannot afford a diagnosis.

Recommendation 31: Remove the age limit and remove (or as a minimum reduce) the rebate restriction on diagnostic assessments under the Medicare Benefits Schedule.

4.3.3 Information dedicated to Autistic people and families.

A straightforward way to improve the accessibility of services and supports to Autistic people and their families is to publish information specifically tailored to their needs. Development of such resources needs to occur through co-design with Autistic people, families, and the autism community with a particular focus on meeting intersectionality issues, various communication formats and channels, considering supported decision making, dignity of risk and substitute decision making.

Recommendation 32: Create and publish information tailored to the needs of Autistic people and their families with a particular focus on addressing various intersectionality issues, communication formats and channels, supported decision-making, dignity of risk and substitute decision-making.

4.4 Governance, Research, Evidence Framework, Evaluation and Reporting

This section responds to whether there is any feedback about the Commitments for Governance, Research and Reporting. These are all top-priority issues and foundational to the success of the National Autism Strategy.

³⁹ Blakemore, M et al. (date not available) 'Multiple and Intersecting Forms of Discrimination Against Autistic Women. For The Attention of the Special Rapporteur on Violence Against Women,' *The Coalition of Autistic Women*.
<<http://www.australianautismalliance.org.au/wp-content/uploads/2017/03/Autistic-Women.pdf>>.

4.4.1 Governance Framework

The Alliance strongly welcomes Commitment 21:

Develop a governance framework to support:

- a. strong accountability mechanisms,
- b. co-leadership and active involvement of Autistic people, as well as parents and carers, and professionals within the autism sector, and
- c. whole-of-government, cross-sectoral and coordinated approaches to implementation

Recommendation 33 is that Commitment 21 further captures the following for clarity and consistency:

1. *underpinned by the Guiding Principles,*
2. *a suitable statement reflecting page 18 of the Draft National Autism Strategy. That is establishing a governance framework:*
 - *that is representative of the diversity within the Autistic and autism community,*
 - *that adopts an inclusive process for consultations,*
 - *that designs actions with Autistic people and their families and carers and support networks to address the multiple and overlapping structural barriers they experience; and*
 - *provides ways for Autistic people and their families and carers and support networks to communicate with the Australian Government in a way that suits them*
3. *a suitable statement reflecting pages 28-29 of the Draft Autism Strategy Plan including proposed timelines, three action plan periods and the length of the National Autism Strategy,*
4. *that Autism strategy is viewed alongside any other policy initiatives and supported by adequate, ongoing funding models (refer to Alliance submission for the National Autism Strategy discussion paper),*
5. *that the detailed strong accountability and governance structures outlined in each of the three Action Plans will include an evaluation of the existing accountability and governance structures supporting change where evidence supports that these have not been successful to date, and outcomes are poor. This includes reviewing contemporary policies so that legislation and policy are aligned and consistent Nationally.*
6. *in the event, the Australian Government commits to DRC Recommendation 4.1 Establish a Disability Rights Act that the National Autism Strategy be referenced in the Act.*

6.4.2 Research

The Alliance strongly welcomes Commitment 22 to Research:

Explore how autism research can best be fostered and applied to policy and service delivery and underpinned by the Strategy's Guiding Principles.

The following recommendations are identified to provide clarity and a systemised approach in line with the Senate Select Committee on Autism recommendations.

Recommendation 34 *Commitment 22 is amended to capture the following:*

- a. *As well as Develop, “Design and Implement” autism research that can best be fostered and applied to policy and service delivery.*
- b. *underpinned by the Strategy’s Guiding Principles, and*
- c. *this research is linked to the National Autism Strategy Commitments, Evidence Framework and Evaluation and Reporting.*

For instance, 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 populations of women and girls, First Nations people, and those with Culturally and Linguistically Diverse (CALD) backgrounds.

Another example is there is little research in the area of high dependency needs including communications.

Recommendation 35 Commit to developing a National Autism Research Framework as recommended in the Senate Select Committee on Autism Recommendation 26. The Framework should commit to best practice approaches to ensure the involvement of the diversity of the Autistic and autism community, including often overlooked cohorts and Autistic researchers.

6.4.3 Evidence Framework

The Alliance strongly welcomes Commitment 23 to Evidence:

Develop a National Autism Strategy Evidence Framework, including a Theory of Change, Program Logic, Outcomes Framework, and Evaluation Framework.

The following recommendations are identified to provide clarity and consistency:

Recommendation 36: *Commitment 23 is amended to capture the following:*

1. *“and underpinned by the Strategy’s Guiding Principles”;*
2. *the National Autism Strategy Framework developed with the National Autism Strategy Oversight Council will form the baseline for the development of the National Autism Strategy Evidence Framework;*
3. *Accountability measures will include:*
 - a. **clear and measurable** outcomes, goals, actions, targets, milestones, and data requirements;
 - b. an **implementation plan** with clearly defined responsibilities;
 - c. **continuous monitoring, adjustment of actions as relevant and annual reporting requirements;**

- d. **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**;
- e. **built-in timelines** for **review** and **renewal** of the strategy (every 5 years) based on the aforementioned monitoring and re-engagement process. This should include a review of contemporary lessons learnt Internationally, Nationally and State/Territory Jurisdictions regarding relevant Strategy.

Please refer to the Alliance's submission to the National Autism Strategy discussion paper for more details.

Recommendation 37: Commit to undertake a review and incorporate as relevant the Senate Select Committee on Autism's Recommendations regarding data collection, including for a National Autism Register (Recommendations 27 and 28).

6.4.4 Evaluation and Reporting

The Alliance strongly welcomes Commitment 24 to Evaluation and Reporting:

Develop a robust Evaluation Plan and reporting mechanism, co-led by Autistic people and the autism community, for the National Autism Strategy.

The following recommendations are identified to provide clarity and consistency:

Recommendation 38: Commitment 24 is amended to capture the following:

- a. "and underpinned by the Strategy's Guiding Principles"
- b. inclusion of family and carers, Autistic community
- c. that is representative of the diversity within the Autistic and autism community,

Recommendation 39: A definition of co-led is added to the Glossary.

5. Section 3: Strategy Gaps

This section responds to what might be missing or other opinions we might have about the draft National Autism Strategy.

The Alliance commends the elements that comprise the National Autism Strategy and looks forward to seeing the developed Governance, Research, Evidence and Evaluation/Reporting details and First Year Actions.

Whilst there are considerable commitments identified it may be possible to make some a subset of others.

In saying that we have identified a number of key areas that should be incorporated that have not been identified. Some of these have been identified in the Alliance's submission to

the National Autism Strategy discussion paper. These have been extracted below for convenience.

5.1 Housing

Due to factors such as low employment rates, high rates of poverty and limited support for independent living, many Autistic people experience high rates of housing insecurity, homelessness and reliance on their family and caregivers for permanent and or temporary accommodation.⁴⁰

When Autistic people with high support needs are unable to stay with or rely on family for monetary support and accessible accommodation, it is common for them to be placed in institutional living environments in group homes, healthcare, and even aged care facilities. While it has been broadly recognised that people with disability have a right to right to choose where they live and whom they live with, a lack of accessible housing and support for independent living means that in reality, Autistic people with high support needs often have little choice but to remain in segregated living.

Relevant Intersectionality Issues

For First Nations Autistic people, Autistic women, the risk of housing insecurity is even more significant due to the high likelihood of experiencing domestic and family violence, family breakdown and caregiving responsibilities. While, like other areas, the availability of data on the rates of domestic and family violence and housing insecurity experienced by Autistic sub-groups is limited, we know from existing research that:

- Women with disability report higher rates of past sexual violence and intimate partner violence than their male counterparts.⁴¹
- Aboriginal women are 35 times more likely to suffer family violence, 80 times more likely to sustain serious injury requiring hospitalisation, and 10 times more likely to die due to family violence, than non-Aboriginal women. 60 percent of Aboriginal and Torres Strait Islander women who experience physical violence have a disability or long-term health condition.⁴²

Unfortunately, despite these high rates of violence among disabled (including Autistic) women; shelters, refuges and emergency accommodation services are generally not accessible to people with disability;⁴³ resulting in a situation where disabled women's only options are to face homelessness or to return to living under a roof with their violent perpetrator.

With adequate investment, NDIS funding for Specialist Disability Accommodation and Supported Independent Living has the potential to empower Autistic people to have choice in accommodation and to transition out of institutions, into supported independent living

⁴⁰ Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, pp. 32.

⁴¹ Australian Institute of Health and Welfare (2022) 'People with Disability in Australia' <<https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/labour-force-participation>>.

⁴² WWDA (2016) 'WWDA Position Statement 1: The Right to Freedom From All Forms of Violence'. *Women With Disabilities Australia*, Hobart, Tasmania <https://wwda.org.au/wp-content/uploads/2016/09/WWDA-Position_Statement_1_-_Violence_FINAL_WEB.pdf>.

⁴³ See for example: the Department of Social Services (2023) 'Safe Places Emergency Accommodation Program (Inclusion Round): Program Design Discussion Paper,' Australian Government, Canberra, p. 4 <<https://engage.dss.gov.au/wp-content/uploads/2023/01/Safe-Places-Inclusion-Round-Discussion-Paper-240123.pdf>>.

arrangements. However, the current eligibility criteria and funding restrictions mean that this funding is available to very few NDIS participants.

Recommendation 40: *Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to support Autistic People to have choice and control of Affordable, Accessible and Safe Housing Options. This includes Supported Independent Living, Homelessness, Effective Emergency Accommodation and transitioning from service or institutional settings as a priority for Autistic people in alignment with any National Strategies.*

5.2 Justice System including first responders, correctional services, and child protection.

Due to social and economic disadvantage, combined with entrenched ableism, intersectional discrimination, and limited access to supports, Autistic people of all ages are overrepresented in the justice system and child protection in all Australian states and territories. While the reasons for this are debatable, there are some key contributing areas of structural disadvantage.

Relevant Intersectionality Issues

When it comes to interacting with the justice system, Autistic people who experience intersectional discrimination are even more likely to have poor experiences or face discrimination. For First Nations Autistic people, for instance, the interaction between ableism and racism creates a situation where individuals are incarcerated without valid reason. In the Disability Royal Commission report on the 'Experiences of First Nations People With Disability,' it was highlighted that a lack of culturally appropriate criminal justice processes, combined with poor understanding of disability means that people with cognitive disabilities have high rates of incarceration;⁴⁴ which is reflected in broader evidence that First Nations people with disability are grossly overrepresented in prisons.⁴⁵ Compounding the discrimination faced by being Autistic, the same report highlighted that First Nations people with disability are also more likely to face ableist attitudes about their ability to plead in court processes and are more likely to be denied decision-making and representation in criminal proceedings through guardianship arrangements.⁴⁶

For First Nations Autistic women, the issues associated with reporting domestic and family violence are also exacerbated. Despite evidence that First Nations people with disability experience domestic and family violence at much higher rates than the general population, First Nations people with disability commonly report being disbelieved or dismissed when they report violence to police. Additionally, when First Nations women do proceed to family court for family violence or related issues, they experience high rates of discrimination and face heightened risk of losing custody battles over their children.

⁴⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) 'The experience of First Nations people with disability in Australia,' Australian Government, p. 5 <<https://disability.royalcommission.gov.au/publications/experience-first-nations-people-disability-australia>>

⁴⁵ See for example Collard, S (2020) 'Royal Commission hears high rates of First Nations prisoners with disability,' NITV, Viewed 12 June 2023 <<https://www.sbs.com.au/nitv/article/royal-commission-hears-high-rates-of-first-nations-prisoners-with-disability/1icq2y8pt>>; Baldry, E, McEntyre, E and Mcausland, R (2015) 'Why Aboriginal people with disabilities crowd Australia's prisons,' The Conversation, Viewed 12 June 2023 <<https://theconversation.com/why-aboriginal-people-with-disabilities-crowd-australias-prisons-48166>>.

⁴⁶ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) 'The experience of First Nations people with disability in Australia,' Australian Government, pp. 6-7 <<https://disability.royalcommission.gov.au/publications/experience-first-nations-people-disability-australia>>

Recommendation 41: *Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Arrest the Overrepresentation of Autistic people dealing with the Justice System and Child Protection issues and Achieve Effective Informed Interactions. This includes:*

- a. Autism Training for the Justice System Workforce including first responders, correctional services, and child protection
- b. Prison-to-community transitions
- c. Improvement of Child Protection processes
- d. Medicare benefit scheme access remains active while incarcerated
- e. NDIS Plans reactivation before release from incarceration

5.3 Transportation and Accessible Supports

Transportation is a key enabler of economic and social inclusion. This includes all forms of transportation - road, rail and air and should extend to assistance animal accessibility on transportation. Important elements are accessibility, availability, and affordability.

A Nationally consistent approach is needed as evidenced by the recent issues with the National Transport Commissioner (NTC) updates to the national driver medical standards ('Assessing Fitness to Drive'), which sets out the considerations and medical criteria for safe driving of drivers with health conditions. Recently, the NTC updated the standards to include autism as a condition that "should be assessed individually", which may involve a practical assessment. This change led to significant concerns among Autistic Australians including cancellations of autism assessment appointments after learning they could be required to disclose their condition under Fitness to Drive standards.

This came about due to a number of issues – this included limited consultation with the Autistic and autism community and interpretation of a national change to individual states.

Recommendation 42: *Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Address Transport Accessibility, Availability and Affordability Challenges.*

5.4 Carer Economy

As reported in the Senate Committee Inquiry on Autism report⁴⁷ despite the well-being of parents and carers being critical to the success of autistic people, there is overwhelming evidence that support for parents and carers is currently inadequate. The indirect economic costs of caring are well known and were one of the factors that led to the establishment of the National Disability Insurance Scheme (NDIS).⁴⁸

⁴⁷ Senate Select Committee report on Autism, March 2022. Services Support and Life Outcomes for Autistic Australians, Chapter 4

⁴⁸ The Productivity Commission estimated that about \$1.5 billion per annum of economic benefits would occur from carers re-entering the workforce.

There is a need to build a sustainable care economy, including interaction with NDIS and capacity building as this is an important element of a successful ecosystem. Modelling⁴⁹ suggests ...

that informal carers of people with intellectual disability and/or ASD in Australia had aggregated lost income of AU\$310 million, lost taxation of AU\$100 million and increased welfare payments of AU\$204 million in 2015. These are projected to increase to AU\$432 million, AU\$129 million and AU\$254 million for income, taxation, and welfare respectively by 2030.

Research from organisations like Autism Queensland indicates that factors that contribute to this include the demands on parents of Autistic students, which often surpass those of parents of non-Autistic students (e.g., demands to collect their children early, attend school meetings or to home-school their children). This means that parents of Autistic students often have reduced opportunities to engage in paid employment which adversely impacts parental wellbeing and financial security.

Relevant Intersectionality Issues

For women who are from low socio-economic backgrounds, are First Nations, culturally and linguistically diverse, from migrant and refugee backgrounds, in LGBTIQ+ relationships, or experience discrimination on the basis of their age; pregnancy and motherhood can present an array of additional barriers. Many migrant and refugee women for example, especially those on temporary VISAs are not eligible for government support payments such as Paid Parental Leave, the Family Tax Benefit (FTB) and the Childcare Care Subsidy (CCS).⁵⁰ Women over 35 years of age are more likely to suffer discrimination from the medical system due to increased gestational risk of complications, people in LGBTIQ+ relationships are often not recognised or accommodated appropriately by pre and post-natal care services⁵¹ and First Nations families experience disproportionately high rates of child removals or interventions from child protection systems.⁵²

Recommendation 43: *Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Build a Sustainable Carer Economy including access to peer parent networks, parenting support needs⁵³, respite and succession plans for the care of their Autistic children.*

5.6 Autism Specific Independent Advocacy

There is a need for both autism specific national systemic advocacy and local generalised and autism specific independent disability advocacy services.

Independent Disability Advocacy is and always will be a critical part of the disability support ecosystem. This is because Independent Disability Advocacy organisations act in the interests of and with the person with disability, without conflict of interest with Government, public and private service providers, the NDIA, or disability service providers, creating a

⁴⁹ Deborah Schofield, D., Zeppel M.J.B., et. al. (2019) *Intellectual disability and autism: socioeconomic impacts of informal caring, projected to 2030*, BJP 215, 654–660. doi: 10.1192/bjp.2019.204.

⁵⁰ ASRC (2020) 'Income support and Centrelink entitlements for temporary visa holders,' *Asylum Seeker Resource Centre*, Viewed 7 June 2023 <<https://asrc.org.au/wp-content/uploads/2013/04/HRLP-Infosheet-COVID19-Jobkeeper-and-Jobseeker-updated-August-2020.pdf>>.

⁵¹ Pregnancy, Birth and Beyond (2023) 'LGBTQIA+ Parents – Facing Discrimination in Pregnancy & Parenthood,' Viewed 7 June 2023 <<https://www.pregnancy.com.au/lgbtqi-parents-facing-discrimination-in-pregnancy-parenthood/>>.

⁵² Campanella, N and Edmonds, C (2020) 'Disability, domestic violence a 'catch 22' as Indigenous children removed from mothers, royal commission hears,' *ABC News*, Viewed 7 June 2023 <<https://www.abc.net.au/news/2020-11-24/disability-domestic-violence-leads-to-removal-of-indigenous-kids/12915728>>.

⁵³ Women With Disabilities Australia (WWDA) (2022). 'Submission on Sexual and Reproductive Rights of Women and Girls with Disability to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.' December 2022. Written by Carolyn Frohmader and Dr Linda Steele for and on behalf of Women With Disabilities Australia (WWDA): Hobart, Tasmania, p. 215

genuine commitment to upholding individual human rights. Independent Disability Advocacy organisations play an interventionist and protective role in prevention and safeguarding, as well as a supportive and developmental role in managing crises and complaints and supporting the achievement of beneficial outcomes.

The National Disability Advocacy Framework (NDAF) recognises the critical role of advocacy. “Under the 2023–2025 NDAF, the Australian Government and state and territory governments have committed to the following objective: People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights, enabling full community participation and inclusion”⁵⁴. Nearly 60 independent disability advocacy organisations throughout Australia are funded through the Commonwealth Government’s National Disability Advocacy Program (NDAP)⁵⁵.

An intake survey between September 2021 – February 2022, undertaken by Disability Advocacy Network Australia (DANA), indicates that Independent Disability Advocacy organisations only have the funded capacity to provide for 31%-36% of requests for support.

Independent Disability Advocacy services are also an enabler in meeting National Agreements, and International Obligations (United Nations Convention on the Rights of Persons with Disabilities)

The Return on Investment in independent disability advocacy is demonstrated by the Cost/Benefit Analysis of disability advocacy. This review demonstrated \$3.50 is returned for each \$1 of cost⁵⁶, freeing up government resources for their next best use and providing many multiplier benefits. The opportunity cost lost for every \$1 not being invested becomes an economic and social cost to society.

Currently, Autistic people and their families are feeling unsupported at times, particularly in relation to NDIS AAT cases, due to the diverse nature of autism and intersectionality issues. This is compounded by the usual tight timeframes due to the reactive nature of advocacy supports currently, no provision for case management and the increasing demand with inadequate funding models to provide effective support.

It is a critical timing for investment aligning with public expectations as trends indicate that the demand for independent disability advocacy will increase, driven by the increasing population of people with disability and increased community expectations for change including from the Disability Royal Commission, NDIS Review (foundational supports) and other review findings. Failure to address this change will create cascading points of pressure on government service provision.

Recommendation 44: *Include a Commitment in the National Autism Strategy to Develop a model and Fund Independent Specialised Autism Advocacy delivered locally in the changing environment.*

⁵⁴ National Disability Advocacy Framework 2023-2025, pg 3, <https://www.dss.gov.au/disability-and-carers-programs-services-for-people-with-disability/national-disability-advocacy-framework-2023-2025-0>

⁵⁵ <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap>

⁵⁶ A Cost Benefit Analysis of Australian independent disability advocacy agencies Anne Daly, Greg Barrett, and Rhiân Williams (2017) op. cit.

5.7 Workforce, Productivity, and Innovation

Currently, disability needs an increased workforce but there has been a national shortage for a number of years. This is coupled with a high rate of burnout, due to the nature of disability involving complex human-to-human interactions, and lower productivity due to the nature of the work.

Furthermore, with low margins making investment in innovation difficult and being time poor the human services sector has not looked to technology to augment human function as a solution, despite the many opportunities where technology can:

- a. augment the current workforce to advance capacity, improve skills, increase productivity, enhance well-being, and reduce workplace incidents.
- b. augment individuals requiring support to achieve greater independence and improve the quality and safeguarding of participants.
- c. create a multiplier effect on the Australian economy.

Emerging technology is an important human innovation partner that can provide life-changing outcomes for future generations of Australians with disability enabling a healthier society, increasing economic and social participation, building greater independence, and contributing positively to the carer economy.

Most importantly it can supercharge productivity of the existing workforce.

This is currently inaccessible to many in the Disability sector due to a lack of:

1. capacity to undertake innovation. Typically, the disability sector is faced with a mismatch between what is needed and the ability of the technologies to deliver desired outcomes and are usually beyond reach to solve and fund on their own.
2. funding models that facilitate access to innovation funds or incentive to commit funds to innovation. While it is recognised that the Profit for Purpose organisations do not pay tax which is beneficial, there is no equivalent R&D incentive scheme as for the commercial sector.
3. commercial arrangements with government to nurture true innovation and undertake trials or rollouts, while reducing the risk of funds not realising their Return on Investment.
4. Cultural awareness to recognise how technology can augment human function with ethical monitoring and trusted intervention without compromising privacy, safety or taking away the “care” aspect.

The current approach is to continue to solve problems in the same way. One possibility is to support a carer economy and the other is to encourage greater representation of people with lived experience in delivering supports and services to Autistic people.

Without a deliberate strategy, there will continue to be many missed opportunities to make real traction in solving the workforce shortage.

Recommendation 45: *Include a Commitment in the National Autism Strategy to Develop and Implement a Workforce and Innovation Strategy that results in a productive, skilled, resilient, value-based workforce and optimises the human capability of Autistic people.*

5.8 Ageing

While all Autistic people face the prospects of a lower life expectancy than the general population, the current older generations of Autistic people are at risk of dying even more

prematurely due to factors such as lack of access to supports and a reliance on large institutional environments; where it is more common for people to die prematurely.⁵⁷

Relevant Intersectionality Issues

For older people who experience intersectional disadvantage, there are a number of compounding issues which impact their experience. For example, older Autistic women who live in aged care facilities are much more likely than males to experience sexual harassment and violence. While statistics on the rates of sexual violence experienced by older Autistic women do not exist, reports on the issue of sexual violence in aged care facilities have indicated that residents with cognitive disabilities are at higher risk.⁵⁸ Additionally, the tendency of older Autistic women to miss social cues, experience communication difficulties and have few family and friends to report issues, makes them a target for violence in the aged care system.

The NDIS is the only national support system tailored to Autistic and disabled people, but currently, people over 65 years are not eligible.

Like all other areas, there is a desperate need for aged care staff to be equipped to support older Autistic people. While many of the qualifications required to become an aged carer are lumped in disability support work qualifications, the majority of these courses are not specific enough to equip individuals to support specific disabilities, and the content is not consistent across providers.⁵⁹

Additionally, in recent years, it has been identified that there is a need to better equip aged care staff and facilities to recognise and respond to instances of poor treatment, neglect, and violence. While the Aged Care Quality and Safety Commission include the remit to investigate and act on instances of violence, abuse, neglect, and poor treatment in aged care facilities through the Serious Incident Response Scheme (SIRS),⁶⁰ current guidelines first require aged care facilities to report an incident within 24 hours and to determine if there is an impact on the victim.⁶¹

Given that most aged care staff are not trained in recognising and responding to abuse and violence, and that the majority of aged care facilities are battling with stretched human resources, these requirements place impossible standards on individuals.

Recommendation 46: Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy for elderly Autistic people.

⁵⁷ Ibid, p. 12

⁵⁸ See for example Knaus, C (2022) 'Shocking' rate of sexual abuse of aged care residents barely changed since royal commission,' *Guardian*, Viewed 12 June 2023 <<https://www.theguardian.com/australia-news/2022/jun/06/shocking-rate-of-sexual-abuse-against-aged-care-residents-barely-changed-since-royal-commission>>.

⁵⁹ See for example: Autism Awareness Australia (2021) 'Beyond School: Further education,' Viewed 13 June 2023 <<https://www.autismawareness.com.au/beyond-school/further-education>>.

⁶⁰ Aged Care Quality and Safety Commission (2023) 'Serious Incident Response Scheme: Frequently Asked Questions,' Viewed 13 June 2023 <<https://www.agedcarequality.gov.au/sirs/frequently-asked-questions>>.

⁶¹ See for example: Alderslade, L (2022) 'Recent data shows over 500 sexual assaults in aged care in three months,' *Aged Care Guide*, Viewed 13 June 2023 <<https://www.agedcareguide.com.au/talking-aged-care/recent-data-shows-over-500-sexual-assaults-in-aged-care-in-three-months>>.

5.8 Early Investment (Intervention)

The draft Strategy appear to have sparse mention of early investment (intervention). Given the importance of early investment in services and supports in the context of Autism a specific commitment to early investment in services and supports should exist particularly in the context of the NDIS Review recommendations for Foundational Supports and the Federal commitment to Early Years.

Recommendation 47: *A further commitment be added to Diagnosis, Services and Supports that captures the development of a strategy regarding Early Investment (Intervention) and how this will interface with the NDIS Review regarding foundational supports and the Federal Early Years strategy to ensure the needs of Autistic people and their families are met.*

6. Conclusion

We thank you for the opportunity to respond and are committed to continuing to work with the Australian Government to achieve the development and implementation of a successful National Autism Strategy in partnership with the government and the diverse Autistic and autism community who we serve to achieve Autistic people thriving in an inclusive society.

Contact:

We welcome the opportunity to discuss this further. Please do not hesitate to contact us:

E: chair@australianautismalliance.org.au

Jenny Karavolos, Co-Chair | M: 0401 988 186 E: jenkaravolos@outlook.com

Chris Varney Co-Chair | M: 0432 405 384 E: chris@icannetwork.com.au