An Integrated and Inclusive Safe Society

Submission to the DSS National Autism Strategy

We welcome the opportunity to discuss further. Please contact:

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ABOUT THE AUSTRALIAN AUTISM ALLIANCE

www.australianautismalliance.org.au

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

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

KEY INFORMATION

Acknowledgement

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

Contributors

The Autism Alliance recognises and thank emphatically to the Autistic people, parents, families, carers and the autism community who have contributed to this submission through a variety of channels and sources:

- Australian Autism Alliance members
- NDIS Review Submission August 2023: Enduring Solutions for a Neurodivergent Population, authors AW Shim and J Karavolos and contributors consisting of the Australian Autism Alliance, Community, professional and research sector members of National Autism Strategy Oversight Council (Clare Gibellini, Heidi La Paglia Reid, Associate Professor Josephine Barbaro, Victoria Gottliebsen, Andrew Pfeiffer, Andrew Shim)
- Australian Autism Alliance Paper: The Autistic Experience 2023 - The Systemic Impact, authors J Karavolos and Heidi La Paglia Reid, and contributors consisting of the Australian Autism Alliance
- Focus groups and discussions.
- 2023 Community Survey with A4
- 2020 Australian Alliance Survey undertaken by 3800+ participants.

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Language

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

National Autism Strategy
Submission
30 October 2023

AUSTRALIAN
Autism Alliance

EXECUTIVE SUMMARY

The following submission is in response to the DSS National Autism Strategy discussion paper that asks a series of questions as outlined in the paper below.

As recognised in the Senate Select Committee on Autism[1] 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 Senate Inquiry on Autism found that key drivers of poor outcomes include:
• Low understanding of autism amongst community and key service provider workforces.
• Delays in diagnosis and early support.
• Complex and poorly integrated service environments.
• Services not designed to meet the needs of Autistic people.
• Autistic needs not being addressed in general disability strategies and approaches

Also, despite the high prevalence of autism, it remains a widely misunderstood condition, and the factors that serve to enable (or disable) Autistic people have been largely overlooked in many of the disability inclusion and accessibility efforts to date. The release of the Disability Royal Commission report further demonstrates that autism is still not recognised and understood, noting however there are a number of recommendations that are very applicable to the National Autism Strategy (NAS). Refer Appendix 1 for comments. What is common is the frustration at the lack of understanding and acknowledgment across all sectors of the unique and often invisible barriers faced by Autistic people.

As a result, it is critical that the NAS, does not operate in isolation and the broader recommendations in this paper occur to underpin the NAS to ensure it is impactful, provides for longevity of a broad vision for government and society to follow and address the intersectionality and accountability gaps that currently exist in the current ecosystem.

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

It is also critical that it is recognised that the experience of autism is diverse, and a one size fits all solution approach will not be sufficient.

Below is a summary of the recommendations in addition to the specific responses to the questions posed by the NAS Discussion paper. This paper primarily focuses to provide an outline of some of the key areas and issues that are often overlooked and has an emphasis on intersectionality issues, given that it is understood that prior reviews and submissions are also being considered and there is an insufficient response period to respond to all areas.

<p align="center">**MODELS OF DISABILITY**</p>

Recommendation 1.1

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

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

Recommendation 1.2

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

GOVERNANCE AND ACCOUNTABILITY FRAMEWORKS

Recommendation 2.1

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

o clear and measurable actions, targets and milestones;

o an implementation plan with clearly defined responsibilities;

o continuous monitoring and annual reporting requirements; and

o evaluation reports through re-engagement with the Autistic and autism community no less frequently than every 3 years.

o built in timelines for review and renewal of the strategy (every 5 years), based on the aforementioned monitoring and re-engagement process, and with the support of a majority-led Autistic and autism community oversight council.

Recommendation 2.2

That the Australian Government implement these accountability measures by:

o Mandating effective governance and frequent monitoring through the introduction of legislation — modelled after the *Autism Act (Northern Ireland) 2011* (NI) or the *Autism Act 2009* (UK) — that builds timelines for regular review and development of the NAS. Noting the Act being considered is not required to be an extensive document but modelled on focussing on capturing these recommendations.

○ Empowering a dedicated, independent, Autistic-led taskforce to oversee progress on implementation KPIs on the local, state/territory, and national level by granting them access to the Disability Reform Ministers.

Recommendation 2.3

That the Australian Government support the Autistic-led taskforce by granting the Autistic-led taskforce with governance and oversight over independent auditors, which shall by legislation have the power to independently investigate cross-jurisdictional complaints and accountability gaps — including lack of progress on implementation KPIs.

INTERACTION WITH LOCAL, STATE, & COMMONWEALTH SERVICES

Recommendation 3.1:

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

Recommendation 3.2:

That a Federal Assistant Minister for Autism, Premier and Cabinet, be appointed to ensure the operationalisation of a co-ordinated and integrated whole of government and whole of life approach.

Recommendation 3.3:

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

Recommendation 3.4:

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

Recommendation 3.5:

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

○ values and behaviours that underpin all the capabilities in the framework.
○ evaluation methodology:
▪ individual assessment of knowledge and/or competence
▪ impact on practice
▪ impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
○ continuous monitoring and annual reporting requirements.
○ built in timelines for review of the framework (every 3 years).

Recommendation 3.6:

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

o First Nations people;

o Women and girls;

o LGBTQIA+ communities;

o Culturally and Linguistically Diverse ('CALD') communities;

o People in regional and remote areas;

o Individuals in the child protection and justice systems;

o Senior (50+ years) people;

o People in supported independent living;

o Students in various education settings; and

o People with complex needs and high dependency needs

Recommendation 3.7:

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

o Do you have a neurodevelopmental condition? Tick all that apply:

▪ Autism or Autism Spectrum Condition, including Autism Spectrum Disorder

▪ ADHD

▪ Dyslexia, Dyscalculia, Dyspraxia, Dysgraphia, or a Specific Learning Disorder (SPDs)

▪ Another neurodevelopmental condition

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**STRATEGY TO SUPPORT THE RIGHTS, AUTONOMY, AND DIVERSITY
OF AUTISTIC PEOPLE**

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Recommendation 4.1: A Human Rights Model of Disability

Recommendation 4.2: Recognition of Divergent Population and Divergent Views

Recommendation 4.3: Moving to an Inclusive Society

Recommendation 4.4: Recognition of the Intersectionality of the Autistic Community

Recommendation 4.5: Addressing Intersectional Discrimination

IMPROVE UNDERSTANDING OF AUTISM POPULATION GROUPS

Recommendation 5.1 A vertically integrated society understanding, accepting, and actively including autism at all levels –Federal, State, Local, Community, Organisations and Individual.

Recommendation 5.2 Change the narrative

SOCIAL INCLUSION

Recommendation 6.1 Increase Community Understanding of Neurodiversity

Recommendation 6.2 A review of the Disability (Access to Premises — Buildings) Standards 2010 with invisible disability in mind

Recommendation 6.3 National Standards for Autism Friendly Environments and Services Across Australia

Recommendation 6.4 Funded Programs under accountable contract models

Recommendation 6.5 Funded Peer support

Recommendation 6.6 Invest in Specialist Disability Accommodation and Supported Independent Living

Recommendation 6.7 Provide Effective Emergency Accommodation

Recommendation 6.8: Autism Training for Justice System Workforce

Recommendation 6.9 Resourcing for supports and accommodations (exiting justice system)

Recommendation 6.10 Prison to community transitions

Recommendation 6.11 Medicare benefits are still accessible while incarcerated

Recommendation 6.12 NDIS Plans are reactivated when released

ECONOMIC INCLUSION

Recommendation 7.1 Training for Educators

Recommendation 7.2 Disability Standards for Education

Recommendation 7.3 Funding for inclusive school practices and early intervention underpinned by choice and control

Recommendation 7.4 Better School Transition Supports

Recommendation 7.5 Fund Peer and Mentoring Support

Recommendation 7.6 Create Pathways to Careers

Recommendation 7.7 Transition Programs to enable sustainable employment

Recommendation 7.8 Workplace Inclusion Initiatives

Recommendation 7.9 Government create placements in the workplace

DIAGNOSIS AND SERVICES AND SUPPORTS

Recommendation 8.1 Training for health professionals working in prenatal, post-natal and early childhood services

Recommendation 8.2 Accommodations for Autistic mothers in maternity wards

Recommendation 8.3 Targeted support for Autistic parents in the pre- and post-natal period

Recommendation 8.4 Supports for Parents

Recommendation 8.5 Information dedicated to Autistic people

Recommendation 8.6 Increase Medicare Benefits (to access Diagnosis)

Recommendation 8.7 Increase availability of assessors

Recommendation 8.8 Improve diagnostic assessments

HEALTH AND MENTAL HEALTH ROADMAP

Recommendation 9.1 Training for health/medical professionals

Recommendation 9.2 Expansion of coverage under the MBS

Recommendation 10.1 Expansion of NDIS Eligibility to include people over 65 years

Recommendation 10.2 Better resource and train staff in the aged care system

Recommendation 10.3 Building a sustainable care economy

Recommendation 10.4 Provide funding for "Preventative" Independent Advocacy and Specialisation

BACKGROUND

Autistic People in Australia

Autism is a lifelong neurodevelopmental difference. Every Autistic person is different, and the support needs for each person differs, and this may change over time, particularly around big life transitions. Autism is highly prevalent and affects people from all walks of life and across the lifespan. It is among the biggest disability groups in Australia.

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

While we wait for the next ABS data to be released, there is evidence that the prevalence rate in Australia is very consistent with the prevalence rate with the Centre for Disease Control [2](USA) and the UK[3].

A recent study[45] screening 13,511 children in Victoria, returned a prevalence rate of 1 in 50 (2%) between 11 and 30 months of age and 1 in 31 (3.3%) between 11 and 42 months of age, based on data collected over 6 years. This was a very tightly controlled, rigoro**us** study with thorough diagnostic assessments to confirm diagnosis, and the use of advanced statistical methods to infer missing data. Therefore, the most current Australian data would indicate that the prevalence is approx. 1 in 31 or 3.3% of the Australian population (approximately 867,000 of Australian's based on current population numbers - 26,268,359 - from ABS December 2022 data)[6].

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

[3] https://www.thelancet.com/journals/lanepe/article/PIIS2666-7762(23)00045-5/fulltext

[4] Bent, C. A., Dissanayake, C., & Barbaro, J. (2015). Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010-2012. *The Medical journal of Australia*, *202*(6), 317–320. https://doi.org/10.5694/mja14.00328

5 Barbaro, J., Sadka, N., Gilbert, M., Beattie, E., Li, X., Ridgway, L., Lawson, L., & Dissanayake, C. (2022). Diagnostic accuracy of the Social Attention and Communication Surveillance–Revised with Preschool tool for early autism detection in very young children. JAMA Network Open, 5(3), e2146415. https://doi.org/10.1001/jamanetworkopen.2021.46415

[6] https://www.abs.gov.au/statistics/people/population

However, it is important to recognise that this is likely an underestimation as there is likely children who do not present with traits clear enough to be identified until school age. More broadly speaking, the burgeoning of research and clinical understanding of autism over the past decade or so has also left many clinicians without the current knowledge to recognise more subtle or 'internalised' presentations of autism, as well as presentations outside of the "white, western" presentation that our current criteria are based upon. This is particularly apparent for populations of women and girls, First Nations people, and those with Culturally and Linguistically Diverse (CALD) backgrounds. It is also recognised that the diagnosis pathway is often expensive, and many do not have access to appropriate services to seek identification, especially in regional and remote areas of Australia. Together this may in part account for the lower diagnostic rates in the broader Australian population.

Other important information:

o 95% of Autistic people have other co-occurring conditions such as ADHD or intellectual disability, specific learning disabilities such as dyslexia or dyspraxia, and/or mental health issues such as depression and anxiety.
o Autism is the largest primary disability group in the NDIS (34%).
o Autism requires a spectrum of solutions as there is no one size fits all. It is a divergent population with divergent needs and views to be addressed and not silenced by one group over another but supported through the principles of:
  o self-determination and choice and control
  o inclusion where the environment is safe and conducive to achieve the outcomes of the individual
  o a need for a range of supports, irrespective of their diagnosis or diagnosis level
o Some Autistic people may never require the NDIS if appropriate supports exist in mainstream settings and in the community. A historical and ongoing lack of appropriate supports in mainstream settings[7] and in the community, however, has led to many Autistic people needing significant and often ongoing supports.

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

KEY DISCUSSION QUESTIONS

1. What does a National Autism Strategy need to achieve?

The National Autism Strategy needs to achieve for every Autistic Australian to live a meaningful life they choose across the lifespan, as an equal member of a safe and integrated society that values the contribution of neurodivergent people.

While there are many recommendations, the legislative and policy recommendations outlined in the Executive Summary from Recommendation 1.1 to Recommendation 3.7 of this paper would underpin the success of the National Autism Strategy (NAS). This will provide for longevity of a broad vision for government and for society to follow and address the intersectionality and accountability gaps that currently exist in the current ecosystem. More detail of these recommendations are available in the Alliance NDIS Review submission paper[8] and an extract provided in Appendix 2.

In the current environment, the NAS would operate as an island as it does not have State Government commitment, unlike the Australian Disability Strategy. While it is understood that government policy seeks NOT to differentiate the separate disability cohorts and indeed there are many aspects of this submission that applies and benefits all disability cohorts particularly given the significant level of co-occurring conditions that exist (refer background section) – it is also time to agree that autism is different and the "whole of disability" strategies are not and will not achieve equitable outcomes when it comes to legislation and policy unless autism is specifically recognised.

These recommendations also provide the opportunity for the Federal government to be demonstrably the exemplar organisation (and for all state government agencies to follow their lead) for autism inclusion practice through investment in organisation-wide knowledge, skills, and confidence in engaging with and including Autistic individuals, their families, and carers. The majority of the 81 recommendations in the Senate Select Committee on Autism report found that the biggest barrier to inclusion is 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.

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

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[8] NDIS Review Submission August 2023: Enduring Solutions for a Neurodivergent Population, authors AW Shim and J Karavolos and contributors consisting Australian Autism Alliance, Community, professional and research sector members of National Autism Strategy Oversight Council (Clare Gibellini, Heidi La Paglia Reid, Associate Professor Josephine Barbaro, Victoria Gottliebsen, Andrew Pfeiffer)

2. What outcomes would you most like to see from a National Autism Strategy?

a. That Autistic people and their parents, families, carers, and the autism community:

   i. are no longer falling behind the outcomes of other Australians;

  ii. that they are integrated in all aspects of society;

 iii. are part of policy and legislation shaping and considered an important priority cohort;

b. There is a vertically integrated society understanding, accepting, and actively including autism is at all levels –Federal, State, Local, Community, Organisations and Individual

c. That 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 ever tier of government relies on the individual needing to navigate the systems, educate, and facilitate the interfaces and gaps.

3. What are your priorities for a National Autism Strategy?

3.1 For the Federal government and the NDIS to be demonstrably the exemplar organisations (and for all state government agencies to follow their lead) for autism inclusion practice through investment in organisation-wide knowledge, skills, and confidence in engaging with and including Autistic individuals, their families, and carers.

3.2 The majority of the 81 recommendations in the Senate Select Committee on Autism report found that the biggest barrier to inclusion is 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.

3.3 Furthermore other priorities that are critical is that:

a. lived experience and self-determination is enabled throughout society

b. all of society better understands:

      i. disability and autism/ neurodiversity

      ii. values lived experience; and

      iii. enables self determination

c. impact, outcomes, and accountability frameworks are put in place to underpin the implementation of the National Autism Strategy

d. monitoring and evaluation occurs

e. independent governance exists

f. Autistic people and parent/families/ carers and autism specific organisations are involved in the co-design, co-production, and co-delivery across the broader eco-system

g. minority groups are prioritised

h. intersectionality issues are recognised

i. the recommendations of the Senate Inquiry report be assessed to identify any amendments based on community engagement and to identify any gaps

j. all government reviews are assessed with an "Autism" lens including the NDIS Review report and the DRC report.

k. appropriate resourcing is provided to enable the recommendations

4. How can the Strategy support the rights, autonomy, and diversity of Autistic people?

4.1 A Human Rights Model of Disability

Across Australia, existing support structures (e.g. the NDIS) and diagnostic services are largely underpinned by the 'medical model' of disability. Under this model, Autistic individuals are viewed as impaired or having a "deficit" and the onus to change is placed on the individual, rather than on their support system, community, or society as a whole.

When abiding by the principles of international human rights conventions such as the CRPD however, it is essential that disability is viewed through the lens of the 'Social Model of Disability' (The Social Model) which allows us to see that individuals are disabled by 'physical, attitudinal, communication and social barriers which' prevent their full and equal and participation in society. While The Social Model has rarely been used in literature as a theoretical tool to understand autism, it is a helpful tool to understand what governments, societies and communities can do to improve the experiences of the Autistic community. As described by Quinn and Degner:

The human rights model focuses on the inherent dignity of the human being and subsequently, but only if necessary, on the person's medical characteristics. It places the individual centre stage in all decisions affecting him/her and, most importantly, locates the main 'problem' outside the person and in society.[9]

At the same time, increasingly inclusive education, employment, and a more neuro-affirming community mean Autistic Australians have better prospects for living and working independently in adulthood. Inclusion, when it works properly, accommodates more Autistic difference … and a well-implemented social model of Autistic disability reduces perceptions of "disorder" characterised in a more medical model of disability. Less of autism is characterised as "disorder".

4.2 Divergent population and divergent views need to be recognised

The Autistic population is divergent with:

- Autistic people being proud of their diversity and celebrate their difference
- Autistic people who do not like reference to disability
- Autistic people who do not wish or require any supports
- Autistic people who want to be supported
- Autistic people who do not want any supports
- Autistic people who have complex and high dependency needs
- Autistic people, after all efforts have been made for supported decision making, need their voice to be heard regarding their life experiences through someone who has lived experience as the parent/ family or carer or by some other chosen person
- Many other permutations

But all want, among other things:

- self-determination and choice and control
- respect and dignity and to be free of abuse, discrimination, and vilification
- equity
- an inclusive and safe society

Hence all these experiences need to be recognised and strategies developed to achieve outcomes for all Autistic people as informed and evaluated through the effective

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[9] G. Quinn and T. Degener, 'The Moral Authority for Change: Human Rights Values and the Worldwide Process of Disability Reform', in Human Rights and Disability: The Current Use and Future Potential of Human Rights Instruments in the Context of Disability, eds. G. Quinn and T. Degener (United Nations, 2002), 13, 14.

channels created to enable all voices to be heard, so that codesign, co-production and co-delivery occurs with and for authentic voices of the respective cohort, including recognising the intersectionality of the Autistic community. Hence the call to action is to look around the table and see who is missing and make the space.

4.3 Moving from a Neurotypical World to an Inclusive Society

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 Rights[10] and the Convention on the Rights of Persons with Disabilities,[11] 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,[12] 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.[13] This need for support is often linked to 'functioning levels,' according to medicalised assessments.

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[10] International Covenant on Civil and Political Rights 1966 ([1980] ATS 23)
[11] Convention on the Rights of Persons with Disabilities 2006 [2008, ATS 12]
[12] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra.
[13] 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.[14] 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,

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

experience unacceptably high rates of incarceration and are rarely included in decisions about services or interventions that are forced upon them.[15]

4.4 Recognising the Intersectionality of the Autistic Community

In Australia and across the world, the common profile of an Autistic person is, and has long been, a white anglo-saxon, usually young, male. Dominant representations of Autism in the media reinforce this with Autistic characters from films and television series like 'Rain Man,' 'The Good Doctor,' 'The Big Bang Theory' and 'ATypical' all being the 'typical' white male. Unsurprisingly, this caricature is not only representative of a bias in the media, but also has reflected the most common traits of people with a formal diagnosis of autism. Due to biases in research and diagnostic processes, as well as a lack of community awareness and other barriers (discussed more in depth below), it is becoming increasingly acknowledged that autism is underdiagnosed in women and girls, First Nations people, culturally and linguistically diverse (CaLD) people, the Lesbian, Bisexual, Transender, Intersex, Queer, Questioning and Asexual (LGBTIQA+) community, older Autistic people and those who experience economic or geographical disadvantage.

In acknowledging this, it also needs to be recognised that the Autistic community is more diverse and intersectional than previously thought and that any attempts to address the various ways in which Autistic people are impacted by multiple and intersecting identities based on factors such as race, gender, culture, age, parenting or carer responsibilities, socio-economic status, and geographical location.

4.5 Addressing Intersectional Discrimination

In identifying issues experienced by the Autistic community, it needs to be recognised that Autistic people with intersectional identities experience have compounded experiences discrimination and poor outcomes based on factors such as lower rates of formal diagnoses, limited access to service provision and the intersection of ableism with other forms of prejudice such as racism, ageism, sexism, homophobia, transphobia, biphobia, xenophobia, and classism.

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[15] 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>

One of the clearest examples of intersectional disadvantage experienced by Autistic people can be seen in access to support systems, such as the National Disability Insurance Scheme (NDIS). While the NDIS is the only nationally funded initiative that has the potential to provide necessary support to all Autistic people, there are considerable differences between the support Autistic people receive based on factors such as age, gender, race, and ethnicity.

According to the most recent statistics on Autistic NDIS participants for example; while 34% of NDIS participants had Autism listed as their primary disability, 90% of this cohort were young people (under 25 years of age), 71% were male and only 6% were First Nations and CaLD[16] Due to restrictions on eligibility criteria, older Autistic people (over 65) are not able to access the NDIS at all[17] and there is no data available on the percentage of LGBTIQA+ Autistic people who are currently NDIS participants.

While these percentages partly reflect rates of diagnosis within the population, they are also indicative of a system which is built for only those who fit the stereotypical presentation of what it means to be Autistic.

5. What needs to improve so Autistic people are better supported across their whole life?

Refer detail in Section 9 regarding Discussion Areas

6. What can be done to better support Autistic people from different population groups, including:

Refer detail in Section 9 regarding Discussion Areas

7. What might help to improve people's understanding of Autism population groups?

Recommendation 5.1 A Vertically Integrated Society

There is a vertically integrated society understanding, accepting, and actively including autism is at all levels –Federal, State, Local, Community, Organisations and Individual. This will be achieved through various education campaigns starting with a public

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[16] NDIA (2022) 'Autism Summary - September 2022,' *National Disability Insurance Agency*, pp. 1 - 3.
[17] NDIA (2022) 'NDIS: Am I Eligible?' *National Disability Insurance Agency*, Viewed 13 June 2023 <https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>.

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.

What does a vertically integrated society look like?

There needs to be a public communication campaign for raising society's awareness and understanding with of course the right messages to shape societal attitudes. We need society to see change such as with government and NDIA reflecting the messages that are being relayed to the public and being accountable if they don't occur.

Federal Government and NDIA also have the opportunity right now to be the leader in what good looks like – they can be the exemplar for all government services to follow. All staff need to have mandatory disability awareness training, not just complaints staff. That is, an investment in organisation-wide knowledge, skills, and confidence in engaging with and including people with disability, their families, and carers.

The majority of surveys indicate that[18] the biggest barrier to inclusion is a lack of disability knowledge, skills, and confidence. The array of systems at all levels in the ecosystem undoubtedly are willing to do better – but do not know how.

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, not being respected.

So we want this to be more than having skills and expertise, culturally aware etc but at the core is to live codes of conduct with values being broken down and translated to behaviours. Hence a competency framework exists with the right behaviour driven performance KPIs, performance management and accountability exercised. This can be exercised immediately as codes of conduct exist. Attitudes such as "it would be much easier for me to do my job if you were not employed" need to cease.

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

Let's go a step further and have the Australian Government takes urgent steps to ensure that all policies, strategies, programs, and interventions at an operational level— for and affecting Autistic Australians and all people with disability are:

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

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

Let's include that the Australian Government ensures that all further policies, strategies, programs, interventions, and research relating to people with autism are co-developed and co-delivered by and for people with autism and their families.

There are many 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.

Recommendation 5.2 Change the narrative

Autistic people and parents of Autistic children are often required to repeatedly justify their support needs. This process can be demeaning and hurtful to the self-respect and identity

of the Autistic person. This does not provide a conducive environment to result in optimal outcomes with a focus on justifying deficits, rather than strength based.

"….. I cannot believe we were made to take a child to a planning meeting, and then spend 2 hours sitting there pointing out every flaw and behavioural issue she has in front of her. It's disgusting…..The only way to get help is to totally downgrade a person into a diagnosis and not be human about it and the recovery time that it took for my daughter after I spoke about her, like that, to someone we don't even know. I think she will never forget it. And it was over 18 months ago."

8. Are there any areas missing from this discussion paper (NAS) that should be a priority in the Strategy?

Refer to Responses to Question 1, 2 and 3 above and Section 10 below.

9. Discussion Areas

9.1 SOCIAL INCLUSION

9.1.1 Inclusion

Many Autistic people and their families report that they are socially isolated from the community 19. Loneliness and social isolation is pernicious. It can adversely impact mental health, education, social and economic outcomes. **20** Surveys repeatedly show that Autistic people and their families experience significant social isolation.

- More than two-thirds of Autistic adults (67.5%) and almost three-quarters of parents/carers (73.4%) responding to the Alliance survey reported feeling socially isolated.

- More than half of respondents reporting they have lost friends because of the way those friends have responded to their autism or the person they care for (61.2% and 63.4%, respectively).

- Almost half of Autistic adults sometimes feel unable to leave the house because they are worried about people behaving negatively towards them (47.5%) with 60.1% of parents/carers reporting this.

- 41.4% of Autistic adults experienced discrimination or stigma.

Despite official recognition from the Australian Government that all people with disability including Autistic people, have the right to participate independently all aspects of life,[21] there are a range of barriers that prevent Autistic people from the full and equal participation in the community and society, including a lack of understanding of Autism, unaccommodating built environments and low levels of supported independent living.[22]

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[19] Submission to the Senate Select Committee on Autism'; Australian Autism Alliance - August 2020

[20] National People with Disabilities and Carer Council, 2009. Shut out: The Experience of People with Disabilities and their Families in Australia. Available at: https://www.dss.gov.au/our-responsibilities/disability-and-carers/publicationsarticles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia

[21] On the Australian Government's Attorney General website notes that Article 9 of the CRPD requires that people with disability have the right to live independently and take part in all aspects of life. See: <https://www.ag.gov.au/rights-and-protections/human-rights-and-anti-discrimination/human-rights-scrutiny/public-sector-guidance-sheets/rights-people-disability#:~:text=Article%209%20of%20the%20CRPD,in%20all%20aspects%20of%20life.>.

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

From early on in life, Autistic children are often ostracised from parenting and play groups, child and family centres and early childhood education due to an inability or unwillingness of other parents, professionals and services to understand Autism and the support and sensory needs of Autistic children. This ostracisation continues throughout life and into adulthood where Autistic people continue to face a range of barriers to their full engagement in multiple areas of the community such as shopping, sports, and recreational activities.

While, in recent years, there has been an increase in initiatives aimed at supporting the sensory needs of the Autistic community, such as quiet or sensory hours in major retail stores and community and family services,[23] these are often scheduled for early hours in the morning, which do not facilitate social inclusion and are considered an optional offering, rather than an obligatory means for services to accommodate for Autistic people.

In addition to a lack of support and consideration for their sensory and support needs, Autistic people experience disproportionately high rates of overt discrimination and harassment,[24] which contributes to an individual's inability or hesitations to participate in the community.

While initiatives like the Australian Disability Strategy (ADS) and the NDIS have the potential to improve the inclusion and participation of Autistic people, their implementation to date has benefited only a small percentage of Autistic people and failed to have any concrete impact on the experiences of the Autistic community as a whole. Through the NDIS for example, participants can gain access to funding to support their participation in the community in the form of support workers, facilitated group activities and more. However, while Autism has been reported as being largest primary disability category among NDIS participants,[25] a breakdown of these statistics tells us that the vast majority of these participants represent the stereotypical, anglo-saxon Autistic young male, while all other sub-groups remain underrepresented.

Additionally, while NDIS funding has greatly benefited some Autistic people, anecdotal evidence tells us that plan funding often does not match up with appropriate and available supports to facilitate community participation. In The Senate Inquiry report, it was noted that

[23] See for example: Woolworths Group (2019) 'Woolworths Rolls out Quiet Hour to Select Stores Across Australia,' <'https://www.woolworthsgroup.com.au/au/en/media/news-archive/2019/woolworths-rolls-out-quiet-hour-to-select-stores-across-australia.html>; Coles (2023) 'Quiet Hour' <https://www.coles.com.au/help/accessibility/quiet-hour>; Eurobodalla Shite Council (2022) 'Libraries Host Sensory Friendly Hour' <https://www.esc.nsw.gov.au/news-and-events/latest-news/2022/libraries-host-sensory-friendly-hour>.
[24] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, p. v
[25] In 2022, 34 per cent of active participants with an approved plan had a primary disability of ASD. See: NDIA (2022) 'Autism Summary: September 2022.' *National Disability Insurance Agency.*

multiple submissions had highlighted that there was a lack of services designed specifically to cater for Autistic people and that Autistic people often have to 'make do' with generic services or services designed for people with intellectual and cognitive disabilities.[26]

<div align="center">

Relevant Intersectionality Issues

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For Autistic people who experience intersectional discrimination, there are a number of compounding factors that impact their community participation and contribute to social isolation. For example, Autistic people who are First Nations or from low socio-economic backgrounds are more likely to live in rural and remote areas where services and community supports are limited; Autistic women and gender diverse people experience high rates of violence and abuse, including coercion which can exacerbate isolation from family, friends and the community; and older Autistic people tend to me less connected to the community due to lower rates of formal diagnosis, limited access to supports and high rates of depression and anxiety.

Recommendation 6.1 Increase Community Understanding of Neurodiversity

As discussed throughout this paper, there is a desperate need to improve community understanding of Autism as well as the capacity of individuals, organisations, and services to accommodate for the needs of Autistic people. In a report on Amaze's survey of community attitudes, it was highlighted that while approximately 85 per cent of Australians have personal connection with an Autistic person, just 29 per cent feel they understand how to support Autistic people; and only 4 per cent of Autistic people and their families agree that people in the community know how to support them.[27]

In recent years, there has been a number of local and state based public awareness campaigns aimed at improving Autism awareness and understanding.[28] However, Australia is yet to see any federally funded, national initiatives aimed at improving public understanding and awareness of Autism. Given the currency and public awareness of the recently launched ADS and the National Autism Strategy (in development), there is a current opportunity for investment.

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

[27] Jones S et al., 2017. 'Experiences of Autistic People and their Families, Centre for Health and Social Research,' *Australian Catholic University*.

[28] For example, As part of the Victorian Autism Plan, the first phase of a public awareness campaign 'Change Your Reactions' ran in Victoria in 2020. In early 2023, Autism Tasmania similarly launched an Autism awareness campaign, 'Be Open to Autism,' which is currently being rolled out across the community, including on public transport.

Recommendation 6.2 A review of the Disability (Access to Premises — Buildings) Standards 2010 with invisible disability in mind

While the *Disability (Access to Premises – Buildings) Standards 2010* are legislated under the Disability Discrimination Act 1992 to make sure: people with disability (and their family members, carers, and friends) have equal access to public facilities,[29] the standards do not apply to existing buildings and contain negligible consideration of the needs of people with invisible disabilities (such as Autistic people).

Recommendation 6.3 National Standards for Autism Friendly Environments and Services Across Australia

In a submission to the Senate Inquiry, it was suggested that there is a development of 'National Standards for Autism Friendly Environments and Services across Government, Business and Community Organisations.' While yet to come into consideration, 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 6.4 State Based Programs under accountable contract models

Provide funds for programs to support the active participation of Autistic people in the community, such as playgroups and facilitated art and music activities for Autistic children, peer-support groups for Autistic young people and adults and initiatives, peer-support aimed at improving the accessibility of healthcare, employment, and education. There are many commercial mechanisms that can be used to ensure social impact is achieved including social bonds, service level agreements and simple KPI performance contracts.

Recommendation 6.5 Fund Peer support

As per Recommendation 6.4 the government could provide funding for under outcome based commercial models for peer-support programs for Autistic individuals, their families, and supporters,[30] which have proved successful in improving a range of outcomes for Autistic

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[29] See: Federal Register of Legislation (2010) *Disability (Access to Premises — Buildings) Standards 2010*, Australian Government <https://www.legislation.gov.au/Details/F2020C00976>.

[30] See for example: Amaze (2023) 'Support Groups,' Viewed 13 June 2023 <https://www.amaze.org.au/support/support-groups/>; Different Journeys (2020) 'Events,' Viewed 13 June 2023 <https://www.differentjourneysautism.com/18plus/>; Autism Tasmania (2023) 'Peer & Social Networks,' Viewed 13 June 2023 <autismtas.org.au/services/peer-networks/>

AUSTRALIAN
Autism Alliance

individuals. Peer support plays an important role in strengthening participant capabilities to exercise their choice and control.

9.1.2 Accommodation

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.[31]

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.[32]
- 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 nonAboriginal women. 60 percent of Aboriginal and Torres Strait Islander women who experience physical violence have a disability or long-term health condition.[33]

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

[32] 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>.

[33] 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>.

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;[34] resulting in a situation where disabled women's only options are to face homelessness or to return to living under a roof with their violence perpetrator.

Recommendation 6.6 Invest in Specialist Disability Accommodation and Supported Independent Living

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

Recommendation 6.7 Provide Effective Emergency Accommodation

In order to support emergency and crisis accommodation facilities to provide training and resources to support Autistic people, funding for staff training and accessible facility upgrades are needed. While there is a lack of research on the specific ways in which emergency accommodation services are failing to support Autistic people, People With Disability Australia (PWDA), through its Building Access project, has recently done comprehensive audits of domestic and family violence services, including emergency accommodation facilities, across New South Wales. Through the project, PWDA has identified a number of areas where services can improve their accessibility.[35]

9.1.3 The Justice System

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 in all Australian states and territories. While the reasons for this are debatable, there are some key contributing areas of structural disadvantage:

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[34] See for example: 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>.

[35] PWDA (2023) 'Building Access project,' *People With Disability Australia* <https://pwd.org.au/projects/building-access-project/>.

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; [36] which is reflected in broader evidence that First Nations people with disability are grossly overrepresented in prisons.[37] 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.[38]

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.

Recommendation 6.8: Autism Training for Justice System Workforce

As with almost all other sectors, there is a desperate need to build the capacity of justice system personnel to understand and support Autistic people. While some states and territories (such as Victoria) deliver disability awareness training to justice professionals, the evidence that there is an overall severe lack of understanding of Autism across the system suggests

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[36] 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>
[37] 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>.
[38] 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>

that existing initiatives are not specific enough to cover the specific experiences and support needs of Autistic people.

Recommendation 6.9 Resourcing for supports and accommodations

Based on the evidence that there is a lack of support for Autistic people in their interactions with the justice system suggest that there is a need for resources to ensure access to appropriate information, accommodations and supports. When engaging with the court system, many Autistic people would greatly benefit from relatively simple accommodations such as the provision of plain language information resources on what to expect in a proceeding and options to have sensory alterations such as dimmed lights and quiet spaces. For Autistic individuals who experience incarceration, there is also significant evidence to suggest that there is a need for support and services to decrease the risk of deterioration of mental health and recidivism upon release from the system.

Recommendation 6.10 Prison to community transitions

Noting that the transition period from prison into the community, poses significant risks for Autistic people, it is evident that there is a need for intervention during this period. Based on existing research, key areas where investment would benefit include funding for accessible housing for rehabilitating prisoners with disability, ongoing support for mental health conditions and pre-planning the transition with the individual.

Recommendation 6.11 Medicare benefits are still accessible while incarcerated

Recommendation 6.12 NDIS Plans are reactivated when released

9.2 ECONOMIC INCLUSION

9.2.1 Education

For Autistic children who often thrive on familiarity and routine and struggle in social settings, especially among others who are unknown to them, it is without question that entering into a school environment can present a whole array of challenges. At a basic level, a typical classroom, including twenty to thirty students, one or two teachers, lots of noise, bright lights, busy walls, and social pressure from other students, itself is a recipe for triggering sensory overload and potential meltdowns or shutdowns in the Autistic pupil before even attempting academic work.

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. With the exception of 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.[39] 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. Similarly, while many Autistic student have co-occurring learning disabilities (such as intellectual disabilities or dyslexia) which can create difficulties with reading and writing, the provision of information in or options to do assignments in alternative formats such as Easy Read, Sign Language, or audio-visual media is unheard of for most subjects.

Although most research about the barriers that face Autistic students are focussed 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.[40] In one response to the Alliance survey for example, a student described how university academics had refused to record lectures to accommodate for their auditory processing delay.

"It's been horrible, I don't feel like I am listened to at all in the [student] support services, and the teaching has been so inconsistent. Half the lecturers straight up refuse to record lectures, disability service did not advocate for my need despite having an auditory processing disorder, they just said that was it and they can't change it. It has taken me 8 years to get to do my last semester of my degree. The whole experience has been depressing."

Due to the inaccessibility of the mainstream education system, it is not uncommon for parents of Autistic children to choose to send their children to specialised schools or to home school.[41] While specialised schools can sometimes offer a better ability to cater for the needs of Autistic students, the majority of specialised schools are not Autism specific and those that are (such as the Sycamore School for Autistic children in Queensland) have long enrolment waiting lists and can present challenges for social integration post school completion.[42]

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

[40] Ibid.

[41] See for example: Autism Spectrum Australia (2017) 'Home Education: An Autism Spectrum Australia (Aspect) funded, developed and implemented research project,' Viewed 8 June 2023 <https://www.autismspectrum.org.au/uploads/documents/Research/Aspect-Practice-Reseach-Insights-Issue10-HomeEducation.pdf>; ABS (2012) 'Autism in Australia,' *Australian Bureau of Statistics*, Canberra.

[42] Roberts, J., Adams D., Simpson K., Paynter J., Westerveld M., den Houting J., Ambrose K., (2022) The longitudinal study of Australian students with autism (LASA): Final Report. *Autism CRC*, Brisbane, p. 8 <https://www.autismcrc.com.au/sites/default/files/reports/2.007RC_LASA_Final-report.pdf>

Research from Autism Queensland indicates that concerns about mainstream schools include:

- Need for more educational support.

- Need for more differentiated learning strategies.

- Need for smaller class sizes to accommodate learning/sensory/ emotional needs.

- Better prevention of bullying

- Support for mental health issues, particularly to overcome significant issues such as school refusal and frequent formal and informal suspension of Autistic students.

Our research also indicated that the demands on parents of autistic students 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 engage in paid employment which adversely impacts parental wellbeing and financial security.

Relevant Intersectionality Issues

For Autistic students who face intersectional disadvantage, 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,[43] the education system curricula being centred around a white colonial history[44] and a risk of experiencing racism from their educators and peers.[45] LGBTIQA+ 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.[46] Autistic students living in rural or remote areas or who experience socio-economic disadvantage are more likely to attend pubic, under resourced schools with even more limited ability to offer support and accommodations;[47] and Autistic women and girls are less likely to even receive

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[43] 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>.

[44] 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>.

[45] 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>;

[46] 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>.

[47] 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/>.

recognition of their support requirements, due to barriers to diagnosis and pressures around compliance and social assimilation.[48] This is just some of the intersectionality issues.

Recommendation 7.1: Training for Educators

There is a desperate need for the training and up-skilling of educators who are responsible for supporting Autistic students.[49] Currently those educators that have an understanding of Autism and how to provide support and accommodations to Autistic students are limited and ad hoc. Autism education is rarely included in course curricula and any training that does exist is lumped in with information on supporting all students with disabilities.

Recommendation 7.2 Disability Standards for 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.[50]

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.[51]

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.[52] Despite this evidence however, there is little that can be done to change to improve school protections due to a lack of accountability mechanisms.

[48] 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>.

[49] Saggers, 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>.

[50] 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>.

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

[52] 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.

Among a number of other recommendations related to the provision of supports 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.[53]

Recommendation 7.3 Funding for inclusive school practices and early intervention underpinned by choice and control

There is significant evidence to suggest that inclusive school practices such as access to learning plans, teachers aids, support workers and quiet spaces can greatly improve the Autistic schooling experience.[54] However, the resources schools have available for these accommodations is limited and often dependent on private income,[55] resulting in a situation where accessing inclusive schooling doesn't only depend on school and teacher willingness, but also the availability of familial income, geographic location, religion and belief system.[56]

There is also a need to provide more funding for autism-specific programs and services and increase access to early intervention services including those that facilitate the transition between specialist and mainstream education.

We should also support the choices of Autistic people and their families by ensuring access to a range of educational settings, that are safe and conducive for each individual.

Recommendation 7.4 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 on opportunities for vocational exploration, and to build aspiration and networks.[57]

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[53] Department of Education (2021) 'Final Report of the 2020 Review of the Disability Standards for Education 2005,' Australian Government, Canberra.

[54] See for example: Saggers, 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>.

[55] See for example: Facts, C (2023) 'Are private schools better than public schools?,' *ABC*, Viewed 8 June 2023 <https://www.abc.net.au/news/2023-01-20/are-private-schools-better-than-public-schools/101867070>.

[56] Larson, S and Forbes, A (2022) 'Going to private school won't make a difference to your kid's academic scores,' *The Conversation*, Viewed 09 June 2023 <https://theconversation.com/going-to-private-school-wont-make-a-difference-to-your-kids-academic-scores-175638>.

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

Recommendation 7.5 Fund 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. One such program is the ICAN Online program which is delivered by Autistic adults providing mentoring programs to 5-22 year old across Australia that is strengths and interest based and as represented by Australian Catholic University, increase young people's positive Autistic identity and belonging.

Recommendation 7.6 Create Pathways to Careers

Pathways need to be created early for Autistic students so that they are building 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. Programs such as offered by the Centre for Autistic Social Entrepreneurship have been demonstrated to be of benefit providing the knowledge and skills to assist Autistic owned and led social enterprises.

9.2.2 Employment

Due to a range of factors, including low educational attainment, limited support for workplace transitions, inaccessible workplace practices and discriminatory attitudes from employers, Autistic people experience much higher rates of unemployment and economic impoverishment than the general population. As a result, Autistic people are disproportionately represented among recipients of income support payments and many Autistic people rely on their families for everyday living costs.

It also very important to recognise that underemployment takes many forms including time fractions and people working less skilled jobs comparative to their skills and abilities and their want for higher skilled jobs and careers. Many who are employed in appropriate roles relevant to their skills and expertise often experience burnout in unsupportive environments due to masking and other factors.

Relevant Intersectionality Issues

For Autistic people who are women, gender diverse, LGBTIQA+, 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.[58] VISA restrictions mean that many temporary residents are only able to work a certain number of hours and in specific areas of employment.[59] Older Autistic people experience high rates of age discrimination when searching for work[60] and Autistic women, gender diverse and LGBTIQA+ people are more likely to experience various forms of gendered and sexual violence, abuse and harassment in the workplace[61] as well as to have caring responsibilities which impact their ability to work.[62]

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;[63]
- Job seekers from CALD backgrounds, make up almost one fifth of the total job seeking population;[64].
- 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;[65]

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[58] 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>.

[59] 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>.

[60] 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>.

[61] 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 Disabilty' <https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00652.PDF>.

[62] 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>.

[63] 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>.

[64] 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>.

[65] 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 LGBTIQA+ people is more than double the national rate;[66]
- Youth (aged 15–24) with disability (25 per cent) are more likely than those aged 25–64 (7.9 per cent) to be unemployed. [67]

Recommendation 7.7 Transition Programs to enable sustainable employment

There is a significant need for investment in effective programs to support Autistic young people to transition from education to employment.

A number of initiatives exist to support transitions to sustainable employment. For example: Ticket to Work myWAY Employability app, and Autism EmployABLE 2 (AE2).

Other programs of benefit to build alternative pathways include the Centre for Autistic Social Entrepreneurship to provide the knowledge and skills to assist Autistic owned and led social enterprises

Recommendation 7.8 Workplace Inclusion Initiatives

Recognising that the majority of employers lack understanding of Autism; it is clear that there is a need for investment in programs that educate the mainstream workforce and promote inclusive employment opportunities. While there is a lack of existing programs that have proved to improve the workplace accessibility of Autistic people, a number of emerging initiatives offer promising possibilities including:

The *Australian Human Rights Commission IncludeAbility* initiative brings together private sector employers and people with lived experience of navigating employment and disability to build the capacity of workplaces to provide supportive and accessible employment opportunities. As part of the initiative, the AHRC has launched a website with a range of resources for both employers and people with disability and is co-designing two pilot programs to support the meaningful employment of people with disability.[68]

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

[67] 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>.

[68] Australian Human Rights Commission (2022) 'Includability' <https://includeability.gov.au/about-includeability>.

Recommendation 7.9 Government create placements in the workplace

Support initiatives along the lines of the DRC Recommendation 7.19 Establish specific disability employment targets for new public service hires in agencies and departments.

In the UK for example, the National Health Service works closely with Ambitious about Autism to find jobs for Autistic people in hospitals (e.g., jobs in food services, porters, record management etc).

9.3 DIAGNOSIS, SERVICES AND SUPPORTS

9.3.1 The Maternal, Prenatal and Postnatal experience

From pregnancy to birth and then parenting, Autistic parents, especially mothers, and mothers of Autistic children face ongoing misunderstanding, ableism, and discrimination from medical, health and social systems which are meant to support them.

Across Australia and the world, disabled and Autistic women and gender diverse are routinely denied the right to become pregnant and have children by guardians, parents, caregivers and medical 'professionals' who hold ableist attitudes about their ability to parent and / or believe it is in the best interests of all parties not to 'pass on' disability.

When an Autistic woman does become pregnant, they face much higher risk of forced or coerced terminations from family as well as medical professionals who routinely check the foetus for any 'genetic abnormalities' from early in gestation. While it is not currently part of widespread practice to 'test for Autism' in utero, new studies are already exploring the ability to do so, in turn suggesting that there is an appetite to terminate pregnancies based on risk of the child being Autistic.[69]

For Autistic and disabled women, or mothers of Autistic children who do go through with a pregnancy, there is more often than not a lack of willingness or ability of prenatal and postnatal health and medical care providers to cater for their support needs and a lack of sector understanding about the Autistic experience. In public health systems for example, Autistic women often have no option but to give birth in busy, bright, and sterile hospital environments, which can be overwhelming to their sensory profile.

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[69] See e.g. Gurion, B (2022) 'A routine prenatal ultrasound can identify early signs of autism, study finds,' University of the Negev, Viewed on 30 May 2023 <https://www.sciencedaily.com/releases/2022/02/220209112107.htm#:~:text=A%20routine%20prenatal%20ultrasound%20in,a%20new%20study%20has%20found>; Chen, WJ et al (2020) 'Autism Spectrum Disorders: Prenatal Genetic Testing and Abortion Decision-Making among Taiwanese Mothers of Affected Children,' *Int J Environ Res Public Health*, Vol. 17, no. 2, p. 476, Viewed 30 May 2023 at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7013751/>

In early parenting, there is similarly a significant gap in support available for Autistic parents. While all women who give birth in the public system are offered support in the form of one-off visits from midwives and child health nurses, Autism specific support is limited.

For Autistic women who have access to the NDIS prior to birth and pregnancy, there is sometimes support in place which can already be of assistance. However, as noted previously, the percentage of Autistic women who are on the NDIS to begin with is extremely minimal,[70] and anecdotal evidence suggests even those that are participants, face a number of barriers to accessing supports specific to the pre- and post-natal period. In one example cited by Women With Disabilities Australia in a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Disability Royal Commission) a pregnant, an Autistic woman with a number of chronic illnesses requested a NDIS plan review to consider additional support that she may require as a parent. In response, the NDIS refused the review stating that "having a baby is not the responsibility of the NDIS".[71]

Relevant Intersectionality Issues

For Autistic women who are from low socio-economic backgrounds, are First Nations, culturally and linguistically diverse, from migrant and refugee backgrounds, in LGBTIQA+ 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).[72] 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 LGBTIQA+ relationships are often not recognised or accommodated for appropriately by pre and post-natal care services[73] and First Nations families experience disproportionately high rates of child removals or interventions from child protection systems.[74]

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[70] NDIA (2022) 'Autism Summary - September 2022,' *National Disability Insurance Agency*, p. 1

[71] 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. 214 <https://wwda.org.au/wp-content/uploads/2023/04/DRC-Submission-SRR.pdf>.

[72] 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>.

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

[74] 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>.

Recommendation 8.1 Training for health professionals working in prenatal, post-natal and early childhood services

There is an extremely low understanding of Autism and the support needs of Autistic parents and children among health professionals working prenatal, post-natal and early childhood services. While, in recent years, there has been some movement on the implementation of training for professionals to identify Autism in early childhood.[75]

Recommendation 8.2 Accommodations for Autistic mothers in maternity wards

In order to minimise the sensory difficulties experienced by Autistic women during childbirth, a number of international studies have recommended consistent resourcing for the provision of accommodations such as altered lighting, private birthing suites and additional support persons.[76]

Recommendation 8.3 Targeted support for Autistic parents in the pre- and post-natal period

Drawing on the evidence that Autistic mothers are much more likely to experience pre and postnatal mental health conditions such as anxiety and depression, which can often continue on into the early years parenting, it is clear that there is an opportunity to improve outcomes by providing target supports for Autistic people during the pre and post-natal period; extremely limited attention has been paid to the need for professionals to develop skills to support Autistic parents.

In order to do this, there needs to be a consistent approach to disability / Autism screening when patients begin their journey through the prenatal healthcare system. However, the development of any such system should be focussed on the patient, not their growing foetus.

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[75] See for example: Latrobe University (2019) 'Life-changing autism training launched,' Viewed 13 June 2023 <https://www.latrobe.edu.au/news/articles/2019/release/life-changing-autism-training-launched>.
[76] See for example: Hampton, S Allison, C Baron-Cohen, S and Holt, R (2022) 'Autistic People's Perinatal Experiences II: A Survey of Childbirth and Postnatal Experiences,' Journal of Autism and Developmental Disorders, Online, Viewed 13 June 2023 <https://link.springer.com/article/10.1007/s10803-022-05484-4>; Turner, L (2019) 'Supporting women with autism during pregnancy, birth and beyond,' *University of South Hampton*, Viewed 13 June 2023 <https://www.researchgate.net/publication/332865043_Supporting_women_with_autism_during_pregnancy_birth_and_beyond>.

9.3.2 Services and Supports

Recommendation 8.4 Supports for Parents

While the NDIS has the potential to bridge the gap between mainstream services and the support needs of Autistic parents, there is currently extremely limited support available through the NDIS to support parenting. While there are supports available to Autistic children which may inadvertently benefit their parents, there is no support directly available to adults to support their capacity to parent.[77]

Recommendation 8.5 Information dedicated to Autistic people

A straightforward way to improve the accessibility of services and supports to Autistic people is to publish information specifically tailored to their needs. Development of such resources needs to occur through co-design with the Autistic and the autism community.

9.3.3 Diagnosis

While it should be recognised that many people self-identify as Autistic and engage in the Autism community without a formal diagnosis, there are significant benefits to a formal diagnosis which are not accessible via self-identification.

In the Alliance survey, of those that were formally diagnosed (66.7%), over half reported the following benefits:

- Allowed me to access supports
- Helped me understand myself
- Helped me understand my needs
- Helped me deal with feelings of being different/inadequate
- Helped me to explain my needs to others
- Helped me find ways to improve my life/situation
- Gave me the confidence to disclose my autism
- Helped give me a sense of belonging.[78]

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[77] 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

[78] Jones, S (no date available) 'Results from consultation survey to inform a submission into the Federal Senate Select Committee on Autism,' Prepared by ACU Engagement for the Australian Autism Alliance, pp. 3-7.

Despite the significant benefits associated with a formal Autism diagnosis however, there are a number of barriers to accessing a diagnostic assessment.

Recommendation 8.6 Increase Medicare Benefits

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.[79] Given the evidence that Autism is often not identified among particular cohorts (such as women and gender diverse people) until adulthood,[80] and that Autistic people are more likely than the general population to experience economic disadvantage,[81] the MBS rebate restrictions mean that many individuals simply cannot afford a diagnosis.

Recommendation 8.7 Increase availability of assessors

Across Australia, there is a limited number of practitioners who are able to provide a formal Autism diagnosis and those that are available typically have long wait lists for appointments. For this reason, individuals seeking assessment and diagnosis through the public system face wait times multiple year wait lists and sometimes even longer in rural and remote locations.[82] Some practitioners also do not offer places for adult assessments.

In order to avoid the detrimental impacts of delayed diagnosis, many individuals and families are forced to seek private assessments, which costs thousands of dollars. For those that can't afford these out-of-pocket expenses, significant delays in diagnosis are inevitable.

Recommendation 8.8 Improve diagnostic assessments

Although processes are changing somewhat with awareness, a number of research studies have indicated that traditional diagnostic assessment processes are fraught with bias on the basis of race and gender.[83] While the specific reasons for these biases require more investigation, it has been theorised that they relate to factors such as biases in background information such as school reports and healthcare records, as well as the influence of the Autistic white male stereotype.

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[79] Services Australia (2023) 'Medicare items for Complex neurodevelopmental disorder and eligible disability,' Viewed 13 June 2023 <https://www.servicesaustralia.gov.au/education-guide-medicare-items-for-complex-neurodevelopmental-disorder-and-eligible-disability?context=20>.
[80] See for example: HIll, A (2021) 'Diagnosis is rebirth': women who found out they were autistic as adults,' The Guardian, Viewed 13 June 2023 <https://www.theguardian.com/society/2021/nov/19/diagnosis-women-autism-later-life>.
[81] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, p. 29
[82] Pillar, S and Whitehouse, A (2023) 'Autism and ADHD assessment waits are up to 2 years' long. What can families do in the meantime?,' *The Conversation*, Viewed 12 June 2023 <https://theconversation.com/autism-and-adhd-assessment-waits-are-up-to-2-years-long-what-can-families-do-in-the-meantime-203232>.
[83] See for example: Kalb, LG et al., (2022) 'Analysis of Race and Sex Bias in the Autism Diagnostic Observation Schedule (ADOS-2),' *JAMA Netw Open*, Vol. 5, no. 4 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9044110/>

While it was thought for many years that Autism is more prevalent in males, recent research has indicated that diagnosis disparities between genders do not reflect actual differences in Autism prevalence, but rather a tendency for Autism to present in women, girls, and gender diverse in a way that is not typically recognised. Compared to males, various research studies have found that women, girls and gender diverse Autistic people are typically more likely to 'mask' their Autism through compliance, mimicking strategies and other compensatory behaviours; that are often not picked up on by families, educators and even clinicians.[84] These masking strategies, combined with social and economic barriers, mean that many Autistic women, girls and gender diverse people go undiagnosed throughout a significant portion of their lives.

Furthermore, despite growing awareness of Autism, many Autistic people report being mis-diagnosed with another condition, most commonly a psychosocial disability, prior to receiving their Autism diagnosis. In the Alliance Survey for example, over half of Autistic adults respondents said their Autism had been mis-diagnosed as something different.

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.[85]

According to the Senate submission from the Coalition of Autistic Women (CoAW), it was highlighted that misdiagnosis with BPD is particularly common, as the symptoms mimic the presentation of Autism in women:

A key feature of autistic females is that they appear able to mask their difficulties much more effectively than males. There may be a complete disconnect between parts of the autistic person's life and relationships that others may not realise, as they may only see one aspect

[84] See for example: Downie, HW et al. (2020) 'Sex/Gender Differences in Camouflaging in Children and Adolescents with Autism,' *J Autism Dev Disord*, Vol. 51, no. 4, pp. 1353–1364 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7985051/>.
[85] See for example: Gesi, C et a. (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>

of the person. In fact, many autistic women report feelings of 'leading a double life', hiding their true selves from the world and having to 'act' to fit in, adapt and cope with the way they experience the world. Partly as a result of this, a common misdiagnosis for autistic women is Borderline Personality Disorder. (The same symptoms can be experienced by those with a diagnosis of both Borderline Personality Disorder and Autism).[86]

9.4 National Roadmap to Improve the Health and Mental Health of Autistic People

Due to factors such as high rates of misdiagnosis and an inaccessible health system, Autistic people commonly don't receive medical care and treatment until their situation is urgent. While there is a lack of national data on the number of Autistic people who experience medical emergencies, the Autism Alliance survey found that 35.1 per cent of autistic adults had attended a hospital emergency department in the 12 months prior to the survey.

Compared to the general population, Autistic people are also more likely to develop preventable co-occurring conditions, including mental health conditions such as depression, anxiety and eating disorders. According to The Senate Inquiry report, it has been reported that between 69–79 per cent of autistic people experience at least one mental health condition during their lifetime; and given the underdiagnosis of Autistic individuals, the real percentage is likely to be even higher. Related to these statistics, Autistic people have a much lower life expectancy than the general population.

While this is partly due to high rates of co-occurring neurological conditions such as epilepsy, Autistic people are also considerably more likely than the general population to die as a result self-inflicted injury (suicide) related to unaddressed health conditions. While available data on suicide rates among Autistic people is limited, one 2019 Australian study of Autistic people found that 35 per cent had made suicide plans or attempts—about five times higher than the general population.[87]

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[86] Coalition of Autistic Women (2019) 'Submission to the Senate Select Committee on Autism.' Edited by Monique Blakemore and Geraldine Robertson.

[87] Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S. and Trollor, J.N. (2019) 'Mortality and cause of death of Australians on the autism spectrum' *Autism Research,* vol. 12 no. 5, doi:10.1002/aur.2086, p. 2; Slade T., Johnston A., Teesson M., Whiteford, H., Burgess P., Pirkis J., Saw S. (2009) 'The mental health of Australians 2. Report on the 2007 National Survey of Mental Health and Wellbeing,' Department of Health and Ageing, Canberra; Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' Australian Government, Canberra, p. 25

Given the evidence that some of the major risk factors for suicide (such as social isolation, unemployment, homelessness, and disability)[88] are all things that Autistic people disproportionately experience, it is evident that drastic preventative measures are needed.

Relevant Intersectionality Issues

While Autistic males are at higher risk of suicide, Autistic women, gender diverse and LGBTIQA+ people are more likely to experience mental health conditions, including anxiety, depression and eating disorders. In their submission to The Senate Inquiry, the CoAW argued that Autistic women and gender diverse people are also at considerable risk of developing post-traumatic stress disorder and other trauma associated mental health conditions as a result of high rates of mis-diagnosis, discrimination, violence and untreated chronic illness.[89] Similarly, there is evidence that older people who are late-diagnosed Autistic commonly experience mental health conditions such as anxiety and mood disorders and are at high risk of a number of chronic physical health conditions such as osteoporosis, heart disease and arthritis.[90]

First Nations Autistic people are also more likely to experience a wide range of physical and mental health conditions as a result of the impact of ongoing racism and discrimination. While information on the experiences of First Nations Autistic people with the health system are limited, a report summarising findings from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability (the Disability Royal Commission) highlighted that First Nations people with disability generally are more likely to experience acute medical conditions and long hospital admissions due to difficulties securing appropriate housing and support, barriers accessing health care in regional areas, the need to travel long distances to access health care, communication and language barriers.[91]

Due to language and cultural barriers, combined with sensory and communication differences, CaLD Autistic people similarly experience difficulties finding accessible healthcare services.

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[88] Australian Institute of Health and Welfare (2017) 'Suicide and self-harm monitoring: Psychosocial risk factors and deaths by suicide,' Australian Government, Canberra <https://www.aihw.gov.au/suicide-self-harm-monitoring/data/behaviours-risk-factors/psychosocial-risk-factors-suicide>.

[89] Coalition of Autistic Women (2019) 'Submission to the Senate Select Committee on Autism.' Edited by Monique Blakemore and Geraldine Robertson.

[90] See for example: Moore, L (2022) 'All About Autism in Older Adults,' *Psych Central,* Viewed 11 June 2023 <https://psychcentral.com/autism/autism-in-older-adults>.

[91] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with
Disability (2020) 'Overview of responses to the Experience of First Nations people with disability in Australia Issues paper,' p. 9 <https://disability.royalcommission.gov.au/system/files/2022-03/Overview%20of%20responses%20to%20the%20Experience%20of%20First%20Nations%20people%20with%20disability%20in%20Australia%20Issues%20paper.pdf>.

Given that people on temporary VISAs do not have access to the same Medicare benefits, cost is likely also a significant barrier to accessing healthcare for CaLD Autistic people.[92]

Recommendation 9.1 Training for health/medical professionals

There is a significant need to upskill, train and resource healthcare professionals to understand, support and accommodate for Autistic individuals. While there is limited evidence of existing large-scale programs with this purpose, the Autism Alliance has previously identified a number of small-scale initiatives to upskill professionals working in mental health.

Recommendation 9.2 Expansion of coverage under the MBS

In order to ensure healthcare is financially accessible to Autistic people, the services covered by the MBS should be expanded for individuals experiencing financial hardship and acute or chronic physical or mental health conditions.

Based on a review of access to mental health, the 2018 MBS Review Taskforce Report from the Mental Health Reference Group[38] recommends a number of strategic adjustments to the Better Access program that would significantly benefit autistic people including:
- Expanding the Better Access program for at-risk patients
- Increasing the maximum number of sessions per GP referral
- Introducing a three-tiered system for patients with a diagnosed mental illness, with
- increased numbers of sessions available to consumers with higher acuity needs
- Enabling family and carers to access therapy.

10. Other Areas

10.1 The 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 lack of access to supports and a reliance on large institutional environments; where it is more common for people to die prematurely.[93]

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[92] Services Australia (2022) 'Medicare: If you're a temporary resident covered by a Ministerial Order,' Viewed 11 June 2023 <https://www.servicesaustralia.gov.au/enrolling-medicare-if-youre-temporary-resident-covered-ministerial-order?context=60092>.
[93] Ibid, p. 12

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.[94] Additionally, the tendency of older Autistic women to miss social cues, experience communication difficulties and have few family and friends to report issues to, makes them a target for violence in the aged care system.

Recommendation 10.1 Expansion of NDIS Eligibility to include people over 65 years
Given that the NDIS is the only national support system tailored to Autistic and disabled people, it is essential that it does not discriminate based on age or any other population-based criteria. While it is possible for older Autistic people to gain support through the aged care system, the evidence that aged care support is rarely tailored to the needs of people with disability, suggests that the two should not be mutually exclusive.

Recommendation 10.2 Better resource and train staff in the aged care system

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.[95]

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),[96] current guidelines first require aged

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[94] 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>.

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

[96] 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>.

care facilities to report an incident within 24 hours and to determine if there is an impact on the victim.[97]

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.

10.2 Carer Economy

As reported in the Senate Committee Inquiry on Autism report[98] despite the wellbeing 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).[99]

Recommendation 10.3 Building a sustainable care economy

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.

Modelling[100] 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 includes 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

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[97] 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>.

[98] Senate Select Committee report on Autism, March 2022. Services Support and Life Outcomes for autistic Australians, Chapter 4

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

[100] 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.

have reduced opportunities engage in paid employment which adversely impacts parental wellbeing and financial security.

10.3 Independent Advocacy

Recommendation 10.4 Provide funding for "Preventative" Independent Advocacy and Specialisation

- There is a need for independent advocacy to be better funded to enable organisations to be more responsive but also to enable a preventative approach so s to support individuals onto the correct pathway and to be prepared rather than being reactive.
- There is a need for specialised independent advocacy services that understand autism. Currently Autistic people and their families are feeling unsupported due to 1. Preconceived beliefs and 2. Not having sufficient domain knowledge to be effective – in 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.

11. Conclusion

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

We trust that the insights and recommendations presented in this submission, will inform the development of the National Autism Strategy. We commend the current consultations and recommend the ongoing consultation with relevant stakeholders as the period to respond with multiple other reviews and reforms in parallel has not been conducive. Adoption of these recommendations in a National Autism Strategy, will dramatically improve the social and economic participation of Autistic people and their families and help deliver significant flow-on multiplier benefits to the broader economy.

The Australian Autism Alliance response to the Senate Select Committee on Autism titled "The Autism Dividend - Unleashing the skills, talent and opportunity of Australia's Autistic community" [101]should also be read in conjunction with this response.

The recommendations are still relevant and supported by a National survey with over 3,800 responses which are still supported today as determined by the feedback from Autistic people and their families through various consultations and information lines. Recommendations cover Assessment and Diagnosis, Women and Girls, Health and Mental Health, Education and Training, Employment, NDIS, Research, and Advocacy.

We also have available on request to provide the outcomes endorsed that resulted from two research reports recently completed (end October 2023) that we have been unable to incorporate properly into this submission due to time constraints:

a. Global Consulting Group, Road Map to Inclusive Education: Developing School Policy Reforms for Australian Schools (K-Y12) for the Australian Autism Alliance

b. Global Consulting, Australian Autism Employment Strategy for Autism Aspergers Advocacy Australia (A4)

We welcome the opportunity to discuss any of the above in further detail and look forward to the opportunity to respond further when the Draft National Autism Strategy is released and continuing to work with government in the implementation phase to create and sustain a more integrated and safe inclusive society for Autistic people and their families.

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

Appendix 1: Comments regarding Disability Royal Commission (DRC) Recommendations

In general:

- Many of the DRC Recommendations are supported but also reinforce the need for not only a specific National Autism Strategy and National Health and Mental Health Roadmap but that any initiatives, strategies, legislation or policies need to have an autism lens applied to them and have specialised component or stream relating to Autism, so the specific needs of Autistic people recognised and met.

- As called out in Senate Inquiry on Autism broader disability reforms, policies and strategies often don't meet the needs of Autistic people.

- Of the 222 recommendations it was identified that there a lack of autism specific findings and recommendations.

- There was specific reference to people with cognitive and intellectual disability. It is important to recognise that only some Autistic people have cognitive impairments and/or intellectual disability.

- Many Autistic people also experience a range of other co-occurring conditions and intersectionality that needs to be recognised and require unique and not generic disability solution. Besides the poorer outcomes experienced than other Australians, including other disabilities as identified in the Senate Inquiry on Autism, Autistic people are particularly vulnerable to abuse, discrimination and segregation in many environments including education and employment and are disproportionately represented in the criminal justice system.

Specific Comments to the Recommendations:

Recommendation 4.1 Establish a Disability Rights Act

The Australian Government's commitment to the enactment of a Disability Rights Act should include Autistic people, families and carers, Autistic led organisations and autism specific representative organisations. Various strategies that have Australian government support such as the Australian Disability Strategy and the National Autism Strategy should be referenced in the Act to ensure all of government commitment at all levels and have bilateral support and therefore continuity, and consistency, hence enabling a focus on actions and not the need for reviews as government positions change.

A legislative framework should also be created for a co-ordinated and integrated, whole of government approach to ensure an ecosystem operating at a systemic level where it is government's responsibility to avoid people falling between the gaps and being handballed

from department to department. This framework should have an impact, outcomes and accountability framework with performance management against a core capabilities framework and code of conduct. Refer to section in paper that outlines details and reporting obligations.

The Act will need to drive the review of legislation and policy across all levels of government to ensure that they align with the interpretation and intent of the Act and relevant strategies and procedures reflect the intended drivers so as to achieve real and improved outcomes for people with disability, consistent with the Act.

Recommendation 4.2 Objects of the Disability Rights Act

This should reference to what is identified in our response under the Executive Summary titled Models of Disability. That is Social and Human Rights model, equity framing, intersectionality, neuro-affirming etc. Please refer to this section for more context and detail.

Recommendation 4.4 Future review of the Disability Rights Act

We request that this consider having a disability led task force, that includes Autistic representation, independent auditors and be informed by evaluation reports through re-engagement with the disability community no less frequently than every 3 years. Please refer to the Executive Summary under the title Governance and Accountability Models for more context and detail.

Recommendation 4.5 The right to non-discrimination and equality before the law

Please consider this in the context of our response to Recommendation 4.4.

Recommendation 4.6 The right to equal recognition before the law

Funded advocacy services should be independent.

It should be considered to extend the reference beyond First Nations and CALD communities. There are many other cohorts that require culturally aware services and supports and differences create barriers, particularly those who have intersectionality with other differences.

Recommendation 4.9 The right to equitable access to health services

The right to voice opinions and to make complaints about health services needs to be in an accessible way.

Recommendation 4.15 Duties supporting compliance with the Disability Rights Act

A mechanism that provides for an independent audit, community evaluation and anonymous survey for those being consulted more directly should exist.

Recommendation 4.17 Limitations on rights

Should this make reference to equity?

Recommendation 4.19 Co-design a new complaints mechanism for people with disability

Ideally the Commission will have the ability to do more than "dispute resolution" and "mediation" such as investigate complaints and take action.

Recommendation 4.20 Enabling remedies through the courts

To enable an integrated whole of government eco system ideally all legislation at all government levels is reviewed to be up to date with more contemporary policies so that legislation and policy is aligned and consistent. For instance, currently there are bullying policies in all jurisdictions at an education and workplace level but the only Vilification Legislation that covers vilification is understood to be in the ACT. Given it is a higher bar to prove and prosecute discrimination, then many of those who cause abuse, segregation and vilification cannot be held to account. Relying on goodwill and policies in settings such as education and employment has demonstrated to date that this is insufficient.

Please also refer to the Recommendation in the Executive Summary under the title "Interaction with Local, State, & Commonwealth services".

Recommendation 4.29 Offensive behaviour

Should this be about demonstrating that the person took advantage of a vulnerable person with disability rather than proving it was done because of the disability.

Currently it is understood that all places in an education setting, or a place of employment is considered a public setting if it is in an area where anyone other student, teacher or employee as relevant to the setting can access. Is that interpretation correct?

Recommendation 4.30 Vilification because of disability

It is considered that the bar may be too high here, particular in relation to education settings. What determines "serious abuse". Should there not be a zero tolerance of abuse and it should be anything that results in abusee being shamed, humiliated etc along the same lines of what employees and students are accountable for that is covered by bullying.

Recommendation 5.2 Review and update of Australia's Disability Strategy

It is requested that it be considered for this to go further and reflect having an impact, outcomes and accountability framework with core capabilities framework and performance measures against outcomes. Refer to Executive Summary under the title "Interaction with Local, State, & Commonwealth services".

Recommendation 5.4 Review of national agreements, strategies and plans

This review should consider referencing the National Autism Strategy and the review should be in the context of what is required to achieve improved outcomes with a plan of targets over 2, 5 and 10 years respectively in alignment with the ADS.

This review should consider referencing the National Health Roadmap for ID and the National Health and Mental Health Roadmap for Autism.

Recommendation 5.5 Establishment of a National Disability Commission

This Commission should be able to independently investigate complaints and have the use of independent auditors to assess outcomes.

The Outcomes for People with Disability report should be extended to reference under Australia's Disability Strategy 2021–2031 (ADS) "and strategies that sit under or align with ADS such as the National Autism Strategy".

For the views and experiences of people with disability, as well as those of families and carers of people with disability to be captured should also include a process independent evaluation on a regular basis.

Recommendations to governments of actions that needed improving should include accountability measures if they are not performed

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

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

We would like for there to be consideration that the government prioritise the development of a separate autism healthcare capability framework to ensure the right competencies and knowledge is reflected, as it is established that generic disability strategies are not effective and not all Autistic people have a cognitive impairment.

It is recommended that this occur alongside of the current development of the National Health and Mental Health Roadmap for Autism. The urgency is as has been identified in the Senate Inquiry on Autism, Autistic people are experiencing unacceptably poorer outcomes particularly in relation to health and mental health. This work could draw on any relevant work undertaken for the intellectual disability capability framework. The outline of a framework, monitoring and evaluation can be seen in the Executive Summary under title "Interaction with Local, State, & Commonwealth services".

Recommendation 6.30 Expand the scope of the National Centre of Excellence in Intellectual Disability Health

We agree with the intent but recommend that the Australian Government create a separate National Centre of Excellence in Autism, given the uniqueness and diversity of autism and while some Autistic people have a cognitive impairment not all do.

Recommendation 7.13 National Roadmap to Inclusive Education

We support for this be amended to reflect a "A National Roadmap for Safe, Quality and Inclusive Education. We also request that there is specific actions and measures to improve outcomes for Autistic people given the poor outcomes that are currently reported. This should also be linked to the National Autism Strategy. Refer to Executive Summary under title "Interaction with Local, State, & Commonwealth services" for recommendations regarding the monitoring, reporting and evaluation.

Recommendation 7.14 Phasing out and ending special/segregated education

We support the choices of Autistic people and their families by ensuring access to a range of educational settings, that are safe and conducive for each individual.

We support the principles of:

- making mainstream schools more accessible to Autistic students
- not having segregation in any environment.
- any design of recommendation 7.14 needs to include Autistic people, their families and autism organisations to ensure that environments are safe and conducive to learning. For those who transition from one environment to another we recommend a detailed roadmap of what this looks like prior to any transition to ensure success.

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

We support that specific and disaggregated targets are set by disability type so as to achieve a real increase in the proportion of Autistic employees in meaningful ongoing employment and that the Employment Inclusion recommendations in this paper are considered.

As per previous comments not all Autistic people have a cognitive impairment but are a priority cohort given the significantly poorer employment outcomes experienced than other Australians, including other disabilities.

Recommendation 7.32 End segregated employment by 2034

We support the choices of Autistic people and their families by ensuring access to a range of employment settings, that are safe and conducive for each individual.

We support the principles of not having segregation in any environment. We support that the development of the. For those who transition from one environment to another we recommend the detailed roadmap includes the design of what this looks like prior to any transition from one environment to another to ensure its success and includes Autistic people, their families and autism organisations to ensure that all environments are safe and conducive.

Recommendation 7.33 Prioritise people with disability in key national housing and homelessness approaches

That the National Housing and Homelessness strategy for people with intellectual or cognitive impairment recognise as well Autistic people.

Recommendation 7.34 Include homelessness in Australia's Disability Strategy

Recommendation 7.39 Preventing homelessness when people with disability transition from service or institutional settings

Recommendation 7.40 Address homelessness for people with disability in the National Housing and Homelessness Plan

It is recommended that these recommendations include:

- increased access to different types of accommodation (including to trial), supported decision making to ensure choice and control, and ensure safeguards are in place
- with monitoring, oversight and assessment of execution.
- ensure homelessness is included as a priority in the National Autism Strategy
- ensure mechanisms for security of tenure
- provide guaranteed access to support services to support people transitioning from service or institutional settings including those from criminal institutions to access to NDIS and Medicare pre-transition

Recommendation 7.44 A roadmap to phase out group homes over a generational timeframe

We support the choices of Autistic people and their families by ensuring access to a range of housing settings, that are safe and conducive for each individual.

It is recognised that it has been stated that there will be a staged approach but would like to just reiterate that considerable innovation and reform to housing models will be required to provide accessible and safe accommodation, particularly for people with the most complex support needs.

Recommendation 8.1 Conditions in custody for people with disability

It is suggested that this goes further and that people with disability are provided with access to Medicare benefits while incarcerated so needs are met and that existing NDIS plans are reactivated prior to exiting incarceration so there is no lag and supports are in place.

Appendix 2: Enduring Solutions: The National Autism Strategy and the NDIS Review

I. Models of Disability

1. Any discussion regarding the interaction between the NAS and the NDIS, as well as any discussion regarding potential solutions to address the gaps and result in improved outcomes for Autistic people, must acknowledge the adverse life outcomes for Autistic Australians, which — as the bipartisan report of the Senate Select Committee on Autism — can, inter alia, include:

    1.1. Autistic people have a life expectancy **20–36 years** shorter than the general population, with over two times the mortality rate;

    1.2. **75%** of Autistic people do not complete education beyond Year 12;

    1.3. the unemployment rate for Autistic people is **almost eight times** the rate of people without disability;

    1.4. **50–70%** of Autistic people experience co-existing mental health conditions;

    1.5. **51%** of Autistic people and their families feel socially isolated; and

    1.6. **39%** feel unable to leave the house due to concerns about negative behaviours.[102]

2. There is particular concern with the poor mental health outcomes faced by Autistic people. The Senate report underscores that in one Australian study of Autistic people without intellectual disability, 66% reported suicidal ideation and 35% reported suicide plans or attempts – about five times higher than the general population.[103] Similar reports of adverse outcomes for Autistic Australians have been noted at the Disability Royal Commission. For example, public hearings of the DRC have illustrated the mistreatment of Autistic employees — when interacting with the Disability Employment Services — and the abrogation of their rights,[104] which is contributing to poorer mental health and adverse life outcomes for Autistic people.[105]

3. As a signatory to the United Nations *Convention on the Rights of Persons with Disabilities* ('*CRPD*'), Australia has a treaty obligation to protect the rights of disabled people at large — including Autistic Australians — to liberty, equality, and personal

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

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

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

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

integrity,[106] including the right to protection from discrimination.[107] For example, Article 29 of the *CRPD* guarantees 'the right of persons with disabilities to work, on an equal basis with others'.[108] The right of disabled people to socioeconomic participation without discrimination is further guaranteed in Article 5, which requires Australia and other state parties to 'prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds'.[109]

4.   Moreover, Article 24 requires that signatory states such as Australia 'enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community',[110] as well as 'ensur[ing] persons with disabilities are able to access general tertiary education, vocational training, adult education and lifelong learning without discrimination and on an equal basis with others'.[111] As the Disability Royal Commission notes, the extent to which the *CRPD* has been implemented for the outcomes of disabled people is relevant for not only discussions of service provisions but also the efficacy of service design in general.[112]

5.   Therefore, the recommendation from the Senate Select Committee on Autism is reaffirmed — that all policies relating to Autistic people are not only 'human rights-based… [but also] are aligned with Australia's commitments under the United Nations *Convention on the Rights of People with Disabilities*'.[113] Any policy, strategy, or framework regarding Autistic Australians — including the NAS — must be explicitly **human rights-based** and **aligned with a Social and Human Rights Model of Disability** as well as the *CRPD* in order to ensure that Autistic Australians can participate in **decision-making**.[114]

6.   Moreover, the Disability Royal Commission notes that structural ableism which is concomitant with other forms of structural marginalisation, such as systemic racism and sexism, is creating disproportionately adverse life outcomes for people with

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[106] *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008) ('*CRPD*').
[107] Ibid arts 4(3), 5, and 33.
[108] Ibid art 27.
[109] Ibid art 5.
[110] Ibid art 24
[111] Ibid art 24(5).
[112] Ron McCallum, 'The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance' (Research Report, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 8 October 2020), 8-9.
[113] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) 366.
[114] Ibid. See also Disability Discrimination Legal Service, Submission No 153 to Senate Select Committee on Autism, Parliament of Australia, *Inquiry into Services, Support and Life Outcomes for Autistic Australians* 21.

disability from diverse backgrounds.[115] For example, First Nations people with disability who experience discrimination which resides at the intersection of racism and ableism must pursue separate claims under the *Racial Discrimination Act 1975* (Cth) and the *Disability Discrimination Act 1992* (Cth), which contributes to inequitable access to justice.[116] Furthermore, 46% of the LGBTQIA+ victim-survivors had a disability according to one DRC submission, indicating a critical need to espouse an intersectional approach to disability and to autism.[117]

7. Therefore, we reaffirm the recommendation — from the Disability Royal Commission — that policies relating to people with disability, including Autistic Australians, must espouse **intersectionality** and principles of **disability justice**.[118] We note that a disability justice approach, by centering the leadership of the most impacted, would implement a rights-based framework which enriches intersectionality and racial justice, which is required for cultural safety.[119]

8. This framing of autism would be particularly impactful for BIPOC — the acronym for '*black, indigenous, and other people of colour*' — communities insofar it would apply an **equity** framing to autism, as opposed to merely a **medical** or biopsychosocial framing, and ensure that any policies or strategies deliver outcomes of social justice.[120] , and in particular pertaining to Autistic Australians (including the NAS) as a population that is often overlooked. Furthermore, we reiterate the recommendation that any policies, strategies, and programs regarding Autistic Australians must be

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[115] Ron McCallum, 'The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia's Level of Compliance' (n 11), 23-24.

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

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

[118] Ibid. See also Ilias Bantekas, 'Article 7 Children With Disabilities', in Ilias Bantekas, Michael Ashley Stein and Dimitris Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 198.

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

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

developed, **designed**, and **delivered** *by* and *for* Autistic people.[121] For example, service provisions for Autistic people can — and should — arise from co-production with Autistic people,[122] who are often otherwise at risk of being omitted, misunderstood, and disregarded.[123]

9. Finally, we recommend that all policies, strategies, and programs for Autistic Australians — including the NAS and the NDIS — implement a model of disability which is **affirmative of neurodiversity**.[124] Neurodiversity Affirming care practices, especially for Autistic people from the LGBTQIA+ community,[125] respect the individual's inherent dignity and hence are not only lifesaving but ethical insofar as they can collaborate with communities rather than seeking to 'correct' them.[126]

10. Neurodiversity-affirmative — or **neuro-affirmative** — approaches are not only **strengths-based**, **accessible**, **inclusive** but also eschews perpetuating stigma and shame,[127] which is reported as a barrier in both health settings and workplaces.[128] Moreover, these supports must be both **person-centred** and **trauma-informed** in order to avoid further alienating the lived experience of trauma within the Autistic community.[129]

11. Therefore, we recommend:

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[121] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) 366.

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

[123] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [5.41].

[124] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) 362.

[125] See Ada Cheung et al, 'Sociodemographic and Clinical Characteristics of Transgender Adults in Australia' (2018) 3(1) *Transgender Health* 229.

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

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

[128] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [13.9].

[129] See, eg, Teal Benevides et al, 'Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project' (2020) 24(4) *Autism* 822; Freya Rumball, Francesca Happé, & Nick Grey, 'Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events' (2020) 13(23) *Autism Research* 2122; Nirit Haruvi-Lamdan, Danny Horesh, & Ofer Golan, 'PTSD and autism spectrum disorder: Co-morbidity, gaps in research, and potential shared mechanisms' (2018) 10(3) Psychological Trauma Theory Research Practice and Policy 290; Nirit Haruvi-Lamdan et al, 'Autism Spectrum Disorder and Post-Traumatic Stress Disorder: An unexplored co-occurrence of conditions' (2020) 24(4) *Autism* 884.

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

- **Recommendation 1.2**: That the Australian Government continue to work towards ensuring that all further policies, strategies, programs, interventions, and research relating to Autistic Australians — including the materials relating to the National Autism Strategy ('**NAS**') and the National Disability Insurance Scheme ('**NDIS**') — be **co-developed**[130], and **co-delivered** *by* and *for* Autistic people.

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[130] chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.autismcrc.com.au/access/sites/default/files/resources/Participatory_and_Inclusive_Autism_Research_Practice_Guides.pdf

II. Governance & Accountability Frameworks

12.   We also note that for the policies and strategies regarding Autistic Australians, including the NAS and the NDIS, to succeed, these policies and strategic plans must be undergirded by robust governance and accountability frameworks.

13.   Firstly, strategic documents and policy frameworks may not effectuate tangible outcomes in terms of implementation due to an accountability gap. Because decentralised monitoring can lead to privatisation of auditing, the absence of a panoptical system for audit and assessment can raise concerns about the accountability of public services.[131] A strategic document targeting autism which does not embed monitoring into its implementation plan would therefore fail to address the accountability gap, as reflected by the recommendations by Scotland's Cross-Party Group on Autism that an Autism Commissioner be established to close the accountability gap at a local level.[132]

14.   Indeed, Northern Ireland and Scotland have both elucidated the need for **effective governance** and **frequent monitoring** with inbuilt **timelines for review**.[133] Without the obligation upon the government to undertake not only a regular review of a strategy but also an **implementation/action plan** with legislated accountabilities such as **implementation KPIs**, the odds of improving life outcomes dwindle.[134] Without **supporting legislation** to mandate the review, monitoring, and implementation of the NAS, the systemic barriers leading to poorer outcomes for Autistic people within mainstream education, employment, and health systems and broader community access will continue, thereby placing further strain on the NDIS.[135]

15.   Systemic barriers leading to poorer life outcomes for Autistic people — systemic barriers that are essentially worsening the functional impairments and further

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

[132] National Autistic Society Scotland, 'The Accountability Gap: A Review of the Scottish Strategy for Autism', (Report prepared for the Joint Secretariat to the Cross-Party Group (CPG) on Autism, National Autistic Society Scotland, October 2020) 91 <https://www.scottishautism.org/sites/default/files/cpg_on_autism_report_-_the_accountability_gap_06.10.2020.pdf>.

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

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

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

disabling Autistic people — must be dismantled within mainstream supports such as health, education, and employment,[136] as segregating Autistic people to rely upon the NDIS will incur indirect economic costs that may affect the sustainability of the Scheme.[137]

16. Therefore, we reaffirm the recommendation — from the Senate Select Committee on Autism — to implement accountability measures which include:

    16.1.1. **clear** and **measurable** actions, targets and milestones;

    16.1.2. an **implementation plan** with clearly defined responsibilities;

    16.1.3. **ongoing monitoring** and **reporting requirements**; and

    16.1.4. **built in timelines** for **review** and **renewal** of the strategy.[138]

17. Moreover, we reiterate that a **dedicated**, **independent taskforce** — steered *by* and *for* Autistic Australians — should oversee the ongoing monitoring and reporting requirements.[139] We recommend that this taskforce be given not only access to meetings of the **Disability Reform Ministers** but also governance and oversight over **independent auditors**, which by legislation will have the power to independently investigate cross-jurisdictional complaints and accountability gaps — including lack of progress on implementation KPIs.[140]

18. We reaffirm the importance of introducing **legislation** to not only build in timelines for review but also empower an independent, Autistic-led taskforce — with governance over independent auditors, situated in Premier and Cabinet, who will monitor and investigate progress on the KPIs on implementation/action plans. Otherwise, a risk that such policies may 'sit on a shelf' exists.[141] Moreover, legislation would eliminate any undermining of progress due to a change-in-government.[142]

19. Therefore, we recommend:

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

[137] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [4.15].

[138] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [5.69].

[139] Amaze Australia, Submission No 47 to Senate Select Committee on Autism, Parliament of Australia, *Inquiry into Services, Support and Life Outcomes for Autistic Australians* 6.

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

[141] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [548].

[142] See, eg, Simon Jarrett, 'The British Journal of Learning Disabilities: A History' (2022) 50(2) *British Journal of Learning Disabilities* 122; s

- **Recommendation 2.1**: That the Australian Government support the National Autism Strategy by implementing accountability measures including:
  - **clear** and **measurable** actions, targets and milestones;
  - an **implementation plan** with clearly defined responsibilities;
  - **continuous monitoring** and **annual reporting requirements**; and
  - **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**.
  - **built in timelines** for **review** and **renewal** of the strategy (every 5 years) based on the aforementioned monitoring and re-engagement process, and with the support of a majority-led Autistic and autism community oversight council.

- **Recommendation 2.2**: That the Australian Government implement these accountability measures by:
  - Mandating **effective governance** and **frequent monitoring** through the introduction of **legislation** — modelled after the *Autism Act (Northern Ireland) 2011* (NI) or the *Autism Act 2009* (UK) — that builds **timelines for regular review** and **development** of the NAS. Noting the Act being considered is not required to be an extensive document but modelled on focussing on capturing these recommendations.
  - Empowering a **dedicated**, **independent**, **Autistic-led taskforce** to oversee progress on **implementation KPIs** on the local, state/territory, and national level by granting them access to the **Disability Reform Ministers**. Refer Figure 1.

- **Recommendation 2.3**: That the Australian Government support the Autistic-led taskforce by:
  - Granting the **Autistic-led taskforce** with governance and oversight over **independent auditors**, which shall by legislation have the power to independently investigate **cross-jurisdictional complaints** and **accountability gaps** — including lack of progress on implementation KPIs.

"There has been significant progress. Awareness of autism has increased hugely. Every council now has an adult autism diagnosis pathway, whereas fewer than half did before the Autism Act. Today, all but a very few councils have a lead commissioner for autism. Autism is also a cross- party priority" UK Parliamentary review of ten years of the Autism Act

III. Interaction with Local, State, & Commonwealth Services

20. **Three-tier**, **legislation approach**. There must be state/territory and local government strategies which are aligned and policed for the effective implementation of a National Autism Strategy.

21. It was recognised in the Australian Disability Strategy ('**ADS**') that there are Australian, state, territory, and local governments (commonly known as local councils) all play a part in delivering services that help people with disability.

22. The NDIS Applied Principles and Tables of Support provides further information and outlines the responsibilities between the NDIS and other service systems that deliver supports to people with disability. These were last updated in 2015.

23. Agreements between the Australian government and state and territory governments are in place to allow the shared responsibility of services, systems, funding and governance of programs and policies that affect people with disabilities.

24. The Outcomes Framework is a key initiative under Australia's Disability Strategy 2021–2031 to measure, track, and report on outcomes for people with disability over the life of the Strategy. Annual reporting against the measures in the Outcomes Framework will show what progress is being made on outcomes for people with disability. The Outcomes Framework has 85 measures across the 7 outcome areas of the Strategy and 3 types of measure - system measures, population measures and community attitude measures. While there were some favourable trends before baseline in the areas of inclusive homes and communities, safety rights and justice, and education and learning, there were also unfavourable trends in employment and financial security, safety rights and justice in the areas of domestic and family violence and also health and wellbeing.

25. Despite the intention that in most cases one level of government has the main responsibility for delivering the system, as more than one government is involved in funding or delivering a service system, the interfacing is poor. The current significant reviews and reforms occurring in Australia in parallel indicates that principles and policies alone are not sufficient. Specifically, to autism, as reported through the Senate Select Committee report on Autism, Autistic Australians were experiencing such significantly poorer outcomes that the life expectancy for Autistic Australians was listed as **20-36** years shorter than that of the general population, with over two times the mortality rate.[143]

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

26.   Even where the Australian Government provides a number of disability services nationally, with the intention that the same service is received no matter which state of territory the person is in has not been effective.

27.   A **whole-of-government** and **whole-of-life** approach which coordinates and integrates Commonwealth, State, and local government services is necessary to provide comprehensive support.

28.   The NAS does not have this support at a state level, although it is recognised that two states have committed to a State Autism Strategy. As identified earlier, a key recommendation of Scotland's Cross-Party Group on Autism to "seek to solve the accountability gap" is the establishment of an independent auditor – such as a taskforce to not only uphold the rights of Autistic people but also ensure that effective policy and laws are implemented appropriately at a local level.

29.   Further to this, we reiterate that the Australian Government must ensure a **whole-of-government approach**, an **Assistant Autism Minister** to the Prime Minister (on a Federal level) be to ensure the operationalisation of a co-ordinated and integrated whole-of-government and whole-of-life approach.

30.   It is reiterated that strategies such as the NAS which target Autistic Australians – at any government level – is viewed alongside any other policy initiatives and linked to funded strategies.

31.   Disability, and particularly for autism with significant co-occurring conditions also, as a factor of intersectionality makes individuals more vulnerable and requires an independent, disability specific approach also to education and training. While a strengths perspective is endorsed to reinforce that all with disability are not inherently vulnerable, cultural attitudes and beliefs of the community towards people with disability to remove onus on people with disability to keep themselves safe or to find the right service to contact must be reformed[144]. 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

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[144] DACCSA, Interface of Systems with Disability, 2020 [8]

processes for people with disability as they're vested with the responsibility to right entry point, provide information, fill out forms and seek external support. Other frameworks are also limited such as the Office of Public Advocate, Community Visitors Scheme and Health and Community Services Complaints Commission.

32. The scope of each statutory body is nuanced and navigation of these processes for the individual is disempowering, cumbersome and overwhelming. Existing frameworks are unable to reach and protect people with disability who can't be accommodated by the limited scope of multiple systems and mechanisms for complaints and reporting. The increase in matters relating to abuse, neglect and violence and disability service complaints can in part, be attributed to the degree to which these reporting mechanisms have become inaccessible. Government systems access points need to better understand each other and communicate effectively to carry out consistent triaging and warm referral of people with disability.

33. Furthermore, the systems that are in place to support people have their rights met such as the Australian Human Rights Commission ('**AHRC**') do not result in effective outcomes as their role is as mediators. The significant research[145] and literature on school refusal within the Autistic community (reframed to "school can't[146]" withing a neurodiversity affirming framework) supports this, as Autistic students are often bullied, excluded, forced to change school, is home, schooled, or become completely disengaged from school altogether.

34. High quality information and training is a key enabler for implementation. Training requirements and quality accreditation of training (as a response to missed quality) are common. An example is the UK have developed a national autism core capabilities framework[147] 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.

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

- **Recommendation 3.1**: That the Australian Government support the National Autism Strategy by having the **development and implementation** of an Autism Strategy **at each of the State and Territory** levels of Government, and in turn, at **each Local Council** aligned with the National Autism Strategy **supported**

[145] https://link.springer.com/article/10.1186/s13034-020-00325-7
[146] https://www.livingonthespectrum.com/education/school-refusal-school-cant/
[147] https://www.autismhampshire.org.uk/assets/uploads/Autism_Capabilities_F0ramework_Oct_2019_1.pdf

through legislation. (The commitment by Victoria and South Australia to a State based Autism Strategy is recognised).

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

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

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

- **Recommendation 3.5:** That the Australian Government support the National Autism Strategy by implementing a **national autism core capabilities framework** to identify key capabilities for those working with and for supporting Autistic people including:
  - **values and behaviours** that underpin all the capabilities in the framework.
  - **evaluation methodology**:
    - individual assessment of knowledge and/or competence
    - impact on practice
    - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
  - continuous monitoring and annual reporting requirements.
  - built in timelines for review of the framework (every 3 years).

- **Recommendation 3.6:** That the Australian Government **prioritise support** for and consultation with the following demographics of Autistic Australians:
  - First Nations people;
  - Women and girls;
  - LGBTQIA+ communities;
  - Culturally and Linguistically Diverse ('CALD') communities;
  - People in regional and remote areas;

- o   Individuals in the child protection and justice systems;
- o   Senior (50+ years) people;
- o   People in supported independent living;
- o   Students in various education settings; and
- o   People with complex needs and high dependency needs.
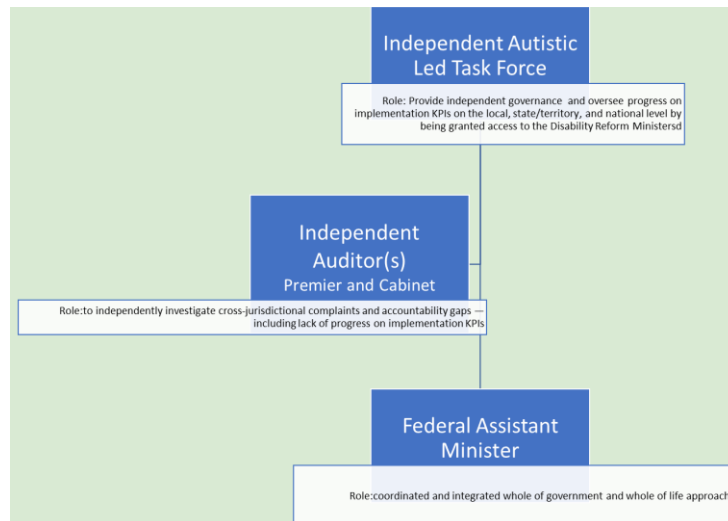
Figure 1: Governance Model

V. Any Other Related Matters

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

37.   Therefore, we recommend:

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