

The Autism Dividend

*Unleashing the skills, talent and opportunity of
Australia's autistic community*

Submission to the Senate Select Committee on Autism



August 2020

The Australian Autism Alliance thanks the thousands of autistic people, their families and carers for their contributions to this submission. Our submission raises issues and contains quotes and statistics that may be confronting to read. It is our hope that by including the unfiltered voices of autistic people, the real need for meaningful change will be highlighted.

The Australian Autism Alliance - 'One Strong Voice for Autism'

The Australian Autism Alliance (the Alliance) was established in 2016 to create 'one strong voice for autism.' Our purpose is to improve the life chances of autistic people and to facilitate collaboration within the autism community.

The Alliance is a national network of 12 diverse autism organisations and brings together autistic led organisations, research bodies, advocacy groups and service providers.

AEIOU Foundation

AMAZE

Autism Queensland

Autism SA

I CAN Network

Autistic Self Advocacy Network (ASAN)

Australasian Society for Autism Research (ASfAR)

Autism Spectrum Australia

Autism Association of Western Australia

Autism Aspergers Advocacy Australia (A4)

Autism Tasmania

The Sycamore School



Autism CRC is an Alliance supporter



Recent work of the Alliance includes:

- creation of a Federal Election Manifesto in 2019
- advocating for establishment of the Disability Royal Commission
- commissioning 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. The survey was conducted by the Australian Catholic University under the direction of Professor Sandra Jones, an autistic academic, with a panel of autistic people. Survey questions were mapped against the Inquiry's Terms of Reference. Over 3,800 responses were received.

The Australian Autism Alliance has substantial national reach

- Reaches over 170,000 people through our communication channels
- Employs over 3,000 staff
- Employs, or provide pathways to employment, for over 350 autistic adults
- Contributes to the Australian economy by generating and delivering an estimated \$200m of supports and services
- Builds capacity of the broader community through training and advisory services for over 60,000 people per year
- Covers nearly all of Australia
- Has significant national and international linkages for advocacy, research and service delivery
- Provides direct support to over 30,000 autistic people across the lifespan from early childhood to adulthood
- Operates 230 service outlets across Australia

Table of Contents mapped against the Terms of Reference (TOR)

RECOMMENDATIONS	3
OVERVIEW	7
EXECUTIVE SUMMARY	ERROR! BOOKMARK NOT DEFINED.
A NATIONAL AUTISM STRATEGY IS LONG OVERDUE – TOR I.....	11
BARRIERS TO ASSESSMENT AND DIAGNOSIS NEED TO BE URGENTLY ADDRESSED - TOR A.....	14
GIRLS AND WOMEN NEED SPECIAL ATTENTION – TOR C.....	18
AUTISTIC PEOPLE FACE STARK HEALTH AND MENTAL HEALTH INEQUALITIES - TOR F(I).....	19
EDUCATION IS KEY TO LIFE CHANCES – TOR F(II).....	28
LIFTING EMPLOYMENT OUTCOMES FOR AUTISTIC PEOPLE MUST BE A PRIORITY – TOR F(III).....	ERROR! BOOKMARK NOT DEFINED.
THERE IS MUCH ROOM TO IMPROVE THE NDIS FOR AUTISTIC PARTICIPANTS – TOR H.....	ERROR! BOOKMARK NOT DEFINED.
RESEARCH IS KEY TO EVIDENCE-DRIVEN APPROACHES TO AUTISM - TOR J.	ERROR! BOOKMARK NOT DEFINED.
AUTISTIC PEOPLE AND THEIR FAMILIES EXPERIENCE EXTREME SOCIAL ISOLATION – TOR K.....	ERROR! BOOKMARK NOT DEFINED.
THE VOICES OF AUTISTIC PEOPLE NEED TO BE AMPLIFIED THROUGH ADVOCACY – TOR L.	ERROR! BOOKMARK NOT DEFINED.

Recommendations

A National Autism Strategy – Term of Reference I

1. Develop and fund a National Autism Strategy co-produced with autistic people.
 - Include targets and actions in key priority areas across the life course including early learning; education and training; employment; community participation; community attitudes; health and wellbeing outcomes; justice and research.
 - Measure and report annually and publicly on outcomes, including for key population groups: females, Cultural and Linguistically Diverse (CALD) people and First Nations communities.
 - Embed the Autism Strategy as a component of the National Disability Strategy, and incentivize the development of complementary state and territory autism plans.

Assessment and Diagnosis – Term of Reference A

2. Extend the Medicare rebate to cover the full costs of autism assessment and diagnosis for children and adults.
3. Fast track implementation of the National Guideline for Assessment and Diagnosis of Autism Spectrum Disorder across all jurisdictions, service systems and sectors.
4. Strengthen system capacity to reduce wait times for an autism assessment to three months post referral. Wait times in each region need to be monitored and reported on.
5. Support early identification of autism by:
 - Building capability in universal service platforms – particularly maternal and child health services and General Practitioners to detect warning signs and refer young children for assessment.
 - Supporting the further development of detection apps, including strengthening cultural responsiveness for diverse communities.

Women and Girls – Term of Reference C

6. Support the development of screening and diagnostic tools to better identify autism in women and girls and gender diverse people.

Health and Mental Health – Term of Reference F(i)

7. Implement a systemic approach through national and state health service sectors to strengthen the autism competency of healthcare professionals, with a particular focus on GPs, emergency staff and mental health practitioners.
8. Strengthen pre and post-natal care for autistic mothers by:
 - Developing autism-specific tools and processes to screen for and identify pre- and post-natal depression in autistic mothers; and
 - Providing an enhanced maternal and child health care offering for autistic mothers and families with autistic children.
9. Develop a National Roadmap to improve health services for autistic people.
10. Introduce autism friendly universal design principles across hospitals and major health infrastructure, starting with quiet, low sensory emergency departments, waiting and treatment rooms in public hospitals.

11. Extend, quality assure and mandate training in autism for mental health services. Introduce a system of accreditation that enables autistic people to identify mental health practitioners with proficiency in autism.
12. Implement the MBS Review Taskforce's recommendations relating to the Better Access program for mental health, including increasing the number of sessions available for people with higher needs and enabling families and carers to access therapy.
13. Develop a dedicated National Plan on Autism in Mental Health that is complementary to the next iteration of the National Mental Health and Suicide Plan.

Education and Training – Term of Reference F(ii)

14. Overhaul the National Disability Standards to positively reframe inclusive education as a right, strengthen protections and create accountabilities in the education system to progressively improve key inclusion metrics.
15. Expand targeted measures to increase participation of autistic children in early learning programs.
16. Upscale professional development on autism for educators, education support staff and leaders – in early learning, schools and post-secondary settings. Investigate embedding requirements to undertake autism training in educator standards and registration processes.
17. Increase accountability and transparency around how disability funding is used and the outcomes of students receiving it.
18. Improve transitional support for young autistic people to explore and navigate vocational and post-school employment options. Implement the recommendation from the Shergold Review into Senior Secondary Pathways that all senior secondary students with disability have access to work experience and have an individual post-school transition plan in place prior to leaving school.
19. Incentivise programs and strategies by vocational and higher education providers to bridge the gap for autistic people in receiving post-school qualification. Set targets for autistic people to take up opportunities – such as free TAFE and the new JobTrainer initiative.

Employment – Term of Reference F(iii)

20. Include specific measures for autistic jobseekers within public sector employment initiatives including the NDIS Participant Employment Strategy, public sector disability employment targets, social procurement policies and the upcoming National Disability Employment Strategy.
21. Establish a federal social procurement framework requiring Australian Government contractors to deliver training and employment opportunities for marginalized jobseekers – including autistic people. A Federal purchasing strategy that preferences social enterprises should accompany this.
22. Expand demonstration projects to strengthen the evidence base on effective and efficient models that support the sustained employment of autistic people. Use these to inform systemic reforms to Disability Employment Services and Jobactive.

23. Include an autistic employment stream as part of a COVID-19 job creation schemes– providing deep wage subsidies and preferencing employers who can demonstrate inclusive practices.
24. Convene a wide-ranging autism employment summit, co-produced with autistic people, that brings together employers; TAFE; autistic people; autistic employment assistance programs, community organisations; researchers and governments to identify measures to enable autistic people to find and maintain work as Australia recovers from the pandemic.

NDIS – Term of Reference H

25. Overhaul ECEI. Provide automatic access as participants to the scheme for every child with an autism diagnosis and enable immediate access to comprehensive early intervention. Explore extension of the ECEI offering until age 8 to support improved transition to school.
26. Establish a specific NDIS autism and neurodevelopmental participant stream and dedicated training for all NDIA and partner staff in access and planning.
27. Develop clear, transparent and accessible eligibility criteria for autistic people, including a robust and reliable tool for determining eligibility, leveraging the National Guideline for Autism Assessment and Diagnosis.
28. Co-design tailored NDIS information to meet the needs of autistic people.
29. Expand investment in pre-planning support and peer networks, drawing on the successful NDIA Disability Support Organisations program.

Research – Term of Reference J

30. Continue funding national, collaborative research at scale following the sun-setting of the Autism CRC.
31. Develop a National Autism Research Strategy, as a component of a future National Autism Strategy. Priorities identified by the Australian Autism Research Council should be adopted.

Social Isolation – Term of Reference K

32. Fund a public education campaign to improve understanding of autism and how to support autistic people.
33. Position the Australian Government as exemplars in autism friendly environments by providing sensory maps, social scripts and modified environments across federal venues. Incentivise business, community, sports and arts organisations to do likewise.

Advocacy – Term of Reference L

34. Fund user-led autism specific advocacy services (individual and systemic) and support their capacity and capacity building activities to operate nationally, in parallel with generalist disability advocacy services.
35. Develop a nationally consistent approach to advocacy, with clear and agreed roles for the Commonwealth Government and the States and Territories, built on an ongoing and consistent funding model. Ensure funding growth is applied to advocacy programs in order to maintain pace with CPI and the increased demands caused by the rollout of the NDIS.

Overview

The Australian Autism Alliance aims to provide ‘One Strong Voice for Autism’

The Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. Operating as a cohesive network of 12 organisations with a diverse focus on autism, we have a national reach that brings together autistic-led organisations, research bodies, advocacy groups and service providers.

Our work is informed by autistic people and in particular, parents of autistic children. Readers of our submission will note that there are quotes throughout. These are community responses to the Alliance’s survey and represent the unfiltered words of autistic people and their families.

[This is an unprecedented Inquiry, conducted during unprecedented times](#)

This unique opportunity to discuss the current and future approaches to improving the wellbeing of autistic people in Australia is being conducted under the shadow of the most significant public health and social challenge of the last century.

The impact of the pandemic on all aspects of life, including the work of the Parliament, is unprecedented and must be acknowledged.

Amidst the rapidly changing public policy environment, the impact of the pandemic on the lives of autistic people and their families must be considered. Already experiencing significantly poorer education, mental health, social participation and employment outcomes compared to the broader population, autistic people have been hit hard by the pandemic.

With unemployment across Australia heading into double digits, those with existing labour market disadvantages (autistic people have among the highest unemployment rates of any population group in the nation) are likely to fare badly.

[Autistic people are at high risk of being caught in the long tail of disadvantage following the coronavirus crisis. Without targeted and sustained measures, the pandemic and its aftermath risks sending the metrics on key life outcomes for autistic people backwards.](#)

There is high aspiration and huge untapped talent in the autistic community. If harnessed, it will contribute to strengthening Australia’s recovery, productive capacity and community resilience.

The policy choices made during this crisis and as we emerge out the other side, can deliver a better, more inclusive and sustainable future for our nation. This Inquiry has the opportunity to drive these choices and shape post-pandemic Australia to enable autistic people to thrive.

Executive summary

The Alliance welcomes the ground-breaking work of the Senate Select Committee on Autism and its inquiry (the Inquiry). We embrace the opportunity to speak directly to the Senate about the current state of affairs for the autism community in Australia, to outline our priorities for improving the lives and wellbeing of autistic people and to provide recommendations for reform.

Our submission is directly informed by the lived experience of the autistic people and their families and guardians who contributed to the largest consultation survey of the autism community conducted in Australia, as well as the thousands of autistic people and their families who interact with Alliance members on a daily basis. The Alliance commissioned the consultation survey specifically for the Senate Inquiry.

The Inquiry is the first national process of its type in Australia. It offers a unique opportunity for the Senate and the autism community to work together to advance the circumstances and life outcomes of autistic people.

There is a high prevalence of autism 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. Actual prevalence in the community is likely to be much higher as many adults have not been diagnosed.

In the context of the National Disability Insurance Scheme, 31% of participants have a primary autism diagnosis, and an additional 5% of participants have autism as a secondary disability – the largest diagnostic group within the Scheme. In the younger age groups, the lion's share of participants are autistic: 65% of those aged 7-14 years and 54% of 15-18 year olds.

Autistic people have among the worst life outcomes

In education, employment, mental health, life expectancy, social and community life – autistic people consistently have among the worst outcomes compared with other disability and vulnerable population groups. These dire outcomes come at a huge cost to autistic people, their families and the broader Australian community. They require urgent and dedicated action. Importantly, these outcomes are not primarily caused by the 'disability' itself, but rather by a lack of an enabling and supportive environment.

Australia needs a National Autism Strategy

A National Autism Strategy is needed to drive an intentional and coherent approach to shifting the dial on outcomes for autistic people. It would provide an overarching and bi-partisan frame for mutually reinforcing policy, service and program responses across different domains and jurisdictions. A Strategy would articulate a shared vision with tangible outcomes and actions in key priority areas across the life course including early learning; education and training; employment; community participation; community attitudes; health and wellbeing; justice and research.

Reforming assessment and diagnosis of autism is a key opportunity

Australian families are facing significant delays and high costs in the assessment and diagnosis of autism, with typical waits for child assessments in public system of between one and two years. This pushes many into the high-cost private system, creating a divide between those who can afford timely private assessments and diagnoses, and those who are forced to wait in the log-jammed public system.

Such delay has real and lasting impacts for us all. Evidence clearly shows that effective early interventions and support can have dramatic and lasting effects on the development of autistic children. In contrast, delayed diagnoses can have a domino effect – with children who start autism specific early interventions later at significantly higher risk of developing intellectual disability and being much less likely to attend mainstream school. That said, there are benefits of diagnosis at any age.

Fast-tracking implementation of the National Guidelines for the Assessment and Diagnosis of Autism Spectrum Disorder, facilitating access to rapid and affordable diagnosis, and supporting early detection of autism must be a priority for the Committee.

The NDIS is a game-changer, but must better respond to the needs of autistic people

NDIS participants with autism as their primary diagnosis constitute the largest single group within the NDIS (31%), however autistic people express widespread dissatisfaction with the scheme, which is vindicated by the comparatively poor outcomes experienced by autistic participants.

Positive adjustments to the NDIS – including ECEI - will dramatically improve the social and economic participation of autistic people and their families, helping realise the scheme’s vision and deliver significant flow-on benefits to the broader economy.

Much can be done to lift education and employment outcomes

Education is pivotal to improving life chances and equipping autistic people to meet Australia’s contemporary and future workforce needs. There is huge potential to lift the educational attainment of autistic people through much higher rates of school, VET and university completions.

Raising expectations about the potential of autistic students, backed by measures to enable their participation demands concerted national action. Our education systems must be held to account for doing better by autistic learners.

Autistic people overwhelmingly want to work and have much to contribute to Australia’s productive capacity, yet their talent and potential is not being realised. We see significant opportunity to make deep inroads into current high levels of unemployment, underemployment and low labour market participation among autistic people – building on proven autism employment approaches. Pro-active measures to promote autistic employment in the post-pandemic economy need to be embedded in recovery efforts.

The health and mental health of autistic people is unacceptably poor

Autistic people experience poor health and mental health outcomes across many key indicators, including life expectancy (autistic people are more than twice as likely to die before age 75), prevalence of mental illness (50-70% have co-occurring mental health issues) and high rates of suicide

The health inequalities faced by autistic people are cause for alarm. They justify a swift, targeted intervention from all levels of government and the health system to arrest what is an unacceptable gap in health outcomes for a significant cohort of the Australian population.

There is a burning platform for change, and the Alliance is ready to work closely with the Inquiry to drive reform

In order to support this landmark opportunity for change, the Australian Autism Alliance is investing significant joint effort. We have:

- Undertaken Australia's largest and most comprehensive consultation survey of autistic people and their families and carers
- Supported autistic people and their families and carers to participate directly in the Inquiry
- Prepared joint and individual submissions, as well as appearing as witnesses before the Inquiry.

We present the following submission for the Inquiry's consideration and stand committed to work closely to ensure our recommendations are understood.

Upon completion of the Inquiry, we will work closely with the Commonwealth and State and Territory Governments to implement long-lasting positive reforms that improve the lives, wellbeing and opportunities for autistic people in Australia.

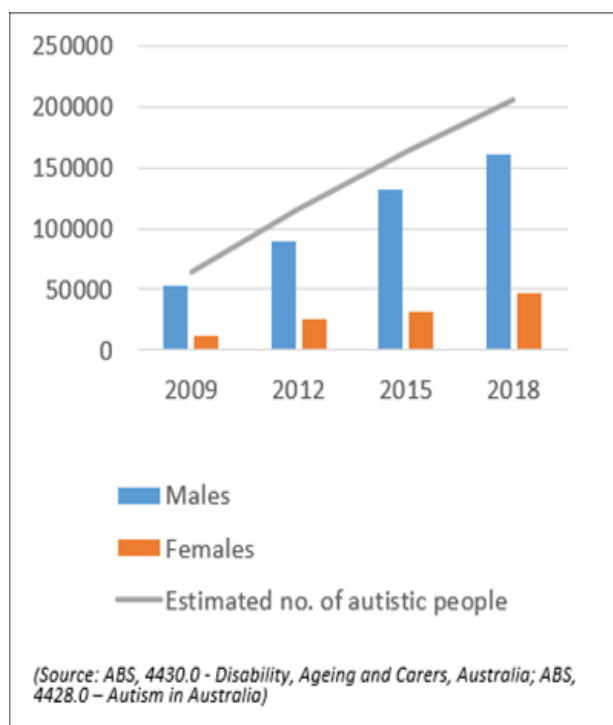
A National Autism Strategy is long overdue

There is a high prevalence of autism in Australia

Improved recognition of autism and the reclassification of Asperger's Syndrome has contributed to a dramatic increase in people diagnosed with autism in Australia – up 217% - over the last decade (far greater than for other disabilities).

In 2018 the ABS reported there were 205,200 people in Australia with an autism diagnosis – 1.3% of males and 0.4% in females. Given the large numbers – particularly adults – who remain undiagnosed, true prevalence is likely to be considerably higher.

ABS figures put the prevalence rate of autism diagnoses for children aged 5-14 years in Australia at 3.2% (99,300 children). These children are our future. The actions taken now will dramatically impact their life trajectory.



Autistic people have among the worse life outcomes

In education, employment, mental health, life expectancy, social and community life – autistic people consistently have among the worst outcomes compared with other many other disability and vulnerable population groups.

Autistic people with intersecting disadvantages – those in low socio-economic households and neighbourhoods; with co-occurring disabilities; with low English proficiency; and those living in regional and remote communities face heightened risks of even poorer outcomes.

These dire outcomes come at a huge cost to autistic people, their families and the broader Australian community.¹ They demand urgent and dedicated action.

Policy responses to autism across Australia are overwhelmingly patchy and haphazard

Australia lacks a coherent approach to addressing autism. Instead, the policy and program landscape is piecemeal, and dotted with small, disconnected and fragmented initiatives delivered through multiples service systems – chiefly education, health, disability, and social services – and across all levels of government.

¹ Synergies Economic Consulting, 2013. *Cost-benefit analysis of providing early intervention to children with autism*. Available at: <https://www.synergies.com.au/wp-content/uploads/2019/09/Productivity-Commission-Cost-Benefit-Analysis-of-Providing-Early-Intervention-to-Children-with-Autism-2013.pdf>

The recently released Victorian Autism Plan 2019² is the only whole of government autism plan in Australia.

Australia needs a National Autism Strategy

A National Autism Strategy would create an intentional and coherent approach to shifting the dial on outcomes for autistic people. It would provide an overarching and bi-partisan framework to drive coordinated and mutually reinforcing policy, research, service, and program responses across different domains and jurisdictions. It would cover autistic people across the life course – including through key life transitions – and across the spectrum.

A National Autism Strategy would create a shared vision with tangible outcomes and actions in key priority areas including early learning; education and training; employment; community participation; community attitudes; health and wellbeing; justice and research. It would need to be regularly refreshed (3-5-year intervals) to reflect fast changing landscape, with agreed accountabilities for achieving outcome goals.

There are two main reasons Australia needs a National Autism Strategy:

- 1) The size of the autistic population is growing beyond that of other disabilities and is likely to be the largest disability in Australia today.
- 2) Autistic people have among the lowest social and economic outcomes of other disability and vulnerable groups.

Specific and dedicated action on autism is both an equity and economic necessity.

While a strategy in and of itself is no silver bullet, analysis by Autism Europe³ highlights that countries with a national autism strategy bring about positive impact and change for autistic people, even if they do not achieve all their objectives. Likewise, a UK Parliamentary Report undertaken ten years after their *Autism Act* was introduced found that while there has been improvements in some areas, including healthcare and social services, there is still a long way to go.⁴ They underscore the need for an enabling framework – such as a national strategy – to be underpinned by strategic actions, measureable outcomes, accountabilities for delivery and co-ordinated funding.

A National Autism Strategy would complement, not fragment Australia's broader disability policy

The Committee may hear arguments there should not be a diagnostic-specific strategy for autism and that a National Disability Strategy is sufficient to cover all disabilities. Respectfully, we disagree.

The Alliance acknowledges the excellent work that has been done in cross-disability policy, leading to major gains in support and resourcing for the disability community. However, despite all this work, key indicators and outcomes for autistic people have not advanced. This is unacceptable.

The large numbers of people with autism, the distinct challenges faced, and the opportunity to make significant gains with a well targeted and tailored response make an autism-specific strategy a national imperative.

A National Autism Strategy should not exist in a vacuum. Instead it ought to be situated as a complementary part to the broader architecture of the National Disability Strategy and the National

² Victorian Government, 2019. *Victorian Autism Plan*. Available at: <https://www.statedisabilityplan.vic.gov.au/victorian-autism-plan>

³ Available at https://www.autismeurope.org/wp-content/uploads/2018/02/ASDEU_State-of-the-art-autism-policies.pdf

⁴ Available at: https://www.autism.org.uk/~media/nas/get-involved/media-centre/newsdocs/nas_appga_report.ashx?la=en-gb

Disability Agreement. As with the NDIS, this would incentivise and create an imperative for state and territories to develop complementary autism plans.

But should avoid shortcomings of the National Disability Strategy

A fundamental flaw of the current National Disability Strategy (NDS), which is earmarked to be addressed in the next iteration, is the absence of an outcomes framework. This has made it challenging to track change or to hold governments and mainstream service providers to account.

A comprehensive outcomes framework is vital to a future National Autism Strategy, backed by indicators and measures to monitor change. Progress against these outcomes should be transparently monitored and reported on – ideally through an annual report to Parliament. This would need to be informed by the collection of robust data on the outcomes of autistic people across the life course.

Comparison of outcomes across Australia’s different jurisdictions, and for key population groups including females, culturally and linguistically diverse, and First Nations peoples is crucial to understanding challenges and tailoring responses.

A further weakness of the NDS has been the lack of transparency around funding, other than funds allocated to the NDIS. A National Autism Strategy would need to come with a funding allocation to implement agreed measures.

Co-production with autistic people is critical

Reflecting the principle of “nothing about us without us,” a National Autism Strategy ought to be co-produced from end to end with autistic people and their families and carers. Shared governance would support continued attention and accountability, even as political leaders come and go and governments change.

Inspiration can be drawn from the recent refresh of Closing the Gap which has seen processes and governance overhauled to embed the voice, aspirations and experience of First Nations peoples.

Recommendation: National Autism Strategy

1. Develop and fund a National Autism Strategy co-produced with autistic people.
 - Include targets and actions in key priority areas across the life course including early learning; education and training; employment; community participation; community attitudes; health and wellbeing outcomes; justice and research.
 - Measure and report annually and publicly on outcomes, including for key population groups: females, Cultural and Linguistically Diverse (CALD) people and First Nations communities.
 - Embed the Autism Strategy as a component of the National Disability Strategy, and incentivize the development of complementary state and territory autism plans.

Barriers to assessment and diagnosis need to be urgently addressed

Diagnosis matters

Diagnosis is crucial to accessing autism-specific early intervention in a timely manner. Every moment counts for infants and children. Early diagnosis yields significant return on investment, while delays in accessing appropriate support significantly impact life outcomes.

Those who receive their autism diagnosis as adults enjoy substantial benefits. Autistic respondents to our survey reported the following advantages of receiving a diagnosis:

- 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.

Increased access to diagnosis should lead to cost savings to the public purse over time. Diagnosis enables access to appropriate services and supports, which in turn boosts social and economic participation, and reduces the costs of care and income supports.

There are major barriers to diagnosis

Medicare coverage is woefully inadequate

Medicare rebates for autism assessment and diagnosis are only available for children under 13 years and only partially cover costs. This leaves young people and adults exposed to prohibitively high costs for seeking a formal diagnosis.

There is a move to change this, with the Allied Health Reference Group of the Medicare Benefits Schedule (MBS) Review Taskforce recommending the age cap be lifted to 25 years⁵ given the increasing diagnosis of autism in people between the ages of 13 and 25. The MBS Review Taskforce is yet to provide its final recommendations to the Government.

While the Alliance welcomes moves to lift the age cap, there is a strong social and economic case to remove the age cap altogether so that people of any age – including adults (who often discover their own autism as a result of their child’s diagnosis) have coverage. Failing to provide clear pathways and more affordable access to adult diagnosis has significant adverse impacts.

“Medicare also needs to provide item numbers for adult autistic diagnosis that are meaningful and bring the cost of getting a private diagnosis into affordable territory. I, and many of my autistic friends, cannot get updated paperwork to allow us to apply for DSP and/or NDIS simply because we can’t afford it.”

⁵ Report from the Allied Health Reference Group, 2018. Available at [https://www1.health.gov.au/internet/main/publishing.nsf/Content/BEB6C6D36DE56438CA258397000F4898/\\$File/AHRG-Final-Report.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/BEB6C6D36DE56438CA258397000F4898/$File/AHRG-Final-Report.pdf)

The public system is log-jammed

Those seeking assessment and diagnosis through the public system face long wait times of up to two years, with regional, rural and remote communities often waiting longer. These delays adversely impact a child's outcomes.

Out-of-pocket costs of assessment and diagnosis are prohibitive for many

Long wait times in the public system are pushing many families into paying for private diagnosis, despite the high cost impost it places on family budgets. The cost of undertaking assessment tends to increase with age, reflecting increased complexity of diagnosing older children and adults.

Two thirds of autistic adults and 36% of parents/carers responding to our survey regarding experiences with their children identified cost as a barrier to seeking diagnosis. 40% reported paying over \$1,000, with out-of-pocket costs ranging up to \$3,000.

Misdiagnosis is a live issue

Over half of autistic adults responding to our recent survey revealed they were misdiagnosed with another condition before being diagnosed as autistic. 31.1% of parents/carers reported the same experience for children in their care. Girls and women are at high risk of being un-diagnosed or misdiagnosed, which is discussed in the next section of our submission.

Increased access to diagnosis coupled with the rollout of the National Guidelines (discussed below) will build sector capacity and capability.

First Nations peoples face additional barriers to assessment and diagnosis

While there is little research focused on autism and Aboriginal and/or Torres Strait Islander people, there are indications that there are lower diagnosis rates for First Nations groups.⁶ Likewise, a lower proportion of First Nations participants in the NDIS have a primary disability of autism (28%) compared with non-Indigenous participants (31%).⁷

The National Guideline for Assessment and Diagnosis of Autism Spectrum Disorder offers an important way forward

There are a multitude of assessment and diagnosis practices across different jurisdictions, service systems, and between public and private diagnosticians – with some falling short of best practice. This creates inequities, inefficiencies, confusion and distress among those seeking assessment and diagnosis.

The National Guidelines developed by Autism CRC represent an important opportunity – outlined in detail in Autism CRC's submission to this Inquiry. Informed by international best practice, the Guidelines are designed to drive a consistent and evidence-based approach.

The Guidelines were the result of an extensive and extended consultation process. They have been endorsed by the full Council of the National Health and Medical Research Council and were launched by the federal ministers for Health and Social Services in 2018. While there has been some progress, there is much that still needs to happen to put the Guidelines into effect.

⁶ Bailey, B. & Arciuli, J., 2020. *Indigenous Australians with autism: A scoping review*. Available at: <https://journals.sagepub.com/doi/full/10.1177/1362361319894829>

⁷ NDIA, 2019. Aboriginal and Torres Strait Islander participants, 30 June 2019. <https://data.ndis.gov.au/reports-and-analyses/aboriginal-and-torres-strait-islander-report>

In addition to the important consistency of approach, the Guidelines will deliver cost savings by rationalising assessment requirements and funding mechanisms across service systems - including health, disability and education. This will reduce duplication and the frustrating need for multiple assessments across systems.

Implementation of the Guidelines needs to be fast tracked, including by mandating use across jurisdictions and services.

System capacity needs to be increased to reduce wait times

Timely assessment and diagnosis is dependent on increased system capacity. While full implementation of the National Guidelines should free up some capacity, consideration needs to be given to investment to creating new capacity, particularly within the public system.

International norms are for autism assessments for children and adolescents under 19 to start within three months of referral.⁸ Australia needs to reduce wait times to comparable levels.

The age of diagnosis needs to shift downwards

Age of diagnosis matters. Autism can be detected very early, often in the first one to two years of life. The difference in outcomes for those children who are diagnosed by two years compared with those diagnosed after age three is stark. This is because a critical early window to influence the developing child's brain is accessed. The adjacent diagram (reproduced from the Olga Tennison Autism Research Centre's submission to this Inquiry) highlights the significant difference – in terms of intellectual capacity and participation in mainstream schooling - even a short delay in diagnosis can make to a child's trajectory.⁹

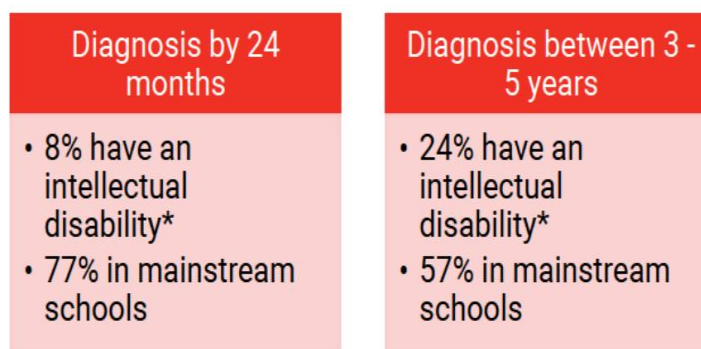


Figure 1 – Effects of early diagnosis *(IQ < 70) at school age

Despite improvements in awareness and diagnostic processes, the average age of diagnosis remains too high:

- The average age of diagnosis is around nine years: 43% of participants in the Study of Australian School Leavers with Autism were older than nine when diagnosed.¹⁰
- For children diagnosed by age seven, the average age of diagnosis is just over four years of age.¹¹

There is an imperative to act swiftly to address these delays.

⁸ Taylor, L. et al, 2016. *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane. Available at: <https://www.autismcrc.com.au/sites/default/files/inline-files/Diagnostic%20standards%20for%20autism%20in%20Australia%20-%20Final%20report.pdf>

⁹ Clark, MLE, et al 2017. *School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder*. Available at: <https://link.springer.com/article/10.1007/s10803-017-3279-x>

¹⁰ Lawson, L.P., Haschek, A., & Richdale, A.L. 2019. *Study of Australian School Leavers with Autism, Baseline Profile, 2018*. Available at: https://www.autismcrc.com.au/sites/default/files/SASLA_Baseline%20Profile%20Snapshot%20-%202018_updated%2010.7.19.pdf

¹¹ Taylor, L. et al, 2016. *Autism Spectrum Disorder Diagnosis in Australia: Are we meeting Best Practice Standards?* Autism Co-operative Research Centre, Brisbane. Available at: <https://www.autismcrc.com.au/sites/default/files/inline-files/Diagnostic%20standards%20for%20autism%20in%20Australia%20-%20Final%20report.pdf>

Universal early years services can play a pivotal role in early identification of autism

Early years points of contact – particularly child and maternal health services and general practitioners who are engaged with our youngest children have the potential to play a much greater role in early detection and referrals.

Autism CRC and La Trobe University have successfully trialled early childhood autism detection tools with maternal and child health services. Training has recently been rolled out to maternal and child nurses across Victoria and Tasmania with 98% of nurses reporting confidence in detecting early signs and making appropriate referrals.¹² This approach, which effectively leverages existing infrastructure, ought to be replicated nationally.

Apps can also support early detection

The Olga Tennison Autism Research Centre at La Trobe University has developed an app-based tool called ASDetect¹³ to assist parents in the early identification of autism. This free app guides parents through a series of evidence-based activities with children aged 11-30 months. It tests their social attention and communication behaviours and assigns a risk assessment for the potential likelihood of autism. Studies that informed the development of ASDetect have shown that 81%-83% of children who were identified as having a high likelihood for autism did in fact have autism, with the remaining 17%-19% being formally diagnosed with other developmental delays.¹⁴

ASDetect is now available in English, Mandarin Chinese, and Spanish – with potential for expansion into further language groups. It provides a critical tool to parents and health professionals, and could be an excellent preliminary screening measure in remote and service-light regions.

Recommendations: Assessment & Diagnosis

2. Extend the Medicare rebate to cover the full costs of autism assessment and diagnosis for children and adults.
3. Fast track implementation of the National Guideline for Assessment and Diagnosis of Autism Spectrum Disorder across all jurisdictions, service systems and sectors.
4. Strengthen system capacity to reduce wait times for an autism assessment to three months post referral. Wait times in each region need to be monitored and reported on.
5. Support early identification of autism by:
 - building capability in universal service platforms – particularly maternal and child health services and General Practitioners to detect warning signs and refer young children for assessment
 - supporting the further development of detection apps, including strengthening cultural responsiveness for diverse communities.

¹² La Trobe University, Olga Tennison Autism Research Centre 2018. Available at:

<https://www.latrobe.edu.au/news/articles/2018/release/life-changing-autism-training-funded>

¹³ Olga Tennison Autism Research Centre ASDetect information page: <https://www.latrobe.edu.au/otarc/asdetect>

¹⁴ Barbaro, J & Dissanayake, C. 2010. *Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: the social attention and communication study*. Available at: <https://pubmed.ncbi.nlm.nih.gov/20495475/>

Girls and women need special attention

Girls and women are under-diagnosed

Current ABS figures reveal the estimated ratio of autistic boys and men to autistic girls and women is 3.5:1. This is likely a significant underestimate.

There is an ongoing systemic failure to identify and diagnose autistic girls and women, reflecting a lack of recognition and understanding across sectors of the differences in how autism presents in girls and women compared to boys and men.

The National Guidelines for Assessment and Diagnosis include consideration of gender and gender diversity. However, commonly used autism screening and diagnostic tools – such as the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised – reflect a presentation more commonly found in boys and men than women and girls, and may lack the sensitivity and specificity required to identify autistic characteristics in women and girls.¹⁵

And are more likely to be diagnosed late or misdiagnosed

Girls are, on average, being diagnosed later than boys – often not until adolescence or adulthood. Nearly two-thirds of female respondents to the Study of Australian School Leavers with Autism (65.9%) were diagnosed at age nine or older compared with 37.7% of males.¹⁶

Autistic women are more likely to receive a primary diagnosis of a mental health condition rather than autism.¹⁷

“My child has missed out on so much help because of her late diagnosis at 14 years old. I believe with so many girls being diagnosed later in life there should be an ‘early intervention program’ for recently diagnosed people- not people of a certain age.”

Gender diversity must be considered

There is emerging evidence that autistic people are represented in greater numbers in asexual and transgender communities, compared with the general population.¹⁸ The needs of this cohort need to be better understood and met.

Recommendation: Girls and Women

6. Support the development of screening and diagnostic tools to better identify autism in women and girls and gender diverse people.

¹⁵ Lai, M., et al 2015. *Sex/gender differences and autism: Setting the scene for future research*. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4284309/>; Rynkiewicz, A., et al 2016. *An investigation of the ‘girls/women camouflage effect’ in autism using a computerized ADOS-2 and a test of sex/gender differences*. Available at <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-016-0073-0>

¹⁶ La Trobe University Olga Tennison Autism Research Centre. *Response to the Select Committee on Autism Inquiry into the services, supports and life outcomes for autistic people in Australia*. July 2020. Submission number 55, pg. 8.

¹⁷ Brown, C., Fuller-Tyszkiewicz, M., Krug, I. & Stokes, M.A. 2019. *Diagnostic overshadowing in autistic women*. Poster presented at International Society for Autism Research, Montreal.

¹⁸ Glidden D et al. 2016. *Gender Dysphoria and Autism Spectrum Disorder: A systematic review of the literature*. Available at [https://www.smr.isexmed.org/article/S2050-0521\(15\)00004-9/pdf](https://www.smr.isexmed.org/article/S2050-0521(15)00004-9/pdf)

Autistic people face stark health and mental health inequalities

Autistic people face a huge gap in health outcomes

Local and international evidence shows that autistic people experience significant health inequalities:

- International evidence reveals autistic people have a **life expectancy of 20-36 years shorter** than the general population.¹⁹
- A 2019 study found autistic people are more than **twice as likely to die before turning 75** as the general population. This is largely due to the high incidence of mental health conditions.²⁰
- Mental ill health impacts the majority of autistic people with between **50-70% of autistic people experience co-existing mental health conditions**. Anxiety and depressive disorders are the most prevalent, particularly among autistic females.
- **Suicide is a major issue**. A 2015 study found that adults with autism and no additional learning disability are over **9 times more likely (relative to a general population) to commit suicide**.²¹ 66% of adults newly diagnosed with ASD contemplate suicide, compared to 17% of the general population, and 35% plan or attempt to end their lives.²² Research involving a cohort of 50 autistic adults, found a 36% suicide attempt rate, compared to 4.6% in the general population.²³

These statistics are staggering and justify the mobilisation of Commonwealth and State and Territory Governments in a concerted effort to reform health and mental health services to ensure that autistic people can access them in a timely and appropriate way.

Accessing health care is challenging

While identifying single causes of health disparities is fraught, personal insights from autistic people and parents caring for their autistic children captured in our survey consistently identify real barriers to healthcare accessibility. These include:

- **Systemic chasms** between key health and mental health system services.
- Frequent challenges in receiving health and mental health care that is skilled, empathetic and responsive to their needs – with **low confidence in health professionals understanding of autism**.
- **Communication difficulties**: 76.6% of autistic adults and 84.7% of parents/carers responding to our survey reporting access challenges due to communication issues.

¹⁹ Hirvikoski T et al 2015. *Premature mortality in autism spectrum disorder*. Available at: <https://pubmed.ncbi.nlm.nih.gov/26541693/>; Guan J, Li G. *Injury mortality in individuals with autism*. Available at: <https://pubmed.ncbi.nlm.nih.gov/28323463/>

²⁰ Hirvikoski T et al 2015. *Premature mortality in autism spectrum disorder*. Available at: <https://pubmed.ncbi.nlm.nih.gov/26541693/>

²¹ Ibid.

²² Cassidy, S., et al, 2014. *Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study*. Available at: [https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(14\)70248-2/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70248-2/fulltext)

²³ Paquette-Smith, M. et al, 2014. *History of suicide attempts in adults with Asperger syndrome*. Available at: <https://pubmed.ncbi.nlm.nih.gov/25113892/>

- **Health care environments:** 90.5% of autistic adults and 93.6% of parents/carers survey respondents reported challenges in accessing healthcare due to anxiety caused by the environment and 84.4% of autistic adults and 90.8% of parents/carers reporting challenges related to sensory sensitivities.

These barriers echo findings of the Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder about the challenges autistic people face when accessing mainstream health services.

This causes high emergency department presentations and hospital admissions

The Victorian Inquiry found that autistic children and teenagers are 10 times more likely to be admitted to hospital for medical illnesses and complaints, suggesting effective preventative and primary health care is not being accessed.

Respondents to our survey reported a high utilisation of hospital emergency departments, with 35.1% of autistic adults and 27.7% parents and carers reporting that they had attended one in the past 12 months. In contrast, an ABS study found around 12.7% of people aged 25-64 had at least one emergency department presentation in a year. The rate of ED presentations for autistic people far exceeded even that of people aged 85 years and over, 24.4% of whom presented at an ED.²⁴

There is a dual burden associated with the presenting at EDs and being admitted as an inpatient, with higher costs to the health system incurred when healthcare is delivered in an acute setting, and the significant stress placed on patients when receiving care in a hospital.

Autistic people attend hospitals at approximately double the rate of the broader population. This is a clear indicator of a primary healthcare system that is not meeting their needs.

Maternal health care is a particular challenge for autistic women

The challenges autistic people report with accessing healthcare coalesce for many women during pregnancy, childbirth and postnatally.

Although autistic mothers access antenatal classes, many report that the process of birth was not adequately explained to them.²⁵ While advances in healthcare and medicine have made great strides in reducing some of the medical risks associated with childbirth, many of the measures and systems in place can unintentionally act as triggers and stressors for autistic women. For example, bright lights and loud, busy birthing suites can be overwhelming sensory experience; inattention to appropriate communication; different understandings of consent to touch and a broad lack of understanding about how an autistic mother might be processing an already stressful situation can

²⁴ Australian Bureau of Statistics, 2017. *Patient Experiences in Australia: Summary of Findings, 2016-17*. Available at: <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/4839.0~2016-17~Main%20Features~Hospital%20admissions%20and%20emergency%20department%20visits~5>

²⁵ Ibid.

cause pain and suffering and can severely limit access to mainstream medical facilities.²⁶ The need to upskill health professionals and address health care environments is paramount.

Maternal mental health is a significant concern, with staggering rates of depression being recorded in the perinatal period. 40% of autistic women experience pre-natal depression, and 60% of autistic mothers experience post-natal depression (compared with 12% generally).²⁷ These rates underscore the urgency of introducing pro-active measures to detect and address depression among autistic mothers.

Autistic mothers are more likely to have experienced psychiatric conditions, and report greater anxiety, higher rates of selective mutism and a higher likelihood of finding motherhood an isolating experience.²⁸

And mothers of autistic children often experience stigma and discrimination, which can manifest in many ways including through negative interactions with social services. Research in the UK found that approximately 1 in 5 mothers of an autistic child were assessed by social services; of those, 1 in 6 had their child compulsorily placed for adoption. Further, allegations and investigations of suspected fabricated illness amongst autistic children and their siblings were two orders of magnitude higher.²⁹

Challenges for both autistic mothers and mothers of autistic children point to the need for enhanced maternal and child health support. Victoria's Enhanced Maternal and Child Health Program (EMCHP)³⁰ provides a possible model. It provides more intensive support for families with complexities and heightened risk factors, including through additional home visits and connections with community supports. Autism ought to be a trigger for access to enhanced support. Such a measure would need to be accompanied by upskilling of maternal and child health nurses in autism.

Understanding of autism among healthcare providers needs to be strengthened

In our survey, an overwhelming majority (86.7% of autistic adults and 82.1% of parents/carers) of respondents reported challenges due to health professionals' lack of understanding about autism.

While 96.5% of autistic adults said that they had seen a GP in the past 12 months, only 22.5% felt their GP had a good knowledge of autism. Almost a third of autistic adults (32.6%) rated the GP's knowledge of autism as poor.

Hospital emergency departments and their staff were identified as being of a particular challenge, with 45% of survey respondents noting that the knowledge and understanding of autism was poor.

Healthcare professional have identified the need to develop their skills and knowledge in autism. A recent Australian study of professionals involved in providing care to autistic people found that

²⁶ Blakemore, M., Robertson, G., Hansford, S., Richardson, T., Dalcombe, J., Smith, S., McCaffrey, N. 2017. *Multiple and intersecting forms of discrimination against autistic women*. Available at: <http://www.australianautismalliance.org.au/wp-content/uploads/2017/03/Autistic-Women.pdf>

²⁷ Pohl, A.L., Crockford, S.K., Blakemore, M. et al., 2020. *A comparative study of autistic and non-autistic women's experience of motherhood*.

²⁸ Pohl, A.L., Crockford, S.K., Blakemore, M. et al., 2020. *A comparative study of autistic and non-autistic women's experience of motherhood*. Available at: <https://molecularautism.biomedcentral.com/articles/10.1186/s13229-019-0304-2>

²⁹ Pohl, A.L., Crockford, S.K., Blakemore, M. et al Positive and Negative Experiences of Mothers with Autism

³⁰ Victorian Department of Health and Human Services, 2019. *Enhanced maternal and child health program guidelines*. Available at: <https://www2.health.vic.gov.au/about/publications/policiesandguidelines/enhanced-maternal-child-health-program-guidelines>

while most felt confident (59% strongly agreed or agreed) over 80% wanted further training, particularly in communication, behaviour and mental health management.³¹ Factors identified as contributing to difficulties in providing care included lack of knowledge of autism, lack of time, experience and resources.³²

There are a range of tools and resources to upskill health professionals on autism (e.g. Autism CRC's Comprehensive Health Assessment Protocol for Autism, an autism pathway in the HealthPathway portal and professional development modules on autism) however uptake is not widespread. A systematic approach to upskill health professionals is needed.

Despite many reports of healthcare settings that are not responsive to the needs of autistic people, there are examples of how small changes implemented by attentive and considered clinicians can revitalise an environment and make it accessible.

“My local GP is brilliant. Appointments are made for late morning before they have their break or late in the afternoon. We usually have double appointments so I have time to answer questions and discuss health concerns. This is great for my children who I am teaching how to self-advocate in healthcare settings. Before we go into the room, he always has the blind open and the flickering fluoro lights that cause me pain are off.”

Healthcare environments need to be more sensitive to the needs of autistic people

Autistic people report significant challenges in accessing mainstream health services, with almost 85% of respondents experiencing barriers related to sensory sensitivities such as brightness of light, smells and odours, touch, patterns and textures. Over 90% of autistic people reported challenges in being able to attend and access healthcare facilities due to the anxiety that these environments cause.

“The world is chaotic... it's hard to exist in when everything is louder, brighter, noisier and smellier. It would be nice for all health professionals to understand that the anxiety and sensory overwhelm is very real and, instead of trying to devalue the experience, provide support for it instead.”

“Clinical spaces are very scary for my autistic son. His anxiety goes through the roof and on some occasions, we haven't been able to achieve what was necessary (flu vaccination, or a blood test for example).”

Our fundamental health infrastructure – specifically public hospitals, general practices and primary care facilities – must do better at improving accessibility for autistic people.

The National Safety and Quality Health Services Standards include clear expectations for hospitals and regulated health services to partner with consumers in their care, and the Australian Charter of Healthcare Rights provides that individuals have the absolute right to access healthcare and treatment that meets their needs. These standards and rights can sometimes take a back seat in an overstretched healthcare environment, however the parlous health outcomes experienced by autistic people demand greater accountability.

³¹ Urbanowicz, A et al., 2020. *The experiences, views, and needs of health professionals who provide care to adults on the autism spectrum, Research and Practice in Intellectual and Developmental Disabilities*. Available at:

<https://www.tandfonline.com/doi/abs/10.1080/23297018.2020.1735943?journalCode=rpj20>

³² Ibid.

Inspiration can be drawn from significant gains made to improve cultural responsiveness of healthcare settings for people from different cultural and linguistic backgrounds, and First Nations peoples. Actions to address diverse needs includes the provision of multilingual signage, modified clinic times and locations and the provision of interpreter services.

In response to the Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder, the Victorian Health and Human Services Building Authority has established a working group to develop guidelines for supporting autistic people in healthcare waiting spaces. And some health services are working to address communications issues – with Frankston Hospital introducing communications boards and care passports.

Such an approach is needed across the nation to ensure low sensory environments are embedded in key care settings - with sensory sensitive spaces and clinic times, and that measures are taken to reduce communication barriers. This can be achieved without major capital expenditure. Moreover, the benefits of improved accessibility for autistic people will be enjoyed by all patients.

A National Roadmap to improve health services for autistic people is needed

Development of a National Road Map for Improving Health Services for People with Intellectual Disability is currently being driven by the federal Minister for Health. There is great value in setting out the aims and goals for a specific cohort of people – in this case people with intellectual disability – and coordinating a response that includes input from the community and healthcare providers.

The significant gaps in health and wellbeing outcomes and the prevalence of co-morbidities experienced by autistic people (including high rates of intellectual disability) compared to the broader population provide ample reasons to justify the development of a roadmap specific to the needs of autistic people.

International jurisdictions and health systems have implemented similar policies aiming to address health inequalities experienced by autistic people:

- In the **United Kingdom** the **NHS Long Term Plan** (2019) includes specific actions ‘to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people,’ and to improve their health and wellbeing.³³ Legislative options regarding training are also being explored, with a Bill introduced into the House of Lords that would make training on ‘learning disability and autism’ mandatory for health and social care staff involved in certain roles in England.
- In the **USA**, the **Academic-Autistic Spectrum Partnership in Research and Education** (AASPIRE) has developed resources that are designed to improve the healthcare of autistic people, with resources targeted for both autistic people and healthcare providers (primary health care providers in particular).³⁴

There is an extreme need for effective mental health support for autistic people

The mental health of autistic people is demonstrably poorer than the broader Australian population, with accessibility challenges compounding the significant social isolation and anxiety, and low levels

³³ National Health Service (UK), 2019. *Long Term Plan*. Available at: <https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf>

³⁴ Academic-Autistic Spectrum Partnership in Research, 2020. *AASPIRE Healthcare Toolkit*. Available at: <https://autismandhealth.org/>

of employment that is prevalent in the autism community. The Royal Commission into Mental Health Services in Victoria's interim report noted:

The prevalence and type of mental illness may also vary across the different forms of disability or neurodevelopmental conditions. For example, research indicates that people with autism are particularly vulnerable to mental illnesses such as anxiety and depression, especially in late adolescence.

While the Royal Commission is strictly focused on the Victorian context, the sentiments expressed are sound and acknowledge the importance of addressing the autism community's mental health needs at the highest level.

Concurrently, the Australian Capital Territory's Standing Committee on Education, Employment and Youth Affairs has concluded its inquiry into youth mental health in the ACT. Regarding the accessibility of mental health services for young autistic people, the Committee noted its disappointment in hearing accounts of autistic young people being refused support or receiving inappropriate treatment in the mental health system. In its recommendations, the Committee suggested that Child and Adolescent Mental Health Services expand their work to cater for autistic youth, and that the mental health sector and Child and Youth Protection Services need better training, knowledge and understanding about autistic youth.³⁵

A detailed understanding of autism must be considered core to the work of mental health services and staff. It is not acceptable for autistic people to have to continually advocate for their right to have mental health challenges addressed in a way that is responsive to an autism diagnosis.

Autistic people face significant barriers to accessing effective mental health support

The dual burden of healthcare and mental health workers who are not well-equipped to work with autistic people and tight limits on public and MBS-subsidised mental healthcare is resulting in too many autistic people lacking the mental health support they require. Almost a third of respondents to the mental health section of our survey reported they had not been able to get appropriate support for their mental health condition/s. Key barriers include:

Long wait times are impacting on the mental health of autistic people

49% of autistic adults and 65.2% of parents/guardians reported that long wait times were a key barrier to accessing mental health services.

The Royal Commission into Victoria's Mental Health System's interim report details significant challenges with regards to waiting times for access community, public and specialist mental health care, particularly for people experiencing crisis situations and young people accessing Headspace services. For example, a major public hospital in Melbourne's east received over 10,000 calls to its Child and Youth Mental Health Service, with over 3,000 calls being abandoned by the caller in response to wait times.

³⁵ ACT Parliament, Standing Committee on Education, Employment and Youth Affairs, 2020. *Youth Mental Health in the ACT*. Available at: https://www.parliament.act.gov.au/_data/assets/pdf_file/0007/1613518/EEYA-Report-9-Youth-Mental-Health-in-the-ACT.pdf

If a system that is largely designed to reflect the needs of neurotypical people is buckling under the pressures of demand, systemic access challenges are likely to disproportionately disadvantage autistic people.

Many mental health practitioners lack an understanding of autism. It is hard to find those who do (68.9% of autistic adults said that it is difficult to find a mental health practitioner who understands autism); and difficult to find a mental health practitioner who understands their specific situation.

Correspondingly, some of the barriers mental health professionals encounter include a lack of autism training; no easily available information and guidance for supporting autistic people with mental health conditions; and a disconnected mental health system.³⁶

Acknowledgement of individual preferences and self-identity are key to developing positive therapeutic relationships. A person's positive self-identity as autistic must be recognised by mental health and healthcare professionals and this may influence the type of mental health treatments preferred by that person.

The importance of supporting autism understanding in mental health professionals is recognised internationally, with clinical guidelines in the UK containing recommendations regarding the necessary knowledge and understanding of autism for relevant staff supporting autistic people, considerations regarding advice that should be sought, and possible adaptations to behavioural and clinical interventions.³⁷

The Alliance is aware of a number of small scale initiatives to upskill mental health providers in Australia for example:

- Autism Queensland is initiating a project intended to address the accessibility of mental health settings for autistic people.
- Key staff at Melbourne University's Mindful Centre for Training and Research in Developmental Health and Orygen Youth Mental Health Service conduct training and development activities in autism for mental health staff in Victorian public hospitals.

There is a strong need to extend, quality assure and mandate training in autism for public and private mental health services. Equally, a system of accreditation that enables autistic people to easily identify mental health practitioners with proficiency in autism is required.

The cost of accessing primary mental healthcare is prohibitively high

78% of autistic adults reported cost as the reason they haven't received support for their mental health condition, and more than 46% reported that they lack the necessary funding to access mental health services.

While the high cost of accessing private mental healthcare is not limited to autistic people, this cost burden is disproportionately felt given their high rates of mental ill-health and low rates of employment and workforce participation.

³⁶ Amaze, 2019. *Submission to the Royal Commission into Victoria's Mental Health System*. Available at: <https://www.amaze.org.au/wp-content/uploads/2019/09/Amaze-Yellow-Ladybugs-Different-Journeys-Submission-RCVMHS.pdf>

³⁷ National Institute for Health and Care Excellence, 2016. *Autism spectrum disorder in adults: diagnosis and management*. Available at: <https://www.nice.org.uk/guidance/CG142/chapter/1-Guidance#interventions-for-coexisting-mental-disorders>

The MBS (Better Access) program should work better for autistic people

The Better Access to Psychiatrists, Psychologists and General Practitioners Program currently enables general practitioners to refer patients for up to ten individual and ten group allied mental health services per calendar year.

Given the high rate of mental health co-morbidities, this can leave autistic people and their families with the impossible choice between rationing appointments to spread access across the year or facing ruinous out-of-pocket costs to maintain care.

The MBS Review Taskforce Report from the Mental Health Reference Group³⁸ 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.

The Alliance supports these measures and believes they would make real and appreciable improvements to the mental health of autistic people.

The Inquiry can take collaborative action on Mental Health

We anticipate the Victorian Mental Health Royal Commission will make findings and recommendations about the mental health of autistic people. These will be instructive given significant federal levers including the National Mental Health and Suicide Plan, National Health and Medical Research Funding and funding agreements with mental health service providers. The Productivity Commission's current work on the national architecture of the mental health system could also be of relevance to this Inquiry.

Following these processes, we would like to see a **National Plan on Autism in Mental Health**. This dedicated plan would be complementary to the next iteration of the National Mental Health and Suicide Plan.

Improving mental health services for autistic people will contribute to significant improvements in the health, wellbeing, social and economic participation and relationships of autistic people. It will also provide cross-systems savings in health, mental health and social services budgets.³⁹

³⁸ MBS Review Taskforce (2018), *Report of the Mental Health Reference Group*. Available at: [https://www1.health.gov.au/internet/main/publishing.nsf/Content/BEB6C6D36DE56438CA258397000F4898/\\$File/Report%20from%20Mental%20Health%20Reference%20Group.pdf](https://www1.health.gov.au/internet/main/publishing.nsf/Content/BEB6C6D36DE56438CA258397000F4898/$File/Report%20from%20Mental%20Health%20Reference%20Group.pdf)

³⁹ Australian Advisory Board on Autism Spectrum Disorders, 2012. *The Interface between Autism Spectrum Disorders and Mental Health: The Ways Forward*. Available at: <http://sofasd.org.au/d7/sites/default/files/The%20Interface%20between%20ASD%20and%20Mental%20Health%20AAB>.

Recommendations: Health & Mental Health

7. Implement a systemic approach through national and state health service sectors to strengthen the autism competency of healthcare professionals, with a particular focus on GPs, emergency staff and mental health practitioners.
8. Strengthen pre and post-natal care for autistic mothers by:
 - Developing autism-specific tools and processes to screen for and identify pre- and post-natal depression in autistic mothers; and
 - Providing an enhanced maternal and child health care offering for autistic mothers and families with autistic children.
9. Develop a National Roadmap to improve health services for autistic people.
10. Introduce autism friendly universal design principles across hospitals and major health infrastructure, starting with quiet, low sensory emergency departments, waiting and treatment rooms in public hospitals.
11. Extend, quality assure and mandate training in autism for mental health services. Introduce a system of accreditation that enables autistic people to easily identify mental health practitioners with proficiency in autism.
12. Implement the MBS Review Taskforce's recommendations relating to the Better Access program for mental health, including increasing the number of sessions available for people with higher needs and enabling families and carers to access therapy.
13. Develop a dedicated National Plan on Autism in Mental Health that is complementary to the next iteration of the National Mental Health and Suicide Plan.

Education is key to life chances

Autistic students are not faring well in education and training

Autistic students are faring worse than most other cohorts across the education spectrum – from early learning, through schools, and into further and higher education.

- **Barriers to education can mean many autistic people leave school very early:** Around one-third of autistic students only achieve Year 10 or below (compared with 17% of students without disability). These very early school leavers are at high risk of a lifetime of disadvantage.
- **Autistic people are under-represented in Vocation Education & Training**
Just 17.9% of autistic people have a Certificate III; diploma or advanced diploma as their highest qualification, compared with 29.4% of all people with disability.
- **University completions are very low:** Autistic people are half as likely to get a bachelor degree or higher (8.1%) as all people with disability (16.1%). People without disability are four times more likely to attain a university qualification.

A recent Australian study found that autistic school leavers are less likely to be employed, more likely to attend technical and further education (TAFE) than university, more likely to enrol in higher education on a part-time basis and less likely to be engaged in both higher education and employment, than their non-autistic peers.⁴⁰

There are significant barriers to successful engagement with education and training

Learning environments can be very challenging for autistic students. Barriers include communication, social interaction, unique learning styles and an environment and system that is not designed with autistic students in mind. Often individual needs are not met and individual strengths are not recognised or harnessed for learning. Key issues reported in research and in our survey include:

A culture of low expectations and damaging assumptions of low capability

Autistic students face an increased risk of under-performing academically relative to their level of intelligence.⁴¹ They well and truly face the “soft bigotry of low expectations”.

“Never felt supported at high school and career advisor suggested he should find a trade. It was made clear to the school he hoped to achieve an athletic scholarship to a US college which has subject requirements for eligibility, however the school would not allow him to do some of the required subjects as they did not have the ability to support him, making the process a lot more challenging. All students should have access to support needed at school to help them achieve the outcomes they hope to achieve.”

⁴⁰ Flower, RL. Et al., 2020. Brief Report: *What Happens After School? Exploring Post-school Outcomes for a Group of Autistic and Non-autistic Australian Youth Journal of Autism and Developmental Disorders*. Available at: <https://link.springer.com/article/10.1007%2Fs10803-020-04600-6>

⁴¹ Ashburner, J. et al., 2010. *Surviving in the mainstream: Capacity of children with Autism Spectrum Disorders to perform academically and regulate their emotions and behaviour at school*. Available at: <https://www.sciencedirect.com/science/article/abs/pii/S1750946709000798?via%3Dihub>

Low understanding of autism among educators and trainers

Concerns about the understanding and knowledge of autism among educators and trainers mirrors that found in other key parts of the mainstream service system. The need to upskill education staff in supporting autistic students is uncontroverted. Teacher knowledge about autism in mainstream schools is limited: teachers report being unsure how to best support autistic students.⁴² Respondents to our survey repeatedly identified a lack of capability in these settings.

“As a teacher, I do not think that enough training is provided to mainstream teachers and support staff to understand autism well enough. I taught in mainstream schools, but now in a special school, and I know that mainstream schools are nowhere near well enough equipped with the knowledge, strategies or resources to successfully integrate children with more complex autism.”

“Maybe neurodiversity modules and units could be introduced into training, and as required qualifications to be able to teach or be in charge of the structure of a school, in the same way OHS learning is required”

There are range of initiatives aimed at addressing these gaps in knowledge and understanding, most notably the federally funded Positive Partnerships Program which focuses on home-school partnerships in supporting autistic students, including for CALD and First Nations families. However, this has limited reach and high demand means sessions are often over-subscribed. The Program has undergone external evaluations, all of which have recommended that it be extended Program funding lapses at the end of 2020, which further compounds the challenges of bridging the gap between home and school settings. The on-line platform InclusionED⁴³ also exists.

At a state level, Queensland’s Autism Hub (profiled below) is a stand out example that has the potential to be further strengthened and replicated around the nation to build system capability.

Queensland’s Autism Hub – providing dedicated support for the education sector

Introduced as part of the Queensland Department of Education’s ‘Advancing education, an action plan for education in Queensland’, the Autism Hub is designed to build the capacity of school leaders, teachers and parents, and support the inclusion of autistic students.

Autism coaches are located in 7 regions across Queensland. They provide schools with advice on how to best support autistic students in an inclusive environment, and improve their educational outcomes. A website provides autism specific resources including the Queensland School Autism Reflection Tool (QsArt) which is designed to enable school leaders to consider and implement school improvement processes for autistic students.

The Hub is guided by input from the Autism Hub Advisory Group. Further information is available at <https://ahrc.eq.edu.au/>

⁴² Sagers, B. et al., 2018. *Australian Autism Educational Needs Analysis – What are the needs of schools, parents and students on the autism spectrum? Final Report*, Autism CRC. Available at: <https://www.autismcrc.com.au/sites/default/files/inline-files/Educational%20Needs%20Analysis%20-%20Final%20report%20Version%202.pdf>

⁴³ *InclusionED* is an online resource and national community of practice providing evidence-based and research-informed teaching practices and resources for educators to employ in supporting students with diverse learning needs and styles in inclusive mainstream schools. It is based on principles of Universal Design for Learning and was developed from Autism CRCs School Years Program. Available at: www.inclusioned.edu.au

TAFE hosts large numbers of autistic students and is well placed to provide a gateway to employment, yet has no systemic approach to supporting autistic learners. This must be addressed.

Low rates of adjustments and modifications made for autistic students

Less than half of parents with schools aged children responding to our survey reported that adjustments made at school were mostly or completely adequate. Just over a third indicated that adjustments were partly or not at all adequate. The most common school adjustments reported were learning related including having a key point of contact at the school to discuss their child's needs and progress; modifications to curriculum, assessment and exam conditions; and access to an education aide.

Of those who disclosed their diagnosis to further and higher education institutions, about half of the autistic adults (48.2%) and 22% of parents/carers reporting on behalf of an autistic person indicated that **no adjustments** were made by the institution.

"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."

For those who received adjustments, the most common were modified assessment/exam procedures, provision of a disability support person, a quiet room/area, and establishing a process by which they can leave the classroom without explanation if they need to take a break.

Lack of positive support for social and emotional wellbeing

Our survey revealed an absence of support for the social and emotional wellbeing of autistic students.

Autistic students are significantly more likely than their non-autistic peers to be targets of bullying⁴⁴, and suffer depression and anxiety.⁴⁵

"His life at university has been impacted by his refusal to tell the university that he is autistic, he feels that it would single him out and expose him to the same bullying he experienced at high school."

"Had to be home schooled for high school due to bullying. No educational support provided as my mother had to do this all on her own."

High rates of suspensions and exclusions for autistic students⁴⁶ and the use of restrictive practices remain a live issue (as highlighted by the Disability Royal Commission). There is no agreed and consistent approach to positive behaviour management across education and learning settings, which further disenfranchises autistic learners.

⁴⁴ Van Roekel, E. et al., 2010. *Bullying among Adolescents with Autism Spectrum Disorders: Prevalence and Perception*. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2809311/>

⁴⁵ Kim, J. A. et al., 2000. *The prevalence of anxiety and mood problems among children with autism and Asperger Syndrome*. Available at: <https://journals.sagepub.com/doi/10.1177/1362361300004002002>

⁴⁶ Barnard, J. et al., 2000. *Inclusion and autism: Is it working?* Available at: https://www.researchgate.net/publication/251814768_Inclusion_and_Autism_Is_It_Working

Transition support is critical

Many autistic children are starting school without an individualised learning plan – meaning schools are not ready to receive them and make the adjustments needed to get off to a good start.

Lack of support in making the transition from secondary school to further study and employment is a common experience for autistic students. A small percentage of autistic adults (11.1%) and a quarter of parents/carers (24.2%) responding to our survey indicated that an “ok or good level of support” was provided to assist the transition from secondary school to further study. More than half (62.9%), and almost half (41.8%), respectively, indicated that no support was provided. A number of other studies reveal consistent findings.⁴⁷

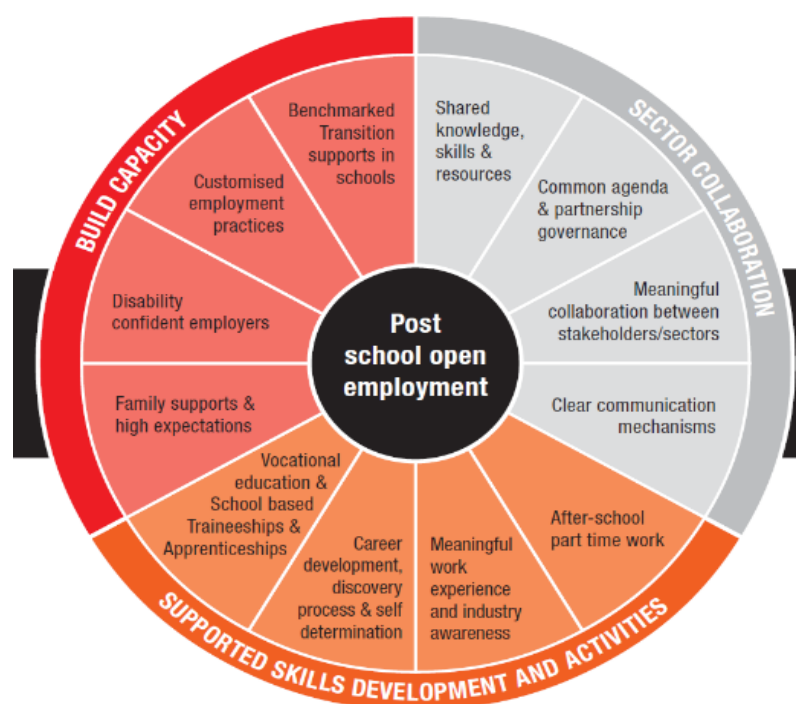
Autistic school students rarely participate in work experience, which severely impacts on opportunities for vocational exploration, and to build aspiration and networks.

A number of initiatives exist to support transitions, for example:

- **Ticket to Work** is demonstrating significant improvements in employment opportunities and outcomes for young people with disability,⁴⁸ including autistic young people. It provides a holistic approach (see adjacent diagram) including opportunities for work experience, vocational exploration and links to employers.

Reliance on a mix of philanthropic, corporate and state based grants means it has limited reach and long term sustainability issues.

- **myWAY Employability app** has just been launched by Autism CRC (Aug 2020). This free app is designed for autistic young people (aged 14-30 years) and covers careers exploration matched to strengths and interests, career planning, further education and employment pathways. It includes practical resources around preparing for work experience and job applications.⁴⁹
- The federally funded **School Leavers Employment Support (SLES)** program is available to those on NDIS Plans who are in their last year of school (and sometimes the following year). Shortcomings include its access commences too late in a student’s school life, a lack of aspiration around student potential and prospects and narrow eligibility criteria.



⁴⁷ OTARC, 2019. *Study of Australian School Leavers with Autism (SASLA): A longitudinal study of post-school outcomes for young people with and without autism, 2014 – 2021*. Available at: <https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years>

⁴⁸ Information about Ticket to Work is available at: <https://tickettowork.org.au/>

⁴⁹ Information and links to resources are available at: mywayemployability.com.au

The **Shergold Review into Senior Secondary Pathways** (currently being considered by the COAG Education Council) recommends that all senior secondary students with disability have access to work exploration in school and an individual post-school transition plan in place prior to leaving school.⁵⁰ The Alliance endorses this recommendation.

The Disability Standards for Education need to be substantially overhauled

Discrimination against autistic students in the education system is a common experience. Research by Amaze found that many autistic students are denied enrolment in mainstream settings or have to move secondary schools due to a lack of support.⁵¹ Likewise, over one-third of parents responding to our survey reported that they felt that their child had been discriminated against in school or when seeking to access an education.

The fact that autistic students are over-represented in special schools⁵², that numbers of students with disability in segregated settings are on the increase,⁵³ as is home schooling for children with special learning needs⁵⁴ speaks volumes about a system that ignores the needs and rights of autistic people.

“Our son's school has completely left him out of every school camp, mainstream excursion and Aboriginal education experience.”

A review of the Disability Standards for Education (DSE)⁵⁵ is currently underway. This work will run in parallel with the Inquiry, and we hope the processes will be complementary.

Many of the shortcomings identified in the previous review of the DSE's (undertaken in 2015) remain outstanding. Key concerns include that the standards are viewed as aspirational, rather than a mandatory requirement; that they are difficult to enforce in practice; that individual breaches do not inform systemic change; and that the right to adjustments is constrained by the very significant caveat about these not impact other students or teachers. With a number of key inclusion indicators going backwards, the DSE's are not delivering.

The DSE's need to be substantially overhauled to positively reframe inclusive education as a right, strengthen protections and create accountabilities in the education system for progressively improving outcomes (e.g. improved school attainment, reduced suspensions and expulsions, elimination of restrictive practices). The National Consistent Collection of Data project creates opportunity for improved accountability around use of funding and the effectiveness of adjustments made.

⁵⁰ COAG Education Council, 2020. *Looking To The Future, Report Of The Review Of Senior Secondary Pathways Into Work, Further Education and Training*. Available at: <https://uploadstorage.blob.core.windows.net/public-assets/education-au/pathways/Final%20report%20-%2018%20June.pdf>

⁵¹ Jones S et al., 2017. *Experiences of Autistic People and their Families*. Centre for Health and Social Research, Australian Catholic University. Available at: https://www.amaze.org.au/wp-content/uploads/2019/06/Education-Community-Attitudes-and-Lived-Experiences-Research-Report_FINAL.pdf

⁵² Australian Bureau of Statistics, 2018. *Autism in Australia. Survey of Disability, Ageing and Carers, 2018*. Available at: <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018>.

⁵³ Australian Institute of Health and Welfare, 2017. *Disability in Australia: Changes over time in inclusion and participation in education*. Available at: <https://www.aihw.gov.au/getmedia/34f09557-0acf-4adf-837d-eada7b74d466/Education-20905.pdf.aspx>

⁵⁴ NSW Education Standards Authority, 2020. *Home Schooling Data reports relating to 2019*. Available at: <https://educationstandards.nsw.edu.au/wps/wcm/connect/426e1f11-5752-4c1c-bdcc-68b880c0e0b3/Home+Schooling+Data+relating+to+2018+for+publication+on+NESA+website.pdf?MOD=AJPERES&CVID=>

⁵⁵ Australian Government, Department of Education, Skills and Employment. *The Disability Standards for Education, 2005*. Available at: <https://www.education.gov.au/disability-standards-education-2005>

Much can be done to make education settings more inclusive for autistic students

Autistic students should have access to an education system that provides an inclusive culture and a multi-faceted, individualised, needs based approach to learning that is tailored to their strengths and unique learning styles. Our survey respondents reported the following as helpful in supporting them to engage with learning:

- Educators who understand autism
- Transitions support
- Access to mentoring
- Assistance with planning/managing the study workload
- Inclusive practices (e.g. chill out spaces, supporting needs for visual/aural input)
- Assistance in communicating with facilitators/peers
- Assistance with physical access to study spaces
- Having an Individualised Inclusion Plan and meeting with teaching staff to discuss the Plan
- Having a contact person for queries about enrolment and institutional processes
- Support with academic skills development
- Social support
- Assistance with accessing financial supports.

“...it would have been extremely helpful to have a dedicated autism department on campus (and on all the campuses), where students could freely access face-to-face specific help, workshops, groups, peer mentoring and private support for their autism, which I feel would also help to lower the stigma...”

Although not widespread, or at scale, there are some promising examples of inclusive practices. The DSE webpage captures exemplar case studies, some of which relate to autistic students in early learning, schools and post-secondary environments.⁵⁶ Common themes in these case studies are reflective of what our survey respondents identified as being helpful.

A stand-out example (profiled below) that we urge the Committee to explore, and potentially visit, is the Australian Catholic University’s Autism Inclusion Program.

Australian Catholic University – helping autistic students reach their potential

ACU launched the Autism Inclusion Program on its Melbourne and Ballarat campuses in 2020. The Program will be rolled out across all campuses in 2021. This comprehensive offer seeks to both work individually with students through academic, social and wellbeing supports while also addressing structural barriers to inclusion. The Program is designed to be embedded in the activities of the university, with strong cross-unit collaboration. Core elements include:

- Access to comprehensive information for (prospective) autistic students
- Working with schools to support transition (including presentations at Future Students events)
- Peer mentoring program, including ongoing PD for mentors
- Academic skills workshops
- Education Inclusion Plans
- Professional Development for teaching and administrative staff

⁵⁶ Case studies are available at: <https://docs.education.gov.au/node/40601>

- Resource library
- Environmental audits and adjustments
- Low-sensory room on campus (Melbourne room being refurbished, Ballarat room identified for refurbishment)
- Sensory maps (being developed by OT placement students)
- Social events (initially online due to Covid)
- Webpage: <https://www.acu.edu.au/student-life/student-services/autism-at-acu>
- Student portal page: <https://www.studentportal.acu.edu.au/acuinfo/ss/autism-at-acu>

Development and implementation of the program is being led by autistic staff and students. The Program's Steering Committee includes representatives of key ACU portfolios. An Advisory Group includes current and former autistic students and academics from ACU and other universities.

Recommendations: Education & Training

14. Overhaul the National Disability Standards to positively reframe inclusive education as a right, strengthen protections, and create accountabilities in the education system for progressively improve key inclusion metrics.
15. Expand targeted measures to increase participation of autistic children in early learning programs.
16. Upscale professional development on autism for educators, education support staff and leaders - in early learning, schools and post-secondary settings. Investigate embedding requirements to undertake autism training in educator standards and registration processes.
17. Increase accountability and transparency around how disability funding is used and the outcomes of students receiving it.
18. Improve transitional support for young autistic people to explore and navigate vocational options. Implement the recommendation from the Shergold Review into Senior Secondary Pathways that all senior secondary students with disability have access to work experience and have an individual post-school transition plan in place prior to leaving school.
19. Incentivise programs and strategies by vocational and higher education providers to bridge the gap for autistic people in receiving post-school qualification. Set targets for autistic people to take up opportunities – such as free TAFE and the new JobTrainer initiative

Lifting employment outcomes for autistic people must be a priority

Autistic people want to work and have much to offer

Autistic people aspire to work. Of our survey respondents who are not in paid employment, well over half indicated they would like to be employed.

There is strong evidence that autistic people can bring great strengths and capabilities to the workforce, and make skilful, reliable and loyal employees. Indeed, there is a sound business case for neuro-diverse workplaces, which can deliver competitive-advantages including productivity gains, quality improvement, boosts in innovative capabilities, increases in employee engagement and reputational enhancement.⁵⁷

More than ever, Australia needs to unleash its latent under-utilised potential to drive and sustain economic and social recovery. There is high aspiration and huge untapped talent in the autistic community. If harnessed, it will contribute to strengthening Australia's recovery, productive capacity and community resilience.

Employment outcomes for autistic people are inexcusably poor

The most recent ABS statistics on autistic employment are from 2018. Despite Australia's strong economic growth at that time, unemployment among autistic people was a staggering 34.1% - more than three times the rate for all people with disability and almost eight times the rate of people without disability at the time.⁵⁸

This will almost certainly be worse in the current environment.

Labour force participation among autistic people was just 38%, well short of all people with disability (53.4%) and less than half that of people without disability (84.1%). The employment rate was very low at 27.3%.

Under-employment and under-utilisation of skills is widespread, and many autistic people work in Australian Disability Enterprises.

"Working in a disability enterprise has been ok. He has the supports and some understanding of his autism. However it is repetitive work with little stimulation and I know he is capable of so much more if we could find the right environment. Also, the system of a disability enterprise is very unfair monetarily...they only pay the employees \$3-4 per hour."

Poor employment outcomes negatively impact other areas of life

Employment status has been shown to significantly impact mental health, wellbeing, economic security, social and community connections. The employment status of parents can also impact the development and educational attainment of children.

⁵⁷ Harvard Business Review, 2017. *Neurodiversity as a Competitive Advantage*. Available at: <https://hbr.org/2017/05/neurodiversity-as-a-competitive-advantage>

⁵⁸ Australian Bureau of Statistics, 2018. *4430.0 Disability, Ageing and Carers, Australia: Summary of Findings 2018*. Available at:

<https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>

Autistic people face a range of barriers to employment

Our working age survey respondents not in paid employment reported the following reasons

Main reasons for not having a paid job	Autistic adult [n=350]*		Parent/carer of autistic adult [n=268]*	
	n	%	n	%
Lack of understanding of autism from potential employers	133	38.0	109	40.7
Lack of support available to find a job (e.g. lack of knowledge about what jobs are available or how to get them)	117	33.4	102	38.1
Lack of support available to help me get to and support me in a job	108	30.9	102	38.1
Unable to attend or perform well in interviews due to my autism/anxiety	125	35.7	115	42.9
Don't know what I/they would like to do	67	19.1	68	25.4
Can't find the right job	94	26.9	81	30.2
Difficulty preparing a job application / job applications have not been successful	100	28.6	60	22.4
Illness / poor health prevents me / them from seeking employment	123	35.1	60	22.4
Not interested in working	18	5.1	19	7.1
Other (SPECIFY)	161	46.0	107	39.9
None (EXCLUSIVE)	2	0.6	0	0.0
Unsure (EXCLUSIVE)	2	0.6	7	2.6
Prefer not to say (EXCLUSIVE)	4	1.1	1	0.4

Autistic people currently encounter a range of barriers when seeking to enter and remain in the workforce. Key barriers include:

Relatively low educational attainment rates and poor translation of qualifications into employment

The vast majority of jobs growth is in occupations that require post-school qualifications (either VET or higher education).⁵⁹ Yet too many autistic people are not attaining the education and qualifications needed to support economic participation.⁶⁰

But for those who do complete further or higher education, many are not achieving the employment outcomes that would usually flow from their qualification. Research by Aspect found a third of autistic people with Bachelor's degrees are unemployed – which represents significant productive capacity that is going unutilised.⁶¹

⁵⁹ Australian Government, 2018. *Australian Jobs Report*. Available at: <https://australianjobs.employment.gov.au/jobs-and-training/education-and-employment>

⁶⁰ Ibid

⁶¹ Autism Spectrum Australia, 2013. *We Belong: The experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism*. Available at: https://www.autismspectrum.org.au/uploads/documents/Research/Autism_Spectrum_WE_BELONG_Research_Report-FINAL_LR_R.pdf

Negative perceptions about autistic people by employers

Persistent misbeliefs and common myths stymie the efforts of autistic job seekers, with many employers believing autistic people will be less capable, or that it will be burdensome or costly to provide any required assistance, modifications or adjustments. Of our autistic adult survey respondents who were currently or previously employed, less than a third (30.4%) had told their employer that they are autistic. The most common reasons for not disclosure were concerns that they would be judged negatively and/or lose the job or have their hours reduced.

“I am an intelligent, articulate, pedantic, passionate person. Yet, not a single employer would give me a chance. Not in my teens, not my 20s and not my 30s. I gave up. Taking a chance on any person who appears to have the drive and ability to do a job should be enough, despite their obstacles (and if anything the fact they are striving to overcome and deal with their obstacles and have been for decades, should demonstrate the gusto of the person, which is always overlooked).”

Lack of employment services tailored to the needs of autistic jobseekers

Autistic jobseekers are generally not faring well through the Disability Employment Services and Jobactive programs. DES have no requirements for training their staff in autism and achieve low rates of successful work placements for autistic jobseekers.⁶²

Our survey results showed high proportions of autistic people without work identified a lack of available help to find and keep a job.

“Disappointed in understanding and inconsistency of disability support agencies. High turnover of staff, not enough time support given. Not enough choice in agencies. Some won’t even get back to you after several attempts to contact them. Feel like they’re in it for the funding not the promises they advertise.”

“Employment agencies need to be better equipped to understand people with autism.”

While there are some promising small-scale bespoke initiatives – such as DXC Dandelion, Xceptional, Specialisterne’s programs with a handful of public sector agencies and private employers (e.g. IBM, Westpac) – these are of micro scale and are few and far between.

Recruitment processes that effectively eliminate autistic candidates

Recruitment processes are one of the largest barriers to employment. Difficulties with job application processes, including performing well in interviews was a common issue for our survey respondents seeking work.

“Writing my CV, answering the selection criteria and the interview. My brain especially doesn't function well in interview situations - my mind goes blank, I can't remember how to say some things, I stumble over my words and sometimes stutter, I don't know where to look... I have difficulty interpreting their questions and figuring out what they're looking for in an answer ... I have difficulty not stimming during interviews and have to have great control over my face to not indicate all the turmoil and confusion going on inside my head.”

⁶² Australian Government, 2017. *Disability employment services – Outcome rates by disability type*. Available at: <https://lmip.gov.au/default.aspx?LMIP/Downloads/DisabilityEmploymentServicesData/DESOutcomeRatesbyDisabilityType>

Barriers to employment leave many autistic people with substantial gaps in their CV's, which in turn makes it harder to get shortlisted for a job.

Lack of flexibility in workplaces to make adjustments to support autistic employees.

Of our autistic adult survey respondents who had disclosed their diagnosis to their employer, the most common response to the question of what adjustments had been made was none (31.8%).

Less than one in ten reported that adjustments had been made to the sensory environment, and fewer still reported information had been provided to others in the workplace on how to support them at work. More common adjustments included flexible hours, providing a set work routine, avoiding changes and adapting communication methods to match preferences.

"All kinds of 'normal' stuff is MUCH harder when you have sensory processing issues, for me an open plan office with fluro lights is like trying to work in a disco. A desk that is also near the lunchroom has actually brought me to panicky tears just from the noise. "Team building" activities often directly make you feel more isolated and different and are often even more anxiety producing."

"I wish the mantra 'bring your whole self to work' applied to us. We're welcome as long as we act like everyone else."

Real gains are possible in autistic employment

Common themes identified in research and reinforced by our survey around what helps autistic people to secure and sustain work include:

- Tailored pre-employment and in-work support
- Access to volunteer and work experience opportunities
- More support from employment agencies – including writing CVs (and where necessary post-placement support)
- Autism friendly recruitment processes – including clarity of role and adjustments to the application process
- Employers to have a better understanding of autism
- A commitment to inclusive employment practices
- Training and empathy of employers and co-workers
- A mentor, support person or advocate within the workplace
- Better understanding of sensory issues and sensory accommodation
- Flexibility with participation in work social event
- Proper enforcement of anti-discrimination laws.

Autistic people need to benefit from initiatives aimed at increasing employment for people with disability

There are a number of promising initiatives being driven by Australian governments to support employment of people with disability. However, given autistic people fare so poorly in employment vis-à-vis people with disability more generally, there is considerable risk that, without targeted measures, autistic people will not share equitably in the benefits of these initiatives.

NDIS Participants Employment Strategy:

The NDIS Participants Employment Strategy includes targets to increase the proportion of NDIS participants in paid employment (from 24% to 30% by 2025) and incrementally increase the proportion of participants with training and employment goals.

Critically, the Strategy commits to developing and delivering a specific response to employment challenges for autistic participants (along with other cohorts experiencing poor employment outcomes) and to publish annual employment results including data split by industry, disability type and age.⁶³

The Information, Linkages and Capacity Building (ILC) Investment Strategy includes an economic participation strand which can support employment connections, employer inclusiveness and self-employment. It is critical some of this funding is directed to autism specific initiatives, and that there is transparency in its allocation.

Additionally, the NDIA and Partners in the Community are required to employ a quota of people with disability in their workforce.

Public sector disability employment targets:

Public sector disability employment targets have recently been introduced in some states (e.g. Victoria has a target of 6% by 2020 rising to 12% by 2025),⁶⁴ and nationally (7% employment target for people with disability across the Australian Public Service by 2025) will open up new opportunities. Targeted measures are needed to ensure autistic jobseekers are well placed to take up and successfully sustain these opportunities.

There are a handful of small public sector autism employment programs – such as the RISE program in the Victorian Department of Health & Human Services (profiled below) – which can inform broader autism accessible employment approaches across Australia’s public sectors.

RISE – a win-win for autistic recruits and the Victorian Government

In 2017, the Victorian Department of Health and Human Services (DHHS) launched the RISE program. It created career opportunities for autistic people in records management.

Initially designed with Specialisterne, the program includes pre-selection and training and assessment programs to prepare recruits for the job; training for managers and co-workers; in-work and career development support. DHHS has recently taken the lead in recruitment onboarding and ongoing support of RISE participants. There is no interview process. Instead, potential recruits can take part in a discovery day and a paid two-week internship. For those that find the work a good fit, a four-week paid assessment period follows before a formal offer of employment. La Trobe University’s pilot study provides a detailed account of the model.⁶⁵ The program has won a Tech Diversity award.

Preliminary assessments indicate RISE team has a lower error rate in data entry than the industry standard.

To date, RISE has been a success, with 20 recruits across successive intakes. There has been high retention, with most remaining in their roles. Some have been seconded into roles elsewhere in

⁶³ NDIA, 2019. *NDIS Participant Employment Strategy*. Available at: <https://www.ndis.gov.au/about-us/strategies/participant-employment-strategy>

⁶⁴ Victorian Government, 2018. *Victorian Public Sector Disability Employment Action Plan 2018-2025*. Available at: <https://vpssc.vic.gov.au/wp-content/uploads/2018/10/Getting-to-work.pdf>

⁶⁵ Olga Tennison Autism Research Centre, 2019. *The Rise@DHHS autism hiring program: Examining the impact on the individual and their workplace*. Available at: <http://otarc.blogs.latrobe.edu.au/wp-content/uploads/2019/02/Rise@DHHS-Autism-Employment-Industry-Report-by-La-Trobe-Uni-2019-1.pdf>

the VPS, including through a purpose-built opportunity to try working with the Department of Environment, Land, Water and Planning in digital mapping. There are moves to replicate the RISE model in other Departments.

DHHS are also initiating a stream for autistic trainees through the Youth Employment Scheme (YES) scheme to create a pathway for autistic young people.

Social procurement measures:

A number of state governments have introduced social procurement measures that require generation of employment opportunities for marginalised jobseekers by contractors delivering publically funded projects of significant scale. Purchasing arrangement that preference social enterprises – including those hiring people with disability – have also been introduced in some jurisdictions.

Other than the Indigenous Opportunity Policy, the Australian Government has no social procurement measures to ensure marginalised jobseekers enjoy opportunities flowing from government purchasing and contracts with external providers.

National Disability Employment Strategy:

We welcome work underway in DSS to develop a National Disability Employment Strategy. The relatively poor outcomes for autistic people demand the need for an autism focussed response within this Strategy.

Bold new employment measures for autistic people are needed to ensure employment outcomes do not go backwards in the pandemic

The Federal Government allocated \$2million (over 3 years 2019-2022) to autism specific employment initiatives to implement its 2019 election commitment. Some of this funding has gone to Specialisterne⁶⁶ to train and support businesses and recruitment agencies to become autism-competent; and some is supporting continuation of the successful IT focussed DXC Dandelion Program.⁶⁷

While this funding is welcome, the scale is insufficient to markedly shift the dial on employment outcome for autistic people. Upskilling Disability Employment Service providers in how to better meet the needs of autistic job seekers is pivotal to achieving outcomes at scale. LaTrobe University are undertaking a trial on this (with NDIS ILC funding).

In the COVID and pandemic recovery economy, with high unemployment across the board, those with existing labour market disadvantage will fare worst. Without bold measures, Australia's appalling employment outcomes for autistic people will get worse.

Job creation schemes with very deep subsidies are anticipated to be a feature of the recovery landscape. A large scale autism employment program – preferencing employers with inclusive practices – ought to be included as an element of this.

⁶⁶ Media release from Sen. The Hon Ann Ruston, available at: <https://ministers.dss.gov.au/media-releases/5891>

⁶⁷ Additional information available here: https://www.dxc.technology/au/ahp/142235-the_dxc_dandelion_program

An autism employment summit would help inform the Inquiry's work

As Australia grapples with how to create jobs and get people into work following the pandemic, it is timely to identify tangible measures to ensure autistic jobseekers are not left further behind.

It would be fitting for the Committee to support a National Autism Employment Summit in early 2021. Building on previous Autism at Work events, it could bring together a broader range of stakeholders with the aim of delivering practical change and tangible models for employers to have a successful experience of hiring autistic people. The summit would include employers; TAFE; autistic people of all capability including those with intellectual disabilities; autistic employment assistance programs, service providers, community organisations; researchers and governments.

Recommendations: Employment

20. Include specific measures for autistic jobseekers within public sector employment initiatives including the NDIS Participant Employment Strategy, public sector disability employment targets, social procurement policies and the upcoming National Disability Employment Strategy.
21. Establish a federal social procurement framework requiring Australian Government contractors to deliver training and employment opportunities for marginalized jobseekers – including autistic people. A Federal purchasing strategy that preferences social enterprises should accompany this.
22. Expand demonstration projects to strengthen the evidence base on effective and efficient models that support the sustained employment of autistic people. Use these to inform systemic reforms to Disability Employment Services and Jobactive.
23. Include an autistic employment stream as part of a COVID-19 job creation schemes– providing deep wage subsidies, preferencing employers who can demonstrate inclusive practices.
24. Convene a wide-ranging autism employment summit, co-produced with autistic people, that brings together employers; TAFE; autistic people; autistic employment assistance programs, community organisations; researchers and governments to identify measures to enable autistic people to find and maintain work as Australia recovers from the pandemic.

There is much room to improve the NDIS for autistic participants

The NDIS is game changing. However, rapid roll out has been accompanied by significant implementation challenges – particularly for autistic participants. Current reforms measures (Participant Service Guarantee, Workforce Strategy and Thin Market measures) are welcome. And key reform opportunities may flow from the Government's upcoming response to the Tune Review and ECEI Reset process.

These processes need to be accompanied by specific reforms to improve the experiences and outcomes of autistic participants – as the largest cohort in the scheme. We acknowledge the efforts of the NDIA's Autism Advisory Group in seeking to drive autism-related improvements.

There are around 123,000 autistic participants in the scheme (or approx. 143,000 if you include those with secondary disability of autism in the count): 31% of participants have a primary autism diagnosis, and an additional 5% of participants have autism as a secondary disability.⁶⁸ In the younger age groups, the lion's share of participants are autistic: 65% of participants aged 7-14 years and 54% of those aged 15-18 years.

The Tune Review found that the NDIS service delivery response works well in general for adults with a physical disability, but not so well for other cohorts, including specifically people with developmental delay.⁶⁹ It is absolutely critical that the scheme works well for the sizeable group of autistic participants.

"We feel like they haven't really delivered on many things they said they'd help us with."

The current iteration of ECEI is not a good fit for autistic children

There is significant concern that participation in ECEI can delay access to diagnosis.

Further, the light touch and short-term approach of an Early Intervention plan can postpone autistic children accessing the intensity of supports early enough that evidence shows makes a real difference to their trajectory.

Instead, autistic children need to be admitted as scheme participants and provided with a robust individually funded disability plan (rather than a short term EI Plan) at the earliest opportunity. This will provide the best return on investment for the NDIS in the long run.

Systematic reviews clearly demonstrate that intensive and comprehensive early intervention support for autistic children, starting as young as possible, is key to improving their life outcomes, enabling them to be as independent as possible and participate to their full potential in education, employment and their community.⁷⁰ The upcoming report from Autism CRC (commissioned by NDIA) on the evidence base for early interventions should provide an important contribution.

⁶⁸ NDIA, 2019. *Outcomes for participants with ASD*. Available at: <https://data.ndis.gov.au/reports-and-analyses/outcomes-participants-autism-spectrum-disorder>

⁶⁹ Tune AO PSM, D., 2019. *Review of the National Disability Insurance Scheme. Removing Red Tape and Implementing the NDIS Participant Service Guarantee*. Available at: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

⁷⁰ Prior, M et al., 2011. *A review of the research to identify the most effective models of practice in early intervention of children with autism spectrum disorders*. Available at: https://www.dss.gov.au/sites/default/files/documents/10_2014/review_of_the_research_report_2011_0.pdf; Roberts J, Williams K., 2016. *Autism Spectrum Disorder: Evidence-based/evidence-informed good practice for supports provided to preschool children, their families and carers*. Available at:

Providing early intervention to children with autism has (at its most conservative estimate) been shown to deliver a Benefit-Cost Ratio of 4.1.⁷¹

The Tune Review made important recommendations that if implemented will improve supports available to families accessing ECEI. These include funding in advance of a plan so that supports can be rapidly obtained, and greater flexibility for families to access in-home supports and respite.⁷²

When working well, ECEI enables access to comprehensive supports, strengthens family capacity including within natural settings, uses family centred practice and a key worker model (subject to worker caseloads), and importantly as a functional pathway into the NDIS.

The ECEI Reset process needs to deliver a strengthened ECEI offering. Consideration should be given to stretching the pathway from age 6 to age 8, bringing it into alignment with the early years' transition (generally understood to be 0-8 years). This would enable stronger transition support to school, easier interface with early years' services, extended support for families, a focus on building capabilities in natural settings and continuation of a key worker model in a developmentally appropriate setting.

Significant barriers remain to entering the scheme

Repeated themes from our survey and engagement include:

- There is a **lack of information and support** for autistic people and their families/carers to apply for the NDIS
- Concern that **NDIA assessment tools are not fit for purpose** and unfairly screen out autistic people.⁷³
- **Lack of support for autistic people not admitted to the scheme.** Over 80% of our survey respondents with unsuccessful NDIS applications reported not being given information about other supports.

There is a poor understanding of autism among NDIA planners and partners

Just 18.1% of autistic adults and 31.8% of parents/carers reported that their planner had a good understanding of autism in our recent survey.

“After battling with the NDIS for the last few years, talking with many families in similar situations I find the entire process disgraceful. The lengths you have to go through to even obtain funding let alone an appropriate amount is exhausting, over complicated and

<https://webcache.googleusercontent.com/search?q=cache:kVtO3NLKyIJ:https://www.aph.gov.au/DocumentStore.ashx%3Fid%3Db203535f-060d-48f5-bcf6-276ce828aa19%26subId%3D670195+&cd=3&hl=en&ct=clnk&gl=au>

⁷¹ Synergies Economic Consulting, 2013. *Cost-Benefit Analysis of Providing Early Intervention to Children with Autism*.

Available at: <https://www.synergies.com.au/reports/cost-benefit-analysis-of-providing-early-intervention-to-children-with-autism/>

⁷² Tune AO PSM, D., 2019. *Review of the National Disability Insurance Scheme. Removing Red Tape and Implementing the NDIS Participant Service Guarantee*. Available at: https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf

⁷³ The NDIS utilises *DSM-5* Levels 2 and 3 as conditions by which children and adult autistic people are likely to meet access requirements to the NDIS. *DSM-5* clearly states that the severity levels should not be used to determine eligibility for services given the levels can change over time and with different assessors.

stressful. Once you have jumped through all the hoops there is still no guarantee that the random person who decides the plan who has never actually met your child, or who has any really knowledge of the disability and what daily life is really like makes decisions that determine how much support you can access.”

“I feel like the information about what we can ask for in our plan is very nebulous and piecemeal and it's pot luck if the person we are paired with knows much or little. My main concern and disappointment is with the constant shuffling of staff, which disrupts the continuity of care/information dissemination and relationships. As an autistic person myself, I find dealing with new people, with bureaucracy/paperwork/form filling/questions (feel like interrogations) draining and difficult and it takes me a long time to build up trust in that relationship. We have been with the NDIS 4 years and have had three people in that planning role so far. Next year we will also get someone new as our son will have aged out of the ECEI pathway. I am dreading it. It is exhausting to have to go through his history all over again.”

The Scheme is deficit focussed

Autistic people and parents of autistic children are often required to repeatedly justify why their support needs should be met by the NDIA. This process can be demeaning and hurtful to the self-respect and identity of the autistic person.

“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.”

Participants are not well-equipped to exercise choice and control

The overwhelming majority of respondents reported needing more support to engage with the planning process and the NDIA. Just 31.6% of autistic adults and 35.8% of parents/carers felt they had enough information in advance to understand the planning process.

These challenges are further compounded by the market model that the NDIS is predicated upon, which requires participants and their carers to broker directly with service providers in an environment often marked by poor information regarding the types and appropriateness of services that are on offer. Within the NDIS market, where some providers remain unregistered, participants are left to themselves distinguish between evidence-based supports and other marketed offerings.

Pre-planning support and peer networks need to continue, drawing on successful experiences of the previous NDIS Disability Support Organisations (DSO) program – the funding for which has now lapsed. Program evaluations (unpublished) highlighted the benefit of pre-planning and the efficiencies they delivered in the planning process by improving participants understanding of how to prepare for their meeting. Likewise, peer support plays an important role in strengthening participant capabilities to exercise their choice and control.

Individual funding is often inadequate and it is hard to access supports in some areas

Just over one-third of respondents with a current or pending NDIS plan reported that their NDIS funding is adequate.

A lack of appropriate services can also limit access to support, with two-thirds reported difficulty in accessing disability support services after receiving NDIS funding.

Thin and non-existent markets continue to pose major challenges for autistic people and their ability to access essential supports, particularly for those with complex care needs and those living in rural and remote Australia.

We acknowledge that the NDIA has taken steps to publish its policies in relation to thin markets and its view of intervention, however there are significant risks for autistic participants nationally and in particular for those with complex care needs living outside of major cities. The number of autistic NDIS participants is significant and growing, and ensuring there are enough autism-specific supports in the NDIS market is critical.

There are significant barriers to accessing the Complex Needs Pathway

The Complex Needs Pathway within the NDIS recognises that participants with particular personal circumstances may require specialised planners to ensure that their needs are appropriately supported. However, there remains a lack of transparency around the pathway, and specifically, how participants are identified for referral into the Pathway.

Only eight autistic adults and 59 parents/carer respondents to our survey indicated that they were accessing the Complex Support Needs Pathway – yet 414 reported having a Level 3 autism diagnosis, which is indicative of complex needs. Low awareness of the pathway was reflected by the 61.1% of autistic adults and 69.2% of parents/carers with a current or pending NDIS plan reported that they don't know about the NDIS Complex Support Needs Pathway.

Lack of a provider of last resort under the NDIS model remains a live issue for participants with multiple complexities who may be unattractive to providers. The Australian Parliament's Joint Standing Committee on the NDIS recommended (and the Government in its response to the Inquiry agreed)⁷⁴ that the NDIA urgently release its policy on provider of last resort arrangements. Despite this, a lack of clarity and information remains. While the NDIA has developed the Maintaining Critical Supports approach, and within that, the Exceptionally Complex Support Needs Program, it's unclear whether these measures will be sufficient to ensure all participants are able to be connected with providers willing to support them. We urge this Inquiry to keep a watching brief on this.

Outcomes for autistic participants are comparably poor

Recent NDIA reports into participant and family/carer outcomes reveal poorer outcomes for autistic people compared with most other disability groups. While there were improvements recorded in some domains, there was deterioration in others. In particular, worsening outcomes were recorded in social and community participation with an increased proportion of young people reporting

⁷⁴Government response to Joint Standing Committee Inquiry into NDIS Market Readiness, March 2020. Available at: https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MarketReadiness/Government_Response

having no friends; and families of pre-schoolers reporting being less likely to feel welcome in community, cultural or religious activities than children with other disabilities.⁷⁵ Outcomes for families and carers of autistic participants aged from birth until 14 years of age were also much poorer across a number of domains.⁷⁶

The NDIS needs a dedicated Autism and Neurodevelopmental Stream

Limited understanding of the needs of autistic people, and inconsistencies in funding processes were both common themes in our survey responses regarding the NDIS.

The NDIA has developed specialist streams for people with psychosocial disability and hearing loss, enabling NDIA and Partners in Community staff in those areas to build specialised skills and expertise.

A similar approach is urgently needed for autistic participants. A specialist stream would build autism expertise among NDIA staff, LACs and ECEI staff, including the functional impacts of autism, how to support autistic people to engage in the planning process and the evidence-based supports to derive the best short and long-term outcomes in autistic people. While we recognise current efforts, including the Autism Staffing & Recruitment Strategy, there is a long way to go to make the scheme autism proficient.

And needs information dedicated to autistic participants

A straightforward way to improve the accessibility of the NDIS to autistic people is to publish information on the Scheme specifically tailored to their needs. Development of such resources needs to occur through co-design with autistic people and the autism sector.

Recommendations: NDIS

25. Overhaul ECEI. Provide automatic access as participants to the scheme for every child with an autism diagnosis and enable immediate access to comprehensive early intervention. Explore extension of the ECEI offering until age 8 to support improved transition to school.
26. Establish a specific NDIS autism and neurodevelopmental participant stream and dedicated training for all NDIA and partner staff in access and planning.
27. Develop clear, transparent and accessible eligibility criteria for autistic people, including a robust and reliable tool for determining eligibility, leveraging the National Guideline for Autism Assessment and Diagnosis.
28. Co-design tailored NDIS information to meet the needs of autistic people.
29. Expand investment in pre-planning support and peer networks, drawing on the successful NDIA Disability Support Organisations program.

⁷⁵ NDIA, 2020. *NDIS Participant Outcomes Report, 30 June 2019*. Available at: <https://data.ndis.gov.au/reports-and-analyses/participant-outcomes-report>

⁷⁶ NDIA, 2020. *NDIS Family and Carers Outcomes Report, 30 June 2019*. Available at: <https://data.ndis.gov.au/reports-and-analyses/family-and-carer-outcomes-report>

Research is key to evidence-driven approaches to autism

Evidence informed policy, programs and practice will improve outcomes

Autism has been beset with policy and practice that is not founded in evidence. Independent evidence around what works, why and for whom is particularly important in a market-driven system of supports, so that people can make informed choices.

As Australia heads towards a post-pandemic future of budget austerity, the importance of evidence-informed policy and high-quality public services has never been more starkly underscored. Public policy and funded programs related to autism need to be responsive to the needs of autistic people and informed by evidence-based research. This will require ongoing and well-placed investment in autism research.

Funding for autism research is disproportionately small

Autism-specific research funding receives a disproportionately small allocation of the federal research investment. The high prevalence of autism in the community and within the NDIS ought to attract a proportionate research budget.

A co-ordinated national approach to autism research is critical

The Australian Autism Alliance highly values the work of the Autism Co-operative Research Centre. Autism CRC co-ordinates and leads evidence-based research into autism across a wide-range of partners and supporting agencies, and translates evidence-based research into practice. It is essential to linking what could otherwise be a disconnected suite of research projects, adding value to each and ensuring that the knowledge attained through each project is understood and applied nationally.

Despite this crucial role, funding for the Autism CRC is only confirmed until 2021. There is a risk that the significant gains in understanding of autism and the needs of autistic people will backslide. It is essential that the national coordination of autism-specific research and collaborative projects continues.

Guided by a National Autism Research Strategy that reflects community priorities

A National Autism Research Strategy should be developed as a key component of a future National Autism Strategy. It would complement the National Disability Research Strategy that is under development.

Autism CRC has established the Australian Autism Research Council comprising key stakeholder groups to determine national priorities for autism research. Following a process of community consultation, the Council identified ten autism research priority areas - Communication; Education; Employment; Health and Wellbeing; Justice; Family and Carer Support; Choice in Living and Housing; and Gender, Diversity and Inclusion. A process, including focus groups of autistic people, families and professionals, is now underway to determine the research agenda for each priority area, informed by community need. The Council's charter requires it to review and update research priorities as defined by community stakeholders.

The Australian Autism Research Council's work can serve as an important foundational piece in a future National Autism Research Strategy. Given the priorities are being generated and endorsed by the broad community of autistic people and their families, these areas ought to be preferred when allocating future research funding.

Recommendations: Research

30. Continue funding national, collaborative research at scale following the sun-setting of funding for the Autism CRC.
31. Develop a National Autism Research Strategy, as a component of a future National Autism Strategy. Priorities identified by the Australian Autism Research Council should be adopted.

Autistic people and their families experience extreme social isolation

Most autistic people are socially isolated

Loneliness and social isolation is pernicious. It can adversely impact mental health, education, social and economic outcomes.⁷⁷ 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 our 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.

“Autistic children and their parents are often ostracised by society, even by people we know well.”

The broader community has little understanding of autism

Although there is widespread awareness of autism, there is a low level of understanding and very low knowledge and confidence about how to be supportive. Amaze’s survey of community attitudes revealed that while 85% of Australians have personal connection with an autistic person, just 29% feel they understand how to support autistic people; and only 4% of autistic people and their families agree that people in the community know how to support them.⁷⁸

As part of the Victorian Autism Plan, the first phase of a public awareness campaign ‘Change Your Reactions’ ran in Victoria earlier this year.⁷⁹ This is the first campaign of its type in Australia. The campaign aims to encourage more helpful and informed attitudes, with the longer-term goal of encouraging more inclusive behaviours.⁸⁰ Initial evaluation results are very strong. A second phase of the campaign is currently on hold because of the pandemic.

There is a need for public education campaign to be delivered nationally to both increase understanding of autism and inform the community how to better support autistic people.

Built environments can better accommodate the needs of autistic people

Autistic people encounter a range of environmental barriers (each autistic person will experience these differently) that restrict participation in community life. Challenges include:

- **Crowded places:** The most common reason autistic adults and parents/carers who responded to our survey primarily avoided particular places were the crowds/number of people (91.7% and 86.9%, respectively).

⁷⁷ 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/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

⁷⁸ Jones S et al., 2017. Experiences of Autistic People and their Families, Centre for Health and Social Research, Australian Catholic University.

⁷⁹ View the campaign at <https://changeyourreactions.com/>

⁸⁰ Victorian Government, 2019. *Victorian Autism Plan*. Available at: https://www.statedisabilityplan.vic.gov.au/application/files/5115/7543/9606/1805022_Victorian_Autism_Plan-WEB.pdf

- **Sensory overload:** Lighting, acoustics, smells, colours, spatial features, flooring and other design elements can trigger sensory processing difficulties. 82% of autistic adults responding to our survey avoided particular places because of the levels of light and noise or sensory processing difficulties.
- **Lack of information:** Access to information about a place is important – including through non-verbal channels and signs.⁸¹ Commonly co-occurring mental health conditions; in particular, anxiety can escalate in new/unknown environments or situations, or when an unexpected event or sudden change occurs in the environment.⁸²

A handful of innovative organisations and businesses across Australia have taken steps to create autism friendly environments including Museums Vic, Gold Coast Airport (profiled below), Surf Life Saving Australia and Shoes and Sox footwear stores.

Gold Coast Airport's Hidden Disability Scheme

Gold Coast Airport partnered with Autism Spectrum Australia to implement a comprehensive assessment based 'Hidden Disabilities' scheme that includes a range of web-based resources to aid preparation and predictability for autistic people and their families, on-site sensory accommodations and extensive staff training.

Significantly, this has led to the creation of Hidden Disability resources for the Australian Airports Association.

There is huge potential to expand the number of autism-friendly settings as a way of enabling greater participation in community and economic life by autistic people. The autism friendly app being developed by the Autism Association of SA (with ILC funding) will map autism friendly spaces, activities, businesses and services. It would be valuable to monitor how this impacts on participation in community life.

Recommendations: Social Inclusion

32. Fund a national public education campaign to improve understanding of autism and how to support autistic people.
33. Position the Australian Government as exemplars in autism friendly environments by providing sensory maps, social scripts and modified environments across federal venues. Incentivise business, community, sports and arts organisations to do likewise.

⁸¹ Shell, S., 2016. *Why buildings for autistic people are better for everyone*. Available at: <https://network.aia.org/HigherLogic/System/DownloadDocumentFile.ashx?DocumentFileKey=3fff74f0-6418-8e5f-00ed-4eb38eabd8&forceDialog=0>

⁸² Kerns C, et al., 2014. *Traditional and atypical presentations of anxiety in youth with autism spectrum disorder*. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5441227/pdf/nihms859304.pdf>

The voices of autistic people need to be amplified through advocacy

Advocacy is a fundamental right

The capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government are enshrined in the United Nations Convention on the Rights of Persons with Disabilities.

Advocacy services support people with disability to exercise their rights and freedoms by the provision of individual advocacy support; supporting people to advocate for themselves; and influencing long-term, systemic changes for a group of people.

There is considerable scope to improve support for disability advocacy

Funding for disability is shared between different levels of government. The Commonwealth funds disability advocacy agencies through the National Disability Advocacy Program (NDAP), whilst all state governments except South Australia have their own programs to fund disability advocacy at a systemic and individual level.

Key challenges facing disability advocacy include a lack of funding growth to meet increased demand,⁸³ inconsistency in implementation of Commonwealth and state disability advocacy funding,⁸⁴ a lack of nationally consistent data for disability advocacy and funding uncertainty post 2020. The Productivity Commission has highlighted that the responsibility for providing advocacy funding is unclear, with some governments operating on a 'wait and see' basis pending confirmation of what funding will be provided through the Australian Government's National Advocacy Program and the NDIS.⁸⁵

The NDIS has created extra demand for services. Data from the Disability Advocacy Resource Unit (DARU) found that the number of reports for disability services and the NDIS increased by 70% upon introduction of the NDIS.⁸⁶ The NDIS has passed significant burden to families to navigate the scheme and a market of supports and service systems.

The United Nations' Committee on the Rights of Persons with Disabilities has expressed concern about the unsustainability and inadequacy of resources for continuous, individual and independent advocacy programmes in Australia.⁸⁷

Autism-specific advocacy services are needed

In our survey, we asked about people's confidence and understanding in engaging in self-advocacy activities. The insights were illuminating.

⁸³ Productivity Commission, *Report of Government Services 2018*, Table 15.8A. Available at: <https://www.pc.gov.au/research/ongoing/report-on-government-services/2018>

⁸⁴ Commonwealth funded organisations can be found here: <https://www.dss.gov.au/disability-and-carers/programs-services/for-people-with-disability/national-disability-advocacy-program-ndap-operational-guidelines/list-of-agencies-funded-under-the-national-disability-advocacy-program>. Victorian funded organisations can be found here: <https://providers.dhhs.vic.gov.au/disability-advocacy-organisations>

⁸⁵ Productivity Commission, 2019. *Review of the National Disability Agreement – Study Report*. pp. 14. Available at: <https://www.pc.gov.au/inquiries/completed/disability-agreement/report>

⁸⁶ Disability Advocacy Resource Unit, 2017. *Disability Advocacy by the Numbers*, pp. 16. Available at: <http://www.daru.org.au/disability-advocacy-by-the-numbers-data-integrity-supplementary-report>

⁸⁷ United Nations Committee on the Rights of Persons with Disabilities, 2019. *Concluding observations on the combined second and third periodic reports on Australia*. Available at: <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRICAghKb7yhsnzSGoIKOaUX8SsM2PfxU7sdcbNJQCwIRF9xTca9TaCwjm5OIhnsVv2oxnsujKREtaVWFXhEZM%2F0OdVJz1UEvF5leK6Ycmqrm8yzTHQCn>

- More than 22% of autistic adults reported that they did not know where to get help if they were experiencing violence, abuse or neglect.
- 45% did not know where to get help if they were experiencing discrimination or exclusive practices, such as a lack of opportunities to access education, accommodation, recreation and leisure.
- 39% did not know where to get help with the law, tenancy, Centrelink or with having enough money to meet their needs, or to speak up for themselves and self-advocate in general.

I stumbled across an advocacy group who have been very helpful in preparing for my son's interview, and my daughter's second planning session. It would be great if it was more widely known that advocacy groups are available.

Parents of Autistics must become very strong advocates for their child's needs to be met at school, in community and in healthcare setting. It is a full time job with an enormous mental load for parents to carry. Concerned how parents with limited resources, lower levels of education or from culturally or linguistically diverse backgrounds cope with advocating for their child.

International studies have revealed challenges for autistic people in accessing mainstream disability advocacy services. A UK survey by the National Autistic Society of 55 general, learning disability and mental health advocacy organisations found that 32% of those organisations would not provide services to people who revealed that they had an autism diagnosis. The remaining 62% indicated that they experienced significant difficulty working with autistic people and had little confidence in the ability to advocate effectively for this population.⁸⁸ Much of the concern expressed was around their understanding of autism or concerns about advocating for people with communication difficulties. Although that study is now more than 15 years old, these findings align with recent commonly reported experiences of autistic people in Australia.

Autistic people require advocacy services that are user led and have a thorough understanding of the issues faced by autistic people. General disability advocacy groups tend to lack this detailed understanding. Autistic-led advocacy groups can build autism competency within general advocacy groups, as well as directly support autistic people and their families.

We need a dedicated service that understands our difficulty in advocating for ourselves to support us to get our needs met. This needs to be independent of the NDIS so that everyone can access it before/during/after NDIS or even if they are ineligible for NDIS support.

The upcoming review of disability advocacy funding by the Department of Social Services presents an important opportunity to revisit the structure and focus of government-funded disability advocacy programs, including the need for those that meet the specific needs of certain diagnostic groups such as autism.

There needs to be scope for funded advocacy services that are designed to work with autistic people and their families, in parallel to generalist services for people with disability. Notwithstanding the recent moves away from funding diagnosis specific advocacy, the self-advocacy movement for

⁸⁸ National Autistic Society, 2003. *Autism: The Demand for Advocacy*. Available at: <https://www.scie-socialcareonline.org.uk/autism-the-demand-for-advocacy/r/a11G0000017ykclAA>

autistic people is relatively new compared to those with physical and sensory disabilities such as vision and hearing impairment. So rather than seeing this as a step backward it is actually playing catch up in terms of the realisation of the rights of autistic people in comparison to other disabled people.

Systemic and structural advocacy plays an important role in aligning government policy and program design with the needs and expectations of autistic people. There is a clear role for a co-ordinated voice that brings together autistic organisations around the nation to identify systemic issues and inform the Commonwealth Government on policy and program development. This should be complemented by properly funded peak body that represents autism organisations and works within the Disability Representative Organisation landscape.

Recommendations: Advocacy

34. Fund user-led autism specific advocacy services (individual and systemic) and support their capacity and capacity building activities to operate nationally, in parallel with generalist disability advocacy services.
35. Develop a nationally consistent approach to advocacy, with clear and agreed roles for the Commonwealth Government and the States and Territories, built on an ongoing and consistent funding model. Ensure funding growth is applied to advocacy programs in order to maintain pace with the increased demands caused by the rollout of the NDIS.