



AUSTRALIAN
Autism Alliance

Change 4 Autism

In 2019, Australia will choose a new federal government.
We need leaders who will listen to the voices of the autism community.
We need to break down barriers and create opportunity.
We need **Change 4 Autism**.

**Urgent action to eliminate
NDIS barriers to vital supports
for autistic people**

**A National Autism
Strategy to drive change**

**Establish a Royal Commission
into violence, abuse and neglect
of people with a disability**

**High-impact, sustainable
disability advocacy**

Autism in Australia: fast facts

Autism Prevalence

In 2015, the ABS reported there were **164,000 Australians with an autism diagnosis** and a prevalence rate of 2.8% for those aged between 5-14 years (**81,000 children**). However, the true prevalence of autism in Australia is likely to be much higher given the large numbers of autistic adults who remain undiagnosed.



Employment

The **unemployment rate for autistic people was 31.6%** in 2015. This is more than three times the rate for all people with disability and almost six times the rate of people without a disability.



Social Isolation

Research shows that autistic people and their families experience significant social isolation with **51.6% agreeing that they feel socially isolated** and **39.3% agreeing that they sometimes feel unable to leave the house** due to concerns about discriminatory or negative behaviours in the community.



Community Understanding

85% of Australians have personal contact with an autistic person. Despite this, only 29% of Australians 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.**

NDIS

Nationally, **29% of all NDIS participants have identified autism as their primary diagnosis**, the largest diagnostic cohort.



Mental Health

50-70% of autistic people experience a co-occurring mental health condition. In 2012, the Autism Advisory Board on ASD conservatively estimated that around 100,000 autistic people in Australia had a co-occurring mental health condition.



Health

International studies have found that **autistic people have a life expectancy between 20 and 36 years shorter than the general population.**

Diagnosis

Waiting times for diagnosis in the public system can be **between 12 months to two years**, with longer waits occurring in regional, rural and remote Australia. There are significant costs with accessing private assessment and diagnosis, with a mean cost of \$580 but ranging up to \$2,750.



Autism friendly places

Research shows that **67.8% of autistic people avoid community spaces due to the level of light or noise.** Respondents reported how few adjustments are made for autistic people to support their sensory needs: **only 9.4% of employers, 3% of post-secondary education settings, and 19.4% of schools make adjustments.**



Education

More than **35% of autistic students will not reach Year 11**, and **only 6.5% have a bachelor's degree** or above. Autistic people are half as likely to get a bachelor's degree compared to all people with a disability and a quarter as likely as the general population.



Women and girls

The **estimated ratio of autistic boys and men to autistic girls and women is currently closer to 3:1**; however experts agree this may be an underestimate due to the systemic issues with presentation and diagnosis.

Urgent action to eliminate NDIS barriers to vital supports for autistic people

The National Disability Insurance Scheme (NDIS) has the potential to be life changing for autistic people in Australia.

- 29% of NDIS participants are autistic – the largest cohort within the Scheme.
- Timeliness is the most common subject of complaints to the NDIA, amounting to one third of all complaints by participants.
- Early intervention for autistic children is estimated to produce a net benefit of \$365 million, however under the NDIS, children are currently facing up to 12 months delay in accessing early intervention services.
- The NDIA is using the DSM-5 Levels 2 and 3 to determine eligibility for NDIS. This method is deeply flawed – the DSM-5 itself clearly states that the severity levels should not be used to determine service eligibility.
- NDIS participants are often not getting the right plan due to little or no understanding of autism by planners – 65% of autistic NDIS participants (or their carers) rated their planner's knowledge and understanding of autism as None to Moderate.

We can make change:

- **Create an Autism and Neurodevelopmental stream** to build autism expertise within the NDIS, and offer better planning outcomes and simplify the NDIS process for autistic people and their families.
- **Reduce wait times to six weeks** with interim funding packages available so supports can be accessed while applications are being processed. This needs to happen for all NDIS participants, with a priority on autistic children to automatically receive early intervention support as specified within the NDIS Act.
- **Determine clear and accessible eligibility criteria** for autistic people, including the creation of robust and evidence-based tools to ensure assessments are autism appropriate and consistent.
- **Ensure that the Jobs and Market Fund** stimulates targeted growth in the autism services, including early intervention services and particularly for participants with complex needs, in thin markets and in regional and remote areas.

Case study: Charlie

Charlie is four, with the social skills of a 9 month old. NDIS confirmed his eligibility and access in March 2018. Despite paediatrician's advice, five diagnostic reports and individual research supporting his need for intensive support, Charlie's family were told his request was not justified, forcing them to use their life savings to fund his therapies. With the support of an advocate, his plan was finally approved 9 months later.

Case study: John

John is a 19 year old autistic university student. He sought transport support from the NDIS as the sensory and social environment of public transport is overwhelming, plus support to assist with his organisation, planning and time management due to challenges with executive functioning. The Local Area Co-ordinator told John that, as a university student, he would not be eligible for the NDIS.

John withdrew from university, impacting his self-esteem, his dependency on his family and his future economic and community participation.

A National Autism Strategy to drive change

Internationally, national autism strategies have been shown to create positive change for autistic people. It's time for Australia to develop our own 5-year National Autism Strategy.

- 85% of Australians have a personal contact with an autistic person, but only 29% feel they know how to support autistic people. Only 4% of autistic people agree that people in the community know how to support them.
- Wait times for diagnosis in the public system can be up to two years, or even longer in regional, rural and remote Australia. Private assessment and diagnosis are costly (up to \$2,750).
- 35% of autistic students achieve Year 10 or lower, compared with 18% of students without a disability.
- The unemployment rate for autistic people is 31.6% – almost six times the rate of people without disability.
- 50–70% of autistic people experience a co-occurring mental health condition.
- Autistic people have a life expectancy 20–36 years shorter than the general population.

We can make change:

- **Make it easier for people to access diagnosis** by reducing waiting times, implementing the Autism CRC national diagnostic guidelines and establishing Medicare items for adult diagnosis.
- **Let autistic students thrive** through a national strategy to reduce disparity in education attainment, strengthen compliance with the Disability Standards for Education and commit to ongoing implementation and evaluation of the Quality Schools funding model.
- **Lift employment of autistic people** by providing greater school-to-work supports, create more autism employment programs and pathways with the public and private sector and put employment at the forefront of NDIS planning for workforce-age participants.

- **Improving understanding of mental health and autism** including how to identify and support autistic people experiencing mental health conditions. Research, capacity building and service collaboration can be promoted through a Mental Health and Autism Summit.
- **Support autistic people to live longer, healthier lives** by educating healthcare professionals and bringing lessons from international best practice to our own healthcare spaces.
- **Increase social inclusion** and participation by making public places, housing and major events autism friendly.
- **Better identify and support autistic women and girls** by funding research into screening and diagnosis, and ensuring they are supported through the NDIS process with appropriate services.

Case study: Joey

Joey and his parents wanted him to attend their local primary school, along with his two older siblings. Upon enrolment, the Principal raised doubts about the school's ability to support Joey. He became increasingly anxious about going to school, was regularly sent home due to meltdowns, and eventually ran away. It was decided that Joey should only attend school for three hours per day until his behaviour "improved". Joey's mother could no longer maintain her part-time work, and his parents now worry that Joey's time at school won't ever increase. They are considering legal action.

Establish a Royal Commission into violence, abuse and neglect of people with a disability

Fractured and closed systems have hidden decades of violence, abuse and neglect of autistic people – and all people with disability.

- Federal and Victorian inquiries into abuse and neglect of people with a disability recommend a Royal Commission into this issue.
- In January 2019, the NDIS Quality and Safeguards Commission revealed it had received 29 reports of sexual assault and 184 reports of abuse or neglect of NDIS participants in three months.

We can make change:

- The Alliance supports the broader disability sector in calling for a **Royal Commission into violence, abuse and neglect of people with disability**, which will support the work of the NDIS Quality and Safeguard Commission.
- **Create a nationally consistent framework** to work towards the elimination of restrictive practices across all service systems and sectors, facilitated by the Council of Australian Governments.

High-impact, sustainable disability advocacy

Advocacy services seek to support people with disability to exercise their rights and freedoms – however, disability advocacy services are facing growing demand with dwindling funding.

- The number of reports for disability services and the NDIS increased by 70% from 2014–2016, in line with the introduction of the NDIS.
- Autistic people require advocacy services that are user-led and have a thorough understanding of the issues they face in the community.
- Disability advocacy faces many issues, including: a lack of funding growth and certainty post-2020; inconsistency in implementation of Commonwealth and state disability advocacy funding; a lack of nationally consistent data; and extra demand for services created largely by the NDIS.

We can make change:

- **Support autistic people to navigate complex systems** and supports by funding autism-specific advocacy services.
- **Ensure the sustainability and efficacy of advocacy** by undertaking an independent evaluation in 2020 to inform future funding arrangements.
- **Develop a nationally consistent approach** to disability advocacy, outlining clear roles and responsibilities for Commonwealth and state and territory governments.

Case study: Fabian

Fabian, aged 21, is autistic and lived in a boarding house. He had been experiencing mental ill health and repeatedly presenting at emergency departments, as he felt he was in an ongoing crisis. An advocate began to work with Fabian, autism professionals and mental health services to better understand his needs. Without this support, Fabian's situation would have escalated; advocacy meant that he had better support, new housing and a safer way to manage his feelings.



About the Australian Autism Alliance

The Australian Autism Alliance was established in 2016 in recognition of the need to create 'one strong voice for autism'. We are a diverse national network of 11 autism organisations combining autistic-led organisations, research bodies, advocacy groups and service providers.

The Alliance brings together organisations representing autistic people, their parents and carers and professionals who provide services which aim to improve the life outcomes of all autistic Australians.

www.australianautismalliance.org.au

