Australian Autism Alliance 2019 Federal Election Manifesto

# Change 4 Autism

## How the next Commonwealth Government can make positive change for autistic people across Australia

AUSTRALIAN
Autism Alliance

# Contents

# 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 professional who provide services who aim to improve the life outcomes of all autistic Australians.

Together, our organisations currently:

- Reach over 170,000 people through our communication channels
- Provide direct support to over 30,000 autistic people across the lifespan from early childhood to adulthood
- Operate 230 service outlets across Australia
- Employ in excess of 3,000 staff in Australia
- Employ, or provide pathways to employment, for 350 autistic adults
- Contribute significantly to the Australian economy by generating and delivering an estimated $200m of supports and services
- Build capacity of the broader community through training and advisory services for over 60,000 people per year
- Have significant national and international linkages for advocacy, research and service delivery

We trust that this document provides clear guidance to all parties and candidates for the upcoming 2019 federal election on the priorities for supporting autistic people and their families.

**Terry Burke**
Co-Chair
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## Australian Autism Alliance Partners

- 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

# 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.

## 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.

NDIS

## 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.

## 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.

## 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.

## 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.**

## 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.**

## 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.

Federal Election 2019

# Australian Autism Alliance priorities

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

Ensure the support needs of autistic people (29% of all NDIS participants) are met by the NDIS and mainstream services.

- **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 for 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 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.

## Develop a National Autism Strategy to drive change

Develop a 5-year National Autism Strategy with measurable targets and outcomes, in partnership with autistic people and their families/carers, to include action on key priorities
to improve life outcomes of autistic people. The key focus areas for the National Autism Strategy are:

- **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.

**Photo Source: I CAN Network's**
**'Humans on the Autism Spectrum' Campaign**

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

- 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

- **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.

**Photo Source: Amaze**

# About autism

**Autism is a lifelong, neurodevelopmental condition which affects the ability of all diagnosed individuals to participate in interactions with other members of society at work, at play and in all aspects of daily living.**

Autistic people generally have a limited range of unusually strong interests; this often leads to developing specific areas of skill and knowledge which may contrast with the way in which an individual functions in other areas of living. Autistic people also experience differences in the way in which the brain interprets daily experiences. For example, individuals may be unable to locate pain or may have a pain response to bright light. These differences require adjustments for individuals to participate in both social and built environments.

According to the Australian Bureau of Statistics, there were 164,000 Australians with an autism diagnosis in 2015 and a prevalence rate of 2.8% for those aged between 5-14 years (81,000 children). The ABS continues to record significant growth in the number of Australians with an autism diagnosis with a rise of 42% since 2012.[1] However, the ABS estimate is likely to be well below the true prevalence of autism in Australia given the large numbers of autistic adults who remain undiagnosed. Currently, around three times as many males are diagnosed as females. Autism commonly presents with other conditions, such as intellectual disability, epilepsy, anxiety and/or depression.

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> Recent research has found that 98% of Australians have heard of autism and 85% of Australians have a personal contact with an autistic person.

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Despite this, only 29% of Australians feel they have a good understanding of how to support an autistic person, with only 4% of autistic people and their families agreeing that people in the community know how to support them.[2]

This document outlines the Australian Autism Alliance's vision of how the next Commonwealth Government can make positive change for autism, including a number of key initiatives to ensure the needs of autistic people are met, autism understanding increases and the participation of autistic people grows in all aspects of community life.

These priorities have been developed in partnership with autistic people and their families and carers.

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

**Ensure that the needs of autistic people (29% of participants) are met through the NDIS:**

- Design, implement and evaluate a specific autism and neurodevelopmental stream within the next 12 months;
- Commit to reducing waiting times (from entering the scheme to finalising a plan) to 6 weeks, with interim funding packages to immediately access supports whilst the NDIS process is undertaken. This should happen for all NDIS participants, with a priority of children in ECEI. The NDIA must also monitor and report on wait times.
- Determine transparent and accessible eligibility criteria for autistic people, including a robust, evidence-based eligibility tool; and
- 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.

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

Underpinned by insurance principles of investing early to increase a participant's economic, social and community participation, the NDIS could improve long-term outcomes while reducing long-term costs to the scheme, governments and the broader community. It has been projected that by 2019-20 the NDIS will cost about $22 billion each year[3] – however, there is strong evidence that the economic gains of a fully implemented NDIS will far exceed its costs.

Since inception, 29% of all NDIS participants have a primary diagnosis of autism, representing the Scheme's largest diagnostic cohort.[4] Despite this, independent and government inquiries have consistently found that the NDIS is failing autistic people in: i) accessing the Scheme and engaging in the planning process; and ii) providing meaningful choice and control over support services.

While intended to represent a fundamental shift from a ration-based to an entitlement-based scheme, autistic people are often faring worse. Funding packages for many autistic children are grossly inadequate and access to early intervention is being delayed by up to 12 months or more. Autistic people with complex needs and/or those living in rural and remote areas are also further disadvantaged due to transition related gaps in service provision.[5]

While government has responded too many of the concerns raised in recent inquiries and reports – including establishing an Autism Advisory Group (AAG) to strengthen the system for autistic people and their families/carers – urgent action is required.

## Establish clear and consistent eligibility criteria for autistic people

The National Disability Insurance Scheme Act 2013 (S25), states that a person meets the early intervention requirements if a child has one or more cognitive, neurological and sensory impairments that are permanent and that early intervention supports is likely to benefit the child. As autism fits into all of these categories, it is clear that all autistic children should be provided automatic access to Early Childhood Early Intervention (ECEI).

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. The issue with utilising the *DSM-5* autism diagnostic levels is that it is a subjective professional assessment that can change between assessors.[7] *DSM-5* clearly states that the severity levels should not be used to determine eligibility for services.

A robust and reliable tool to ascertain eligibility for autistic people – that doesn't rely on *DSM-5* ratings – with an autism-appropriate functional assessment, is urgently needed and should continue to be pursued. Clear, accurate and consistent communication is also needed regarding diagnostic requirements for autistic people to enter the scheme as participants, combined with a robust strategy for implementation of the new national diagnostic guidelines for autism (discussed below).

## Ensure all autistic people, and their families/carers are supported by the NDIS

While the NDIS will provide packages of support to a substantial number of autistic people, there will be many autistic people who will not meet the criteria for an individual package.

All autistic people must be supported to easily access appropriate information, linkages and referrals through an adequately funded and implemented NDIS Information, Linkages and Capacity Building (ILC) framework. This framework must prioritise the building of autism capacity for mainstream services and the broader community to ensure they are more are more inclusive of autistic Australians.

Support for autistic people, through access to appropriate short term accommodation (respite) services must also be provided through the NDIS. A clear criteria and pathway to access short term accommodation, together with appropriate levels of funding, is urgently needed. Planners need to build a better understanding of the amount of short term accommodation care that is reasonable and necessary, and plans need to more clearly identify funds in plans that can be used for these services.[8] It is well understood that strong wellbeing of autistic participants and their carers is needed for a cost-effective NDIS. The Productivity Commission has highlighted that there are widespread concerns about the future of short term accommodation.[9]

## Improve the autism competency of planners

A lack of autism understanding among NDIA staff, Local Area Coordinators (LACs) and ECEI staff has negatively impacted on the rights of autistic people to participate and have their support needs understood and met during the planning process (including planning meetings) to ensure they receive an appropriate and responsive plan. Research from Amaze found that 65% of respondents rated their planner's knowledge and understanding of autism as *none to a moderate.*[10]

Autistic people must be empowered to set their own goals, be involved in every step of the NDIS planning process, and exercise self-determination through choice and control over their support services. These rights are currently being hindered by NDIA and LAC staff who do not have sufficient knowledge of autism and how to engage autistic people in the planning development and implementation process.

> With almost one-third of participants identifying as autistic, the Scheme must meet the support needs of autistic people to achieve its goals.[11]

A report commissioned by the NDIS recommended that children with an autism diagnosis should receive **20 hours per week of early intervention.[12]** Despite this, there is evidence that there are funding shortfalls in plans for autistic children, with the level of support provided in many plans not aligning with recommended evidence-based practice guidelines. Accordingly, many children are not accessing the recommended/best practice level of support and therapies to achieve optimal outcomes.[13]

## An Autism and Neurodevelopmental Stream

Urgent investment is needed for a specialist Autism and Neurodevelopmental stream, building on the approach of the recently adopted Psychosocial Disability stream. 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.

A dedicated Autism and Neurodevelopmental stream would lead to better planning outcomes, greater efficiencies, and help simplify the NDIS process for autistic people and their families. Training would also be given to all NDIS staff, LACs and ECEI staff about autism and evidence on effective supports, so that they are appropriately skilled to support autistic people and their families/carers to achieve their goals.

In addition, to improve participant understanding of the NDIS, information on the Scheme specifically tailored to the needs of autistic people and their families/carers must be available. The development of such resources should occur through co-design with autistic people and the autism sector.

Investment in pre-planning support and peer networks must also continue, drawing on successful experiences funded through the Disability Support Organisations (DSO) program, which has improved efficiency in the planning process as participants have a better understanding of how to prepare for their meeting.

## Reduce delays

Timeliness is the most common subject of complaints to the NDIA, amounting to one third of all complaints by participants.[14] Anecdotal evidence suggests that the timeframe from eligibility determination to plan approval can now exceed 12 months. Although timeliness is a key issue across the NDIS, it is especially an issue for the Early Childhood Early Intervention pathway.

**Lack of understanding regarding how autism impacts a person's daily life is prevalent amongst NDIS planners and partners. In addition, the management of scheduling and attending appointments can have a significant negative impact. The following case studies illustrate the nature of the problem and the impact on the lives of NDIS participants.**

## Case study: John

John is a 19 year old NDIS participant and university student. He sought assistance from the NDIS with transport (although physically capable, the sensory and social environment of public transport means that John is unable to function effectively once he arrives at his destination) and supports to assist with day-to-day organisation, planning and time management due to his executive functioning difficulties. The Local Area Coordinator advised him that as a university student he would be ineligible for any supports under the NDIS.

John withdrew from university. Not only did this have a significant impact on his self-esteem and his future economic and community participation, it made him more dependent on his family than would be necessary if appropriate supports were provided.

## Case study: Tim

Like many autistic people, 4 year old Tim has sensory sensitivities and rigid thinking. His mother instructed the ECEI coordinator who visited her at home not to touch him. Despite this, the ECEI coordinator tickled Tim, presumably in an attempt to build rapport. The coordinator was asked again not to touch Tim, and even Tim was able to loudly advocate for himself, saying 'Please don't touch me, I don't like it'. The Coordinator then demonstrated her complete lack of understanding of autism by picking Tim up.

Tim became very distressed and the meeting was derailed. Tim's mother spent considerable time calming him down and Tim's parents asked the ECEI Coordinator to leave. Tim's parents have lost faith in the NDIS process and in staff to understand and respond appropriately to information provided about their child's needs.

Photo Source: Amaze

## Early Childhood Early Intervention (ECEI) pathway delays

The ECEI pathway is failing children, with substantial delays in processing. Any delay in accessing services could have a significant detrimental impact on the short and long-term outcomes of autistic children.

> A child simply cannot wait to access early intervention services, yet we are commonly hearing that families are waiting 6–12 months, or sometimes longer.

Systematic reviews of the evidence clearly demonstrate that intensive early intervention support for autistic children, accessed as early as possible, is key to increasing their developmental trajectory over their lifetime, allowing them to be as independent as possible and participate to their full potential in education, employment and their community.[15] Providing early intervention to autistic children (at its most conservative estimate) has been shown to produce a net benefit of $365.7 million and a benefit-cost ratio of 4:1.[16]

The NDIS has set a guideline of prioritising plan development to within six weeks for children under six with a developmental delay, where there is evidence that delay in early intervention supports would reduce the effectiveness of those supports or lead to a worsening in the impairment of the child. The next Federal Government must commit to reducing waiting times (from entering the scheme to finalising a plan) to six weeks, and for this to be monitored and publicly reported by the NDIA.

Within this six week period, participants should also have access to funding for reasonable and necessary supports. Currently, fewer than 15% of all NDIS participants receive an annual support package of less than $10,000.[17] Based on these packages, the insurance principles of the scheme and the critical need for early intervention, it is recommended that interim support of approximately $1,000 per month (to support participants between the date of eligibility determination to plan finalisation) would be money well spent to enable participants to meet at least some of their needs immediately, and produce cost-efficiencies in the long term.

The Alliance considers that the six week timeframes and interim funding packages should apply to all NDIS participants, however, priority should be given to ECEI participants due to the implications for their development trajectory.

## Case study: Charlie

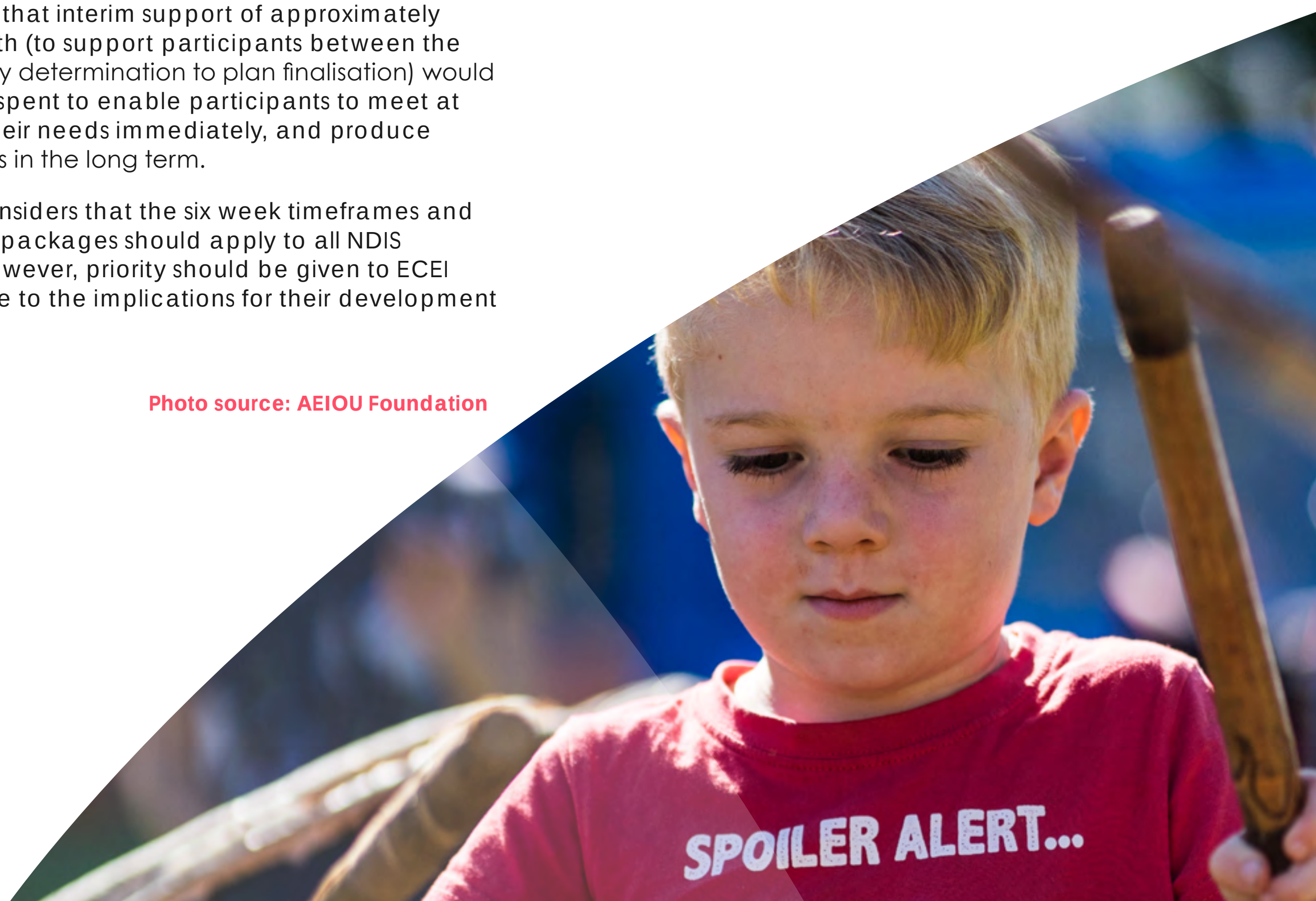
Charlie*, aged 4, is autistic. He had the social skills of a nine month old, would bite himself, ingest inedible items (e.g. rocks, sticks), and scratch or pinch others when distressed. He refused food in unfamiliar settings and was not toilet trained.

Charlie accessed the NDIS in March 2018, **waiting more than nine months** to receive a plan. On paediatrician's advice and individual research, Charlie's family sought evidence-based early intervention (approx. 20 hours of therapy per week). After an NDIS planning meeting in August 2018, a three month 'intensive support plan' was submitted for approval.

Again, Charlie and his family waited. On 20 November – nearly three months later – more evidence was requested. After providing five diagnostic reports and a recommendation letter from a specialist therapist, the family was informed that intensive supports were not justified, and Charlie should be in mainstream childcare, rather than the autism-specific service requested by the family. Charlie's family sought advocacy assistance and, in December, Charlie's plan was finally approved.

Charlie was denied intensive therapy during a crucial time in his development. His family felt intimidated and helpless in the face of a complex and unpredictable system. They lost precious time for Charlie, and their own financial security, as they used life-savings to fund interim therapy costs in the nine months they waited for desperately-needed supports.

Photo source: AEIOU Foundation



## Stimulating targeted growth in the disability services sector

Autistic people must be empowered to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports. Choice and control require concerted development in both the supply and demand sides of the NDIS Market and a robust approach to quality and safeguards.

Autistic people must have access to a range of service providers with sound knowledge and skills in autism, regardless of their level/types of needs and whether they live in regional or remote areas. This issue is particularly acute in terms of accessing professional support, such as allied health professionals and in early intervention services for children. To ensure the disability support sector remains sustainable, particularly in rural and remote areas, government-led stimulated growth will continue to be essential. Government-led initiatives will also be required to build autism competencies among service providers. By comparison, the Queensland Department of Education and Training has funded an autism hub, training autism coaches for schools.

For participants with complex needs, the new NDIS complex support needs pathway to improve NDIS experiences and outcomes and pricing tiers to ensure the availability of appropriately skilled workers are a welcome first step. However these measures must form part of a comprehensive approach developed by Federal and state/territory governments to ensure appropriate service provision and that other unmet needs of this cohort are met.[18]

The next Commonwealth Government should 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: Alex

Alex is an autistic adult with high support needs who is cared for by his father, Margus, a 65 year old single dad.

Alex is not having his needs addressed for short term accommodation in his plan, putting incredible strain on Alex and Margus – who has his own health concerns, having recently undergone a complete hip replacement.

Alex's short term accommodation was previously block funded by the Queensland Department of Disability Services, Alex's contribution to the cost of four overnights during the week was $235 which was affordable and paid from his Disability Support Pension. The balance of costs was covered by the block grant. When the NDIS took effect from 1 July 2018, Alex (and many other participants) did not receive sufficient funding to cover the cost of his stays, at around $2,700 each. This is a prohibitive expense – however, with no short-term accommodation options now viable for Alex and Margus, they are struggling to maintain their relationship and individual wellbeing.

With no respite from his caring role, Margus is suffering from chronic sleep deprivation, which is debilitating and quickly breaks down his resilience and general well-being. He is exhausted and is often so fatigued that he feels like a 'dysfunctional zombie'. This environment is causing incredible strain for Alex and Margus, and without a clear path forward the situation will only deteriorate.

Photo Source: Amaze

## The next Commonwealth Government must ensure that the NDIS is fully funded and delivering for autistic people:

- A specific NDIS autism and neurodevelopmental participant pathway and training are implemented for all NDIA and partner staff in access and planning.
- Wait times from entering the scheme to finalising a plan are reduced to a maximum of six weeks, with immediate funding supports in the interim. This should happen for all NDIS participants, with a priority on autistic children to automatically receive early intervention support as specified within the NDIS Act (S25). The NDIS to monitor and publically release data on the timeframes for access and plan development/ finalisation.
- Information on the NDIS is specifically tailored to the needs of autistic people and their families/carers are developed and accessible. The development of such resources should occur through co-design with autistic people and the autism sector.
- Clear, transparent and accessible eligibility criteria for autistic people, including a robust and reliable tool for determining their eligibility.
- 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.
- The ILC framework meets the information, linkages and referral needs of autistic people and ensures mainstream services and the broader community are more inclusive of autistic Australians.
- The short term accommodation needs of autistic people, to also support the needs of carers, with adequate information about access to short term accommodation and funding in plans.
- Investment in pre-planning support and peer networks is continued, drawing on successful experiences funded through the Disability Support Organisations (DSO) program.
- That the Autism Advisory Group (AAG) continues to provide expert advice to the Minister responsible for Disability and the NDIA.
- Implement the recommendations from the Joint Standing Committee into the NDIS inquiry into assistive technology (AT).

# A National Autism Strategy to drive change

**Develop a robust, sustainable and measurable 5-year National Autism Strategy, in partnership with autistic people and their families/carers.**

**85% of Australians have personal contact with an autistic person. Despite this, only 29% of Australian feel they have a good understanding of 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.**[19]

Autistic people currently experience poorer social and economic outcomes than any other disability, particularly in education, employment and social isolation.

Across Europe, a number of countries have developed national autism plans and the UK has autism specific legislation – this is currently for adults only, but children will be included in the refresh, which is currently under consultation. The US also has enacted autism-specific legislation.

Analysis by Autism Europe has found that countries that have a national autism plan or strategy appear to bring about a positive impact and change for autistic people, even if they do not necessarily achieve all their objectives towards the full respect of the rights of autistic people.[20]

The Victorian Government Inquiry into Services for People with Autism Spectrum Disorder recommended the development of a National Autism Strategy. Such a strategy would have various benefits, including:

- Increase understanding of autism in the community;
- Create a common set of aims for policy makers, service providers, departments and agencies; and
- Determine targets and expected outcomes against which progress can be reviewed.[21]

The Alliance now calls on the next Federal Government to develop a National Autism Strategy to provide a targeted approach to support autistic people and drive inclusion, support and well-being of all autistic Australians. The National Autism Strategy must be developed in collaboration with autistic people, their, families and carers, and other stakeholders including service providers, researchers, the NDIA and other relevant parties.

The Alliance notes and supports the Productivity Commission's Review of the National Disability Agreement calling for a modern, person-centred disability agreement, with clearly defined roles and responsibilities of all governments and a co-ordinated outcomes framework of meaningful, quantitative measures between the National Disability Agreement, the National Disability Strategy and the National Disability Insurance Scheme.[22]

However the Productivity Commission's report has not acknowledged the specific and unique needs of different disability groups and that a targeted response for particular cohorts, such as autism, is required. Other National Agreements such as the National Housing and Homelessness Agreement, targets different homelessness cohorts.

A National Autism Strategy linked to the National Disability Strategy and National Disability Agreement would address this gap for the autism community.

Finally, to truly embed autism as a bipartisan priority across parties and governments, scoping of a national Autism Act should be prioritised. Drawing on legislation enacted in the United Kingdom and the United States, an Autism Act would require:

- Publication of an updated National Autism Strategy every 5 years;
- Statutory guidance for mainstream and specialist services to implement the National Autism Strategy;
- Monitoring and evaluation of the National Autism Strategy's impacts; and
- Collection, analysis and reporting of autism data, including prevalence, community attitudes and experiences across key social determinants including: health, mental health, education and employment.

A national public education campaign to improve understanding of autism would lead to greater community understanding of autistic people and how best to support them.

There is also a need for research across the lifespan of autistic people. In particular it is noted that there is a lack of research into autistic Aboriginal and Torres Strait Islanders.[23]

To support the need for research and data collection about autism, the Commonwealth should continue to fund the triennial collection of the ABS' Survey of Disability, Carers, and Ageing, including continuing the dedicated analysis of autism in Australia, as recommended by the Productivity Commission.[24]

### The next Commonwealth Government must:

- In collaboration with autistic people, develop and fully fund a 5-year National Autism Strategy, including
  - Clear outcomes and targets, including nationally consistent data collection about autistic people, including data from the NDIS, education, health and justice sectors.
  - Investigate the creation of a National Autism Act.
  - Fund a public education campaign to improve understanding of autism and how to support autistic people.
  - Support research across the lifespan of autistic people and also further research into Aboriginal and Torres Strait Islanders.
- Adopt the recommendations for the Productivity Commission's report Review of the National Disability Agreement.

## Access to assessment and diagnosis

### Ensure all autistic children and adults wait no longer than three months for an autism assessment, post referral.

Autism assessment and diagnostic services should be readily available to all people who require them, irrespective of age, gender, locality, financial status, race or cultural identity.

The earlier a diagnosis of autism can be made, the earlier evidence-based autism-specific early intervention can commence, maximising outcomes for children, adolescents and adults, and increasing the developmental trajectory across their lifetime, with the most conservative cost benefit ratio of 4:1.[25]

Many autistic children can be reliably diagnosed by the age of 24 months, and there is general agreement that children can demonstrate recognisable autism symptoms in their first 12 months. However, research shows that the average age of diagnosis among children (under 7) is between 4 and 6 years of age.[26]

For many autistic people (particularly autistic women), a diagnosis of autism may not occur until adulthood, following many years of anxiety, social difficulties, and challenges entering and maintaining employment. This is largely due to an ongoing lack of knowledge among health professionals of how autism presents in adulthood and their failures to delineate between autism and mental health conditions (such as anxiety or depression) or recognize the co-occurrence of autism with a mental health condition.

For adults seeking an autism assessment cost can be a significant barrier, given there are no Medicare items for adult assessment and diagnosis. Many autistic people will also require cognitive assessments to determine appropriate supports and services across their lifetime, yet there are currently no Medicare items for these assessments.

Barriers to accessing an autism diagnosis have also been found to include:

- A lack of autism understanding by primary healthcare professionals;

> Waiting times for diagnosis ranged from one week through to two years, with longer waits occurring in the public system and in regional, rural and remote Australia;

- Significant costs in accessing an assessment, ranging from $0–$2,750, with median cost being $580; and
- Significant lack of clinicians providing diagnostic assessments in regional, rural and remote areas of Australia.[27]

### The next Commonwealth Government must:

- Review Medicare items to ensure they cover the full costs of autism assessment and diagnosis for children and adults, as well as cognitive assessments for autistic people.
- Fund implementation of the Autism CRC Diagnostic Guidelines including professional development opportunities for existing diagnosticians.
- Monitor waiting time, from referral to autism diagnosis to measure impact of reform.

**Photo Source: I CAN Network's 'Humans on the Autism Spectrum' Campaign**

# Autism-appropriate education

## Ensure that autistic people have the opportunity to optimise their educational attainment.

Educational attainment for autistic students is lower than compared to all students with a disability. Whilst the *National Disability Standards for Education (2005)* states that every autistic student has the right to a quality education on the same basis as students without disability, from early education, school, vocational education and university, countless students are refused enrolment and do not have reasonable adjustments made for their learning needs, leading to poorer levels of educational attainment.

The ABS reports that 34.7% of autistic students only achieve Year 10 or lower, compared with 17.8% of students without a disability. Further, 6.5% of autistic students have a bachelor's or higher degree, compared with 28.7% of students without a disability.

Learning environments can be very challenging for autistic students. This is largely due to the challenges autistic students face with communication, social interaction and their unique learning styles in an environment and system that is, in many ways, not designed with their needs in mind. Often individual needs are not met and individual strengths are not recognised or harnessed for learning.

This is further illustrated by evidence which shows that autistic students are significantly more likely than their non-autistic peers to be suspended or excluded[28], targets of bullying[29], suffer depression and anxiety[30] and under-perform academically relative to their level of intelligence.[31]

In addition to the right to access education, the *National Disability Standards for Education* (2005) enshrines that students with a disability should not be discriminated against in Australian educational settings and that reasonable adjustments must be made to accommodate their needs. This is simply not occurring.

52% of Australians agree/are unsure if schools can refuse to enrol autistic students.

44% of respondents reported having to move secondary schools due to a lack of support. This research also found that only 3% of post-secondary education and 19.4% of schools made adjustments for autistic students to support their sensory needs.[32]

The Urbis *Review of the National Disability Standards for Education* conducted in 2015, found that resolution of formal complaints usually occurs through confidential conciliation and this limits the contribution the complaints process makes to systemic improvement over time through precedent setting and publicity. A more proactive model of compliance monitoring would lead to more consistent implementation of the Standards. This should be explored as part of National Autism Strategy.

The National Autism Strategy should address this by providing a clear path to lift autistic education attainment, supported by research, with targeted programs and training for educators to understand autism, including practical measures to support autistic people to flourish in the classroom.

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.

The new Quality Schools funding model, informed by the *National Consistent Collection of Data of School Students with Disability* is a welcome step towards ensuring funding is better targeted and nationally consistent to meet the needs of all students with disability. The next government must be committed to the ongoing review and strengthening of this model to ensure it meets the needs of all students with disability, including the unique needs of autistic students.[33] This should include appropriate investment in transition support for autistic children each year.

## Case study: Joey

When it came time for Joey to go to school, his parents were keen for him to attend his local primary school along with his two older siblings. At home he loved his puzzles, computer, and reading books about dinosaurs.

Things did not go well from the start. Upon enrolment, the school principal expressed his reservations that the school would be suitable for 'a student with autism like Joey'.

Joey's teacher had taught autistic students previously, but admitted after a few weeks that she didn't know what adjustments she could or should make to cater for Joey's sensory and learning needs.

Joey became increasingly anxious about going to school, and his mother received frequent calls to come to pick him up throughout the school day, because he had had a 'meltdown'.

After an incident where Joey 'ran away' to the far end of the school grounds, an Individual Planning Meeting was called and attended by Joey's parents, teacher, principal and school psychologist. It was decided that Joey should only attend school for 3 hours per day until his behaviour improved.

Joey's mother was not able to maintain her part-time employment under this arrangement, and his parents are very worried that the school does not have a plan for re-transition to increase Joey's time at school. They have made an appointment with the regional education manager and are considering legal action.

### The next Commonwealth Government must:

- Ensure that a National Autism Strategy includes key outcomes and indicators, supported by a clear plan and funding to lift autistic education attainment, including:
    - Support research and data collection to understand why there is disparity in educational attainment for autistic people compared to non-autistic people and people with other disabilities, including practical measures to support it;
    - Commit to incentivise programs and strategies by higher education providers to bridge the gap for autistic people in receiving post-school qualifications;
    - Support the national rollout of education and training of educators on autism and provide practical solutions around how to support their learning;
    - Explore options for appropriate investment in transition support for autistic children each year; and
    - Explore developing a national framework for positive behaviour support in educational settings.
- Explore the feasibility of a nationally consistent monitoring and accreditation model to strengthen proactive compliance with the National Disability Standards for Education that would complement the present complaints-based compliance model.
- Commit to ongoing implementation and evaluation of the Quality Schools funding model, in collaboration with relevant stakeholders, including autistic students and their families, including:
- Support for, and implementation of, the findings of the National School Resourcing Board's review of the loading for students with a disability to be delivered in 2019.

# Increase autistic employment

## The Commonwealth Government must show leadership in the employment of autistic people.

Autistic people bring a range of strengths, interests and skills to the workforce but face barriers finding, maintaining and engaging in employment.

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**In 2015, the Australian Bureau of Statistics found that the unemployment rate for autistic people was 31.6%.[34] This is more than three times the rate for all people with disability and almost six times the rate of people without disability.**

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Illustrating this further, only 2% of NDIS supports for people over 25 years and 5% of supports for people aged 15–24 years were for employment.[36]

Autistic people currently encounter a range of barriers when seeking to enter and remain in the workforce, with the biggest being employer attitudes. It is often assumed that autistic employees will be less capable, or that it will be burdensome or costly to provide any required assistance, modifications or adjustments. These views have been found to be common in surveys of employer attitudes by various disability and industry groups.

Further barriers to employment for autistic people can include:

- Relatively low educational attainment rates;
- Lack of appropriately targeted and skilled disability employment services to support autistic people to find employment;
- Interview processes and the social reciprocities of the workplace;
- Negotiating adjustments that may be required to workplace routines, workloads, access and sensory requirements;
- Discrimination, harassment and bullying; and
- National disability employment programs and support services failing to meet their needs.

The National Autism Strategy should provide a clear path to improve employment outcomes for autistic Australians, including analysis of supports provided to autistic people inside and outside the NDIS. Opportunities to encourage more system level employment of autistic people (rather than individual level subsidies currently provided) should be explored to ensure the private sector is encouraged to employ autistic people.

**Photo Source: I CAN Network's 'Humans on the Autism Spectrum' Campaign**

The Federal Government should lead by example for disability employment, however with only 3.6% of Australian public servants having a disability[36], there is clearly more work to be done, including setting an Australian Public Service target for autistic employment.

The recent announcements of an NDIS Participant Employment Taskforce and the $19.9 million in economic participation grants are a welcome first step but a more outcome-based approach is needed to address the employment outcomes of autistic people.

## Case study: Ben

Ben was diagnosed with autism as a child and his parents have spent his life advocating for inclusion and equal opportunities for him. Whilst in Year 12 at a special disability unit, Ben and his parents started exploring post–school employment options for him.

They encountered very low expectations from others about Ben's capacity and options, and were constantly pushed towards either attending a day options programme or working part-time at an Australian Disability Enterprise (ADE). Ben and his parents didn't want these options for him and knew he had skills and interests that he could use in the workplace with support. His parents also found that there was a lack of autism-specific training or further study options, and that mainstream employment options were not appropriate or suitable for Ben. There was a significant lack of awareness and understanding of autism among many employers, which made open employment opportunities unsuitable for him.

The journey to employment caused significant stress for Ben and his family. While he has now achieved his goal of owning his own gardening business, hours of administration and self-advocacy meetings were needed to convince others that this was a better pathway. Today, funding is still at risk of being reduced, and Ben and his family are left uncertain and stressed about his future.

### The next Commonwealth Government must:

- Ensure that a National Autism Strategy includes key outcomes and indicators to improve autistic employment, including:
  - Analysis of employment outcomes for autistic people who are a participant of the NDIS, in comparison to those outside the scheme;
  - Greater investment in early transitional support for school aged autistic students (12–24 years) to prepare for and enter into the workforce. This includes greater investment in individualised career mapping and planning for autistic students at school age, including students who do not receive funding through NDIS;
  - Explore opportunities to encourage and incentivise more system level employment (instead of individual level incentives such as wage subsidy) of autistic people, such as providing tax incentives for large businesses that prove they meet employment targets for autistic people.
- Commit to an APS autism employment target, including large scale graduate and employment programs specifically targeting autistic people.
- Encourage the NDIS to take an employment-first approach, making 'finding and keeping a job' an NDIS core support for participants approaching workforce age, rather than a capacity building support.

## Support mental health

### Improve understanding of mental health and autism and high rates of suicidality, through upskilling the mental health sector and a comprehensive research agenda.

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.[38] A recent Swedish study found that autistic adults (with no additional learning disability) are over nine times more likely, relative to the general population, to commit suicide.[39]

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The current estimate is that 50–70% of autistic people have a mental health condition.[37]

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It is important to note that many autistic people experiencing mental health conditions may not actually know or feel confident knowing whether they are experiencing a mental health condition.[40] As such, the prevalence may be higher. Autistic women and girls in particular are often misdiagnosed, or solely diagnosed with conditions such as learning disabilities, anxiety and/or eating disorders (with some undergoing unnecessary interventions and/or taking unnecessary medications).[41]

Australian research has found that autistic people and their families suffer from social isolation, with:

- 51.6% agreeing that they feel socially isolated;

**Photo Source: I CAN Network's 'Humans on the Autism Spectrum' Campaign**

- 40.6% agreeing that they have lost friends because of the way those friends have responded to their or their family member's autism; and
- 39.3% agree that they sometimes feel unable to leave the house because they are worried about people behaving negatively towards them because of their or their family member's autism.[42]

Autistic people face significant barriers when seeking support for their mental health.

These barriers can include a lack of autism recognition and understanding by mental health practitioners. It can also include a lack of coordination and collaboration between mental health, mainstream health, disability services and other sectors, including education, employment, justice and housing. No coordinated approach exists to ensure professionals across these sectors can access the level of autism knowledge and skills required to diagnose, meaningfully treat or facilitate the treatment of mental health conditions in autistic people.

As a result, mental health services are not taking responsibility for the mental health needs of autistic people, with many mental health practitioners often assessing an autistic person's mental health concerns as simply part of their autism, and redirecting the person to disability services. This leads to mental health conditions often not being diagnosed or adequately treated, resulting in poor health, an increased risk of suicide, and other poor educational, social and employment outcomes.

A lack of autism understanding among mental health practitioners can also de-value neurodiversity. A patient's positive self-identity as an autistic person must be recognised by mental health and healthcare professionals as this may influence the types of mental health interventions and treatments preferred by the patient. Acknowledgement of individual preferences and self-identify are key to developing positive therapeutic relationships.

### The next Commonwealth Government must:

- Coordinate Australian Governments to engage with autistic people and the autism community to build understanding of mental health and autism, current barriers to diagnosis and support and how healthcare services may better tailor their supports to autistic people. This understanding should then be filtered into:
  - The Sixth National Mental Health Plan and implementation Plan (due in 2023);
  - Opportunities for research funding under the National Health and Medical Research Council; and
  - Funding agreements for mental health service providers.
- Fund a Mental Health and Autism Summit – hosted by the Alliance in partnership with mental health peak organisations – to bring together mental health and autism researchers, practitioners and consumer representatives to identify research priorities, capacity building requirements and service collaboration.

## Improve healthcare for autistic people

### The Commonwealth Government must develop a strategy to improve the health outcomes of autistic people.

There are many factors that could have implications for poorer health outcomes. Autistic people often have a co-occurring condition – for example, approximately 20% of autistic people have co-occurring epilepsy.[44] However, autistic people are not consistently given the health care from professionals that meets their needs, which may compound these poorer health outcomes.

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International studies have found that autistic people have a life expectancy between 20 and 36 years shorter than the general population.[43]

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The Autism Inquiry found that accessing mainstream health services (such as hospital emergency departments, dental services, and mental health facilities) had various challenges for autistic people due to the sensory sensitivities, communication difficulties, a lack of collaboration between services, and a lack of autism competency on how to best support autistic people among health professionals.

This is particularly critical in hospital emergency departments, where autistic children and teenagers are 10 times more likely to be admitted to hospital for medical illnesses and complaints.[45]

A UK study found that almost 40% of General Practitioner participants reported never having received formal training in autism. Despite demonstrating good knowledge of its key features, GPs reported limited confidence in their abilities to identify and manage the health issues of autistic patients.[46] This finding correlates with a US study found that autistic participants experienced significant healthcare disparities in comparison with general sample, including higher unmet needs and lower satisfaction.[47]

There is also evidence that autistic people need greater support with reproductive healthcare, including sex education and support during pregnancy.[48]

A National Autism Strategy must improve health outcomes for autistic people, with a focus on building the autism competency of healthcare professionals. As a pivotal first step, this should also include a review into international best practice in how to best support autistic people within the mainstream health system, so that Australia can implement best practice within health policy and procedures. This should also explore the feasibility of addressing autistic people's sensory needs, through quiet rooms in emergency departments and other inpatient and outpatient areas, as recommended by the autism inquiry.[49]

### The next Commonwealth Government must ensure that a National Autism Strategy includes key outcomes and indicators to improve autistic health outcomes, including:

- Improving the autism competency of healthcare professionals, with a particular focus on GPs and emergency staff;
- A review of international best practice in how to best support autistic people within mainstream health services, including reproductive health care; and
- Testing the feasibility of quiet rooms in emergency departments and other inpatient and outpatient areas.

## Create autism friendly places

### Make public places, housing and major events 'autism friendly'.

Autistic people face a range of barriers to participation in community life due to a lack of autism friendly environments (including across schools, workplaces and public places).

For autistic people, access issues can relate to:

- Structure or physical features of the built environment: including lighting, acoustics, smells, colours, spatial features, flooring and other design elements. They may also include the way information is conveyed, for example a lack of non-verbal communication or signs.[50]
- Cognitive and/or social differences: including a need for routine/predictability and sensory processing difficulties, such as delayed or single channel processing (i.e. may not be able to process all sensory input, such as hearing, seeing and feeling where their body is in space, simultaneously).[51]
- 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.[52]

Each autistic person will experience these issues differently. Some people with hypersensitivity may experience mild to moderate anxiety and distress, while others will experience a high level of sensory overload and anxiety.

Australian research found that 67.8% of autistic people avoid community spaces due to the level of light or noise.

This research also found that only 9.4% of employers, 3% of post-secondary education and 19.4% of schools made adjustments for autistic people to support their sensory needs.[53]

Designing environments to be autism friendly can not only reduce anxiety and increase participation and independence of autistic people, it can also be cost-saving and benefit the wider community.

While some innovative organisations across Australia have taken steps to create autism friendly environments, autistic people continue to face significant environmental barriers when seeking to access public places and events. It is well-known that social isolation can lead to poor mental health, education, social and economic outcomes.[54] A comprehensive and government-led approach to building and promoting autism friendly environments, ideally through the National Construction Code, is urgently needed across Australia.

### The next Commonwealth Government must:

- Support the inclusion for a minimum accessibility standard applied through the National Construction Code. As part of this consider how it can consider the needs of autistic people.
  - Consideration to whether Liveable Housing Design Guidelines could better meet the needs of autistic people.
- Support development of a social enterprise for autistic people to consult on how to develop autism friendly spaces.
- Provide funding and/or grants potentially through ILC grants for business and community organisations to develop social scripts and sensory maps, and/or modify their environment to support venue/event access.

## Respond to the specific needs of autistic women and girls

### Improve screening and diagnosis for women and girls so that they are diagnosed as early as possible, and cater for their needs through specifically designed services and supports.

There is an ongoing systemic failure to identify and diagnose autistic girls and women, due to a lack of recognition and understanding across sectors of the differences in how autism presents in girls and women compared to boys and men, as well as historic gender biases in autism screening and diagnostic tools.

Commonly used autism screening and diagnostic tools – such as the Autism Diagnostic Observation Schedule [ADOS] and the Autism Diagnostic Interview-Revised [ADI-R] – 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.[55]

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

Girls are, on average, being diagnosed later than boys – often requiring numerous assessments – and are often not diagnosed until adolescence or adulthood, meaning they miss out on critical early intervention to enable them to participate socially and economically to their full potential.

Many autistic women and girls are not receiving funding or appropriately tailored supports or services. Many intervention programs/approaches are designed with the stereotypically male characteristics of autism in mind. Also, employers often don't recognise the strengths of autistic women or know how to support their needs.

> The prevalence of mental health conditions, such as anxiety and depressive disorders, are higher among autistic girls and women than autistic boys and men.

As a result of these factors, autistic women and girls are at increased risk of social isolation, abuse and discrimination.

In addition, there is emerging evidence that autistic people are represented in greater numbers in asexual and transgender communities, compared with the general population.[56] The needs of this cohort need to be better understood and met.

## The next Commonwealth Government must:

- Fund research into screening and diagnostic tools to better identify autism in girls and women.
- Ensure the NDIA takes comprehensive steps to ensure that autistic girls and women are supported throughout the NDIS planning process, and can access cost-effective supports and services.
- Ensure the NDIA has specific grant funding rounds dedicated to women with disability for: comprehensive mentoring, peer support, advocacy and social opportunities for autistic girls and their families.

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

**The Alliance supports the broader disability sector in calling for a Royal Commission into violence, abuse and neglect to support the work of the NDIS Quality and Safeguard Commission for its national roll out by 1 July 2020.**

### In recent years there have been two key inquiries into the abuse and neglect of people with a disability:

- In 2015, the Federal Senate Community Affairs References Committee inquiry into *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*
- In 2016, the Victorian Family and Community *Development Committee Inquiry into Abuse in Disability Services.*

Both recommended a Royal Commission into violence, abuse and neglect of people with disability.

The Federal Senate Committee noted that the *'nature of disability (requiring communications or transport support to present evidence) combined with the closed nature of institutions, means that the most vulnerable people and those most likely to have been abused, may not have been able to contact the inquiry'.* Based on this it concluded that *'only a Royal Commission with investigative powers, funded and empowered to visit institutions, could properly conduct an inquiry, and give full weight to the seriousness of this issue.'*

Further evidence for a Royal Commission is demonstrated by media reporting that the NDIS Quality and Safeguards Commission (NSW and South Australia) revealed in January 2019 that it had received 29 reports of sexual assault against NDIS participants, and 184 reports overall of abuse or neglect in three months.[57]

The Alliance considers that a Royal Commission should have terms of reference that are broader than the disability services sector, and include education, health and justice sectors to ensure that the Royal Commission is comprehensive. This is recommended because abuse and neglect of people with a disability occurs in various mainstream settings and can be operating at a system-level. This is supported by the recent Victorian Ombudsman report titled *Investigation into the imprisonment of a woman found unfit to stand trial.*[58]

> This report highlighted the case of 'Rebecca', an autistic woman, who was imprisoned for 18 months simply because there was nowhere else for her to go, despite being found unfit to stand trial.

The Royal Commission would support the continual work of the NDIS Quality and Safeguards Commission for its full national rollout by 1 July 2020. The Alliance supports work already undertaken by the Commission, including development of the National Disability Insurance Scheme (Restrictive Practice and Behaviour Support) Rules 2018, which detail how the Quality and Safeguarding Commission will regulate and monitor the use of restrictive practices in the disability sector. However, the Alliance recognises that more work can be done, particularly to develop a national approach to work towards eliminating restrictive practices across all service systems and sectors.

## The next Commonwealth government must establish a Royal Commission into abuse and neglect of people with a disability, that:

- Is broader than the disability services sector and includes education, health and justice sectors;
- Recommends a nationally consistent framework that works towards eliminating restrictive practices across all service systems and sectors, is facilitated by the Council of Australian Governments, draws on evidence informed strategies and includes consistent definitions of key terms, such as for seclusion and physical restraint; and
- Assesses whether the recommendations of prior inquiries have been implemented and a governance structure to ensure Commonwealth and state and territory governments implement the recommendations.

**Photo Source: I CAN Network's 'Humans on the Autism Spectrum' Campaign**

# High-impact, sustainable disability advocacy

**Reform disability advocacy to be more inclusive of autistic people and develop clear roles and responsibilities across all levels of government, including consistent, ongoing funding arrangements that ensure demand is met.**

**Advocacy services support people with disability to exercise their rights and freedoms through: the provision of individual advocacy support; supporting people to advocate for themselves; and/or influencing long-term, systemic changes to ensure rights and freedoms are attained and upheld.**

Disability advocacy also provides broader economic benefits, with the Disability Advocacy Network Australia (DANA) reporting that every dollar used by Australia's independent disability advocacy agencies delivers $3.50 in benefits.[59]

Commonwealth and state governments both provide separate funding to disability advocacy agencies across Australia. 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.

There are a number of key issues facing disability advocacy, including a lack of funding growth[60], extra demand for services created largely by the NDIS[61], inconsistency in implementation of Commonwealth and state disability advocacy funding[62], 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.[63]

In particular, the NDIS has created extra demand for services. Data from the Disability Advocacy Resource Unit (DARU) from 2012–2016 found that the number of reports for disability services and the NDIS increased by 70% in 2014–15 and 2015–16. The timing of this increase is in line with the introduction of the NDIS.[64] It is assumed that this trend would continue following further rollout of the NDIS. The NDIS has also passed significant burden to vulnerable families to not only navigate the NDIS, but also supports and service systems, with a constant need to distinguish between evidence-based supports and qualified providers and non-evidence-based supports/supports provided by untrained providers.

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

In 2003, the National Autistic Society (UK) surveyed 55 general, learning disability and mental health advocacy organisations, finding that 32% of these services will not provide services to people who reveal that they have an autism diagnosis. Of the other 68%, most expressed that they have significant difficulty working with autistic people, and had little confidence in their ability to advocate effectively in this population. Much of the concern expressed was around their understanding of autism or concerns about advocating for people with communication difficulties.[65] Although that study is now more than 15 years old, these findings align with recent commonly reported experiences of autistic people in Australia.

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This evidence demonstrates the need for disability advocacy organisations to build their autism competency to be able to provide high quality advocacy services for autistic people.

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**Photo Source: I CAN Network's 'Humans on the Autism Spectrum' Campaign**

## Case study: Fabian

Fabian* was diagnosed with Autism Spectrum Disorder as a child and is now 21. Due to family breakdown, Fabian is living in a supported residential facility (boarding house). Fabian has also been experiencing mental ill health due to a range of biological and environmental factors.

Fabian began presenting at emergency departments as he felt he was in an ongoing crisis. Professionals noted that he had some significant adjustment issues and subsequently diagnosed him with Borderline Personality Disorder.

Though somewhat estranged from Fabian, his mother arranged an individual advocate to work with him – to which Fabian consented. The advocate worked with Fabian, autism professionals and the acute mental health services to help the service better understand autism and developmental issues as a better explanation of his behaviour than the diagnosis of Borderline Personality Disorder. The advocate also worked with the state housing provider and homelessness services to find Fabian better accommodation. With Fabian, a plan was developed that addressed his presentations at emergency departments and the individual advocate pressed for services to support Fabian in his new home, where he would feel safer with support workers checking on him daily.

Without the involvement of the individual advocate the very real crisis that Fabian was facing would have escalated. Advocacy meant that Fabian had better support, new housing and a safer way to manage his feelings.

## The next Commonwealth government must:

- Fund autism specific advocacy services and support their capacity and capability building activities.
- Implement the Productivity Commission inquiry’s recommendation (10.4) from the NDIS Costs report (2017) to:
  - Collect data on disability advocacy and its outcomes, linked to data held by the NDIA; and
  - Undertake an independent evaluation of disability advocacy at the beginning of 2020 to inform future funding arrangements. As part of the evaluation it should consider:
    - Developing a nationally consistent approach to disability advocacy, outlining clear roles and responsibilities for Commonwealth and state and territory governments, including an ongoing and consistent funding model;
    - Ensuring funding meets the demand for disability advocacy, specifically due to the increased demand driven by the NDIS; and
    - Providing consistent funding under different advocacy models, including training to support disability advocacy organisations to build their autism capacity in leadership and governance.

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