

# A Brief Submission to the Select Committee on Work and Care

The Australian Autism Alliance is focussed on autistic people and has strong interests in matters that affect their carers and other associates. Following is a brief and rapidly prepared submission to your inquiry.

Demographic changes relating to autism are the massive increase in numbers of people being diagnosed with autism spectrum disorder. In 1994, reports indicated that 4-10 children per 10,000 were autistic. In 2022, over 3% of school-age children are autistic NDIS participants. The rate varies between states: the rate in 6.2% in Victoria and 5% in South Australia.

Following is data prepared recently for the Commonwealth Health Department.

Age (years)	NDIS – autism			rates	
	0 to 6	7 to 14	15 to 18	0 to 6	7 to 14
<b>ACT</b>	248	1,325	398	0.63%	2.97%
<b>NSW</b>	7,124	23,869	6,100	1.03%	2.90%
<b>NT</b>	148	568	102	0.61%	2.03%
<b>QLD</b>	4,257	17,125	4,267	0.96%	3.05%
<b>SA</b>	1,795	8,622	2,406	1.29%	5.01%
<b>TAS</b>	431	1,513	469	1.04%	2.87%
<b>VIC</b>	5,197	21,159	4,707	0.93%	6.23%
<b>WA</b>	1,587	6,782	2,301	0.66%	2.41%
<b>Australia</b>	20,788	80,972	20,752	0.95%	3.09%

Other data sources, such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) [section on autism](#), indicate that there are more autistic Australians than this; not all autistic Australians are NDIS participants. We await the next ABS SDAC, due next year, to see how many autistic Australians there are now, and their outcomes in education, employment, etc. Hopefully, autistic Australians who are ineligible for the NDIS require less care and support, function more independently, than NDIS participants though there is doubt that their needs are met through other specialised disability supports and / or mainstream services. We await more complete investment and development of capacity building for autism readiness across disability and mainstream service sectors.

The reason for this 30+ times increase in the number of autistic children over three decades is not clear. While some people say that the increase is due to broader diagnostic criteria, this is simply untrue: changes to the diagnostic criteria for autism spectrum disorder (and the previous labels), when tested, show little impact on who met the criteria. Some of the increase is due to greater awareness resulting in more autistic people being assessed and then being diagnosed autistic.

In the past, there were more than 4 times as many autistic males compared to females. The ratio is changing – the [NDIS Quarterly Report 2021-22 Q4](#) p163 says the male to female ratio for NDIS participants is now 2.7:1.

Our organisation still gets occasional reports of health professionals advising parents “put your autistic child in an institution and get on with your life”, even though this is no longer an option (and not one that many parents would contemplate).

### **Caring for an autistic child places a substantial (and poorly understood) burden on a family.**

The burdens include

- Financial burdens
  - Increased care costs
  - Decreased earning potential
- Breakdown of family structures (high proportion of single parent families)
- Significant increase in parent and carer need to build knowledge, skills, and confidence in very proactively advocating for their child at each and every stage of their child’s journey. This is necessary because of the significant gaps in the autism understanding across all mainstream services. For example – a child will experience lower outcome if they do not have a parent capable of active – and often daily interaction with their schools, childcare, medical services, etc.
- Life-long change in choice and control and life outcomes for parents and carers
  - Decreased work opportunities for parent/s
  - Reduced recreation / holiday choices
  - Constrained choices for home location.
  - Community and social interactions

Mothers are frequently required to leave their work to collect their child from school when the child is suspended or expelled for reacting to being bullied. [Autistic children are much more likely to be bullied](#); and when they are they are often blamed and mistreated for their consequent behaviour. This can lead to school refusal and/or home-schooling. And the mother is unable to work.

Even if the mother can continue working, the imposition on her career is substantial. She works reduced hours, is considered less reliable, and has fewer opportunities and promotions. Callander & Lindsay’s (2018) abstract<sup>1</sup>, an Australian research paper, says:

Parental employment is a significant factor in ensuring financial ability to access care for children with autism spectrum disorder. This article aimed to identify the influence of autism spectrum disorder on parental employment and whether childcare access may effect labour force participation using the *Longitudinal Survey of Australian Children*, with 12 years of follow-up data (2004–2015). Parental employment when the child was aged between 0 and 11 years was assessed. A significantly larger percentage of parents whose children had autism spectrum disorder were *not* in the labour force when their child was aged between 2–3 and 10–11 years. However, between the ages of 2 and 5 years, these differences were not significant after accounting for maternal and paternal age, education attainment, marital status and mother labour force status prior to birth. Childcare access did not moderate the

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<sup>1</sup> Callander EJ, Lindsay DB. *The impact of childhood autism spectrum disorder on parent’s labour force participation: Can parents be expected to be able to re-join the labour force?* Autism. 2018;22(5):542-548. doi:[10.1177/1362361316688331](https://doi.org/10.1177/1362361316688331)

relationship between autism spectrum disorder and maternal labour force participation. Once children were of schooling age, mothers of children with autism spectrum disorder had up to two times the odds of being not in the labour force compared to other mothers, after adjusting for confounders. Evaluations of new interventions for children with autism spectrum disorder should consider how the proposed service impacts on the labour force participation of parents of children with autism spectrum disorder, particularly when the children are of schooling age.

The **financial impact** on the family of an autistic child was estimated in 2014 to be \$34,900 per year on average (see <https://a4.org.au/node/881>). Compared to average household income, the financial impact is enormous.

"The majority of that cost, 90 per cent of it ... is because of the lack of the chance to have employment because parents have to stay home and take care of the children with autism, because they don't get the support they need,"

A financial impact brings increased stress and anxiety that is detrimental to health, mental health and wellbeing. Parents of autistic children are often autistic or have significant autistic traits themselves which leads to both intrinsic and extrinsic barriers to economic participation.

The increased number of school-age autistic children is not matched by increased services to meet their needs. There are few discernible efforts at state/territory to recognise and develop the required services and workforce. Parents/carers are expected to dump autistic children in mainstream schools and out-of-school care, settings that lacked skilled staff or adequate resources.

So, families – typically mothers – are required to provide the support safety net for their autistic child. Many parents of autistic children must work reduced hours because they need to provide care for their autistic child. Or they are often required to collect their child early from school, or from childcare, because the settings cannot support the child when the child is distressed.

Employment outcomes for autistic people are abysmal. Autistic people are less likely to be employed than people with disability generally, and the general employment rate for Australians with disability is unacceptable. A survey conducted by the Autistic Self Advocacy Network AUNZ shows that employment support is the second highest priority for autistic people and autistic parents of autistic children.

Autistic adults are likely to live with their parents. Parents remain primary carers typically because reasonably they have little confidence in accommodation supports for autistic adults. Parents of autistic adults contribute substantially to the [estimated and largely unrecognised \\$77.9 billion \(in 2020\) worth of care from Informal Carers](#).

Modelling<sup>2</sup> suggests ...

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

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<sup>2</sup> Deborah Schofield, D., Zeppel M.J.B., et. al. (2019) *Intellectual disability and autism: socioeconomic impacts of informal caring, projected to 2030*, BJP 215, 654–660. doi: 10.1192/bjp.2019.204.

Basically, many parents of autistic children often have a substantial and ongoing caring role for their adult off-spring, a load that is carried disproportionately by a small minority of people in the community. Where multiple generations within a family are autistic, care needs increase; households include and support multiple generations of autistic people, some with high support needs.

People in regional and remote settings report limited access to disability services and supports. Consequently, families and carers carry an increased burden of support for people in their care. Inevitably, the caring burden impacts adversely on work and employment.

Too often, carers who advocate for a person in their care are seen as problematic, troublemakers. This is evident in the especially adverse treatment that the NDIS has for Informal Carers in AAT matters.

The COVID-19 pandemic impacted substantially on families of autistic people. Many autistic people simply do not understand COVID-19 and how it disrupts the daily routines that most of them depend on for their quality of life. Many autistic people are extremely distressed when their daily excursions are denied, when their routines and services are changed or unavailable.

While we don't have concrete data, the autism community is deeply concerned that:

- Australia's economic system, where profits explode, wages stagnate and people with disability are typically unemployed, is especially detrimental for autistic people, their carers, and their supports.
- Supports like Jobkeeper were substantially less effective for (accessible to, or inclusive of) people caring for autistic children.
- Multiple generations of autistic people are affected by lack of employment opportunities, employment supports, and quality care and support, to enable economic participation for both autistic carers and their adult offspring leading to further entrenchment of inequality.

Many people experience discrimination based on their association with a person with disability, but there are very few successful prosecutions. The protection intended by sections 7 and 8 of the *Disability Discrimination Act 1992* are imaginary.

As we understand it, workplace law protects workers and visitors in disability service workplaces, but protection for people with disability in such settings is unclear or absent.

Some responsibilities fall unfairly on carers. While Mark's (not his real name) Informal Support was at work, NDIS-funded support workers took Mark, an adult with severe cognitive disability, to a shopping centre. Mark got upset and as they were leaving, he damaged the car of a member of the public with his hand. The bill for repairs was given to Mark's Informal Support who was not present and had nothing at all to do with the "incident". The incident would not have happened had Mark been with his Informal Support, but they still end up being held responsible. That is completely unreasonable.

We thank you for your interest in these issues and look forward to the outcome of this inquiry.

**Addendum:** this story may be of interest - <https://www.sbs.com.au/news/insight/article/i-flew-first-class-every-weekend-now-i-survive-through-government-support/7m9jlb1b>