Australian Autism Alliance

A Brief Submission to the Select Committee on Work and Care

8 September 2022

The Australian Autism Alliance (Alliance) is focussed on autistic people and their families and has strong interests in matters that affect their carers and other associates. Following is a brief submission to your inquiry due to time pressures.

There is a high prevalence of autism in Australia:

In relation to demographics, there are massive increases 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 is 6.2% in Victoria and 5% in South Australia.

Following is data prepared recently for the Commonwealth Health Department.

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

Notwithstanding the above, the reason for this significant increase in the number of autistic children over three decades is not clear. While the increase has been indicated to be 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, it has been reported that 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 in 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 with societal attitudes and understanding maturing).

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

These burdens include:

1. Financial burdens
    - Increased care costs
    - Decreased earning potential
2. Breakdown of family structures (high proportion of single parent families)
3. 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, child care, medical services, etc etc.
4. 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

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. Additional complexity is also experienced if a parent or parents are autistic or have other impairments leading to both intrinsic and extrinsic barriers to economic participation.

Modelling[1] 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.

For context:

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[2], 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.

---

[1] 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.

[2] 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

> Childcare access did not moderate the 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 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 put 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.

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

In a national survey with over 3000 respondents that the Australian Autism Alliance commissioned in 2020 undertaken by the ACU Engagement (ACU 2020 Survey) more than half of autistic adults and parents/carers agreed or strongly agreed that:

- they feel socially isolated (67.5% and 73.4%, respectively);
- have lost friends because of the way those friends have responded to their/the person they care for’s autism (61.2% and 63.4%, respectively);
- are criticised for their management of their daily organisation and planning due to their/their family member’s autism (64.9% and 57.8%, respectively);
- feel sometimes unable to leave the house because they are worried about people behaving negatively towards them because of their/the person they care for’s autism (47.5% and 60.1%).

In the same survey more than one-third of autistic adults (42.1%) and about a third of parents/carers (31.5%) have lost their job due to their or the person they care for’s autism. Similar proportions have members of their family who they no longer speak to because of the way they have responded to their/the person they care for’s autism(37.4% and 39.6%, respectively).

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 people aspire to work. Of the ACU 2020 Survey respondents who are not in paid employment, well over half indicated they would like to be employed.

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

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.

In the ACU 2020 Survey approximately half of the autistic adults who completed the survey reported owning (27.9%) or renting (26.4%) their home; with 17.5% living with parents/guardians. The majority of parents/carers responding on behalf of an autistic person aged 18 or over reported that this person was living at home with parents/guardians (72.1%).

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. Additionally, where multiple generations within a family are autistic, complexity of care increases and households may include and sustain autistic parents and their adult offspring 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 Administrative Appeals Tribunal (AAT) matters. However, carers must become very strong advocates for their child's needs to be met at school, in community and in healthcare setting. It is a full-time job with an enormous mental load for carers to carry. There is significant concern in addition how parents with limited resources, lower levels of education or from culturally or linguistically diverse backgrounds cope with advocating for their child.

In the ACU 2020 Survey, we asked about people's confidence and understanding in engaging in self-advocacy activities. The insights were illuminating.

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

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 do not 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.

In the ACU 2020 Survey 41.4% of autistic adults experienced discrimination or stigma. "Autistic children and their parents are often ostracised by society, even by people we know well." The broader community has little understanding of autism Although there is widespread awareness of autism, there is a low level of understanding and very low knowledge and confidence about how to be supportive.

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.

Contact:
Jenny Karavolos (she/her)
Co-chair, Australian Autism Alliance

Addendum: Story that may be of interest - https://www.sbs.com.au/news/insight/article/i-flew-first-class-every-weekend-now-i-survive-through-government-support/7m9jlbb1b

About the Australian Autism Alliance

www.australianautismalliance.org.au

The Australian Autism Alliance aims to provide ‘One Strong Voice for Autism’. The Alliance was established in 2016 and aims to improve the life chances of autistic people and facilitate collaboration within the autism community. Operating as a cohesive network of organisations with a diverse focus on autism, we have a national reach that brings together key autism organisations representing and led by autistic people, advocacy groups, peak bodies, service providers, and researchers. We reach over half a million people through our communication channels and provide support to people with autism across the lifespan. Most importantly, our work is informed by autistic people and their families and carers.

Supporter