LA TROBE UNIVERSITY

La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Select Committee on Autism

July 2020

Inquiry into the services, support and life outcomes for autistic people in Australia

ENQUIRIES
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INTRODUCTION

La Trobe University welcomes the opportunity to provide a submission to the Select Committee on Autism. The first dedicated autism research centre in Australia – the Olga Tennison Autism Research Centre (OTARC), established in 2008 – is housed within La Trobe University. La Trobe University is an essential participant in the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), established in 2013. The OTARC Director was part of the original bid team for the Autism CRC, with three of our staff leading projects in the CRC.

OTARC's research aims to:

- Facilitate positive developmental outcomes in the lives of autistic people, from early childhood to adulthood.
- Enable autistic people to realise their full potential, participate in the community, education and employment, to enjoy life and to actively and meaningfully contribute, throughout their life.
- Support families in the care and support for their autistic children.

The focus of this submission is to provide evidence-based, community-driven recommendations[1] that will contribute to achieving these aims. In making these recommendations we will be drawing on evidence from our research in the following areas:

- **Development of effective and valid strategies and tools to facilitate identification and diagnosis of autism in children under 3 years.**
  Studies in this area led to the development of an early identification tool, the establishment of an Early Assessment Clinic, an app for parents and a 2019 DHHS project training 1500 Victorian Maternal and Child Health nurses in the early signs of autism.
- **Evaluation of early intervention strategies.** Studies in this program are investigating the long-term outcomes of autistic children diagnosed early, of children integrated in mainstream settings, and the support their families provide and need. These studies led to the joint establishment of the Victorian Autism Specific Early Learning and Care Centre (now The Margot Prior Autism Intervention Centre, AIC) associated with the La Trobe Community Children's Centre.
- **Vocational Pathways Research & Development Program.** In this program we are investigating supports required by autistic youth and adults for transitioning to and succeeding in tertiary education and/or employment. Much of the evidence presented in this part of the submission comes from four studies, 1. The DHS Victoria study surveying autistic youths, their families and service providers (2014), 2. The SASLA study (Study of Australian School Leavers with Autism, 2014-2020), 3. ALSAA study (Study of Australian Autism in Adulthood, ongoing), and the DXC Dandelion study (employment support for autistic adults, 2016-current) [2].
- **The effect of co-occurring conditions on autistic individuals.** These studies seek to understand the conditions that frequently accompany autism and the support needs of autistic individuals who are affected by them. The aim is to educate practitioners in the specialised treatment of these individuals and to establish a specialist treatment clinic. Relevant evidence also comes from the SASLA study. This research area recently piloted an insomnia intervention for autistic adults.

[1] In making this submission to the Committee we consulted with the autism community in a 2020 survey of the community of our Study of Australian School Leavers with Autism (SASLA). The SASLA community is comprised of autistic individuals aged 17–27, their parents/carers, members of autism specific organisations and individuals who work with autistic people. Twenty-two community members responded, and selected quotes are published herein with their permission.

[2] SASLA and ALSAA studies are funded by the Autism CRC. The SASLA study included autistic and non-autistic respondents aged 17–27 and their parents/carers. The ALSAA study included autistic and non-autistic adults 25 years and older and their families/carers. The DXC Dandelion project was funded by DXC Technology.

Please note that we use a mixture of identity-first (e.g., 'autistic person') and person-first (e.g., 'person with autism') language, to reflect the diversity of preferences in the autism community.

The terms of reference addressed in this submission are: a, b, c, e, g, h (iv), j and n.

SUMMARY OF RECOMMENDATIONS

1. Development of a national autism plan in consultation with autistic individuals, families, autism organisations, service providers and researchers.
2. Provision of funding for Early Assessment Clinics in each state and territory in Australia, including a lead clinic at La Trobe University's Olga Tennison Autism Research Centre (Budgeted at approx. $1.25 million per year over 4 years for Victoria).
3. Training of all Maternal and Child Health Nurses (or equivalent) in each state and territory in Australia to identify the early signs of autism.
4. Co-funding by Government and industry to continue development of online tools for the early identification, assessment and diagnosis of autism to facilitate access for underserved regional, rural, and remote communities.
5. Funding for the development and implementation of autism training for healthcare providers working with older children, adolescents and adults.
6. Conduct a comprehensive epidemiological study into ASD prevalence in Australia in order to ascertain diagnostic and service needs for autistic people throughout their lifespan.
7. Thorough training of primary, educational, medical, and allied health staff on the early presentation of the male and female autistic phenotype to reduce the age of diagnosis, particularly in girls.
8. Equip services and develop supports to successfully transition for autistic people from school into further education and employment.
9. Provide support for parents/carers of autistic youth transitioning from high school into further study and employment.
10. Equip Disability Employment Service (DES) and train their staff to work confidently with autistic job seekers. This must be based on the experiences of autistic clients with accessibility, barriers and what works or does not work for employment placements.
11. Develop and adopt best practice guideline for clinicians in the identification and treatment of co-occurring conditions in autistic people.
12. Educate mental and physical healthcare and service providers about the unique clinical presentation of co-occurring conditions in autism and train them on the appropriate use of validated tools to identify and treat these conditions.
13. Develop and implement evidence-based therapies designed for autistic individuals living with co-occurring conditions such anxiety, depression, suicidal ideation and sleep difficulties.
14. Implement changes in service settings to accommodate autistic clients including longer consultation times and reduced wait times (expedited triage of care), reduced sensory stimulation in waiting and testing rooms.
15. Training clinicians to support mental health and promote well-being in autistic clients.

16. The creation of an Australian training package to increase knowledge and awareness of autism in the workplace, including reasonable workplace adjustments and supporting individual differences.

17. A review of Disability Employment Service (DES) to assess knowledge and awareness of autism and practices in providing appropriate support.

18. A national industrial relations guideline to guarantee equitable accessibility of recruitment practices for autistic people.

19. Direct access to the NDIS for toddlers and pre-schoolers with early signs of autism, so that their needs are met directly rather than their having to enter into the ECEI pathway.

20. Adequate training on autism for NDIA staff across all developmental periods so that they are able to be efficacious in their role as planners.

21. The provision of guidelines for individuals/carers in the pre-planning stage of applying for NDIS funding. This must contain detailed explanations and examples of what supports are available and how to best plan an application that addresses the individual and their family's needs to support an autistic person's vision for their life.

22. The introduction of an NDIS quality assurance program that regularly assesses providers ability to fulfil their contractual obligations to their customers in terms of cost benefit and the life goals set by the autistic individual and/or their carer.

23. Establish a dedicated research funding pool for both applied and basic research on autism through the life course.

24. Develop and implement guidelines to increase social inclusion and participation for autistic people from childhood onwards in education, employment and within the wider community.

25. Provision of specialised, accessible and evidence-based mental health care supports for parents and carers supporting autistic people.

RESPONSE TO THE TERMS OF REFERENCE

a) Current approaches and barriers to consistent, timely and best practice autism diagnosis

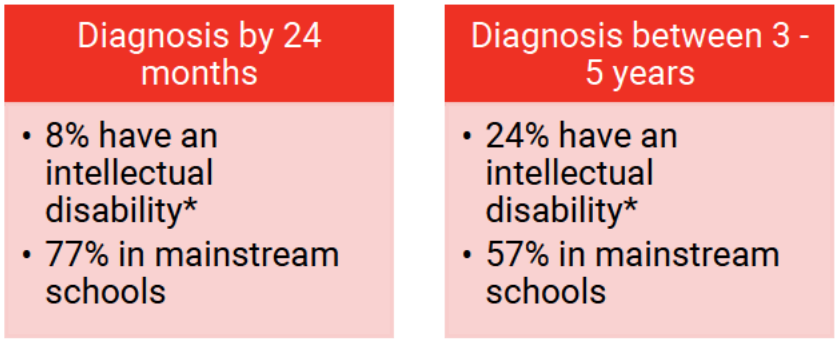


Figure 1 – Effects of early diagnosis **(IQ < 70) at school age*

OTARC studies have found that Australian children who are diagnosed with autism before they turn 2 years are 3 times less likely to receive a secondary diagnosis of intellectual disability and 1.3 times more likely to be in a mainstream school than autistic children diagnosed later (Figure 1). Being diagnosed early also reduces ongoing support required at school age by 30%[3]. Australian children who receive an autism diagnosis and subsequent focussed intervention in the early and critical years (18-36 months) have better school age developmental outcomes. And yet, the average age of autism diagnosis in children remains at about 3-4 years[4].

In the absence of biological markers for autism, diagnosis is based on behavioural observations. Identifying and assessing the early behavioural signs of autism in infancy and toddlerhood is therefore critical to earlier diagnosis and intervention. In June 2017, the Family and Community Development Committee of the Victorian Parliament tabled its Final Report[5] on the Parliamentary Inquiry into Services for People with Autism Spectrum Disorder (ASD). OTARC's Chair and Director, Professor Cheryl Dissanayake, was one of 89 witnesses who reported on the identified barriers to diagnosis, including:

1. Lack of awareness of the very early signs, not just amongst parents but also amongst professionals. She quoted a paediatrician saying "this child (aged 2 years, 3 months) is too young to diagnose with autism", with many GPs and paediatricians continuing to believe that an autism diagnosis is not possible in children under 3 years of age.
2. Long waiting lists for diagnosis. Even those children who are flagged as at risk early end up ageing while on waiting lists for a diagnosis (6 to 18 months) which is highly detrimental to developmental outcomes.
3. Costs to families accessing a private diagnosis in the hope that this will be quicker typically exceed $2,000.

Despite OTARC research showing that a reliable diagnosis of ASD is possible and stable from as early as 18 to 24 months of age[6], less than 3% of children with autism in Australia receive a diagnosis prior to age 24 months, and fewer than 20% receive a diagnosis by 3 years of age[7].

[3] Clark et al (2017), Clark et al (2018)
[4] Bent et al (2015)
[5] Parliament of Victoria (2017)
[6] Barbaro et al (2017)
[7] Figures based on analysis of HCWA data: Bent et al (2015)

The result? Children are not receiving intervention in their early and most critical years.

Earlier identification, assessment and diagnosis:

1. enables children to begin participation in specialised intervention programs at younger ages, maximising their developmental opportunities,
2. promotes greater independence and better quality of life for autistic children and their families,
3. benefits the community by significantly increasing the chances of these children contributing to society and the economy. The social and economic advantages of an early diagnosis are well established[8].

Not all people who are autistic and seeking a diagnosis are young children. Gaining a diagnosis for older children, adolescents and adults is also often a difficult and costly experience, with many simply giving up.

> *"Getting a diagnosis outside of the school system means expense @$500-$2500. Can we improve this for older undiagnosed family members who fit the profile and may also be the primary carer?"* (Family of an autistic individual who works for an autism organisation)

In the SASLA survey of Australian autistic youth we found that[9]:

1. The average age of diagnosis was 9.7 years,
2. only 17.5% were diagnosed at age 3 years or younger (see Figure 2 for details),
3. 49.5% were diagnosed at age 9 years or older which is well beyond early diagnosis guidelines[10], and
4. only 26% had received early intervention.

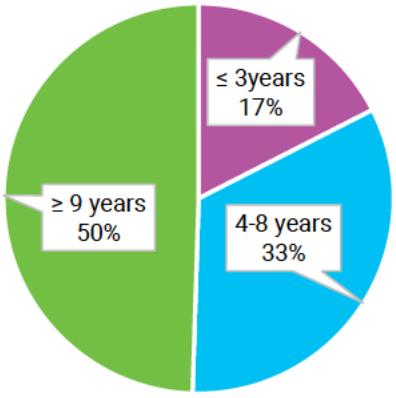


Figure 2 - The age of diagnosis of Australian youth

[8] Buescher et al (2014)
[9] SASLA study https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years;
[10] Whitehouse et al (2018)

Recommendations

1. Development of a national autism plan in consultation with autistic individuals, families, autism organisations, service providers and researchers.
2. Provision of funding for Early Assessment Clinics in each state and territory in Australia, including a lead clinic at La Trobe University's Olga Tennison Autism Research Centre (Budgeted at approx. $1.25 million per year over 4 years for Victoria).
3. Training of all Maternal and Child Health Nurses (or equivalent) in each state and territory in Australia to identify the early signs of autism.
4. Co-funding by Government and industry to continue development of online tools for the early identification, assessment and diagnosis of autism to facilitate access for underserved regional, rural, and remote communities.
5. Funding for the development and implementation of autism training for healthcare providers working with older children, adolescents and adults.

b) The prevalence of autism in Australia

OTARC has conducted four studies relevant to the prevalence of autism in Australia. Two studies used the Social Attention and Communication Surveillance (SACS) method to identify autism prospectively in infants, toddlers, and pre-schoolers, the third used data from the Longitudinal Study of Australian Children (LSAC), and the final study used HCWA (Helping Children with Autism) registration data.

1. For the first SACS study 20,770 infants and toddlers were monitored between 2006 and 2008. The prevalence of autism was 0.84%[11].
2. For the second SACS study 13,564 infants and toddlers were monitored between 2014 and 2018. An autism prevalence of 1.92% was found at 12-24 month of age which rose to 2.73% with the inclusion of 3.5-year-old children.
3. In the LSAC study, the prevalence of autism, ascertained at school age, ranged from 1.5% to 2.5% in two cohorts[12].
4. Finally, the HCWA registration data (2010-2012) showed that prevalence varies dramatically across states and territories, ranging from 0.97% in Victoria to 0.46% and 0.34% in Western Australia and the Northern Territory, respectively[13]. The low percentages in WA and NT presumably indicate the lack of services in their relatively large rural and regional areas.

The variation in prevalence over studies highlights the need for an epidemiological study into autism prevalence in Australia, and the likely lack of diagnostic services and expertise in rural areas.

Recommendations

6. Conduct a comprehensive epidemiological study into ASD prevalence in Australia in order to ascertain diagnostic and service needs for autistic people throughout their lifespan.

[11] Barbaro et al (2010)
[12] Randall et al (2016)
[13] Bent et al (2015)

c) Misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services

Investigating the early presentation of autism in females is critical as autistic females tend to be diagnosed less frequently and later than males, leading to lost opportunities for females to gain early access to services.

We investigated sex[14] differences in the early signs of autism between ages 18 and 24 months and found no difference[15]. The ratio of autistic females to males decreased from 1:15 at 12 months of age to 1:3.2 by 24 months[16]. This may indicate that infant females are more likely to be missed than older females and that close monitoring of females is required when conducting developmental surveillance for autism in young children. For this reason, OTARC's training for Victorian Maternal and Child Health Nurses on the early signs of autism has a dedicated module to address possible gender bias in diagnosis.

The above conclusion is supported by our analysis of the SASLA data, with females in this study less likely to be diagnosed at 3 years of age or under and far more likely to be diagnosed at 9 years or older than males (Figure 3).

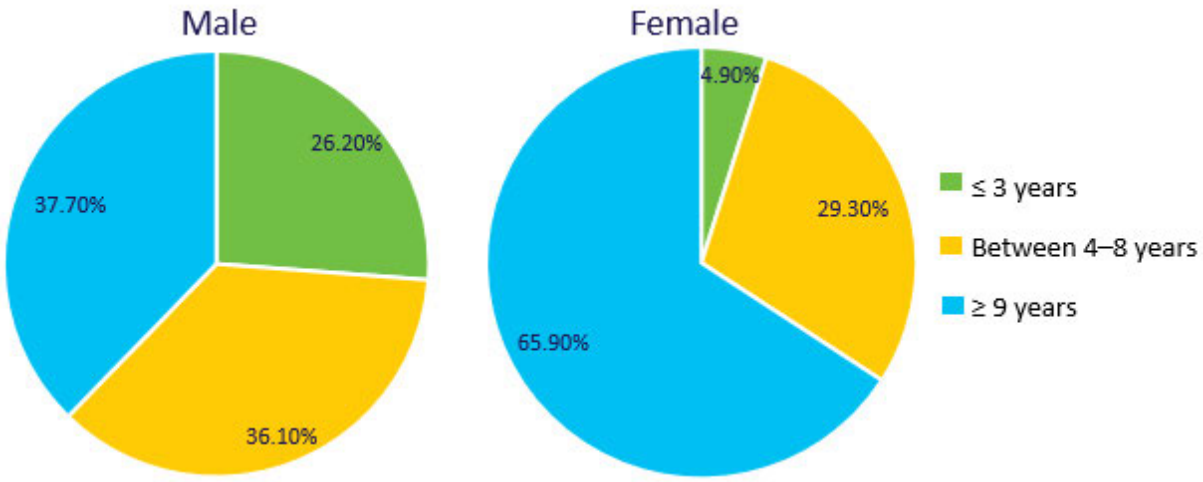


Figure 3 – SASLA respondents age of diagnosis by gender

> *"We need to re-educate the medical and diagnosis profession on the myth that autism is primarily (a) male condition. Coupled with that is the need for a new set of criteria to readily diagnose females on the spectrum."* (Family member of an autistic individual and works with autistic people)

Currently, for every female diagnosed with autism there are roughly three to four males[17,18], a ratio that changes when factors such as language, cognitive abilities, and age are considered[19]. For example, in children without an associated intellectual disability the prevalence of girls vs. boys diagnosed with autism is much lower (1:10) than when there is intellectual disability (1:1.5). This pattern tells a two-part story: 1. biologically, autism might not affect males and females equally, and 2. autistic girls without co-occurring intellectual disability are being missed, only to be diagnosed later, if at all.

[14] Sex refers to the chromosomal, gonadal and anatomical characteristics associated with biological sex.
[15] Hollier et al (2018); 197 infants and toddlers (44 female:153 male)
[16] Barbaro et al (submitted for publication)
[17] Fombonne (2009)
[18] Loomes et al (2017)
[19] Jellet et al (2019)

Why is this happening? There are several possible reasons:

- females may be more inclined, better able, or taught to mask their autism,
- females tend to desire friendships and develop strategies like watching and impersonating other girls,
- females' early social success becomes more difficult to achieve with age due to increased complexity of the social world and the effort of masking comes at a cost to their wellbeing and sense of identity,
- female 'special interests' may not stand out as being unusual (e.g., toy animals, Disney) and they may be more 'gender typical',
- females may cope with strong emotions by turning them inward (internalising, leading to anxiety and depression) rather than outward (externalising, observable as challenging behaviour), meaning they can fly under the radar,
- the diagnostic tools used for autism diagnosis have a male bias and are less effective for identifying autism in females, and
- diagnosticians who are unfamiliar with the female autism phenotype might carry this male bias, looking for the signs of autism they are used to seeing in males; girls don't necessarily fit the stereotype.

> *"I think it is so important that diagnostic services and support services are aware that females may (sic) present differently and may have different support needs. I also think this message needs to get out to the general community as many families and individuals, still to this day, may not think their daughter/ themselves are autistic due to this misconception and this may prolong seeking a diagnosis and access to appropriate supports which can have detrimental effects on the individual. I think a big part of this would also need to include raising awareness among educators and GPs (who are usually the first point of contact regarding developmental concerns)."* (Individual who works with autistic people)

In conclusion:

1. Females are less likely to be referred for assessment than males because their autism symptoms may be less pronounced or missed in the absence of co-existing disabilities.
2. Referred girls are less likely to get a diagnosis of autism than boys because of a male bias in diagnostic tools and diagnostician's experience.

Recommendations

7. Thorough training of primary, educational, medical, and allied health staff on the early presentation of the male and female autistic phenotype to reduce the age of diagnosis, particularly in girls.

e) The demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages

Demand and adequacy of autistic children's services

Services in Australia for young autistic children were first addressed in the Helping Children with Autism Initiative (HCWA), targeted for children aged 0–6 years. While this initiative was quite successful, with long term impacts on sector, including the establishment of the Autism Specific Early Learning and Care Centres (ASELCC) with the Victorian Centre based at the La Trobe University Bundoora Campus (now called the Margot Prior Autism Intervention Centre or AIC), there remains much need for services for all autistic children, regardless of age, including:

1. better early identification initiatives embedded within universal services,
2. increased access to diagnostic services for all ages (discussed above),
3. increased capacity for early intervention (building on the ASELCC model),
4. adequate training for early childhood and school educators to help autistic children learn and develop, and to address challenging behaviours within both specialised and mainstream settings, and
5. more support for families, particularly from post diagnosis, to access services as needed for their child throughout his/her development.

Demand and adequacy of services for autistic adults

In several of our studies of autistic individuals and their parents/carers have expressed concern about the availability and cost of services across the lifespan[20]. For example, a thematic analysis of data of the SASLA community survey in 2020 identified significant problems with accessibility and adequacy of services, including:

- difficulty locating available services, particularly after high school,
- lack of adaptation of the curriculum to cater for individual needs of autistic students in education settings,
- lack of support to acquire employability and upskilling,
- lack of day programs,
- lack of practical supports and accommodations at university,
- lack of supports in fostering decision making, living skills and self-advocacy,
- difficulty navigating the system if you do not fit typical categories of support, and
- lack of post diagnosis supports.

> *"It's frustrating to find the scarce gold nuggets of information for adults on how to manage themselves. It's even more frustrating to see information targeted for the more physical, typically presenting symptoms, and not knowing what I can do to help myself. My only source of information, my only community, cannot help me. I'm left to go to blog posts and information I cannot trust, hoping for something to be true, and hoping it's not detrimental, because that's all that's left. I need this community to guide me. I don't want to hurt myself through ignorance."* (Autistic individual)

[20] Flower et al (2019)

The analysis also identified inadequacies in knowledge of autism and associated difficulties in front-line service providers, including many psychologists and psychiatrists, police and support workers. Making interactions between autistic persons and service providers unnecessarily stressful and difficult.

> *"There is insufficient support and understanding of an autism diagnosis. For example, in paperwork from Centrelink they ask how long he will (sic) have Autism."* (Family of an autistic individual and works with autistic individuals)

Demand and adequacy of services for the transition from school to further study of autistic people

Support services for autistic Australians with and without an intellectual disability who are moving from school to further education are fundamental to make this transition a successful one. However, recent research highlights some of the concerns with transition support[21]. In Australia, only 28% of transition aged autistic youth said they had received support, with 77% saying that they would have liked to receive support. This indicates a high demand for support and inadequate access to existing support[22].

> *"When someone turns 18, they don't stop being autistic - autistic children become autistic adults and still need support?"* (Family of an autistic individual)

A study funded by DHS Victoria and entitled "Supporting transition to and participation in tertiary education for students with an Autism Spectrum Disorder"[23] highlighted some of the concerns of existing transition support. Focus groups of autistic students and their families revealed that

- students had difficulties choosing a course and lacked transition support,
- students' educational needs were not met,
- students were not well prepared for higher education, and
- students' social needs in higher education were not adequately met (Figure 4).

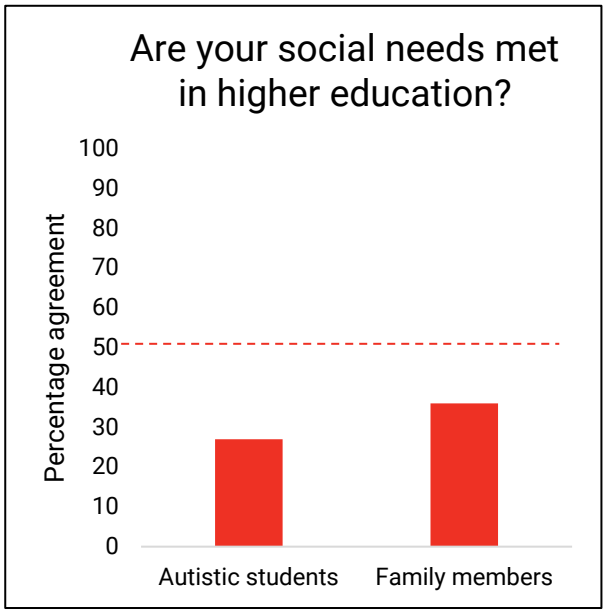


Figure 4 – Percentage agreement that "students' social needs were met in higher education"

Figure 5 shows a summary of the challenges reported by the participants in the DHS study.

[21] e.g. Cai and Richdale (2016), Parliament of Victoria (2017)
[22] Flower et al (2019)
[23] Richdale et al (2012), Cai et al (2016); Focus groups: autistic individuals (N=23), their families (N=15), tertiary institution staff (N=31) and online survey; staff (N=65), family members (N=28) and student participants (N=16).



Figure 5 – Key areas affecting progress in higher education.

Autistic University and TAFE students said:

> *"For me organizing myself is difficult because I don't know how long it takes to do things. So I think it'll take a day but ends up taking 4 days. And then that displaces your whole plan."*
>
> *"My brain is unable to process multiple information at the same time. I can think about my own thoughts and what I need to say for the topic, but I can't think about the person, what they are feeling, and what they need to hear."*

Tertiary education staff also felt that the challenges facing autistic students were substantial and that they needed specialised training and institutional support for working effectively with autistic students (see comments in box below).

Staff members or parents talking about challenges of autistic students:

"But he was always anxious, always very literal. I said that I thought he should dictate the work to me and he was horrified and he said, "I would never presume to dictate to you."

"My son was very poorly supported for the transition from high school to adult life and this was stressful for both of us. His mental health was severely impacted"

"It was made very clear at the start that he works to quite a rigid framework, that he needs structure. That became apparent in the first class when he advised me that at five past 10 it was five past 10 and I said there would be a break at 10 o'clock."

"In high school [my son] was depressed. It's very important to have a counsellor to speak to. Family, even if they are close, it's not enough."

"No matter how aware you are of autism, sometimes you can make the mistake yourself and think oh-oh, damn, that's why his behaviour has changed, because you've ruined his or her routine. That's why he's arcing up. We've stuffed up something. If you're not aware of autism, as an employer or as a teacher, yeah you really can cause a lot of disruption to their lives and not be aware of it."

The recommendations following on from the DHS study were as follows:

1. There is a need for clarification of policies about disclosure of autism conditions on enrolment; balancing the need for privacy against the enhancement of support for affected students.

2. Standardisation of support availability for autistic students is required through the provision of guidelines for disability support staff and teaching staff in tertiary education.

3. Professional development in autism is required to increase the knowledge among both academic, support, and other staff about the characteristics of autism and associated learning and psychological disorders.

4. Resourcing for supporting autistic students in tertiary education institutions should be increased.

5. As far as possible, and while preserving the privacy of affected students, teaching staff should be made aware of students' disabilities to enable them to provide targeted support.

6. Support activities for autistic students should be based on assessment of individual needs, as these vary greatly from case to case.

7. In staffing disability units, cognizance should be taken of the specialized nature of the support needs of autistic students.

8. Disability Support Units may require additional staff in order to provide for the specific needs of autistic students, including services such as orientation activities, social supports and mentoring.

9. There should be more extensive use of mentoring in supporting autistic students.

10. Support is needed at the secondary education level for students with disabilities as they prepare for transition to tertiary education.

Demand and adequacy of services for the employment of autistic people

Australia has a free national disability employment service (DES). However, autistic community members observe that these services

- are largely tailored to individuals with an intellectual disability, and
- do not meet the needs of the autistic population.

Data suggest that national DES placement rates for autistic clients are both variable and low[24]. Autism Spectrum Australia[25] have similarly reported on the limited transition-to-employment services available, with 50% of Australian parents noting a lack of appropriate employment support and a majority reporting issues with post-school service supports. Only 35% of autistic youth accessed job seeking supports and 35% reported having no knowledge of services that can help young people with a disability find a job[26].These data suggest that there is a fundamental lack of adequate national employment services for autistic people. While there has been recent progress with the "Autism@Work" movement in Australia, with companies like Specialisterne and DXC Technology implementing autism employment programs, these programs service only a small minority of the autism community and are not inclusive of individuals with a co-occurring intellectual disability.

Demand and adequacy of mental and physical health services for people in Australia

Demand for mental and physical health services is high in autistic populations. It is well established that autistic people are at a high risk of co-occurring conditions including mental and physical health difficulties with 79% currently experiencing anxiety, 37% experiencing depression in their lifetime and higher rates of epilepsy and hearing or visual impairment[27].

Australian autistic youth were significantly more likely to report having a current diagnosis of depression, anxiety and/or ADHD than non-autistic youth (Figure 6). In addition, a large pooled Australian study[28] found that 38% of autistic adults aged 15-80 years had clinical levels of both anxiety and depression symptoms. These figures clearly demonstrate substantial need for autistic-specific mental health supports in early adulthood.

Physical co-occurring conditions such as sleep disturbances are also common, with 64% of autistic individuals in the age range 15-80 years reporting poor sleep, compared with only 46% of on non-autistic adults of similar ages[29]. Furthermore, mental health problems[30] and rates of unemployment[31] are commonly associated with poor sleep in autistic adults. It is therefore important that health practitioner recognise and treat sleep difficulties alongside mental health.

[24] Department of Jobs and Small Business (2017)
[25] Autism Spectrum Australia (2013)
[26] SASLA study (youth aged 15-25)
[27] Kent et al (2017), Do et al (2017), Hollocks et al (2019), Thomas et al (2017), Uljarević et al (2019)
[28] SASA, ALSAA and Dandelion study
[29] SASA, ALSAA combined data
[30] Joveveska et al (2020)
[31] Baker et al (2019)

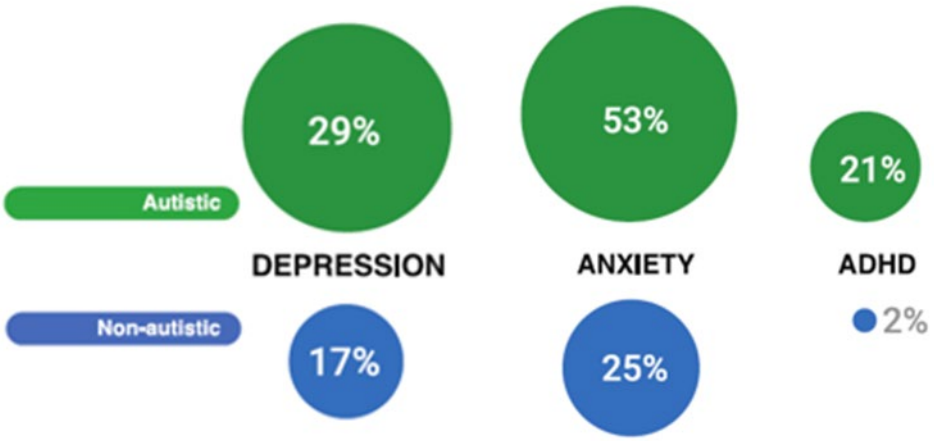


Figure 6 – Self reported mental health difficulties in Australian autistic youth aged 15 to 25 years[32].

People with autism are also at significant increased risk of dying by suicide compared to the general population. Suicide is the leading cause of premature death in people with autism of average IQ or above. The problem is exacerbated by stigma and lack of knowledge about suicide in autism. Suicidal ideation was experienced by 36% of a sample of Australian autistic adults. However, across the UK, US and Australia, research has demonstrated that autistic individuals have great difficulty accessing appropriate mental health supports for suicide prevention. This has informed the development of a specific autism suicide risk model focused on psychosocial factors (i.e., social isolation, loneliness) that may be exacerbated by autism symptoms[33].A submission to the Royal Commission into Victoria's Mental Health System[34] by AMAZE, with content provided by OTARC researchers, identified a population of autistic people in crisis:

1. Mental health professionals felt unqualified to work with autistic people,
2. Autism specialists lacked training in mental health treatment.

Most currently available tools for clinicians to diagnose mental health conditions have been designed for non-autistic people and have not been validated for autistic people, leading to challenges because:

- autistic individuals may experience symptoms differently,
- understand or answer questions in a way that's unfamiliar to clinicians,
- clinicians who are unfamiliar with autism may misinterpret symptoms of autism as features of a different clinical condition, and
- clinicians may ignore or overlook co-occurring conditions, assuming they are part of autism, an issue known as diagnostic overshadowing.

Clearly, systemic changes are needed to better support autistic clients. An international scoping review (including Australian studies) of patient-service provider interactions with individuals with autism in healthcare settings undertaken in 2019, found six themes to inform improvement of services[35]. It found that:

- The complexity of working with autistic patients was beyond service providers' usual role.

[32] Lawson et al (2019) SASLA baseline snapshot
[33] Hedley et al (2017), Hedley et al (2018)
[34] AMAZE submission to the Royal Commission into Victoria's Mental Health System (2019)
[35] Morris et al (2019)

- Limited knowledge and resources negatively affected service provision to autistic patients and their families.
- A lack of training or prior experience with autistic patients was a barrier to care.
- Communication and collaboration were flagged as relevant to service provision as autistic patients and their families require unique communication and environmental accommodations.
- A need for information and training to enhance the quality of service provision.
- The need for care coordination and systemic changes to increase accessibility and efficiency of care.

Recommendations

8. Equip services and develop supports to successfully transition for autistic people from school into further education and employment.

9. Provide support for parents/carers of autistic youth transitioning from high school into further study and employment.

10. Equip Disability Employment Service (DES) and train their staff to work confidently with autistic job seekers. This must be based on the experiences of autistic clients with accessibility, barriers and what works or does not work for employment placements.

11. Develop and adopt best practice guideline for clinicians in the identification and treatment of co-occurring conditions in autistic people.

12. Educate mental and physical healthcare and service providers about the unique clinical presentation of co-occurring conditions in autism and train them on the appropriate use of validated tools to identify and treat these conditions.

13. Develop and implement evidence-based therapies designed for autistic individuals living with co-occurring conditions such anxiety, depression, suicidal ideation and sleep difficulties.

14. Implement changes in service settings to accommodate autistic clients including longer consultation times and reduced wait times (expedited triage of care), reduced sensory stimulation in waiting and testing rooms.

g) The social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people

"Without considered and sufficient support, autistic people become under-functioning people. They are capable of soooo much when properly supported. Without this support, instead of contributing to the economy and their own social life, they cost the health system and the unemployment (social) system a lot of $$$." (Family of an autistic individual)

As we have covered previously in the submission (Term of Reference e, pg. 11), access to transition support is generally low and demand high in autistic young adults[36]. As well, services to support autistic youth and adults in tertiary education and employment are inadequate, if not lacking. This is a problem that can have wide ranging negative social and economic impacts, such as:

- increased burden on mental health and employment services,
- increased reliance on welfare because of lack of income,
- increased pressure on families, and
- lack of independence.

Because of the absence or inadequacy of services the burden of supporting autistic children, youth and adults in Australia usually falls on their parents and the impact on families in terms of social, emotional and economic stress can be extensive. Dr Nancy Sadka (a researcher at OTARC and parent of two autistic boys) gave a first-person account of what is required from a parent of autistic children/adults:

> *"navigating the NDIS is a long and challenging process. It took me a year to prepare for our support planning meeting to ensure adequate funding. I accounted for every hour of every day, 365 days, 8,760 hours, and it did not stop there. Receiving an adequate plan is only the first step, trying to implement the plan is another matter. I fight with providers who are lacking in knowledge on how to operate under the NDIS. I recruit support staff, provide monthly rosters for support staff, check signatures against hours provided, document and lodge them weekly, approve invoices against line items, keep an expense ledger, budget funding so it will last for the duration of his plan, keep up with NDIS changes, and get ready for the next year's plan review. So if you think that the NDIS is all about funding the individual, think again. It is my second full time job."*[37]

As this excerpt shows, the failure to provide adequate services that are easy to navigate and access comes with a significant cost in terms of time, stress and dealing with uncertainty not only to autistic people but also for those who support and care for them.

<u>Employment</u>

Employment offers a means of empowering autistic adults to become more engaged and active within their communities, with potential to improve their own outcomes as well as to contribute to the broader Australian community and serving to increase GDP. The employment rate for autistic people in Australia is estimated to be only 27% which is much lower than for individuals with other (53%) or without disabilities (84%)[38]. These figures are well below the OECD average indicating much scope for improvement. The economic costs of not

[36] SASLA study (youth age 15-25)
[37] Flower et al (2019)
[38] Australian Bureau of Statistics (2018)

moving to best practice employment interventions for people with autism are significant, even if interventions target relatively small numbers of individuals.

> *"An autistic person that is well adjusted can work, often in highly skilled work and contributes significantly to the Australian community (even if it takes more effort up front), whereas one who is not, becomes a burden financially and socially to those around them."* (Autistic individual)

Recent innovations such as the Dandelion Program[39] to support autistic people to gain meaningful employment and other approaches such as the Better Outcomes and Successful Transition for Autism[40] and Employment Circles of Support[41] are all beginning to assist with getting autistic people (albeit in small numbers) into the workplace. The Dandelion program is estimated to have generated $26 million for Australia's GDP over five years[42]. The significant costs in not doing so are highlighted in a report by PwC, which estimated that by not improving the employment participation rate of people with disabilities by 10% Australia would miss out on potential GDP gain of $40-43 billion between 2012-2021[43].

> *"I don't want her (daughter, sic) unemployed on Centrelink, anti-social and slowly becoming more and more mentally unsound without stimulation. As her carer I can't keep doing the same thing for 50+ years. I need strategic assistance at key points in her life to help her become the best she can."* (Family member of an autistic individual who also works with autistic individuals)

Our work within the Dandelion Program has indicated that many autistic adults are willing and able employees but face significant barriers to gaining and maintaining meaningful employment as a result of:

1. Limited work history and/or access to work experience and/or training opportunities.
2. Recruitment practices that disadvantage autistic applicants (e.g., unclear advertisements, use of interviews that rely on social communication skills).
3. Workplace physical and cultural environments that do not consider individual needs (e.g., sensory environment, ambiguous workplace practices).
4. Lack of knowledge and training about autism by employers and supervisors (and the wider community).
5. Lack of service provision for individuals seeking employment assistance.
6. Lack of knowledge and training about autism by Disability Employment Service (DES) providers (notably we are unaware of Australian data on either the efficacy of DES for autistic Australians, their level of autism knowledge, or the accessibility of DES to all autistic people). Adding to this point, Labour Market Information Portal data indicates few autistic job seekers receiving DES help are placed into work, e.g. in 2017 autism was 16% of DES providers' case load, but on average only 25% of these people were linked into jobs[44].

Our research suggests that programs which provide extended onsite vocational training and support benefit autistic job candidates and facilitate effective transition into the workplace. Such changes can serve to decrease the significant costs associated with un- and under-employment of autistic Australians.

[39] Nicholas et al (2019), Krzeminska et al (2019), Hedley et al (2019), Hedley et al (2018), Hedley et al (2017)
[40] Hatfield et al (2017)
[41] Bytschkow (2016)
[42] PricewaterhouseCoopers (2015)
[43] PricewaterhouseCoopers (2015), Hedley et al (2017), Deloitte Access Economics (2015),
[44]Australian Government (2017)

Retention of autistic staff can be improved by:

1. Recruitment practices that allow demonstration of skills (e.g., paid internships or traineeships),
2. Autism awareness training for all staff,
3. Extended exposure to the role and workplace prior to commencing employment,
4. Reasonable adjustments and individual support, and
5. Providing opportunities for career progression.

> *"Employers need more training in how to include this group of people who are actually incredibly capable and loyal employees given half a chance."* (Family of an autistic individual)

Co-occurring conditions economic and social impacts

As discussed under Term of Reference e (pg. 14) autistic people have high rates of various co-occurring conditions. OTARC research[45] found that autistic participants that were classified as having a sleep disorder (55%) were more likely to be unemployed compared to autistic adults without a sleep disorder. Along with high rates of anxiety also being reported as a co-occurring condition by autistic Australians (53%), co-occurring conditions are a major barrier to participation in the community and ultimately the Australian economy.

Autistic tertiary students reported a need for structure and routine which can be lacking in education settings[46], increasing stress and anxiety, and decreasing productivity and social participation. Anxiety and meltdowns can affect an individual's ability to complete education and impact employment.

> *"I've had a screaming fit in the middle of the corridor at the admin building. My particular lecturer walked away from me when I asked for help and I said, don't you walk away. And I really lost it."*[47]
> (Autistic tertiary student)

Co-occurring conditions can be barriers to participation in further education and the workforce. Without a clear understanding of how to best support autistic Australians in their vocational endeavours, we seriously risk limiting a large proportion of the Australian population contributing the Australian GDP (as detailed on pg. 18). To this end, we have developed a resource and training package addressing autistic mental health and well-being in the workplace[48].

Recommendations

15. Training clinicians to support mental health and promote well-being in autistic clients
16. The creation of an Australian training package to increase knowledge and awareness of autism in the workplace, including reasonable workplace adjustments and supporting individual differences.
17. A review of Disability Employment Service (DES) to assess knowledge and awareness of autism and practices in providing appropriate support.
18. A national industrial relations guideline to guarantee equitable accessibility of recruitment practices for autistic people.

[45] Baker et al (2019)
[46] Richdale et al (2012)
[47] Richdale et al (2012)
[48] Bury et al (2020)

h) The adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people

i. **Autism understanding within the NDIS**
ii. **The utility of the Early Childhood Early Intervention Pathway for autistic children**
iii. **The ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings**
iv. **The adequacy and appropriateness of supports to empower autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services**

The general feedback received at OTARC from a variety of sources, including the parents we see and serve is that there is very limited understanding of autism within the NDIS, especially amongst planners who are the main points of contact with these families. As a case in point, we have seen the levels of stress and anxiety increase dramatically in families who previously accessed the Victorian ASELCC based on DSS funding but who now have been transitioning into the NDIS. The timeframes, the demands for sufficiently funded plans, and the requirements on families to navigate the NDIS are hugely different to that experienced previously, impacting their well-being and sense of efficacy.

With regards to the ECEI pathway, the delays to access and the level of service provided is insufficient to meet the needs of young autistic children. Our current understanding on the importance of early and intensive behavioural supports for autistic children to impact developmental progress means that the ECEI pathway will be less effective. While this cannot be properly ascertained without data collection on children's outcomes, from the reports received to date, utility is low.

In the SASLA community survey[49] in 2020, a large proportion of respondents reported that they did not see the NDIS as an inclusive, participatory or accessible system. They made the following comments regarding the NDIS:

- gaining capacity to engage with services does not mean there are quality providers available,
- families are overwhelmed by the complexity of the system,
- families are struggling to obtain the support that is required through the system (see comment by Dr Sadka above), and
- families continued to feel helpless because they had not seen any improvement in their situation with the new system.

Parents/carers were having great difficulty navigating the system when it came to future planning for their charge's independence, with one family member saying:

> *"One life phase that concerns me is when the Parent/Carers die and their Will hasn't been made adequately for a person with Autism. I'm worried that unless we make provision for Parent/Carers to make adequate Wills our homes/money (sic)/superannuation etc may get lost and not be protected for our succeeding loved one. E.g, We made Wills last year only to be told we'd need a specialist to write a . . . suitable one ($3-5000.00 sic). We asked the NDIS to help us get the best service for this and they said Wills were not deemed something that was for our son who had the NDIS Plan. We disagree."* (Family of an autistic individual)

[49] SASLA community survey (Jan 2020)

Recommendations

19. Direct access to the NDIS for toddlers and pre-schoolers with early signs of autism, so that their needs are met directly rather than their having to enter into the ECEI pathway.

20. Adequate training on autism for NDIA staff across all developmental periods so that they are able to be efficacious in their role as planners.

21. The provision of guidelines for individuals/carers in the pre-planning stage of applying for NDIS funding. This must contain detailed explanations and examples of what supports are available and how to best plan an application that addresses the individual and their family's needs to support an autistic person's vision for their life.

22. The introduction of an NDIS quality assurance program that regularly assesses providers ability to fulfil their contractual obligations to their customers in terms of cost benefit and the life goals set by the autistic individual and/or their carer.

j) The adequacy of funding for research into autism

Prior to the establishment of the Autism CRC in 2013, there was no federal autism-specific research funding, with the exception of that provided to the six Autism Specific Early Learning and Care Centres, to undertake the Child and Family Outcomes Strategy (CFOS) between 2009–2020. While incredibly important, together these funds have focused on applied research, with basic research on autism being historically underfunded.

The only dedicated autism research funding available historically was that provided by the Apex Trust for Autism which funded small projects to the order of a couple of thousand dollars annually. Other NFP organisations have also contributed funds for individual projects. It was in this context that Mrs Olga Tennison, our namesake, funded us at La Trobe University to undertake autism research. Her generosity and commitment to autism research is evident in the $5.8 million that she has already contributed, and which enabled the establishment of Australia's first research centre dedicated to autism.

Despite the systemic lack of funding in Australia for autism research, Australian autism researchers have made significant contributions to autism science internationally, beginning with the research of Professor Margot Prior back in the early 1970s. It was no accident that she was recognized with a Lifetime Achievement Award by the International Society for Autism Research in 2018.

To continue Australia's contribution to both basic and applied autism research within the current competitive international environment, more funds are needed which are specifically directed to researching a condition that is prevalent in 1 in 56 people (latest CDC data, 2020). Research on autism is expensive. For example, gold standard assessments of autism are vitally important in research as it allows researchers to confirm, with confidence and scientific rigor, that the participant has a diagnosis of ASD. The cost of a single assessment at our Early Identification and Diagnosis Research Program is approximately $2,000 per participant given the time and expertise required to accurately assess the behaviour of a child by highly trained professionals.

There is a severe gap in research exploring the autistic experience in adulthood. There is a lack of large-scale longitudinal studies which are important in assisting us to predict pivotal outcomes for autistic adults and the impact of co-occurring conditions, accessibility to services and adequacy of supports. There are few available evidence-based psychological interventions for autistic adults that have the capacity to improve their physical and mental well-being, with funding needed to progress the necessary research to develop and test these interventions that will ultimately improve and even save lives.

Recommendations

23. Establish a dedicated research funding pool for both applied and basic research on autism through the life course.

k) The social inclusion and participation of autistic people within the economy and community

Social inclusion involves feeling accepted within your local community and being able to contribute to society in a meaningful way through participation in mainstream activities like employment and education.

> *"To engage, contribute and be part of society is ultimately what every person desires and for autistic adults this remains a significant challenge."* (Family of an autistic individual)

Inclusion may include:

- the acceptance of children in mainstream education with teachers being trained to respond to their individual needs,
- gainful employment within a responsive work environment,
- autistic students being accepted in the social activities of their fellow students at TAFE and university,
- providing housing and support to enable independent living,
- the portrayal of an autistic character in a film by someone who is autistic, and
- altering the focus of research by including autistic people, their families and carers in design and execution of studies, as well as in translating findings into practice.

True inclusion can lead to greater acceptance and less abuse of autistic people in the general community, with a larger proportion of them participating and being represented in all facets of society.

However, OTARC research has shown that inclusion of autistic people in Australian society is still 'a work in progress'. Our findings on bullying, vocation participation and independent living are a case in point.

We found while there are high levels of bullying in Australian youth in general[50] (Figure 7), autistic youths are reporting significantly higher levels than their non-autistic peers. This may serve as a disincentive for societal participation and certainly indicates a lack of social inclusion by peers. Bullying once again came up as a concern not only during high school but also as autistic youth transitioned into workplaces[51]

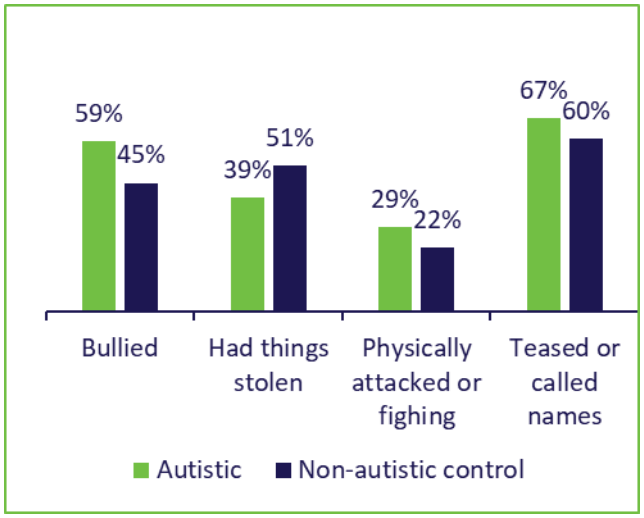


Figure 7 – School experiences of autistic youth in Australia

To answer the question about participation in the Australian economy and community, we surveyed Australian autistic and non-autistic youth who had completed high school about the activities they were currently undertaking. Figure 8 shows that following high school, compared to non-autistic youth, autistic youth are:

- more likely to NOT be engaged in either, study or work (2.8 vs 17.2%),
- more likely to be studying without working at the same time (29.0 vs 49.4%), and
- much less likely to study and work at the same time (51.4 vs 18.4%).

[50] SASLA study (youth aged 15-25)
[51] SASLA community survey (Jan 2020)

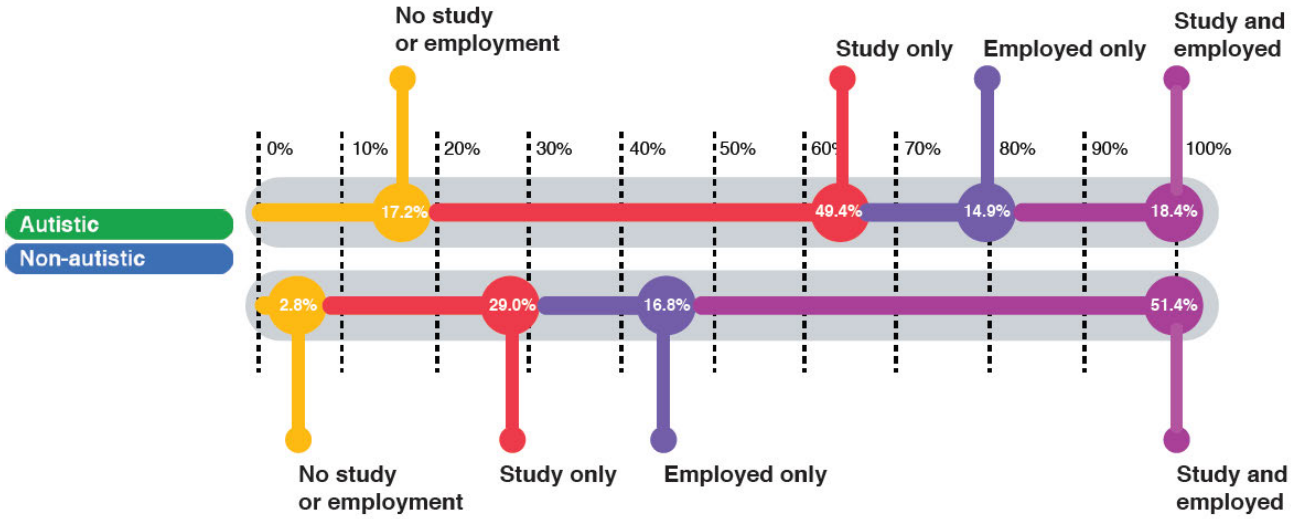


Figure 8 – SASLA baseline post school participant activity[52]

There is still a lot of work to be done to enable autistic adults to live independently. Only 10% of young autistic adults in Australia reported living independently from family[53]. In a large, Australian longitudinal study[54] we found that living independently (i.e. living alone or as a couple vs. living with family) was related to better psychological quality of life for autistic adults. Many autistic adults are not functioning independently, only 10% are in long-term sexual relationships or married, 25% reported having only a single friend[55]. Independence cannot be overlooked when assessing social inclusion and participation in community and the economy.

> *"There are few services to assist with meaningful engagement in the community that are easily accessed by a population that has many social skills deficits, especially for adults with the diagnosis. There are few sensory suitable public places for people with autism."* (Family of an autistic individual and works with autistic people)

> *"Inclusion and participation in the community is paramount in the physical and mental health of people living with ASD. I believe that joining both the ASD and non ASD community together on community breaks down stigma fear and ignorance creating a learning format to understand and accept indifference out in the community."* (Family of an autistic individual)

Recommendations

24. Develop and implement guidelines to increase social inclusion and participation for autistic people from childhood onwards in education, employment and within the wider community.

[52] Lawson et al (2019)
[53] SASLA study (youth aged 15-25)
[54] Lawson et al (2020)
[55] Howlin et al (2012)

n) Other matters

Parents/carers and families are pivotal to the success of autistic individuals. They guide and teach children, they offer encouragement and supports through the transition to adulthood, are their children's strongest advocates, navigate government supports and the education system and are crucial to an individual's social support system. And yet, as we have already shown above, parents/carers often report high levels of stress and uncertainty, which contribute to poor mental health outcomes.

In our SASLA study we surveyed parents/carers of autistic youth and found that most were experiencing mild to severe depressive and/or anxiety symptoms at the time of the survey[56] (Figure 9). Sleep issues were also commonly reported with 54% of respondents having trouble sleeping. The high levels of sleep difficulties, anxiety and depression in this sample suggest that there is an urgent need for mental health support for parents/carers of autistic people. Supporting the carers can only improve the wellbeing and quality of life of their dependents and in turn the wider community.

> "In short, support the Carers because we support the Autistics, 24hrs a day. We are aging but we are still needed, have influence and can only give what we have in our tanks. Once depleted we give up."
> (Mother of an autistic individual)

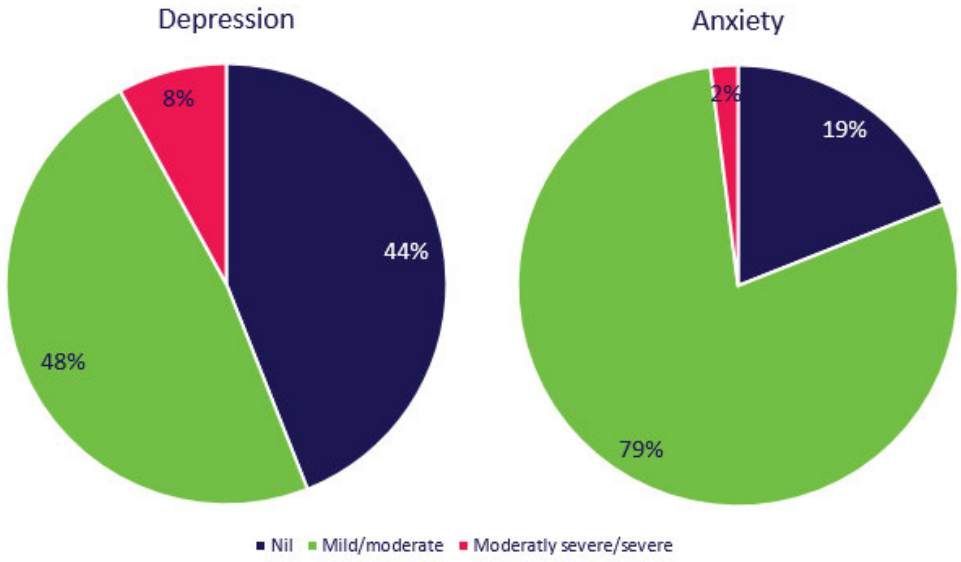


Figure 9 – Clinical levels of anxiety and depression symptoms experienced by parents/carers of autistic Australians.

Recommendations

25. Provision of specialised, accessible and evidence-based mental health care supports for parents and carers supporting autistic people.

[56] Flower et al (2019) SASLA Parent/Carer Profile Snapshot

Acknowledgements

La Trobe University

La Trobe University undertakes world-class, high-impact research that addresses the major issues of our time. La Trobe placed in the top 400 in all three major global rankings, and is now ranked the top 1.2 per cent of universities worldwide. La Trobe's broad fields of research are rated by the Federal Government at above or well above world standard.

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The Olga Tennison Autism Research Centre

The Olga Tennison Autism Research Centre (OTARC) is Australia's first centre dedicated to autism research. It has a strong focus on research translation through the development of evidence-based tools, and collaborates with other autism research centres and institutes both in Australia and internationally.

OTARC is situated in the School of Psychology and Public Health within the College of Science, Health and Engineering (SHE) at La Trobe University in Melbourne, Australia.

Website: **https://www.latrobe.edu.au/otarc**
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The Cooperative Research Centre for Living with Autism (Autism CRC) – The Study of Australian School Leavers with Autism

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SASLA Website: **https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years**
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References

AMAZE. (2019). *Submission to the Royal Commission into Victoria's Mental Health System*. https://rcvmhs.vic.gov.au/submissions

Australian Bureau of Statistics. (2018). *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018*. Retrieved from https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018

Australian Government. (2017). *DES Outcome Rates by Disability Type*. Retrieved from https://lmip.gov.au/default.aspx?LMIP/Downloads/DisabilityEmploymentServicesData/DESOutcomeRatesbyDisabilityType

Autism Spectrum Australia. (2013). *We belong too: The experiences, needs and service requirements of adolescents with autism spectrum disorder*. Frenchs Forest, NSW: Autism Spectrum Australia (Aspect).

Department of Jobs and Small Business. (2017). *Department Jobs and Small Business Annual Report 2017-18*. Retrieved from https://docs.employment.gov.au/system/files/doc/other/jsb18-0192_annual_report_207-18_acc_03.pdf

Baker, E. K., Richdale, A. L., & Hazi, A. (2019). Employment status is related to sleep problems in adults with autism spectrum disorder and no comorbid intellectual impairment. *Autism, 23*(2), 531–536. doi: 10.1177/1362361317745857

Barbaro, J., & Dissanayake C. (2010). Prospective identification of Autism in infancy and toddlerhood using developmental surveillance: The Social Attention and Communication Study (SACS). *Journal of Developmental and Behavioral Pediatrics, 31*, 376-385. doi: 10.1097/DBP.0b013e3181df7f3c

Barbaro, J., & Dissanayake, C. (2017). Diagnostic stability of Autism Spectrum Disorder in toddlers prospectively identified in a community-based setting: Behavioural characteristics and predictors of change over time. Autism, 21, 830-840. DOI 10.1177/1362361316654084

Barbaro, J. & Freeman, N. (submitted). Investigating gender differences in the early markers of Autism Spectrum Conditions (ASC) in infants and toddlers.

Bent, C., Barbaro, J., & Dissanayake, C. (2015) Mapping the diagnosis of Autism Spectrum Disorders in children under 7 years in Australia: 2010 – 2012. *Medical Journal of Australia, 22*(6), 317-320. doi: 10.5694/mja14.00328

Buescher A., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of ASDs in the United Kingdom and United States. *JAMA Pediat, 168*, 721-28. doi: 10.1001/jamapediatrics.2014.210

Bury, S. M., Hayward, S. M., Dissanayake, C., & Hedley, D. (2020). *Supporting a neurodiverse workforce: A mental health and well-being resource and training package.* Melbourne: La Trobe University.

Cai, R. Y., Richdale, A. L. (2016). Educational Experiences and Needs of Higher Education Students with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*(1), 31-41. doi: 10.1007/s10803-015-2535-1

Clark, M. L., Barbaro, J., & Dissanayake, C. (2017). Continuity and Change in Cognition and Autism Severity from Toddlerhood to School Age. *Journal of Autism and Developmental Disorders, 47*, 328-339. doi: 10.1007/s10803-016-2954-7

Clark, M. L., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School age outcomes of children diagnosed early and later with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*, 92-102. doi: 10.1007/s10803-017-3414-8

Deloitte Access Economics. (2015). *The economic value of informal care in Australia in 2015.* Australia: Deloitte Access Economics, Carers Australia.

Do, B., Lynch, P., Macris, E. M., Smyth, B., Stavrinakis, S., Quinn, S., & Constable, P. A. (2017). Systematic review and meta-analysis of the association of Autism Spectrum Disorder in visually or hearing impaired children. *Ophthalmic and Physiological Optics, 37*, 212-224. doi: 10.1111/opo.12350

Flower, R. L., Haschek, A., Lawson, L. P., & Richdale, A. L. (2019). *Study of Australian School Leavers with Autism (SASLA): Parent/Carer Baseline Profile 2019*. Brisbane. Autism CRC. Retrieved from https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years

Flower, R. L., Sadka, N., Richdale, A., & Haschek, A. (2019). The Australian context: Commentary on 'Mothers' experiences of the transition of young people with autism spectrum disorder to adult care'…*Research and Practice in intellectual and developmental disabilities, 6*(2), 147-153 doi 10.1080/23297018.2019.1652928

Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research, 65*(6), 591. doi: 10.1203/PDR.0b013e31819e7203.

Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2017). Effectiveness of the BOOST-A™ online transition planning program for adolescents on the autism spectrum: A quasi-randomized controlled trial. *Child and Adolescent Psychiatry and Mental Health, 11*, Article 54. doi: 10.1186/s13034-017-0191-2

Hedley, D., Uljarević, M., ††Bury, S. M., & Dissanayake, C. (2019). Predictors of mental health and well-being in employed adults with Autism Spectrum Disorder at 12-month follow-up. *Autism Research, 12*, 482-494. doi: 10.1002/aur.2064

Hedley, D., Cai, R., Uljarević, M., Wilmot, M., Spoor, J., Richdale, A., Dissanayake, C. (2018). Transition to Work: Perspectives from the Autism Spectrum. *Autism, 22*, 528-541. doi: 10.1177/1362361316687697

Hedley, D., Uljarević, M., & Hedley, D. F. E. (2017). *Employment and living with Autism: Personal, social and economic impact*. In S. Halder & L. C. Assaf (Eds.), Inclusion, Disability and Culture: An Ethnographic Perspective Traversing Abilities and Challenges. New York: Springer.

Hollier, L. P., Joshi, R., Barbaro, J., Dissanayake, C (2018). Gender Differences during Toddlerhood in Autism Spectrum Disorder: A Prospective Community-Based Longitudinal Follow-Up Study. *Journal of Autism and Developmental Disorders, 48*, 2619-2628. doi: 10.1007/s10803-018-3516-y

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (20198). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine, 94*(4)1-14. doi: 10.1017/S0033291718002283

Howlin, P., & Moss, P. (2012). Adults with Autism Spectrum Disorders. *The Canadian Journal of Psychiatry, 57*(5), 275–283. https://doi.org/10.1177/070674371205700502

Jellet, R., & Flower, R. (2019). Five areas of autism research to watch. *Altogether Autism*. Retrieved from https://www.altogetherautism.org.nz/five-areas-of-autism-research-to-watch-adulthood/

Jovevska, S., Richdale, A.L., Lawson, L.P., Uljarević, M., Arnold, S.R.C., and Trollor, J.N. (2019). Sleep Quality in Autism from Adolescence to Old Age. *Autism in Adulthood*. doi: 10.1089/aut.2019.0034

Kent, R., & Simonoff, E. (2017). *Prevalence of Anxiety in Autism Spectrum Disorders.* In Anxiety in Children and Adolescents with Autism Spectrum Disorder: Evidence-Based Assessment and Treatment (pp. 5-32). Elsevier Inc. https://doi.org/10.1016/B978-0-12-805122-1.00002-8

Krzeminska, A., Austin, R., Bruyere, S., & Hedley, D. (2019). The advantages and challenges of neurodiversity employment in organizations. *Journal of Management and Organization, 25*, 453-463. doi: 10.1017/jmo.2019.58

Lawson, L. P., Haschek, A., & Richdale (2019). *Study of Australian school leavers with autism (SASLA): Baseline profile 2018*. Olga Tennison Autism Research Centre (OTARC), La Trobe University. Retrieved from https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years

Lawson, L. P., Richdale, A. L., Haschek, A., Flower, R. L., Vartuli, J., Arnold, S. R., & Trollor, J. N. (2020). Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality. *Autism, 24*(4), 954–967. doi: 10.1177/1362361320908107

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry, 56*(6), 466-474. doi: 10.1016/j.jaac.2017.03.013

Morris, R., Greenblatt, A., & Saini, M. (2019). Healthcare providers' experiences with autism: a scoping review. *Journal of autism and developmental disorders, 49*(6), 2374-2388. doi: 10.1007/s10803-019-03912-6

Nicholas, D. B., Hedley, D., Randolph, J. K., Raymaker, D. M., Robertson, S. M., & Vincent, J. (2019). An expert discussion on employment in autism. *Autism in Adulthood, 1*(3), 162-169. doi: 10.1089/aut.2019.29003.djn

Parliament of Victoria. (2017). *Inquiry into Services for People with Autism Spectrum Disorder*. Retrieved from https://www.parliament.vic.gov.au/400-fcdc/inquiry-into-services-for-people-with-autism-spectrum-disorder

PricewaterhouseCoopers. (2015*). Realising potential: Australian government corporate and NGO partnerships establish the dandelion program to deliver social and economic benefits for workers with autism Spectrum disorder and all Australians*. Australia: PricewaterhouseCoopers. https://www.slideshare.net/HPBVEx/realising-potential-the-dandelion-program

Randall, M., Sciberras, E., Brignell, A., Ihsen, E., Efron, D., Dissanayake, C., & Williams, K. (2016). Autism spectrum disorder: Presentation and prevalence in a nationally representative Australian sample. *Australian & New Zealand Journal of Psychiatry, 50*(3), 243–253. doi: 10.1177/0004867415595287

Richdale, A., Dissanayake, C., & Cai, R. Y. (2012). *DHS final report.* Olga Tennison Autism Research Centre, La Trobe, University, Bundoora.

Thomas, S., Hovinga, M. E., Rai, D., & Lee, B. K. (2017). Brief report: Prevalence of co-occurring epilepsy and autism spectrum disorder: The US National Survey of Children's Health 2011–2012. *Journal of Autism and Developmental Disorders, 47*, 224-229. doi: 10.1007/s10803-016-2938-7

Uljarević, M., et al. (2019). Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-019-04084-z.

Vivanti, G., Dissanayake, C., Duncan, E., Feary, J., Capes, K., Upson, S., … Hudry, K. (2019). Outcomes of children receiving Group-Early Start Denver Model in an inclusive versus autism-specific setting: A pilot randomized controlled trial. *Autism, 23*(5), 1165–1175. doi: 10.1177/1362361318801341

Whitehouse, A. J. O., Evans, K., Eapen, V., Wray, J. (2018) *A national guideline for the assessment and diagnosis of autism spectrum disorders in Australia.* Cooperative Research Centre for Living with Autism, Brisbane.