

September 2020

**Comment on the
Higher Education
Support Amendment
(Job-Ready
Graduates and
Supporting Regional
and Remote
Students) Bill 2020's
potential impact on
autistic higher
education students**

ENQUIRIES

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INTRODUCTION

La Trobe University welcomes the opportunity to provide a submission to the Education and Employment Legislation Committee regarding the proposed Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020. The first dedicated autism research centre in Australia – the Olga Tennison Autism Research Centre (OTARC), established in 2008 – is situated at 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.

Autism spectrum disorder (hereafter referred to as 'autism' and individuals with a diagnosis as 'autistic') is a neurodevelopmental condition characterised by challenges with social communication and interaction; restrictive, repetitive behaviours, interests and activities; and sensory sensitivities¹. Current estimates suggest that 1 in 59 people are autistic².

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 and to actively and meaningfully contribute to society, throughout their life.
- Support families as their autistic children grow and develop.

This submission provides evidence-based, community-driven³ comment that will contribute to achieving these aims. It draws on evidence from our research in the following areas:

- **Vocational Pathways Research & Development.** This area investigates 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 section comes from four studies, and related PhD research:
 1. The DHS Victoria study surveying autistic university and TAFE students, their families and higher education staff (2012)
 2. The SASLA study (Study of Australian School Leavers with Autism, 2014-2020)
 3. ALSAA study (Study of Australian Autism in Adulthood, ongoing)
 4. DXC Dandelion study (employment program for autistic adults, 2016-current).⁴
- **The effect of co-occurring conditions on autistic individuals.** This research seeks to understand the conditions that frequently accompany autism and the support needs of autistic individuals who are affected by them.

In reading the proposed Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020 we have concerns regarding the inclusion of "Schedule 4, Part 2, 36 13 Advice on whether a person is a Commonwealth supported student—failure to complete previous units"⁵

¹ American Psychiatric Association, 2013

² Baio, et al (2018)

³ This submission includes content from consultation with the autism community via a 2020 survey participants in 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.

⁴ SASLA and ALSAA studies are funded by the Autism CRC. The SASLA study includes autistic and non-autistic respondents aged 17–27 and their parents/carers. The ALSAA study includes autistic and non-autistic adults 25 years and older and their families/carers. The DXC Dandelion project was funded by DXC Technology.

⁵ Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020

which “require a student to maintain an overall pass rate of 50 per cent to remain eligible for Commonwealth assistance”⁶.

We believe that mandating a 50% pass rate for all students disproportionately disadvantages autistic higher education students, because:

- front-line service providers, including psychologists and psychiatrists, and support workers are inadequately trained to offer support to autistic higher education students,
- current transition support services for Australian autistic youth are insufficient,
- support services within higher education institutions for autistic students are inadequate or non-existent, and
- the paucity of appropriately trained health professionals in Australia severely limits the ability of these students to obtain the services and documentation to support applications for special circumstances under the Higher Education Support Act 2003.

The combined effect of these specific circumstances creates a greater risk of autistic students withdrawing from study without completing their degree, which has flow-on detrimental effects for autistic people’s employment participation, and for their social inclusion generally.

RECOMMENDATION

Given that there is no provision within this Bill to expand funding for existing support services either to autistic higher education students, or to autistic high school students transitioning to further study, Schedule 4, Part 2, 36 13 of the Bill is likely to unfairly disadvantage autistic Australians and should be deleted.

⁶ Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020 explanatory memorandum.

SERVICE AVAILABILITY AND FRONTLINE WORKER KNOWLEDGE AND TRAINING

Several OTARC studies of autistic individuals and their parents/carers have revealed concerns about the availability and cost of services⁷. A thematic analysis of data of the Study of Australian School Leavers with Autism (SASLA)⁸ community survey in 2020 identified significant problems with accessibility and adequacy of services, including:

- difficulty locating available services, particularly after high school,
- lack of support to acquire employability skills,
- 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)

These barriers are likely to have a negative effect on university study performance. The analysis also identified inadequacies in knowledge of autism and associated difficulties in front-line service providers, including many psychologists and psychiatrists, and support workers. This knowledge gap increases the difficulty and stress involved in collating evidence for special consideration at university.

"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)

SERVICES FOR THE TRANSITION FROM SCHOOL TO FURTHER STUDY FOR AUTISTIC PEOPLE

Support services for autistic Australians 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 support⁹. 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 support¹⁰.

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

⁷ Flower et al (2019b)

⁸ <https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years>

⁹ e.g. Cai and Richdale (2016), Parliament of Victoria (2017)

¹⁰ Flower et al (2019a)

A study funded by DHS Victoria and entitled "Supporting transition to and participation in tertiary education for students with an Autism Spectrum Disorder"¹¹ highlighted some of the problems with transition supports. 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 1).

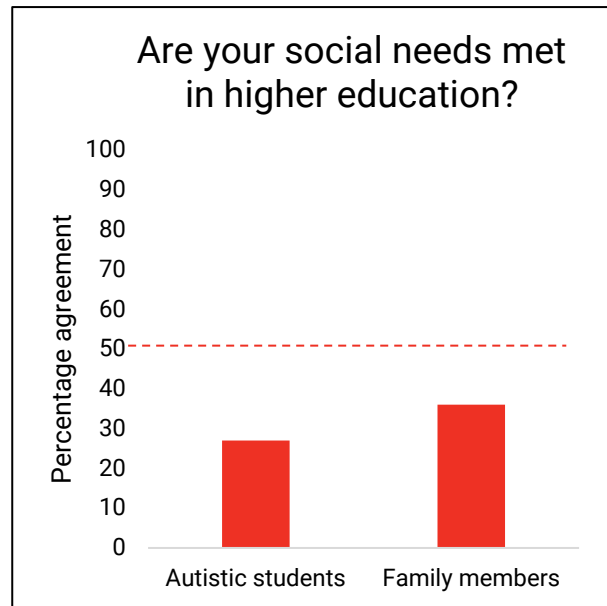


Figure 1 – Percentage agreement that “students’ social needs were met in higher education”

Figure 2 shows a summary of the challenges reported by the participants in the DHS study.

¹¹ 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 2 – Key areas affecting progress in higher education

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).

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.”

Staff members or parents talking about challenges of autistic students:

"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.

Autistic tertiary students reported a need for structure and routine which can be lacking in education settings¹², which increases stress and anxiety, leading to decreased 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."*¹³
(Autistic tertiary student)

Services to support autistic youth and adults in tertiary education and employment are at best inadequate, and at worst entirely 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.

"Without considered and sufficient support, autistic people become under-functioning people. They are capable of so 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)

MENTAL AND PHYSICAL HEALTH SERVICES FOR AUTISTIC PEOPLE IN AUSTRALIA - BARRIERS TO STUDY SUCCESS

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. This population has higher rates of epilepsy¹⁴ and hearing or visual impairment¹⁵, anxiety and depression than the general population. Current rates of clinical anxiety or depression in autistic adults range from 23% to 46%¹⁶, while lifetime rates for anxiety and depression are 42% and 37% respectively¹⁷, which far exceeds the Australian general population rates of 26.3% and 15% for anxiety and depression respectively.¹⁸

Australian autistic youth were significantly more likely to report having a current diagnosis of depression, anxiety and/or ADHD than non-autistic youth (Figure 3). In addition, a large pooled Australian study¹⁹ found that 38% of autistic adults aged 15-80 years²⁰ had clinical levels of both anxiety and depression symptoms. These figures clearly demonstrate substantial need for autistic-specific mental health supports in early adulthood to ensure a successful university career.

¹² Richdale et al (2012)

¹³ Richdale et al (2012)

¹⁴ Lukmanji et al (2019)

¹⁵ Do et al (2017)

¹⁶ Murray et al (2019), Kent et al (2017), Thomas et al (2017), Uljarević et al (2019)

¹⁷ Hollocks et al (2019)

¹⁸ ABS (2008)

¹⁹ SASLA, ALSAA and Dandelion Program study

²⁰ Uljarević et al (2019)

Physical co-occurring conditions such as sleep disturbances, which are associated with poor mental health, are also common, with 64% of autistic individuals in the age range 15-80 years reporting poor sleep, compared with only 46% of non-autistic adults of similar ages.²¹

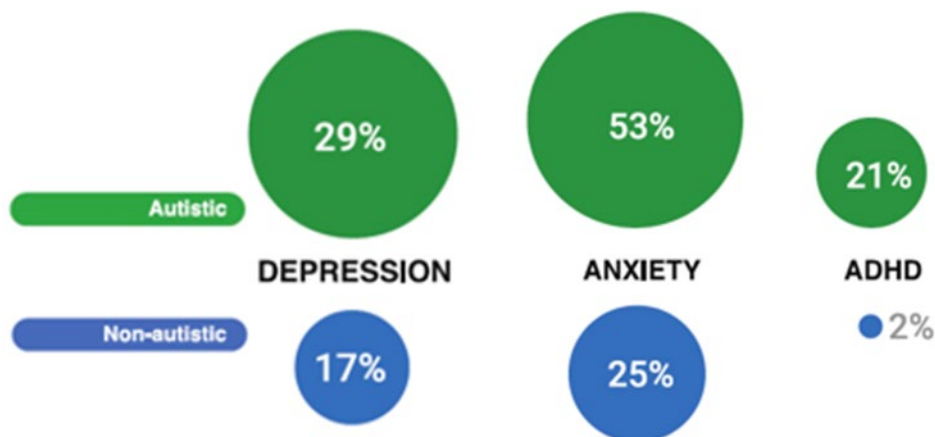


Figure 3 – Self-reported mental health difficulties in Australian autistic youth aged 15 to 25 years²²

A submission to the Royal Commission into Victoria's Mental Health System²³ by AMAZE, with content provided by OTARC researchers, identified significant deficits in professional training:

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,
- autistic individuals may understand or answer questions in a way that is 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.

Clearly, systemic changes are needed to better support autistic higher education students. An international scoping review (including Australian studies) of patient-service provider interactions with individuals with autism in healthcare settings found six themes for informing service improvement²⁴.

1. The complexity of working with autistic patients was beyond service providers' usual role.
2. Limited knowledge and resources negatively affected service provision to autistic patients and their families.

²¹ Jovevska et al (2020), SASLA, ALSAA combined data

²² Lawson et al (2019) SASLA baseline snapshot

²³ AMAZE submission to the Royal Commission into Victoria's Mental Health System (2019)

²⁴ Morris et al (2019)

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

Without widely available mental and physical health services, provided by capable, trained providers, these commonly occurring mental and physical health conditions, in addition to a diagnosis of autism, become a significant barrier to higher education success.

WIDER IMPLICATIONS OF THE BILL

Reducing the ability of autistic Australians to complete higher education reduces their ability to fully participate in Australian society. This will impact on their ability to obtain skilled employment, deprive them of autonomy and independence, and perpetuate their current social exclusion.

Employment

Employment offers a means of empowering autistic adults to become more engaged and active within their communities. It not only has the potential to improve the individual's own outcomes it also serves 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 disabilities (53%) or individuals without disabilities (84%)²⁵. These figures are well below the OECD average, where 60% of those with a disability are employed placing Australia 21 out of 26 OECD nations²⁶, and indicating much scope for improvement. Their employment rate will only worsen if fewer autistic students are able to complete their degrees – an outcome we believe will be a consequence of applying the 50% pass rate indiscriminately to all students.

"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)

Social inclusion

Social inclusion involves being able to contribute to society in a meaningful way through participation in mainstream activities like education, as well as participating in, and being represented in all facets of society.

"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)

There is still a lot of work to be done to enable autistic adults to live independently. In a large, Australian longitudinal study²⁷ we found that living independently (alone, couple, with others) as opposed to dependent living (parents or relatives) was related to better psychological quality of life for autistic adults. For many post-school autistic individuals attending university is a pathway to this independence.

"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

²⁵ Australian Bureau of Statistics (2018)

²⁶ PricewaterhouseCoopers (2011)

²⁷ Lawson et al (2020)

breaks down stigma fear and ignorance creating a learning format to understand and accept indifference out in the community.” (Family of an autistic individual)

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.

Website: www.latrobe.edu.au

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.

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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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