

This submission to the Review of the Disability Standards for Education is from a national Autism Mentoring Community of Practice (AMCoP) that is auspiced and supported by the National Disability Coordination Officer Program. AMCoP was established late 2019 and has membership of a significant number of Universities and TAFE providers across Australia. We thank you for this opportunity to draw attention to the impact of autism on students' participation and success in tertiary education environments and the potential for the Education Standards to alleviate some of the challenges and prevent potentially discriminatory practices experienced by this cohort of students.

How have the Education Standards helped people on the Autism Spectrum access and participate in education and training on the same basis as people without disability?

Background - Autism and Tertiary Education

As the number of people diagnosed with Autism Spectrum Disorder (ASD) continues to grow in Australia, making it the largest primary category in the NDIS¹, so too do participation rates in tertiary education. Evidence from Australia and overseas indicates that there are increasing numbers of students with Autism Spectrum Disorder (ASD) in the higher education sector.² However, despite this increase in enrolments many students are likely to either fall short of their potential or not achieve success in their academic pursuits.³

ABS data indicates that people with ASD are less likely than others to complete an educational qualification beyond school. Only 8.1% have a bachelor degree or higher, compared with 16.1% of those with a disability and 31.2% of those without disability.⁴ Up to 25% of students with ASD withdraw from higher education before completion.⁵ They are also less likely to hold an Advanced Diploma, Diploma or Certificate III or IV compared to people with disability and people who do not have a disability.⁶

Unfortunately, these lower attainment rates are even more concerning given the characteristic autistic tendency for hyper-focus on areas of specific interests, attention to detail, and the higher prevalence of a range of outstanding cognitive skills and talents within the ASD population compared to the general neurotypical population.⁷ Therefore, not only may there be individuals missing out on their potential, our academic institutions are losing some of our best minds from our tertiary systems. Australia may also be missing out on the opportunity to advance many fields of

¹ NDIS, Archived Quarterly Reports 2019-20. Accessed at <https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2019-20#second-quarter-2019-20-q2>

² Owen, C, McCann D., Rayner, C., Devereaux, C., Sheehan, F., & L Quarmby (2016) Supporting Students with Autism Spectrum Disorder in Higher Education. Accessed at <https://www.ncsehe.edu.au/wp-content/uploads/2016/03/Supporting-Students-with-Autism-Spectrum-Disorder-in-Higher-Education.pdf>

³ Ibid.

⁴ Australian Bureau of Statistics (ABS), Autism in Australia. Accessed at <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features102018>

⁵ Autism Spectrum Australia (2012) *We Belong: Investigating the experiences, aspirations and needs of adults with Asperger's disorder and high functioning autism.*

⁶ ABS (n4)

⁷ Meilleur, A-A, Jelenic, P., & L Motttron (2015) Prevalence of Clinically and Empirically Defined Talents and Strengths in Autism, *Journal of Autism Development Disorders*, 45(5).

enquiry and be as commercially competitive as possible in an ever changing national and international corporate landscape which is increasingly valuing diversity of thought and practice.

Students with ASD can face a multitude of challenges in tertiary learning environments such as: general transitioning; understanding and using communication channels; navigating the built environment; adjusting to different teaching formats; adopting helpful study and organisational techniques; limited access to social supports; and reaching out to available services.⁸ Additionally, ASD characteristics can lead to more general difficulties in being an independent student such as managing everyday routines, coping with anxiety, depression and social engagement while trying to manage other common comorbid conditions such as ADHD.

These academic challenges bear a direct relationship to the individual student's autism profile and are frequently at odds with the expectation of tertiary institutions that students will be independent learners responsible for managing their study load and contacting appropriate staff when necessary. The needs of students with ASD are highly idiosyncratic and are often beyond the scope of the usual supports and adjustments provided to students with disability by tertiary education providers.⁹

Mentoring programs

A number of tertiary education providers have invested in specialist programs to better provide equitable and inclusive access to their programs, services, facilities and events for students with ASD and therefore meet their obligations under the Education Standards. These include peer mentoring programs at Curtin University, ANU, University of Newcastle, University of Tasmania, and peer facilitated skills programs at Queensland University of Technology and the University of Southern Queensland. Our AMCoP membership indicates there is strong interest from a number of other tertiary institutions in establishing similar programs to address the present inequity experienced by these students when trying to complete their studies.

Evidence from other practices around Australia and internationally indicate that peer mentor programs are one of the most effective ways to support students with ASD with some of the challenges they face, such as planning and organising their studies, negotiating extensions, navigating on-line learning platforms, and settling into general student life.¹⁰

For example, one recent Australian research review has highlighted the difficulties for students with ASD transitioning into tertiary studies including anxieties about disclosing their disability, and that they often wait until a crisis arises before seeking assistance.¹¹ Having a strong and visible peer mentoring program within their institution provides proactive, individualised support, and can assist students to overcome some of the fear and anxiety they may have about disclosure and seeking the general student supports they need.

Participating in mentoring programs can also mitigate experiences of social isolation and encourage a sense of belonging to a community of learners that in turn can support academic retention and achievement. At the same time it enables students with ASD to develop greater independence and responsibility for their own circumstances, by identifying and making use of available supports both

⁸ Owen et al., (n2)

⁹ Owen et al., (n2)

¹⁰ Owen et al., (n2)

¹¹ Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2019). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*. 12(3).

directly from peer mentors and indirectly from other areas within their education institution, and in doing so increase their chances of academic success at university and at gaining employment later in adult life.

Therefore, a mentor can be considered as the equivalent to an interpreter for a deaf student in that they help the student leverage their academic strengths and improve their ability to participate in education and training on the same basis as people without disability.

During this year ADCET and AMCoP have collaborated to host two webinars on specialist peer programs. One was with mentors and students about how the programs work and the impact it can have, and one with just mentors about the benefits of mentoring for the mentors. Both webinars were hailed as very successful in providing valuable information to the sector. We acknowledge the support and the critical role that ADCET has in this space.

It is also important to note that Universities in the United Kingdom now regard specialist peer mentor programs as an essential adjustment for students with ASD. (See Appendix 1 for links to further information on UK initiatives).

How successful have we been?

Qualitative and quantitative evaluations from multiple stakeholder perspectives indicate that specialist mentoring programs can make a significant positive difference to the education experiences and outcomes of students with ASD (See Appendix 2). Evaluations of the Curtin University Specialist Peer Mentoring Program provide evidence that these programs can improve the social support, general communication apprehension and wellbeing of students with ASD and highlight the importance of interventions which are individualized, flexible, based on a social model and underpinned by social supports.¹²

¹² Siew, C.T., Mazzucchelli, T.G., Rooney, R., & Girdler, S. (2017) A specialist peer mentoring program for university students on the autism spectrum: A pilot study. Accessed at <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0180854>

How do you think the Standards could be improved to help overcome other barriers that may exist for some students on the Autism Spectrum accessing and participating in education and training?

Despite their success and effectiveness at meeting the requirements of the Education Standards, members of our AMCoP who coordinate such programs report high levels of uncertainty in regard to funding. There are no guarantees from one year to the next that programs will continue. This limits the scope for leveraging further off the successes of present programs and for future planning. It also discourages other tertiary institutions from considering the establishment of such programs without certainty of funding going forward.

Autism mentoring programs can be partially funded by the Australian Government of Education, Skills and Employment's Higher Education Disability Support Program (DSP) with the remaining funds provided at the universities' expense and discretion. Unfortunately, these successful mentoring programs are likely to be at greater risk and experience more uncertainty in the foreseeable future due to two factors:

- the current financial restraints within the university sector due to the implications of COVID-19 and global forces
- merging of the performance-based component of the DSP funding model into the Disability Support Fund rolling out over 2020 means funding will be allocated through both claims and formula based models and may mean less overall funding linked to providing student support.

We are therefore seeking consideration of the following three strategies which we believe will help improve tertiary education providers meet their requirements under the Education Standards and hence the participation experiences and outcomes of students with ASD.

1. Capture data on the prevalence of students with ASD in tertiary education

Currently the Australian Government Department of Education, Skills and Employment data collections mechanism - HEIMS – includes no designated code for students on the autism spectrum. Instead this data is incorporated under the neurological condition category. However, recording and tracking the numbers of student with ASD will provide a more accurate picture of this possibly growing cohort, and will allow us to analyse trends, and respond more systematically and strategically. Additionally, in alignment with commonly held premise that we value what we measure and in turn we measure what we value. Hence, we believe it is time to show that we value the participation and achievements of students with ASD in tertiary education through more accurate data collection.

2. Undertake a comprehensive review of the existing mentoring programs

There can be considerable variance between the different specialist mentoring programs provided in universities across Australia. While we believe that there is great value in having a range of different modes and approaches, the sector as a whole could benefit from a review of the existing programs. This could involve an analysis of the differences, comparisons, and the advantages of each of the different approaches, and establish benchmarks for good practice. This could enable not only tertiary providers to adopt

suitable strategies for their context but, more importantly, it could help individuals with ASD and their families make more informed choices about university selection.

3. Urgently provide more secure funding

As a matter of urgency, the Australian Government, establishes a funding stream for tertiary institutions to provide good practice specialist support programs – such as peer mentoring – for students with ASD to ensure they experience equity in tertiary education. This would also align Australia more closely with UK best practice in meeting the academic needs of students with ASD.

In conclusion

We thank you for your consideration of this submission. Members of our AMCoP would welcome the opportunity to provide you with further information should you require this.

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On behalf of

The Tertiary Autism Mentoring Community of Practice

Appendix 1

Links to Further Information on UK Initiatives

Universities in England provide Mentoring support for students with autism through the student's Disabled Students Allowance (government funded). Each student is individually assessed by an Independent Assessor (paid for by government) and given support according to their needs.

- Here is a guide to how it works and how to apply:

<https://www.ucas.com/student-finance-england/disabled-students-allowances#whats-available>.

- Further explanation can be found on the UK National Autistic Society's Advice and Guidance webpage.

<https://community.autism.org.uk/f/adults-on-the-autistic-spectrum/18733/student-finance-and-help-as-a-student>

- Two examples of UK University's specialist peer mentoring programs.

https://issuu.com/universityofexeter/docs/specialist_mentoring_for_autism_spectrum_condition

<https://www.autismhampshire.org.uk/how-we-can-help/university-mentoring-service/university-monitoring-service-subpage-1>

Appendix 2

Research on Curtin Specialist Mentoring Program

Hamilton, J. (2015). *Training and Experience of Mentors working with Tertiary Students with an Autism Spectrum Disorder*. Unpublished Master of Psychology (Clinical) Dissertation: Curtin University, Perth, Western Australia.

Hamilton, J., Stevens, G. & Girdler, S. (2016). Becoming a Mentor: The Impact of Training and the Experience of Mentoring University Students on the Autism Spectrum. *PLoS One*, 11(4):e0153204. doi:10.1371/journal.pone.0153204

McDonald, J., Kidd, T., Ting Siew, C., Hamilton, J., Unwin, L., Thompson, C., Evans, K., Black, M., D'Abbrera, J. & Girdler, S. (2016a) *Specialist Peer Mentoring Module: mentee information booklet*. Brisbane, Queensland: Cooperative Research Centre for Living with Autism.

McDonald, J., Kidd, T., Ting Siew, C., Hamilton, J., Unwin, L., Thompson, C., Evans, K., Black, M., D'Abbrera, J. & Girdler, S. (2016b) *Specialist Peer Mentoring Module: program coordinator manual*. Brisbane, Queensland: Cooperative Research Centre for Living with Autism.

McDonald, J., Kidd, T., Ting Siew, C., Hamilton, J., Unwin, L., Thompson, C., Evans, K., Black, M., D'Abbrera, J. & Girdler, S. (2016c) *Specialist Peer Mentoring Module: specialist mentor toolkit*. Brisbane, Queensland: Cooperative Research Centre for Living with Autism.

Siew, C. (2014). *An Evaluation of the Curtin Specialist Mentoring Program for University Students on the Autism Spectrum*. Unpublished Master of Psychology (Clinical) Dissertation: Curtin University, Perth, Western Australia.

Siew C.T., Mazzucchelli T.G., Rooney R. & Girdler S. (2017) A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PLoS ONE* 12(7):e0180854. <https://doi.org/10.1371/journal.pone.0180854>

Thompson C. , Bölte S., Falkmer T. & Girdler S. (2019) Viewpoints on how students with autism can best navigate university, *Scandinavian Journal of Occupational Therapy*, 26(4), 294-305, DOI: 10.1080/11038128.2018.1495761

Thompson C., Falkmer T., Evans K., Bölte S., & Girdler S. (2018) A realist evaluation of peer mentoring support for university students with autism. *British Journal of Special Education*. 45 (4) 412-434, DOI: 10.1111/1467-8578.12241

Thompson C., McDonald J., Kidd T., Falkmer T., Bölte S., & Girdler S. (2020) "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students, *Scandinavian Journal of Occupational Therapy*, , 1(16) , DOI: 10.1080/11038128.2020.1738545