

Supporting mental health: What young Australian autistic adults tell us

Richdale, A.L., Haschek, A., Lawson, L.P., Haywards, S.M., & Abdullahi, I. (2020). Supporting mental health: What young Australian autistic adults tell us. Melbourne, Victoria: La Trobe University. <https://doi.org/10.26181/5fdc10c56879a>



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program



LA TROBE
UNIVERSITY



Olga Tennison
Autism Research Centre

This document is for health professionals who work with autistic adolescents and adults. The information presented is based on research findings from the Autism CRC's Study of Australian School Leavers with Autism (SASLA)^a.

Summary of clinical implications:

Mental health and wellbeing are critical to supporting autistic Australians, especially for females, those living alone, or with high levels of loneliness, and those with limited social supports.

Increasing adaptive **emotion regulation** strategy use is likely to positively impact mental health outcomes, regardless of maladaptive strategy use.

Targeting **psychological flexibility** in autistic adults has the capacity to reduce anxiety and depression symptoms.

When considering the mental health of autistic adults, satisfaction with **social supports** is more important than the quantity of social supports, while reducing loneliness could buffer against suicidal ideation.

Treating **sleep** difficulties is important for autistic clients; autistic individuals, particularly females, are highly susceptible to sleep difficulties. Better sleep quality is associated with better mental health, and thus sleep difficulties may be positively influenced by the treatment of mental health conditions.

Treating both mental health problems and sleep problems may assist in improving **quality of life** and may lead to improved psychological wellbeing for autistic adolescents and adults.

Both the **HADS** and **PHQ-9** demonstrate similar properties in autistic adult samples to that of community samples and can be used by clinicians to measure anxiety and depression in autistic adults aged 15 to 80.

^a You can contact the SASLA team via email: SASLA@latrobe.edu.au. SASLA is a survey-based study following autistic ($n = 115$) and non-autistic ($n = 218$) adolescents and young adults aged 15 to 25 years over 2 years (baseline, 1- and 2-years). A full cross-sectional profile of the SASLA sample is available [here](#). Many publications from the SASLA use a combined dataset with our sister study – the Australian Longitudinal Study of Adults with Autism (ALSAA)¹ which surveyed autistic and non-autistic adults aged over 25 years of age at baseline and 2 years later (<https://bmjopen.bmj.com/content/9/12/e030798>).

1. Prevalence and predictors of anxiety and depression in autistic youth and adults in Australia

- Autistic adults were more likely to reach clinical cut-offs for depression and anxiety^b compared to non-autistic adults (Figure 1)¹.
- 53% of autistic youth with no co-occurring intellectual disability (15-25 years) reported a current anxiety diagnosis.
- Co-occurring clinical anxiety and depression symptomatology was common in autistic Australians aged 15 to 80 years (Figure 2)¹.

Figure 1: Depression and anxiety prevalence rates for an Australian autistic and general population sample^c.

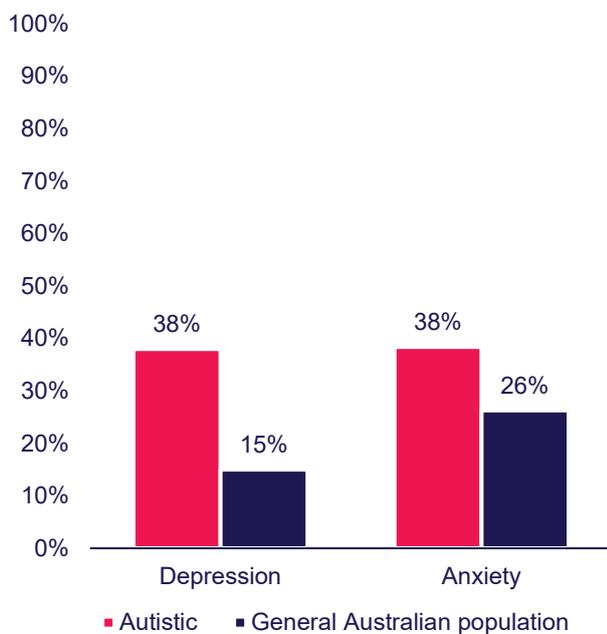
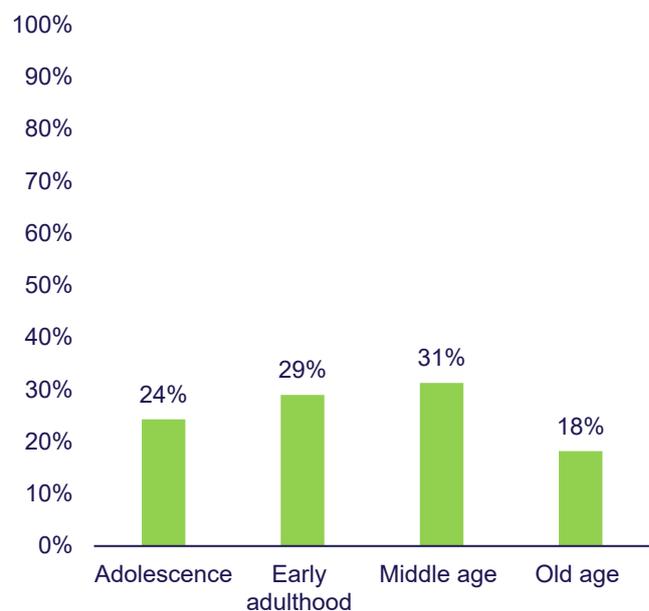


Figure 2: Proportion of autistic Australians meeting clinical cut-off for both anxiety and depression across the lifespan



Predictors of anxiety and depression in autistic Australians (15-80 years)

- 1. Being female** - females were more likely to experience anxiety and depression and reach clinical cut-offs across the lifespan^{1,2}.
- 2. Autism traits** – greater extent of autism characteristics (AQ-short) was related to increased anxiety and/or depression symptoms¹.
- 3. Living conditions** - living alone was associated with higher depressive symptoms¹.
- 4. Loneliness** – high levels of loneliness was associated with elevated depressive symptoms².

^b SASLA & ALSAA data; Depression measured with PHQ-9, Anxiety measured using DSM5-GAD

^c general population data - [2007 National Survey of Mental Health and Wellbeing highlights](#)

5. Social supports – Fewer social supports and lack of satisfaction with social supports was associated with elevated depressive symptoms².

6. Sleep – those with poor sleep quality were more likely to be female, report a mental health condition, be taking medication and have a greater extent of autistic traits³.

Clinical implications

Mental health and wellbeing are critical to supporting autistic Australians, especially for females, those living alone, or with high levels of loneliness, and those with limited social supports.

2. Emotional regulation

Emotion regulation is crucial for healthy adaptation⁴ and maintaining and improving psychological health. Despite common difficulties with emotion regulation in autistic individuals⁵, research shows that intervention can improve emotion regulation in autistic individuals⁶.

Our research found that:

- Adaptive strategies (e.g., reappraisal) buffer against maladaptive strategy use (e.g., suppression) on depression, anxiety and mental wellbeing regardless of autism trait extent⁷.
- Dampening (e.g., reminding yourself that feelings are temporary) and blaming others reduced mood in autistic people⁸.
- Savouring (enjoying the moment) and emotion acceptance strategies improved mood in autistic people⁸.
- The negative effects of long-term suppression usage may be lessened by the long-term use of reappraisal⁴.

Self-regulation of emotion reactivity and behaviour is an important skill that allows an individual to adjust to the demands of a situation in a flexible and controlled way. The SASLA study found that lower levels of self-regulation were related to higher levels of anxiety and insistence on sameness in autistic adults⁹.

Clinical implications

Increasing adaptive emotion regulation strategy use is likely to positively impact mental health outcomes, regardless of maladaptive strategy use.

3. Psychological inflexibility

Psychological inflexibility (e.g., insistence on sameness and intolerance of uncertainty) is very common among autistic individuals and has been linked to poorer mental health outcomes in the non-autistic population.

We found that in autistic adults⁹:

- High levels of insistence on sameness were related to anxiety, and that together higher anxiety and insistence on sameness were related to lower levels of self-regulation.
- The relationship between emotion regulation and mental health is either fully (anxiety) or partially (depression) explained by intolerance of uncertainty.

Clinical implications

Targeting psychological flexibility in autistic adults has the capacity to reduce anxiety and depression symptoms.

4. Suicidal ideation

Autistic people are at an increased risk of suicidal thoughts and behaviour, due to higher levels of social isolation and depression².

We found that²:

- 19.7% of autistic adults had experienced suicidal ideation in the last 2 weeks (2.4% in general population)
- Lower reported loneliness and higher satisfaction with social supports was protective against depression and suicidal ideation.

Clinical implications

When considering the mental health of autistic adults, satisfaction with social supports is more important than the quantity of social supports and thus reducing loneliness could buffer against suicidal ideation.

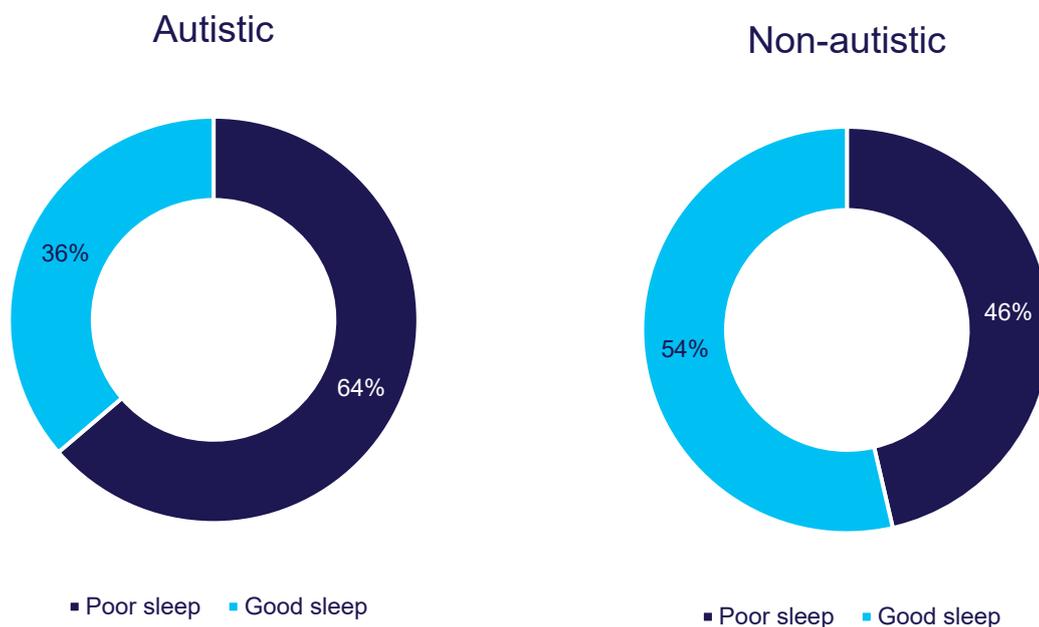
5. Sleep

Insufficient sleep can have a negative effect on multiple aspects of physical and mental health and can impair daytime functioning. Poor sleep quality is very common for autistic people, with difficulty getting to sleep, night waking and shortened night sleep being most common that is, insomnia.

We found that³:

- Greater extent of autistic traits and the presence of a mental health condition, increased risk for poor sleep quality.
- Autistic females were at a higher risk for sleeping difficulties.
- Poor sleep quality was more common for autistic individuals than non-autistic individuals (Figure 3).
- Autistic adults aged 20 to 59 years were at a higher risk for sleeping difficulties, while in adolescence sleep was poor for both autistic and non-autistic young people.

Figure 3: rates of good and poor sleep in an autistic and non-autistic Australian sample



Clinical implications

Treating sleep difficulties is important for autistic clients; autistic individuals, particularly females, are highly susceptible to sleep difficulties. Better sleep quality is associated with better mental health, and thus sleep difficulties may be positively influenced by the treatment of mental health conditions.

6. Quality of life

Mental health, sleep quality and psychological wellbeing are important for autistic adolescents' and adults' quality of life. We found that¹⁰:

- depression and poor sleep quality predicted poorer quality of life,
- increased autonomic symptoms predicted poorer quality of life,
- better psychological wellbeing predicted better quality of life, and
- quality of life at entry into SASLA and ALSAA predicted quality of life 2-years later.

Clinical implications

Treating both mental health problems and sleep problems may assist in improving quality of life and may lead to improved psychological wellbeing for autistic adolescents and adults.

7. Newly validated scales for measuring anxiety and depression in autistic adults

The Hospital Anxiety and Depression scale (HADS)

The HADS questionnaire measures anxiety and depression symptoms in the last week^d. Using a sample of 45 SASLA (Aust sample) + 151 UK Transition longitudinal study (UK sample) autistic adolescents and young adults we found that¹¹:

- The HADS demonstrated statistically similar properties in the autistic sample to a non-autistic sample
 - Internal consistency (Cronbach's alpha) was good $\alpha = .83$.
 - Demonstrated good convergent and divergent validity.

Patient Health Questionnaire-9 (PHQ-9)

The PHQ-9 measures depression symptom severity and functional impairment in the last 2 weeks. Using an Australian sample of 346 autistic + 235 community comparison participants from the SASLA and ALSAA studies ages 15-80 years we found that¹²:

^d The use of the HADS is licensed by GL Assessment. www.gl-assessment.co.uk

- The PHQ-9 demonstrated statistically similar properties in the autistic sample to a non-autistic sample.
 - Internal consistency (Cronbach's alpha) was excellent for autistic and community comparison samples $\alpha = .91$.
 - Demonstrated good convergent validity.

Clinical implications

Both the HADS and PHQ-9 demonstrate similar properties in autistic adult samples to that of community samples and can be used by clinicians to measure anxiety and depression in autistic adults aged 15 to 80.

8. Co-production and consultation

In 2014, a Victorian adult forum was conducted with members of the autism community including autistic individuals, parents, service providers and autism organisations and associations (e.g. Aspect) to establish areas of focus to be included in the longitudinal study. The outcomes from this forum informed the Study of Australian School Leavers with Autism (SASLA) survey composition (e.g. employment, education, physical, and mental wellbeing).

We continue to seek advice from community members comprising autistic adults, autism associations, and parents of autistic individuals including feedback on our research. In 2019, we published our first research article with an autistic co-author who undertook a student placement with the SASLA team. Read more about their experience [here](#).

In January 2020, we invited our SASLA community to help us determine our future research directions for the use of our longitudinal data. The SASLA community is made up of autistic individuals aged 17–27, their parents/carers, members of autism-specific organisations and individuals who work with autistic people. The number one, most important area was mental health.

9. Acknowledgements

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. The authors would like to acknowledge the research participants who dedicated their time to the project. We further acknowledge Dr Mirko Uljarevic and Dr Ru Ying Cai for project establishment and data collection, and members of the Autism CRC Program 3 team

who contributed to project content and recruitment. Staff and non-staff in kind support, including recruitment, was also provided by Autism CRC and Other participants ([listed here](#)), other autism associations, a Victorian Secondary School, and many other individuals.

The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

Website: <https://www.autismcrc.com.au/>

Phone: +61 (0)7 3377 0600

Email: info@autismcrc.com.au

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: <https://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.

Website: <https://www.latrobe.edu.au/otarc>

Blog: <http://otarc.blogs.latrobe.edu.au/>

Facebook: <https://www.facebook.com/OlgaTennisonAutismResearchCentre/>

Email: otarc@latrobe.edu.au

10. References

1. Uljarević, M., Hedley, D., Rose-Foley, K., Magiati, I, Cai, R. Y., Dissanayake, C., Richdale, A.L., Trollor, J. (2020). Anxiety and Depression from Adolescence to Old Age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(9), 3155-3165. <https://doi.org/10.1007/s10803-019-04084-z>
2. Hedley, D., Uljarević, M., Foley, K. R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying depression and suicidal ideation in Autism Spectrum Disorder. *Depression and anxiety*, 35(7), 648–657. <https://doi.org/10.1002/da.22759>
3. Jovevska, S., Richdale, A.L., Lawson, L.P., Arnold, S.R.C., & Trollor J.N. (2020). Sleep problems in autism from adolescence to old age. *Autism in Adulthood*, 2(2), 152-162. <https://doi.org/10.1089/aut.2019.0034>
4. Cai, R.Y., Richdale, A.L., Dissanayake, C., Trollor, J., Uljarević, M. (2019). Emotion regulation in autism: Reappraisal and suppression interactions. *Autism*, 23(3), 737-749. <https://doi.org/10.1177/1362361318774558>
5. Cai, R. Y., Richdale, A. L., Uljarevic, M., Dissanayake, C., & Samson, A. C. (2018). Emotion regulation in autism spectrum disorder: where we are and where we need to go. *Autism Research* 11, 962–978. <https://doi.org/10.1002/aur.1968>
6. Mennin, D.S., & Fresco, D.M. (2009). Emotion regulation as an integrative framework for understanding and treating psychopathology. In A. M. Kring, & D. M. Sloan (Ed.), *Emotion regulation and psychopathology: A transdiagnostic approach to etiology and treatment*. New York: The Guilford Press.
7. Cai, R.Y., Richdale, A.L., Foley, K-R., Trollor, J., & Uljarević, M. (2017). Brief report: Cross-sectional interactions between expressive suppression and cognitive reappraisal and its relationship with depressive symptoms in autism spectrum disorder. *Research in Autism Spectrum Disorders*, 45, 1-8. <https://doi.org/10.1016/j.rasd.2017.10.002>
8. Cai, R. Y., Richdale, A. L., Dissanayake, C., & Uljarević, M. (2020). How Does Emotion Regulation Strategy Use and Psychological Wellbeing Predict Mood in Adults With and Without Autism Spectrum Disorder? A Naturalistic Assessment. *Journal of autism and developmental disorders*, 50(5), 1786–1799. <https://doi.org/10.1007/s10803-019-03934-0>
9. Uljarević, M., Richdale, A.L., Evans, D.W., Cai, R.Y., & Leekam, S.R. (2017). Interrelationship between insistence on sameness, effortful control and anxiety in

- adolescents and young adults with autism spectrum disorder (ASD). *Molecular Autism*, 8(1), 36. <https://dx.doi.org/10.1186%2Fs13229-017-0158-4>
10. Lawson, L.P., Richdale, A.L., Haschek, A., et al. (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. <https://doi.org/10.1177/1362361320908107>
11. Uljarević, M., Richdale, A.L., McConachie, M., Hedley, D., Cai, R.Y., Merrick, H., Parr, J. R., Le Couteur, A. (2018). The Hospital Anxiety and Depression Scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research*, 11(2), 258-269. <https://doi.org/10.1002>
12. Arnold, S. R. C., Lawson, L., Hwang, Y. I., Uljarevic, M., Richdale, A.L., & Trollor, J. (2020). Brief Report: Psychometric Properties of the Patient Health Questionnaire-9 (PHQ-9) in Autistic Adults. *Journal of Autism and Developmental Disorders*, 50(6), 2217-2225. <https://doi.org/10.1007/s10803-019-03947-9>



AutismCRC

Autism CRC

The University of Queensland
Long Pocket Precinct
Level 3, Foxtail Building
80 Meiers Road
Indooroopilly Qld 4068
T +61 7 3377 0600
E info@autismcrc.com.au
W autismcrc.com.au



@autismcrc

Our values



Inclusion

Working together with those with the lived experience of autism in all we do



Innovation

New solutions for long term challenges



Independence

Guided by evidence based research, integrity and peer review



Cooperation

Bringing benefits to our partners; capturing opportunities they cannot capture alone



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program