

Submission
No 25

INQUIRY INTO PREVALENCE, CAUSES AND IMPACTS OF LONELINESS IN NEW SOUTH WALES

Organisation: Olga Tennison Autism Research Centre

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Olga Tennison Autism Research Centre
School of Psychology and Public Health

OLGA TENNISON AUTISM RESEARCH CENTRE:

Response to the inquiry into the prevalence, causes and impacts of loneliness in New South Wales

Latrobe.edu.au/otarc

ENQUIRIES

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INTRODUCTION

La Trobe University's Olga Tennison Autism Research Centre (OTARC) welcomes the opportunity to provide a submission to the New South Wales (NSW) government's inquiry into the prevalence, causes and impacts of loneliness. Established in 2008, OTARC is Australia's first Autism research centre. Our vision is to help Autistic people, their families, and carers thrive. Our internationally recognised research influences global perspectives and drives change through public accountability, community engagement, and collaboration with governments and industries. As a leading global research centre, we prioritise working closely with the Autistic community, advocates, and researchers.

Autism¹ is a lifelong neurodevelopmental difference, characterised by challenges with social communication and interaction, and engagement in non-social differences such as repetitive behaviours, intense interests, and/or unusual sensory experiences including sensory hyper-reactivity. In 2024, 290,900 (1.1%) Australians reported a diagnosis of autism.² This is likely to be an underestimate, with recent studies estimating prevalence closer to 3–4%.³ We estimate that over 296,000 Autistic people currently reside in NSW.⁴

This submission focuses on providing evidence-based recommendations that aim to benefit Autistic residents of New South Wales by highlighting their elevated risk of loneliness (Term of Reference [TOR] b) and the significant impacts this has on their physical and mental wellbeing (TOR c).

Autistic people are particularly at risk of loneliness and social isolation, experiencing higher levels of disconnection than non-Autistic peers. For example, young Autistic Australians frequently report feeling isolated and lacking companionship, with these feelings linked to poorer mental health outcomes such as increased anxiety and depression. Contributing factors include discrimination, stigma, bullying, and "othering," which exacerbate social isolation. Additionally, Autistic adults face unique challenges such as fewer social supports and higher rates of depression and anxiety, all of which contribute to increased loneliness.

Loneliness has significant psychological and physiological impacts, particularly for Autistic people, and is a key risk factor for mental health issues and suicidality. Autistic people experience higher rates of anxiety, depression, and suicidal ideation, with loneliness and poor social support contributing to these risks. This experience is exacerbated by intrapersonal factors such as difficulty expressing emotions and cognitive inflexibility. Autistic people are three to five times more likely to die by suicide than the general population. Systemic barriers, such as difficulty accessing healthcare, further compound the effects, particularly for those with additional vulnerabilities such as higher anxiety, disability, or dissatisfaction with social supports.

¹ American Psychiatric Association (2013); [We use identity-first language \(e.g. Autistic\)](#).

² Australian Bureau of Statistics (2022)

³ Barbaro et al (2010), Barbaro et al (2022), Sadka & Barbaro (2024)

⁴ Australian Bureau of Statistics (2024)

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RECOMMENDATIONS

Our recommendations are based on national and international evidence and are grounded in principles of intersectionality, co-production, neurodiversity-affirming research, the social model of disability, and a human rights approach. These principles acknowledge the intrinsic right of all to inclusion in all aspects of society, and that attitudes, practices, and structures create barriers that hinder people from enjoying equal rights within society.⁵

Recommendation 1. Recognise Autistic people as a priority group for higher risk of loneliness and social isolation.

Recommendation 2. Entrench co-production⁶ principles in all new mental health policy and service delivery initiatives. The New South Wales government authorities will take proactive steps to involve Autistic people from the outset.

Recommendation 3. The New South Wales government to develop and implement an evidence-based, comprehensive, lifespan-focused mental health strategy that emphasises early identification and sustained support for Autistic people experiencing mental ill health. This strategy will:

- provide guidance across the lifespan including primary and high school, and university to eliminate loneliness and improve mental health among Autistic people;
- co-developed with Autistic people and the broader Autism community;
- provide guidance for supports at key transitional stages. For example, critical post-secondary support during the challenging transition out of formal education, often referred to as the "post-school cliff";
- outline training requirements for teachers and mental health service providers about the unique presentation and risk factor of mental ill health of neurodivergent people and the evidence-based supports available;
- provide a road map to increase the accessibility and number of appropriate community-based supports for Autistic people with the goal of ensuring that no Autistic person is isolated within their community.

Recommendation 4. Establish funding targeted, competitive grant or tender opportunities to:

- encourage partnerships between neurodiversity-affirming mental health organisations, autism peak bodies, autism peer

⁵ Australian Human Rights Commission (2007), Commonwealth of Australia (Department of Social Services) (2021)

⁶ den Houting (2021)

groups and community groups to provide safe, supportive environments for individuals of all ages to engage in social activities;

- focus on loneliness in Autistic people with the goal being the development of evidence-based support programs that are community integrated.

Applications that involve the Autistic or autism communities must demonstrate how the proposed project will contribute to the reduction in social isolation and loneliness of Autistic people in New South Wales. They must also demonstrate co-production strategies to ensure the project's relevance to those communities.

Recommendation 5. Implement strengthened, timely transition supports for Autistic students into secondary school and into higher education and training through comprehensive consultation with Autistic students, their families and education, health and care professionals targeting:

- accessible and equitable access to transition supports for Autistic students;
- acceptability and suitability of supports for Autistic students with an intellectual disability;
- supporting social connection and eliminating isolation;
- mental wellbeing.

Recommendation 6. Conduct a review of planning and building legislation with the view to amend these laws to include consideration for accessibility of public spaces for Autistic people.

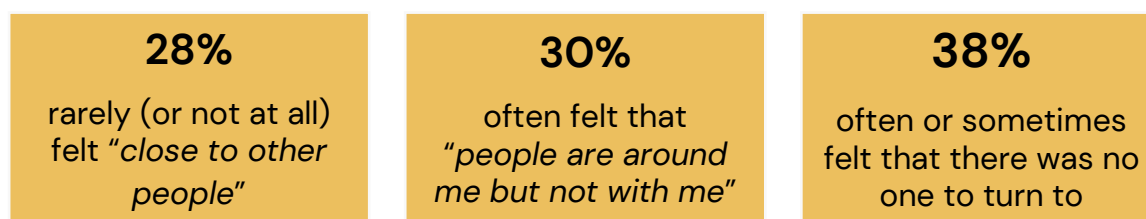
Recommendation 7. Invest in community mental health initiatives that foster social inclusion, particularly for those suffering from depression, which can exacerbate loneliness.

Recommendation 8. The New South Wales government to engage in an evidence-based, co-produced public education campaign on Autism to:

- dispel myths regarding a 'right way' to engage socially;
- increase awareness and acceptance of Autistic social-communication styles, with an aim to facilitate social inclusion of Autistic people;
- facilitate access to co-produced public mental health material specific to Autistic people, such as [The Suicide Response Project](#).

1. AUTISTIC PEOPLE: A POPULATION AT RISK OF LONELINESS AND SOCIAL ISOLATION

Identifying populations most at risk of loneliness and social isolation is critical, and research shows that Autistic people experience higher levels of loneliness compared to their non-Autistic peers across the lifespan.⁷ Despite misconceptions that Autistic people do not desire social and other (e.g., intimate) relationships, Autistic people in fact desire social relationships in the same way as non-Autistic people but, due to social communication differences associated with their clinical diagnosis, and others' responses to these differences which can include rejection, discrimination, and victimisation, face significant difficulties forming relationships with their peers.⁸ Consequently, within this population loneliness is endemic, with dire consequences for mental health and wellbeing. Our research shows that **Autistic Australians experience higher levels of loneliness than their non-Autistic peers**, correlating with elevated depressive symptoms.⁹ We asked young Autistic Australians (15–25 years) about their connections to others. We found that they:



- **Twice as likely** to have often felt "isolated from others" (30%) and "left out" (31%) than non-Autistic youth.
- Almost **3 times as likely** to report a lack of companionship (28%) than non-Autistic youth.

An Australian mixed-methods study¹⁰ shows that Autistic Australian adults score significantly higher on the University of California, Los Angeles (UCLA) loneliness scale than non-Autistic Australian adults. Stronger Autistic traits, reduced contact with friends and family, fewer support persons and lower satisfaction with them, higher levels of depression and anxiety (which are more common in Autistic populations), and decreased self-efficacy were all linked to loneliness in both Autistic and non-Autistic groups. Unemployment significantly contributed to loneliness exclusively among the Autistic group. Qualitative responses from this study found three themes:

1. **Satisfaction and dissatisfaction in socialisation** – participants reported feelings of isolation, with statements like: "I don't really socialise (...) as much as I'd like...I feel more isolated and alone than I do connected with the world," "can't seem to have proper friendships."

⁷ Hedley et al (2018b); Bauminger et al (2008); Orsmond et al (2004); van Asselt-Goverts et al (2015); Whitehouse et al (2009)

⁸ Headly & Young (2006); Symes & Humphrey (2010)

⁹ Hedley et al (2018a)

¹⁰ Ee et al (2019)

2. **Interpreting socialisation** – described past negative experiences that led them to withdraw from social interaction: “people have been so cruel to me, I don't socialise ever anymore.”
3. **Barriers to and supports for socialisation** – some participants felt misunderstood in social settings, sharing sentiments like: “I think I come off to others as aloof when that's not how I am,” “they cannot ever understand what really goes on in my atypical mind.”

This feeling of isolation and disconnection persists over time. Our research¹¹ found that Autistic Australians aged (15–70) experience a **significantly lower quality of life** across four key areas—physical, psychological, social, and environmental—compared to non-Autistic peers. Specifically, in the social domain, which covers personal relationships, social support, and sexual activity, Autistic people consistently reported poorer outcomes. Of concern, social quality of life did not improve over the two years of the study.

1.1. CONTRIBUTORS TO SOCIAL ISOLATION AND LONELINESS

1.1.1. Discrimination, stigma, and "othering"

Several factors contribute to heightened loneliness in the Autistic population. Loneliness in Autistic populations is influenced by several key factors, including **discrimination, stigma, and "othering" (being viewed or treated as fundamentally different)**. These experiences can make it harder for Autistic people to feel accepted, leading to social isolation and poorer mental health. Social and communication differences often result in feelings of being disconnected from others (thwarted belongingness) and feeling like a burden, which contribute to loneliness and is one of the primary factors underpinning suicidal thoughts and behaviour.

“As outsiders, we are teased, ridiculed, ignored, turned on. It seems our behaviour triggers others towards predatory actions, and this includes exclusion. This feels painful and scary. Loneliness holds as many health risks as poor lifestyle choices...”

Hall, 2019¹²

1.1.2. Bullying

Bullying is another major factor contributing to social isolation and loneliness. Bullying in the general population is associated with higher depression symptoms, suicidal ideation,¹³ and suicide attempts, consistent across primary and secondary school settings.¹⁴ Those with multiple marginalised identities (e.g. autism, mental health conditions, other disabilities) tend to show the highest rates of being bullied compared

¹¹ Lawson et al (2020)

¹² Lawson (2020)

¹³ Chang et al (2024)

¹⁴ Klomek et al (2011)

to other vulnerable groups.¹⁵ Bullying of Autistic adolescents is associated with heightened depression and anxiety symptomology, and an increased risk of suicidal thoughts or behaviours.¹⁶ Peer rejection exacerbates these effects, particularly in relation to depression, highlighting the need for targeted prevention programs and further research.¹⁷

In Australia, 50–58% of Autistic youth reported bullying during their schooling.¹⁸

Our research into the bullying experiences of Autistic youth (aged 15–15)¹⁹ found that it is very common, with 58% of Autistic youth without an intellectual disability, 50% of Autistic youth with an intellectual disability and 44% of non–Autistic participants reporting having been bullied or picked on at school. Teasing was the most common form of bullying. Two–thirds of Australian Autistic youth had been teased or called names at school.

Social isolation and loneliness are common among Autistic youth due to difficulties in forming and maintaining peer relationships.²⁰ Challenges associated with social communication, can affect interpersonal relationships and friendships, leaving Autistic youth socially isolated and vulnerable to bullying²¹. This in turn exacerbates anxiety and isolation.²²

“When I was younger and more obviously odd and strange I was thought of as stupid and also badly physically and mentally bullied. I also lost employment. I want to avoid the bullying mostly. I have even been spat at in the street.”

Female, 49²³

1.1.3. Minority stressors

Minority stressors, including everyday discrimination, internalised stigma, and concealment, significantly predict poorer mental health for Autistic people, even when general stress exposure is considered.²⁴ In the general population, social and informal support from family and friends is crucial for seeking professional help.²⁵ However, for Autistic people, fundamental social–communication differences can make it more

¹⁵ Galán et al (2021)

¹⁶ Holden et al (2020); Chou et al (2020); Wright et al (2019)

¹⁷ Wright et al (2019)

¹⁸ Richdale et al (2022)

¹⁹ Richdale et al (2022)

²⁰ Anderson et al (2017)

²¹ Junttila et al (2024)

²² Junttila et al (2024)

²³ Hull et al (2017)

²⁴ Botha and Frost (2020)

²⁵ Han et al (2018)

challenging to form supportive relationships, leading to increased loneliness and depression.²⁶

"I had never heard the verb "othering." Then one day a senior academic, who I had been working with for several years, asked me to participate in his talk. I stood on the stage as I was introduced to the packed conference: "This is Cos, an Autistic adult." So there I was, a woman in late middle age, fully equipped with white hair and breasts; yet apparently this needed stating, out loud, to my face, in front of an audience. I was being shown off as a specimen and I was mortified. Nobody else was introduced as an adult, as people are assumed to be adults, unless they are children."²⁷

To fit in, Autistic people often engage in **masking or camouflaging**, where they use strategies and behaviours to hide or 'mask' their Autistic differences.²⁸ Masking may be done in an attempt to appear "normal" and cope with life in a non-Autistic world or to hide differences that would cause them to stand out, which can include pain and other health-related symptoms. Studies have shown that masking is related to feeling anxious, stressed, sad, and exhausted.²⁹ A 2017 study asked Autistic people about the consequences of camouflaging. The resulting quotes from the study displayed below clearly demonstrate the impact of camouflaging on the Autistic person.³⁰

It's mentally exhausting constantly having to be something else, literally never being able to be myself, and kind of sad too I guess?

Female, 20

I feel sad because I feel like I haven't really related to the other people. It becomes very isolating because even when I'm with other people I feel like I've just been playing a part.

Female, 30

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²⁶ Mazurek (2014); Rai et al (2018a; 2018b)

²⁷ Michael (2021)

²⁸ Cook et al (2021)

²⁹ Bargiela et al (2016); Hull et al (2017); Tierney et al (2016); Miller et al (2021)

³⁰ Hull et al (2017)

2. EVIDENCE OF THE PSYCHOLOGICAL AND PHYSIOLOGICAL IMPACTS OF LONELINESS ON AUTISTIC PEOPLE

2.1. PSYCHOLOGICAL AND PHYSIOLOGICAL IMPACTS OF LONELINESS

Loneliness has profound psychological and physiological consequences that affect mental and physical well-being, particularly for Autistic people. Loneliness is a significant interpersonal risk factor linked to suicidality in Autistic people, alongside unmet support needs.³¹ In addition, several intrapersonal factors contribute to this risk, including alexithymia (difficulty identifying and expressing emotions), emotion dysregulation, rumination, low self-esteem, camouflaging efforts (concealing Autistic traits or behaviour), communicative impairments, and cognitive inflexibility.³² These factors, **particularly loneliness**, play a crucial role in the mental health challenges faced by Autistic people.

2.2. CO-OCCURRING MENTAL HEALTH CONDITIONS

Autistic people are at exceptionally high risk of **co-occurring mental health conditions**,³³ with up to 46% of Autistic adults reporting current clinical anxiety or depression, significantly exceeding rates in the Australian general population (i.e. 26%).³⁴

Autistic people are almost twice as likely to experience mental illness compared to the Australian general population³⁵

Our research showed that female gender and a greater extent of Autistic traits increased the risk for anxiety and/or depression.³⁶ The risk conferred by Autistic traits was due, in part, to feelings of loneliness and (dis)satisfaction with social supports.³⁷ Lower reported loneliness and higher satisfaction with social supports was protective against depression and suicidal ideation.³⁸ Therefore, when considering the mental health of Autistic adults, satisfaction with social supports is more important than the quantity of social supports

³¹ Hedley et al (2018b); Cassidy et al (2018)

³² Arwert & Sizoo, (2020); Cassidy et al (2018, 2020); Connor et al 2020; Costa et al., 2020; Paquette-Smith et al 2014; Richards et al 2019; South et al 2020

³³ Murray et al (2019); Kent et al (2017); Thomas et al (2017); Uljarević et al (2020); Hollocks et al (2019); Lin et al (2018)

³⁴ Australian Bureau of Statistics (2020-21)

³⁵ Australian Bureau of Statistics (2020-21)

³⁶ Hedley et al (2018b); Uljarević et al (2020)

³⁷ Hedley et al (2018b)

³⁸ Hedley et al (2018b)

and thus reducing loneliness could buffer against suicidal ideation. These factors likely have a significant impact on the quality of life experienced by Autistic Australians.

2.3. LONELINESS AND SUICIDE

Autistic people face a significantly heightened risk of suicidal ideation, suicidal behaviour, and premature mortality by suicide when compared to the general population. Our research demonstrates that Autistic people face a threefold to fivefold increased risk of death by suicide, particularly among those without a co-occurring intellectual disability.³⁹ National and global data confirm the significantly elevated risk of **preventable death** by suicide. Using national coronial data, an investigation into suicide by young Australians (2006–2015)⁴⁰ found that 4.6% of young Australian males who died by suicide had a diagnosis of autism—a rate far higher than the estimated national autism prevalence of 1.3%.⁴¹

Loneliness is a transdiagnostic (cutting across diagnostic boundaries) risk factor for suicide;⁴² consistent with this, our research demonstrates that loneliness and poor social support are transdiagnostic risk factors for suicide in Autistic Australians.⁴³ Research indicates that several key factors likely contribute to the significantly increased suicide risk faced by Autistic people. The compounding effects of **cultural and social exclusion**, including discrimination and bullying, exacerbate these risks and further isolate vulnerable people.

Co-developed suicide prevention resources for Autistic people

La Trobe University researchers partnered with the Autistic and LGBTQIA+ communities to address this urgent issue. Led by Associate Professors Carina Chan, Darren Hedley, and Josephine Barbaro, along with Dr. Karien Hill and Mick Leahy, the team launched the [Suicide Response Project](#) website in 2021.

This website provides crucial resources, including 12 accessible modules, animated videos, and fact sheets, offering practical strategies for recognizing and responding to suicide risks. These resources are specifically designed to meet the unique needs of Autistic individuals and those within the LGBTQIA+ community, equipping people with tools to offer effective support.

With backing from Suicide Prevention Australia, AMAZE, and ASPECT, the impact of the project grew in 2023 when its resources were incorporated into the **R U OK?** website, further increasing their availability. This initiative highlights the power of collaborative efforts in creating life-saving resources, offering much-needed mental health support to Autistic people and helping reduce the risk of suicide in this vulnerable group.

³⁹ Santomauro et al (2024)

⁴⁰ Hedley et al (2022)

⁴¹ Australian Bureau of Statistics (2018)

⁴² Glenn et al (2017; 2018)

⁴³ Hedley et al (2018a; 2018b; 2017)

2.4. BARRIERS TO ACCESSING HEALTHCARE

Systemic barriers that Autistic adults face in accessing healthcare and suicide prevention services further compound the negative impacts of loneliness. Australian research demonstrates that Autistic adults encounter significant barriers to accessing healthcare and suicide prevention services,⁴⁴ a finding echoed by international studies.⁴⁵ Nationally, research identified that access to healthcare was confounded by factors including increased autism traits, somatic symptoms, depression, anxiety, loneliness, poorer physical health, greater disability, and decreased satisfaction with social support.⁴⁶ Autistic Australians were more likely to experience barriers to health care if they:

- were gender diverse,
- had higher levels of anxiety,
- experienced greater levels of disability, or
- were less satisfied with their current social supports.

Recommendation 2. Entrench co-production⁴⁷ principles in all new mental health policy and service delivery initiatives. The New South Wales government authorities will take proactive steps to involve Autistic people from the outset.

Recommendation 3. The New South Wales government to develop and implement an evidence-based, comprehensive, lifespan-focused mental health strategy that emphasises early identification and sustained support for Autistic people experiencing mental ill health. This strategy will:

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- provide a road map to increase the accessibility and number of appropriate community-based supports for Autistic people with the goal of ensuring that no Autistic person is isolated within their community.

⁴⁴ Arnold et al (2024); Wilson et al (2024)

⁴⁵ Nicolaidis et al (2015)

⁴⁶ Arnold et al (2024); Wilson et al (2024)

⁴⁷ den Houting (2021)

- Recommendation 4.** Establish funding targeted, competitive grant or tender opportunities to:
- encourage partnerships between neurodiversity-affirming mental health organisations, autism peak bodies, autism peer groups and community groups to provide safe, supportive environments for individuals of all ages to engage in social activities;
 - focus on loneliness in Autistic people with the goal being the development of evidence-based support programs that are community integrated.

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- Recommendation 5.** Implement strengthened, timely transition supports for Autistic students into secondary school and into higher education and training through comprehensive consultation with Autistic students, their families and education, health and care professionals targeting:
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- Recommendation 6.** Conduct a review of planning and building legislation with the view to amend these laws to include consideration for accessibility of public spaces for Autistic people.

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 - facilitate access to co-produced public mental health material specific to Autistic people, such as [The Suicide Response Project](#).

ACKNOWLEDGMENTS

Acknowledgement of Country: OTARC acknowledges that we work on the unceded lands of many traditional Indigenous custodians in Victoria and across Australia. We recognise their ongoing connection to the land and value their unique contribution to our research, to La Trobe University and to wider Australian society. We pay our respects to Elders past and present and thank them for their ongoing care of this beautiful country's land, skies, and waterways.

Diversity: OTARC is committed to embracing diversity and eliminating all forms of discrimination. We will develop and sustain a culture where access, diversity and inclusivity are recognised, valued and celebrated. OTARC welcomes all people irrespective of neurotype, ethnicity, lifestyle choice, faith, sexual orientation or gender identity.

Lived experience: Our research could not happen without the individual and collective contributions of those with lived experience of neurodivergence, and those who love and care for them. We acknowledge and value their unique expertise. Their perspectives are crucial to our mission to enrich the lives of Autistic people, their families and their carers through high-quality scientific research, innovation and translation and our vision for a world where Autistic people, their families and their carers thrive.

Acknowledgment of those lost to suicide and those left behind. We acknowledge and remember all persons lost to us because of suicide as well as the people left behind. We acknowledge the enduring suffering suicide brings and the complex emotions and experiences of all people who have contemplated suicide. We acknowledge that those with lived experience can provide hope, resilience, and support to those at risk.

CONTRIBUTORS

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REFERENCES

*Note: **Bolded text** indicates an author on the paper is an OTARC researcher.*

- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders*. Washington, DC: American Psychiatric Association.
- Anderson, C., & Butt, C. (2017). Young Adults on the Autism Spectrum at College: Successes and Stumbling Blocks. *Journal of autism and developmental disorders*, 47(10), 3029–3039. <https://doi.org/10.1007/s10803-017-3218-x>
- Arnold, S. R., Bruce, G., Weise, J., Mills, C. J., **Trollor, J. N.**, & Coxon, K. (2024). Barriers to healthcare for Australian Autistic adults. *Autism*, 28(2), 301–315. <https://doi.org/10.1177/13623613231168444>
- Arwert, T. G., & Sizoo, B. B. (2020). Self-reported suicidality in male and female adults with autism spectrum disorders: Rumination and self-esteem. *Journal of Autism & Developmental Disorders*, 50(10), 3598–3605. <https://doi.org/10.1007/s10803-020-04372-z>
- Australian Bureau of Statistics. (2020–21). *National Study of Mental Health and Wellbeing*. Retrieved from <https://www.abs.gov.au/statistics/health/mental-health/national-study-mental-health-and-wellbeing/latest-release>
- Australian Bureau of Statistics. (2022). *Disability, Ageing and Carers, Australia: Summary of Findings*. Retrieved from <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
- Australian Bureau of Statistics. (2024). National, state and territory population. Retrieved from <https://www.abs.gov.au/statistics/people/population/national-state-and-territory-population/latest-release#states-and-territories>
- Australian Bureau of Statistics. (2018). *Survey of Disability, Ageing and Carers: Autism in Australia*. Retrieved from <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018>
- Australian Human Rights Commission. (2007). United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Retrieved from <https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd>
- Barbaro, J., & Dissanayake, C.** (2010). Prospective identification of autism spectrum disorders in infancy and toddlerhood using developmental surveillance: the social attention and communication study. *Journal of developmental and behavioral pediatrics : JDBP*, 31(5), 376–385. <https://doi.org/10.1097/DBP.0b013e3181df7f3c>
- Barbaro, J., Sadka, N., Gilbert, M., Beattie, E., Li, X., Ridgway, L., Lawson, L. P., & Dissanayake, C.** (2022). Diagnostic Accuracy of the Social Attention and Communication Surveillance-Revised With Preschool Tool for Early Autism Detection in Very Young Children. *JAMA network open*, 5(3), e2146415. <https://doi.org/10.1001/jamanetworkopen.2021.46415>
- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders*, 46(10), 3281–3294. <https://doi.org/10.1007/s10803-016-2872-8>
- Bauminger, N., Solomon, M., Aviezer, A., Heung, K., Gazit, L., Brown, J., & Rogers, S. J. (2008). Children with autism and their friends: a multidimensional study of friendship in high-functioning autism spectrum disorder. *Journal of abnormal child psychology*, 36(2), 135–150. <https://doi.org/10.1007/s10802-007-9156-x>
- Botha, M., & Frost, D. M. (2020). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health*, 10(1), 20–34. <https://www.jstor.org/stable/48683839>
- Cassidy, S. A., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in Autistic adults. *Molecular Autism*, 9(1), 1–14. <https://doi.org/10.1186/s13229-018-0226-4>

- Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2020). Is camouflaging Autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism & Developmental Disorders*, 50(10), 3638–3648. <https://doi.org/10.1007/s10803-019-04323-3>
- Chang, J. C., Lai, M. C., Chang, S. S., & Gau, S. S. (2024). Factors mediating pre-existing autism diagnosis and later suicidal thoughts and behaviors: A follow-up cohort study. *Autism*. Advance online publication. <https://doi.org/10.1177/13623613231223626>
- Chou, W. J., Wang, P. W., Hsiao, R. C., Hu, H. F., & Yen, C. F. (2020). Role of School Bullying Involvement in Depression, Anxiety, Suicidality, and Low Self-Esteem Among Adolescents With High-Functioning Autism Spectrum Disorder. *Frontiers in psychiatry*, 11, 9. <https://doi.org/10.3389/fpsy.2020.00009>
- Conner, C. M., Golt, J., Righi, G., Shaffer, R., Siegel, M., & Mazefsky, C. A. (2020). A comparative study of suicidality and its association with emotion regulation impairment in large ASD and US census-matched samples. *Journal of Autism & Developmental Disorders*, 50(10), 3545–3560. <https://doi.org/10.1007/s10803-020-04370-1>
- Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in adults with autism spectrum disorder: The role of depressive symptomatology, alexithymia, and antidepressants. *Journal of Autism & Developmental Disorders*, 50(10), 3585–3597. <https://doi.org/10.1007/s10803-020-04433-3>
- Glenn, C. R., Cha, C. B., Kleiman, E. M., & Nock, M. K. (2017). Understanding suicide risk within the Research Domain Criteria (RDoC) Framework: Insights, challenges, and future research considerations. *Clinical Psychological Science*, 5, 568–592.
- Glenn, C. R., Kleiman, E. M., Cha, C. B., Deming, C. A., Franklin, J. C., & Nock, M. K. (2018). Understanding suicide risk within the Research Domain Criteria (RDoC) framework: A meta-analytic review. *Depression and Anxiety*, 35, 65–88. <https://doi.org/10.1177/2167702616686854>
- Cook, J., Hull, L., Crane, L., & Mandy, W. (2021) Camouflaging in autism: a systematic review. *Clinical Psychology Review*, 89,102080. <https://doi.org/10.1016/j.cpr.2021.102080>
- Commonwealth of Australia (Department of Social Services). (2021). Australia's Disability Strategy 2021 – 2031. Retrieved from <https://www.disabilitygateway.gov.au/document/3106>
- den Houting, J. (2021). Participatory and Inclusive Autism Research Practice Guides. Brisbane. Autism CRC. Retrieved from: https://www.autismcrc.com.au/best-practice/sites/default/files/resources/Participatory_and_Inclusive_Autism_Research_Practice_Guides.pdf
- Ee, D., Hwang, Y.I.J., Reppermund, S., Srasuebku, P., Trollor, J.N., Foley, K.R., & Arnold, S.R.C. (2019). Loneliness in Adults on the Autism Spectrum. *Autism in Adulthood*, 1(3):182–193. <https://doi.org/10.1089/aut.2018.0038>
- Galán, C. A., Stokes, L. R., Szoko, N., Abebe, K. Z., & Culyba, A. J. (2021). Exploration of Experiences and Perpetration of Identity-Based Bullying Among Adolescents by Race/Ethnicity and Other Marginalized Identities. *JAMA Network Open*, 4(7), e2116364. <https://doi.org/10.1001/jamanetworkopen.2021.16364>
- Han, J., Batterham, P. J., Calear, A. L., & Randall, R. (2018). Factors Influencing Professional Help-Seeking for Suicidality. *Crisis*, 39(3), 175–196. <https://doi.org/10.1027/0227-5910/a000485>
- Hedley, D., Uljarević, M., Foley, K-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying suicidal ideation in autism spectrum disorder. *Depression & Anxiety*, 35, 648–657. <https://doi.org/10.1002/da.22759>**
- Hedley, D., Stokes, M. A., & Trollor, J. (2022). Suicide by young Australians, 2006–2015; A cross-sectional analysis of national coronial data [Letter to the editor]. *Medical Journal of Australia*, 216(1).**

- Hedley, D., & Uljarević, M.** (2018a). Systematic review of suicide in Autism Spectrum Disorder: Current trends and implications. *Current Developmental Disorders Reports*, 5, 65–76. <https://doi.org/10.1007/s40474-018-0133-6>
- Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C.** (2018b). Understanding depression and thoughts of self-harm in autism: A potential mechanism involving loneliness. *Research in Autism Spectrum Disorders*, 46, 1–7. <https://doi.org/10.1016/j.rasd.2017.11.003>
- Hedley, D., & Young, R.** (2006). Social comparison processes and depressive symptoms in children and adolescents with Asperger syndrome. *Autism : the international journal of research and practice*, 10(2), 139–153. <https://doi.org/10.1177/1362361306062020>
- Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C.** (2017). Social support, depression and suicidal ideation in adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47, 3669–3677. doi:10.1007/s10803-017-3274-2
- Holden, R., Mueller, J., McGowan, J., Sanyal, J., Kikoler, M., Simonoff, E., Velupillai, S., & Downs, J. (2020). Investigating Bullying as a Predictor of Suicidality in a Clinical Sample of Adolescents with Autism Spectrum Disorder. *Autism research : official journal of the International Society for Autism Research*, 13(6), 988–997. <https://doi.org/10.1002/aur.2292>
- Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: A systematic review and meta-analysis. *Psychological Medicine*, 94(4)1–14. <https://doi.org/10.1017/S0033291718002283>
- Hull, L., Petrides, K.V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.C., & Mandy, W. (2017). "Putting on my best normal": social camouflaging in adults with autism spectrum conditions. *Journal of Autism & Developmental Disorders*, 47(8), 2519–2534, <https://doi.org/10.1007/s10803-017-3166-5>*
- Junttila, M., Kielinen, M., Jussila, K., Joskitt, L., Mäntymaa, M., Ebeling, H., & Mattila, M. L. (2024). The traits of Autism Spectrum Disorder and bullying victimization in an epidemiological population. *European child & adolescent psychiatry*, 33(4), 1067–1080. <https://doi.org/10.1007/s00787-023-02228-2>
- 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>
- Klomek, A.B., Sourander, A., & Gould, M.S. (2011). Bullying and Suicide. *Psychiatric Times*, 28(2). <https://www.psychiatrytimes.com/view/bullying-and-suicide>
- 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. <https://doi.org/10.1177/1362361320908107>
- Lawson, W. (2020). Adaptive Morphing and Coping with Social Threat in Autism: An Autistic Perspective. *Journal of Intellectual Disability Diagnosis and Treatment*. 8(3). 519–526. <https://doi.org/10.6000/2292-2598.2020.08.03.29>
- Lin, H. T., Lai, C. H., Perng, H. J., Chung, C. H., Wang, C. C., Chen, W. L., & Chien, W. C. (2018). Insomnia as an independent predictor of suicide attempts: a nationwide population-based retrospective cohort study. *BMC Psychiatry* 18, e117. <https://doi.org/10.1186/s12888-018-1702-2>
- Mazurek M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism*, 18(3), 223–232. <https://doi.org/10.1177/1362361312474121>
- Michael C. (2021). Is being othered a co-occurring condition of Autism? *Autism in Adulthood*, 3(2), 118–119. <https://doi.org/10.1089/aut.2021.0019>

- Miller, D., Rees, J., & Pearson, A. (2021). "Masking Is Life": Experiences of Masking in Autistic and NonAutistic Adults. *Autism in Adulthood*, 3(4), 330–338. <https://doi.org/10.1089/aut.2020.0083>
- Murray, C., Kovshoff, H., Brown, A., Abbott, P., & Hadwin, J. A. (2019). Exploring the anxiety and depression profile in individuals diagnosed with an autism spectrum disorder in adulthood. *Research in Autism Spectrum Disorders*, 58, 1–8. <https://doi.org/S1750946718301612>
- Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., Kapp, S. K., Weiner, M., & Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, 19(7), 824–831. <https://doi.org/10.1177/1362361315576221>
- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of autism and developmental disorders*, 34(3), 245–256. <https://doi.org/10.1023/b:jadd.0000029547.96610.df>
- Paquette-Smith, M., Weiss, J., & Lunsy, Y. (2014). History of suicide attempts in adults with Asperger syndrome. *Crisis*, 35(4), 273–277. <https://doi.org/10.1027/O227-5910/a000263>
- Rai, D., Culpin, I., Heuvelman, H., Magnusson, C., Carpenter, P., Jones, H. J., Emond, A. M., Zammit, S., Golding, J., & Pearson, R. M. (2018a). Association of Autistic Traits with Depression from Childhood to Age 18 Years. *JAMA Psychiatry*, 75(8), 835–843. <https://doi.org/10.1001/jamapsychiatry.2018.1323>
- Rai, D., Heuvelman, H., Dalman, C., Culpin, I., Lundberg, M., Carpenter, P., & Magnusson, C. (2018b). Association between Autism Spectrum Disorders with or without intellectual disability and depression in young adulthood. *JAMA Network Open*, 1, e181465. <https://doi.org/10.1001/jamanetworkopen.2018.1465>
- Richards, G., Kenny, R., Griffiths, S., Allison, C., Mosse, D., Holt, R., O'Connor, R. C., Cassidy, S., & Baron-Cohen, S. (2019). Autistic traits in adults who have attempted suicide. *Molecular Autism*, 10(1), 1–10. <https://doi.org/10.1186/s13229-019-0274-4>
- Richdale, A., **Haschek, A.**, Chetcuti, L., & Lawson, L. (2022). Longitudinal Study of Australian School Leavers with Autism (SASLA): Final Report. Brisbane: Autism CRC. Retrieved from https://www.autismcrc.com.au/sites/default/files/reports/3-016_SASLA_Final-report.pdf
- Sadka and Barbaro. (2024). Australia's rates of autism should be celebrated –but real-life impact, not diagnosis, should determine NDIS support. The Conversation. Retrieved from <http://otarc.blogs.latrobe.edu.au/australias-rates-of-autism-should-be-celebrated-but-real-life-impact-not-diagnosis-should-determine-ndis-support/>
- Santomauro, D. F., **Hedley, D.**, **Sahin, E.**, Brugha, T. S., Naghavi, M., Vos, T., Whiteford, H. A., Ferrari, A. J., & Stokes, M. A. (2024). The global burden of suicide mortality among people on the autism spectrum: A systematic review, meta-analysis, and extension of estimates from the Global Burden of Disease Study 2021. *Psychiatry research*, 341, 116150. <https://doi.org/10.1016/j.psychres.2024.116150>
- South, M., Beck, J. S., Lundwall, R., Christensen, M., Cutrer, E. A., Gabrielsen, T. P., ... & Lundwall, R. A. (2020). Unrelenting depression and suicidality in women with Autistic traits. *Journal of Autism & Developmental Disorders*, 50(10), 3606–3619. <https://doi.org/10.1007/s10803-019-04324-2>
- Symes, W., & Humphrey, N. (2010). Peer-group indicators of social inclusion among pupils with Autistic spectrum disorders (ASD) in mainstream secondary schools: A comparative study. *School Psychology International*, 31(5), 478–494. <https://doi.org/10.1177/0143034310382496>
- 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. <https://doi.org/10.1007/s10803-016-2938-7>

- Tierney, S., Burns, J., & Kilbey, E. (2016). Looking behind the mask: Social coping strategies of girls on the Autistic spectrum *Research in Autism Spectrum Disorders*, 23, 73–83.
<https://doi.org/10.1016/j.rasd.2015.11.013>
- 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.
[10.1007/s10803-019-04084-z](https://doi.org/10.1007/s10803-019-04084-z)
- van Asselt-Goverts, A. E., Embregts, P. J., Hendriks, A. H., Wegman, K. M., & Teunisse, J. P. (2015). Do social networks differ? Comparison of the social networks of people with intellectual disabilities, people with autism spectrum disorders and other people living in the community. *Journal of autism and developmental disorders*, 45(5), 1191–1203.
<https://doi.org/10.1007/s10803-014-2279-3>
- Whitehouse, A. J., Durkin, K., Jaquet, E., & Ziatas, K. (2009). Friendship, loneliness and depression in adolescents with Asperger's Syndrome. *Journal of adolescence*, 32(2), 309–322.
<https://doi.org/10.1016/j.adolescence.2008.03.004>
- Wilson, J., Brown, C. M., Hayward, S. M., Stokes, M. A., Nicholas, D. B., & Hedley, D.** (2024). Autistic adults' experiences seeking and receiving support for mental health and suicidality. *OSF Preprints*. <https://doi.org/10.31219/osf.io/32xqz>
- Wright, M. F., & Wachs, S. (2019). Does Peer Rejection Moderate the Associations among Cyberbullying Victimization, Depression, and Anxiety among Adolescents with Autism Spectrum Disorder?. *Children (Basel, Switzerland)*, 6(3), 41.
<https://doi.org/10.3390/children6030041>