Olga Tennison Autism Research Centre
School of Psychology and Public Health

OLGA TENNISON AUTISM RESEARCH CENTRE:

Response to the Mental Health and Suicide Prevention Agreement Review

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ENQUIRIES
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EXECUTIVE SUMMARY

The issue

In 2023, a Western Australian mother mourned the loss of her two Autistic sons, aged 14 and 21, to suicide within seven months of each other.[1] Despite repeated attempts to access help, the family was left without vital mental health and disability support. In a context of heightened suicide risk and significantly increased mortality due to suicide within the Autistic population,[2] the barriers experienced by this family - and by many Australian families - in accessing mental health and suicide prevention services that are suitable for Autistic people, are cause for deep concern.[3] Our research with Autistic Australians, conducted over the last 8 years, identified specific barriers to accessing appropriate healthcare including long waitlists for specialists (e.g. psychologists, psychiatrists, paediatricians), cost, and being deemed ineligible for services such as the National Disability Insurance Scheme (NDIS), despite their diagnosis and support needs.[4] Autistic people also report that approaches to their experiences by professionals or services, as well as aspects of the autism diagnosis itself (e.g., social communication differences), can create further barriers to access.[5]

There is precedent for prioritizing Autistic people in suicide prevention strategies.

In their *2023 Suicide Prevention in England: 5-year cross-sector strategy*, the United Kingdom government identified the Autistic population as a priority group for suicide prevention.[6] This was a decision based on overwhelming national and international research evidence demonstrating that Autistic people face significantly heightened risk of premature mortality by suicide. Importantly, the UK government recognised that Autistic people are more likely to experience known, multiple, and unique risk factors for suicidal thoughts and behaviour, as well as unique or specific barriers to accessing much-needed supports.[7]

It is time for the Australian Government and peak suicide prevention bodies to acknowledge the increased risk of suicide experienced by Autistic Australians.

It is long past time for the Australian Government and peak suicide prevention bodies to formally recognise the significantly increased mortality of Autistic Australians due to suicide. At the time of preparing this brief, neither the Australian Government nor peak suicide prevention bodies have formally recognised Autistic Australians as a group at significantly increased risk for suicide.[8] Therefore, unlike other at-risk populations, Autistic Australians have not been the focus of suicide prevention efforts, including research, intervention, or funding priorities.[9]

[1] Australian Broadcasting Corporation (2023)
[2] Hedley et al (2022); Santomauro et al (2024); Kõlves et al (2021); Hirvikoski et al (2020; 2016); Jokiranta-Olkoniemi (2021)
[3] Arnold et al (2024); Wilson et al (2024); Nicolaidis et al (2015)
[4] Wison et al (2024)
[5] Wison et al (2024)
[6] Department of Health and Social Care (2023)
[7] Brown et al (2024a); Hedley et al (2018a; 2022a); Dwyer et al (2024)
[8] Suicide Prevention Australia; Suicide Prevention Australia and Centre for Mental Health, University of Melbourne (2023); Australian Government (Department of Health and Aged Care) (2022)
[9] Life in Mind, Fisher et al (2023), National Mental Health and Suicide Prevention Information Priorities Writers Group (3rd ed); Australian Institute of Health and Welfare (2024); Suicide Prevention Australia; Suicide Prevention Australia and Centre for Mental Health, University of Melbourne (2023); Australian Government (Department of Health and Aged Care) (2022)

We call on the Australian Government to explicitly recognise the urgent need for targeted suicide prevention to meaningfully reduce suicide death among Autistic Australians.

Herein we present the evidence supporting our call for recognition of the increased risk of suicide among Autistic Australians and the critical need for widespread change in the government's approach to suicide prevention strategies for this population. We highlight a significant body of research conducted in Australia, supported by international studies, in the hope that this brief will guide recommendations for change to research, policy, and practices that affect Autistic Australians.

Autistic people have a threefold to fivefold increased risk of death by suicide, compared to the general population[10]

Autism[11] is a lifelong neurodevelopmental difference characterised by a) differences in social communication and interaction, b) preferences for repetition and sameness, including engagement in repetitive behaviours and intense interests, and c) atypical sensory experiences including sensory hyper- and/or hypo-reactivity.

In 2022, the Australian Bureau of Statistics reported that **290,900 Australians had been diagnosed with autism spectrum disorder**, a 42% increase from 2018.[12] However, this likely underestimates the true rate of autism in Australia; a recent study in Australian children aged <4 years found 3.3% had received a diagnosis of autism. This is equivalent to **1-in-31 Australian children**.[13] This figure parallels international findings (e.g., UK: 1-in-34, USA: 1-in-36).[14]

Autistic people experience autism-specific barriers to seeking and receiving support for their mental health.[15] Difficulties with executive functioning (e.g., multitasking, planning and organisation skills) may hinder the ability to manage multistep processes or navigate social rules and complex social situations. Social difficulties can complicate the formation of new relationships and managing support networks. Hyper-empathy can lead to intense emotional experiences, affecting personal wellbeing. Concealing Autistic traits to appear 'less Autistic' and more like non-Autistic people may lead to professionals questioning or invalidating one's diagnosis or Autistic experience. This, in turn, may lead to denial of, or difficulty accessing services. Rigidity in routines and heightened stress responses, along with emotional challenges such as alexithymia (difficulty experiencing, identifying, or expressing emotions), emotional dysregulation, Autistic burnout (prolonged and intense fatigue) and sensitivity to rejection, may further inhibit an individual's ability to seek and access help.

Compounding suicide risk, Autistic people often fall into multiple suicide prevention priority groups (e.g. gender diverse, disability, Attention-deficit/Hyperactivity Disorder [ADHD]), representing an intersectional disadvantage.

The relatively high prevalence of autism in Australia, coupled with intersectional disadvantage, autism specific and heightened risk factors, and barriers to accessing supports and services, represents a **burgeoning health crisis for Australia.**

[10] Hedley et al (2022); Santomauro et al (2024); Kõlves et al (2021); Hirvikoski et al (2020); Jokiranta-Olkoniemi et al (2021)
[11] We will use identity first language in this document OTARC language statement - https://www.latrobe.edu.au/otarc/statements/statement-on-language-and-participatory-research
[12] Australian Bureau of Statistics (2022)
[13] Barbaro et al (2022)
[14] Maenner et al (2023); O'Nions et al (2023)
[15] Wilson et al (2024)

Recommendation

The Autistic population in Australia should be acknowledged by the Federal Government's National Suicide Strategy and by Mental Health and Suicide Prevention Agreements as a priority population at significantly increased risk of death by suicide. Robust scientific evidence tells us that Autistic people experience:

- **Significantly increased risk of suicidal thoughts, behaviour, and death by suicide compared to non-Autistic populations,**
- **heightened and unique factors that increase the risk of suicide,**
- **barriers to accessing available suicide prevention supports and services, and**
- **under-resourced staff and professionals who are lacking neuro-affirming/ autism specific training and knowledge.**

Background

La Trobe University's Olga Tennison Autism Research Centre welcomes the opportunity to provide a submission to the Mental Health and Suicide Prevention Agreement Review. to highlight the research we and other experts in the field have undertaken to generate an overarching picture of **the heightened risk of suicide for Autistic people, the factors contributing to this risk, and barriers to accessing suicide prevention services encountered by Autistic Australians.**

Our recommendation is grounded in a **robust scientific evidence base,** cultural humility, and a human rights approach.[16] We acknowledge the intrinsic right of all people to inclusion in all aspects of society and that attitudes, practices, and structures create barriers that hinder individuals from reaching their full potential and enjoying equal rights within society.

About the authors

We have developed this brief in partnership with the **Deputy Director of the NHMRC Centre of Research Excellence in Suicide Prevention/Co-Head of the Centre for Mental Health Research at Australian National University** (Batterham); **Director of the National Centre of Excellence in Intellectual Disability Health** (Trollor); **Orygen Head of Suicide Research** (Robinson); **Autism Spectrum Australia Head of Research** (Gibbs); members of the **Autism Health Roadmap Working Group** (Hedley, den Houting, Lawson, Trollor); **academics and researchers in suicide prevention**, **suicide survivors, and members of the Autistic and broader autism communities** (Batterham, Brown, Dwyer, Haschek, Hedley, John, Lawson, Revill, Robinson, Santomauro, Staheli, Stokes, Templin, Wilson); **clinicians and healthcare**

[16] So et al (2024); Lekas et al (2020); Hedley et al (2022b); https://humanrights.gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd

professionals (John, Rabba); **epidemiologists** (Santomauro, Stokes); and **peak consumer groups** (Amaze, Aspect, Barwon Health, Monash Health, Yellow Ladybugs).

ACKNOWLEDGEMENTS

Acknowledgement of Country. La Trobe University proudly acknowledges the traditional custodians of the lands where its campuses are located in Victoria. We recognise that Indigenous Australians have an ongoing connection to the land and the University values their unique contribution both to the University and the wider Australian society. Sovereignty has never been ceded. It always was and always will be, Aboriginal land.

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.

Language use. In this document we use identity-first language ('Autistic person') as it is the preference of the Autistic authors of this document. We acknowledge and respect those who prefer person-first language ('person with autism') or who have other language preferences.

Navigation

SECTION 1: A HEIGHTENED RISK OF SUICIDE – THE EVIDENCE

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 indicates a threefold to fivefold increased risk of death by suicide in Autistic people, with higher risk in individuals without a co-occurring intellectual disability. National and global data confirm the significantly elevated risk of **preventable death** by suicide. The evidence clearly supports the need for the **prioritisation of suicide prevention efforts within the Autistic population.**

In this section

- **Rates of death by suicide**
- **Number of deaths by suicide**
- **Frequency of death by suicide compared with other causes of death**
- **Suicide attempt**
- **Suicidal ideation**

Rates of death by suicide

Rates of death by suicide in autism vary between studies and countries, primarily due to methodological, sampling, and reporting differences. International studies report up to a ninefold increased risk of suicide death among Autistic people without intellectual disability. Our recent systematic review and meta-analysis showed that Autistic people face a **threefold to fivefold increased risk of premature death by suicide compared to the general population** (Relative Risk [RR]: 2.9, 95% Uncertainty Interval [UI]: 2.06–4.03), with the risk greater in Autistic people without intellectual disability (RR: 5.00 [3.57–7.07]).[17] Unlike in the general population, we found that suicide mortality risk was higher for Autistic females (RR: 3.85 [2.71–5.40]) than Autistic males (RR: 2.10 [1.54–3.01]).[18]

Number of deaths by suicide

National data

Using national coronial data an investigation into suicide by young Australians (2006–2015)[19] found that **4.6% of young Australian males who died by suicide had a diagnosis of autism,** a figure significantly higher than the estimated prevalence of autism in Australia (1.3%).[20] Importantly, the suicide rate is likely an underestimation given the high rates of under-diagnosis of autism[21]— many Autistic females are undiagnosed or receive their diagnosis in adulthood.[22] Given higher suicide risk rates and high levels of late or under-diagnosis in Autistic females, it is likely that the relatively low reported rate of suicide among young females with a diagnosis of

[17] Santomauro et al (2024)
[18] Santomauro et al (2024)
[19] Hedley et al (2022)
[20] Australian Bureau of Statistics (2018)
[21] Zeidan et al (2022); Milner et al (2020)
[22] Rutherford et al (2016); Zenner et al (2019); Lai & Baron-Cohen (2015); McCrossin (2022)

autism that was reported in the Australian coronial dataset (i.e., 0.4%) significantly underrepresents the true rate of suicide death among Autistic females in Australia.[23]

Global data

The current Global Burden of Disease estimated that 746,000 [95% UI: 692,000–800,000] deaths globally in 2021 were due to suicide. Of these,[24] we estimated that **19,300 [12,900–27,800], of these deaths were Autistic persons, equivalent to 31.2 [22.3–43.5] deaths per 100,000 Autistic persons. We also estimated that 13,400 [7660–21600] of these deaths were avoidable if Autistic people were not at greater risk than the rest of the population; this is equivalent to 21.7 deaths [12.8–34.0] per 100,000 Autistic people in 2021.** Number of deaths was overall higher in Autistic males (31.2 [22.3–3.5] deaths per 100,000) than Autistic females (26.2 [18.5–37.1] deaths per 100,000), reflecting the fact that there are more diagnosed Autistic males than females (approximate ratio diagnosed Autistic males to females: 3:1). We estimated that Autistic people accounted for 2.6% [1.7–3.7] of all suicide deaths globally in 2021, of which 1.8% [1.0%–2.9%] of all suicide deaths would be avoided if Autistic persons shared the same risk of suicide as non-Autistic persons.

Frequency of death by suicide compared with other causes of death

International data indicate premature mortality overall is significantly elevated in Autistic compared to general populations. Causes of premature mortality including mental and behavioural disorders, nervous or respiratory system issues, or congenital malformations.[25] Relative to other conditions, it is notable that **suicide death is the only condition where risk is significantly higher in Autistic people without an intellectual disability compared to those with intellectual disability**, although Autistic people with and without an intellectual disability still returned an overall higher suicide risk compared to non-autistic controls.[26] In Australia, death by suicide is classified with broader 'injury and poisoning' codes. Using coronial data from NSW, researchers found that **the leading cause of premature death for Autistic Australians aged 5–64 years was 'injury and poisoning'**; the next most common causes of death were nervous system disorders (e.g., epilepsy).[27] Comparatively, in the general population and within the same age group, the most common causes of death were cancer and circulatory diseases such as heart attack or stroke.

Suicide attempt

Autistic people are also at significantly increased risk of suicide attempt compared to the general population (RR: 3.8 [95% UI: 2.71–5.40]).[28] In addition to placing a significant burden on the Autistic person and their family, the **increased risk of suicide attempt places Autistic people at elevated risk of suicide death**. Risk of suicide attempt was higher for Autistic people without an intellectual disability (RR: 4.3 [3.15–5.97]) compared to those with an intellectual disability (RR: 3.0 [2.18–4.21]). Risk of suicide attempt increased significantly with age.[29]

[23] Hedley et al (2022)
[24] Santomauro et al (2024)
[25] Hirvikoski et al (2016)
[26] Hirvikoski et al (2016)
[27] Hwang et al (2019)
[28] Santomauro et al (2024)
[29] Santomauro et al (2024)

The youngest age of a documented suicide attempt was 7 years[30]

In our own recent research involving Autistic participants from Australia, Canada, and the United States of America, **31% of participants reported having attempted suicide**, with an average of 3.1 lifetime attempts. Concerningly, in Autistic children, **the youngest documented age of suicide attempt was 7 years of age and the average age of first suicide attempt was just 12 years.**[31]

Suicidal ideation

Even when thoughts about suicide do not culminate in a suicide attempt, suicidal ideation places a significant burden on an individual's health and wellbeing, affecting their ability to participate in daily activities or employment. Our research identified 81% of Autistic participants experienced suicidal ideation at some point in their lifespan, and 35% reported recent thoughts of self-harm. The evidence suggests that thoughts about suicide are very common with the Autistic population.[32]

81% of Autistic participants experienced suicidal ideation at some point in their lifespan, and 35% of participants reported recent thoughts of self-harm.

[30] Schwartzman et al (2024)
[31] Schwartzman et al (2024)
[32] Schwartzman et al (2024)

SECTION 2: FACTORS INCREASING THE RISK OF SUICIDE

Research indicates that several key factors likely contribute to the significantly increased suicide risk faced by Autistic people. Late diagnosis can lead to feelings of isolation, negative self-perception, and affect access to timely or early supports. Pronounced Autistic traits and efforts to conceal or 'mask' these traits contribute to mental health issues and stress. Cultural and social exclusion, including discrimination and bullying, heightens suicide risk. High rates of co-occurring mental health conditions, substance use, and life stressors further exacerbate the risk.

In this section

- **Later age of autism diagnosis**
- **Autistic traits**
- **Cultural and social exclusion**
- **Co-occurring mental health conditions**
- **Substance use**
- **Life stressors**
- **Gender diversity**

Later age of autism diagnosis

Suicide risk may be greatest when autism diagnosis occurs later in life.[33] In Australia, the average age of autism diagnosis is 5 years of age.[34] However, and despite autism being reliably diagnosable in children as young as 2 years, data from longitudinal studies[35] by the Autism CRC found that in children and young adults aged 15–25, the average age of diagnosis was 9.8 years, with 51% of participants diagnosed at age 9 years or older. This is well beyond early diagnosis guidelines.[36] Moreover, 90% of participants aged 25 years or over received their diagnosis in adulthood. Late diagnosis can have profound impacts on the individual, for example, through lack of access to timely supports and interventions (e.g., in childhood and young adulthood), on social identity or understanding difficulties when facing life's challenges, high levels of social isolation and, relative to the general population, poorer quality of life, mental health and wellbeing. Without access to appropriate and timely supports, these factors are likely to have a compounding effect increasing suicidal thoughts and behaviour.[37]

Autistic people with multiple marginalised or intersectional identities often face additional diagnostic delays. For example:

- Autistic children from racial and ethnic minority groups are more likely to be misdiagnosed and tend to be diagnosed later than White children.[38]

[33] Cassidy et al (2014)
[34] Gibbs et al (2019)
[35] Richdale et al (2022); Arnold et al (2019)
[36] Whitehouse et al (2018)
[37] Wilson et al (2024)
[38] Angell et al (2018)

- Autistic children from highly educated households tend to be diagnosed earlier than those from less educated households.[39]
- Autistic children from lower socioeconomic status (SES) households tend to be diagnosed later than those from higher SES households.[40]
- Autistic females tend to be diagnosed later than Autistic males, and gender-divergent Autistic people tend to be diagnosed later than cisgender Autistic people.[41]
- Diagnostic delays of up to 14-years were evident in Autistic women who also had an eating disorder, and the delay in autism diagnosis was found to be associated with more severe eating disorder symptoms and higher levels of depression, anxiety and stress.[42]

Autistic traits

Research indicates that greater expression/level of Autistic traits can place an individual at increased risk of mental health problems,[43] including suicidal thoughts and behaviour.[44] For example, higher levels of social communication differences are associated with a higher risk of suicidal ideation[45] and suicide plans,[46] and predict poorer tolerance of distress and higher levels of anxiety.[47]

In addition to Autistic traits directly contributing to suicidality, Autistic people may (knowingly or unknowingly) conceal or 'mask' their Autistic traits, for example to reduce social threat or improve their interactions with non-Autistic people.[48] Masking, whether deliberate or not, exacts a cognitive cost, promotes social hypervigilance, contributes to Autistic burnout (a state of extreme fatigue and heightened stress), and negatively impacts self-esteem and identity. This additional cognitive load is in turn associated with poorer mental health outcomes and higher lifetime rates of suicidal thoughts and behaviour.[49]

"Autistic burnout is one of the very commonly missed and misdiagnosed autistic experiences; most of the markers of burnout are also markers of depression. Clinicians who are not aware of autistic burnout... will miss autistic burnout and are likely to misdiagnose autistic people with depression instead."

Dr Erin Bulluss, Autistic psychologist"[50]

[39] Angell et al (2018)
[40] Kelly et al (2019)
[41] McQuaid et al (2024)
[42] Brown et al (2024b)
[43] Uljarević et al (2020); Bentum et al (2024)
[44] Hedley et al (2018c; 2021; 2024); Culpin et al (2018); Dell'Osso et al (2021)
[45] Hedley et al (2021)
[46] Dell'Osso et al (2019); Culpin et al (2018)
[47] Graham et al (2023)
[48] Pearson & Rose (2021)
[49] Cassidy et al (2020)
[50] Hedley et al (2022b)

Cultural and social exclusion

Discrimination, stigma and othering (viewing or treating a person as intrinsically different) directly contribute to poorer mental health, suicidal thoughts and behaviour. The interpersonal model of suicide posits that feelings of thwarted belongingness and perceived burdensomeness, common among Autistic individuals due to social and communication differences, underlie suicide risk. For example, research among Autistic people found that relationship status (being single vs. in a relationship) indirectly elevated suicide risk.[51] This is particularly relevant given the Autism CRC longitudinal studies reported that 33% to 86% of Autistic participants were single (compared to 15% of non-Autistic controls).[52]

Minority stressors, including everyday discrimination, internalised stigma, and concealment, significantly predict poorer mental health for Autistic individuals, even when general stress exposure is considered.[53] In the general population, social and informal support from family and friends is crucial for seeking professional help.[54] However, Autistic individuals face fundamental social-communication differences that can make forming supportive social relationships more difficult, leading to increased loneliness and depression.[55]

"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."[56]

Loneliness is a transdiagnostic (cutting across diagnostic boundaries) risk factor for suicide;[57] consistent with this, our research demonstrated that loneliness and poor social support were transdiagnostic risk factors for suicide in Autistic Australians.[58] Moreover, our research shows that **Autistic Australians experience higher levels of loneliness than their non-Autistic peers**, correlating with elevated depressive symptoms. [59] We further found that young Autistic Australians (15-25 years) are:

- twice as likely to feel "isolated from others" (30%) and "left out" (31%), and
- nearly three times as likely to report a lack of companionship (28%) compared to non-Autistic youth.

[51] Joiner (2005)
[52] Arnold et al (2019)
[53] Botha and Frost (2020)
[54] Han et al (2018)
[55] Mazurek (2014); Rai et al (2018a; 2018b)
[56] Michael (2021)
[57] Glenn et al (2017; 2018)
[58] Hedley et al (2018a; 2018b; 2017)
[59] Hedley et al (2018a)

"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, 2019)."[60]

Bullying in the general population is associated with higher depression symptoms, suicidal ideation,[61] and suicide attempts, consistent across primary and secondary school settings.[62] Those with multiple marginalised identities (e.g. autism, mental health conditions, other disabilities) tend to show the highest rates of being bullied compared to other vulnerable groups.[63] Autistic adolescents receiving treatment for mental health difficulties and who reported being bullied were twice as likely to develop suicidal thoughts and behaviour compared to those not reporting being bullied.[64] In Australia, bullying is particularly prevalent among Autistic youth with (50%) and without (58%) a co-occurring intellectual disability.[65]

In Australia, 50-58% of Autistic youth reported bullying during their schooling.[66]

Co-occurring mental health conditions

Autistic people are at exceptionally high risk of **co-occurring mental health conditions,**[67] with up to 46% of Autistic adults reporting current clinical anxiety or depression, significantly exceeding rates in the Australian general population (i.e. 26%).[68] Notably, depression is highly associated with the presence of suicidal thoughts and behaviour.[69]

Autistic people are almost twice as likely to experience mental illness compared to the Australian general population[70]

Autistic people are also more likely than the general population to experience **psychosis and schizophrenia,** which may compound the risk of suicide.[71] An early-onset first-episode psychosis is a significant risk factor for suicide[72]; lifetime risk of suicide associated with schizophrenia is around 5%.[73] Depression, hopelessness, and suicidal behaviour are associated with Autistic traits and positive symptoms of schizophrenia for people experiencing their first episode of psychosis.[74] Both psychosis and autism are also associated with sleep problems,

[60] Lawson (2020)
[61] Chang et al (2024)
[62] Klomek et al (2011)
[63] Galán et al (2021)
[64] Holden et al (2020)
[65] Richdale et al (2022)
[66] Richdale et al (2022)
[67] Murray et al (2019); Kent et al (2017); Thomas et al (2017); Uljarević et al (2020); Hollocks et al (2019); Lin et al (2018)
[68] Australian Bureau of Statistics (2020-21)
[69] Hand et al (2020); Hedley et al (2021; 2024); Cook et al (2024); Costa et al (2020)
[70] Australian Bureau of Statistics (2020-21)
[71] Chisholm et al (2015); Upthegrove et al (2018)
[72] Sanchez-Gistau et al (2013)
[73] Hor & Taylor (2010)
[74] Upthegrove et al (2018)

which represent an additional risk factor for suicide.[75] More research is needed to unpack the various contributions of these risk factors to suicide in autism.

Co-occurring mental health conditions can be **difficult to diagnose**, as mental health conditions can present with symptoms that appear similar to common Autistic traits. For example, social anxiety may lead to social avoidance; obsessive-compulsive disorder (OCD) often manifests with repetitive behaviours. Without expert attention, these similarities may result in diagnostic overshadowing — that is, failure to correctly diagnose a condition due to presence of confounding or overlapping symptoms. Furthermore, standard mental health screening instruments may have reduced sensitivity when used with Autistic people.[76]

"And when so much of mental health training is focused around being normal, normative work life, normative relationships, all these things are made for neurotypical people. Even if some people want to aspire to those things, great, but neurobiologically, many of us are not equipped for that and the way that we can be most healthy is by accepting that we are falling outside of the norms."

Axel-Nathaniel Rose[77]

Substance use

Problematic substance use is thought to affect around 8.3% of the Autistic population[78], double that of the general population (about 4% prevalence).[79] Substance dependence is associated with a higher likelihood of death by suicide, particularly involving opioids and alcohol,[80] and for those who have a co-occurring substance use disorder.[81] Alcohol and substance use were found to predict suicide attempts among Autistic people[82], and substance use was associated with a higher number of self-harm events requiring Emergency Department (ED) visits.[83]

Life stressors

Life stressors may be a key psychosocial driver of suicide in Autistic adults. For Autistic people, the exacerbating impact of life stress on suicidal thoughts and behaviour may be increased relative to non-autistic people, particularly for those who lack sufficient supports or coping mechanisms to manage life stress. For example, we[84] found that exposure to life stressors including health/treatment-related stressors, interpersonal loss, and physical danger predicted suicidal thoughts and behaviour in Autistic people.

[75] Reeve et al (2018); Jovevska et al (2020)
[76] Kerns et al (2014; 2021)
[77] Hedley et al (2022b)
[78] Lugo-Marín et al (2019)
[79] Butwicka et al (2017)
[80] Esang & Ahmed, 2018
[81] Poorolajal et al., 2016
[82] Nyrenius et al (2023)
[83] Giannouchos et al (2023)
[84] Moseley et al (2024)

Gender diversity

Compared to cisgender people, rates of autism are significantly elevated among trans and gender diverse people (Odds Ratio [OR]: 4.59 [95% CI: 4.20–5.03]); up to 62% of trans and gender diverse people reported recent (12 month) suicidal ideation and up to 40% have attempted suicide.[85] Overall, however, the intersectionality between gender diversity, mental health and wellbeing, and suicidal thoughts and behaviour is under-researched[86] and little is known about the additional risk factors and barriers to service access that intersectionality might bring.

[85]Hill et al (2023); Warrier et al. (2020)

[86] Polidori et al (2024)

SECTION 3: BARRIERS TO ACCESSING SUICIDE PREVENTION SUPPORTS

Suicide prevention supports are multilayered, including general healthcare, mental health services and suicide-specific supports and services. Autistic Australians face significant barriers to accessing these supports, including economic constraints, geographic isolation, sensory sensitivities, communication differences, and a lack of understanding and accommodations from healthcare providers. These barriers are compounded by systemic factors including the complexity of systems like the NDIS, and the scant availability of specialised, autism-informed care, underscoring the urgent need for improved and accessible healthcare solutions.

In this section

- **General healthcare barriers**
- **Economic barriers**
- **Location, distance, travel**
- **Sensory sensitivities**
- **Communication barriers**
- **Provider barriers**

General healthcare barriers

Australian research demonstrates that Autistic adults encounter significant barriers to accessing healthcare and suicide prevention services, [87] a finding echoed by international studies.[88] 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.[89] 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.

Our study interviewing Autistic adults with a history of suicidal behaviour found that health professionals often lacked an understanding of Autistic people.[90] Given that people who die by suicide are commonly in contact with primary health care services in the month prior to death,[91] it is imperative that healthcare providers and services are aware of the increased risk of suicide in autism, as well as how to manage it appropriately: suicide risk must be identified early and managed appropriately so that Autistic people who are in suicidal crisis receive the supports they need, thereby preventing suicide death.

[87] Arnold et al (2024); Wilson et al (2024)
[88] Nicolaidis et al (2015)
[89] Arnold et al (2024); Wilson et al (2024)
[90] Wilson et al (2024)
[91] Stene-Larsen & Reneflot (2019); Walby et al (2018)

The following quote from Dr Jessica Revill who lost her son Gregory to suicide in 2020 illustrates the importance of communication in healthcare.

"I remember going to a doctor to review my son's idiopathic toe walking. During the interview the specialist, who was perfectly nice, rattled off questions and diagnostics at a hundred miles an hour to my Autistic son. I could see him sink into his shell and submissively nod as he did not grasp what was going on. There were no reasonable adjustments for clinical interview. This lack of adjustment was a repeated experience with health care professionals. Over time, I think he just gave up on the idea that he could ever get any help. There was such a disconnect." **Dr Jessica Revill, Parent Survivor**

Economic barriers

Almost half (45%) of Autistic Australians report concerns about the cost of healthcare or insurance coverage, a significantly higher percentage compared to non-Autistic participants (14%).[92] Our interviews with Autistic Australians found that:[93]

- Treatment can be prohibitively expensive, and it can take considerable time for Autistic adults to find the right healthcare provider.
- The experience of poverty limits their ability to access well-trained professionals.
- The National Disability Insurance Scheme (NDIS) presents challenges, with functional assessments overlooking Autistic support needs, a complicated and lengthy application process, and the system necessitating the medicalisation and pathologizing of Autistic people and their experiences.

Location, distance, travel

Autistic Australians identified location of services, distance to travel and proximity of services to public transport as barriers to accessing healthcare support.[94] Compared to non-autistic Australians (1%), twice as many Autistic Australians did not have a way to get to their doctor's office (3%).[95] A significant proportion of Australians live regionally and remotely in Australia (28%), experiencing poorer access to, and use of, primary health care services compared to those in metropolitan areas.[96] Autistic people who live regionally and remotely are, therefore, likely to experience significant barriers to accessing health supports.

Sensory sensitivities

Our interviews with Autistic Australians[97] revealed that the sensory experience of many healthcare settings may impede Autistic individuals in their attempts to access health services. Emergency departments, for example, can be aversive to Autistic people due to bright lighting, overwhelming noise, and unwanted physical contact. When an Autistic person is experiencing a

[92] Arnold et al (2024)
[93] Wilson et al (2024)
[94] Wilson et al (2024)
[95] Arnold et al (2024)
[96] Australian Institute of Health and Welfare (2024a)
[97] Wilson et al (2024)

suicidal crisis, the impact of the sensory environment may be compounded, potentially resulting in meltdown or escape behaviour.[98] Notably, 33% of Autistic Australians identified sensory discomforts as a barrier to care, and 42% found it challenging to tolerate waiting rooms, in stark contrast to just 1% of non-Autistic people.[99] It is, therefore, clear that sensory needs are a major autism-specific factor contributing to difficulties in accessing healthcare and support services. [100]

Communication barriers

Communication barriers significantly hinder Autistic individuals from accessing effective healthcare. Autistic people typically communicate (and process communication) in ways that differ from the norm, with common differences including atypical or limited verbal communication skills; atypical nonverbal communication style; slower information processing; situational mutism; difficulties with phone calls; and use of augmentative and alternative communication methods. When not adequately accommodated, these communicative differences may contribute to substantial communication barriers for Autistic people.[101] For 25% of Autistic Australians, communicating with their healthcare provider or staff is too difficult, a rate five times higher than non-Autistic people.[102] Additionally, 27% of Autistic Australians felt that their communication was not taken seriously by healthcare providers or staff. Further, when young Autistic people record elevated risk of suicidal thoughts and behaviours on standardised measures, these are frequently not verbally communicated to healthcare providers.[103] This negatively impacts both risk assessment and treatment, with potential to miss individuals at high risk of suicide.

Additional barriers

Healthcare providers often lack meaningful understanding of autism, and Autistic adults in particular. This lack of understanding can manifest in countless ways and is often ultimately expressed as ableism. For example, healthcare providers may:

- Use inaccessible language.
- Fail to provide alternative communication methods.
- Demonstrate a general unwillingness to make necessary accommodations.
- Lack the skill required to appropriately involve supporters throughout the care process.[104]
- Respond inadequately or inappropriately when an individual discloses their autism diagnosis, including invalidating the person's Autistic identity.
- Make inaccurate diagnoses and/or engage in diagnostic overshadowing.
- Make assumptions about an Autistic person's competence.[105]

In a recent Australian study, Autistic people described experiencing othering, stigma, and stereotypes; pathologizing attitudes towards autism; failure to recognise the complex and

[98] Hedley et al (2022)
[99] Arnold et al (2024)
[100] Nicolaidis et al (2015)
[101] Wilson et al (2024)
[102] Arnold et al (2024)
[103] Schwartzman et al (2023)
[104] Nicolaidis et al (2015)
[105] Wilson et al (2024)

interconnected nature of Autistic experiences; and a need to 'mask' Autistic characteristics, despite the cognitive and emotional cost of doing so. [106]

At a systemic level, myriad factors interact to impede access to healthcare services. For example, patients must contend with insufficient availability of adult-specific services; gatekeeping access to support through application of stringent eligibility criteria; restricted service hours; inadequate staffing; and lengthy waiting lists. Upon successfully navigating these barriers to access care, patients may then encounter a "one size fits all" approach to healthcare that erodes their sense of agency, rendering them infantilised and dehumanised.[107] Importantly, evidence indicates that standard therapeutic approaches (e.g., Cognitive Behavioural Therapy, Dialectical Behaviour Therapy, mindfulness-based therapies) may lack efficacy for Autistic people and require adaptation to appropriately accommodate Autistic people's unique needs.[108]

Clinically, a gap exists between knowledge generated through research, and application of that knowledge in practice. For example, suicide risk assessment and interview tools (e.g., the Suicide Ideation Attributes Scale, Modified [SIDAS-M][109] and the Suicide Assessment Kit, Modified Interview [SAK-MI][110]) have been co-developed and validated for use with Autistic people and are freely available, but require further research before they can be incorporated into mainstream clinical use. Similarly, safety plan interventions have been adapted for use with and by Autistic people but are yet to be validated and incorporated into clinical use.

[106] Wilson et al (2024)
[107] Wilson et al (2024)
[108] Wilson et al (2024)
[109] Hedley et al (2023)
[110] Hedley et al (2025)

CONCLUDING REMARKS

It is vital that we understand the complex systemic and individual barriers that prevent many Autistic people from achieving equitable health and wellbeing outcomes. The resulting picture is necessarily bleak. Faced with this stark reality, our community and lived experience partners have highlighted the value of articulating an antithetical — and as it stands, hypothetical — reality: a reality in which Autistic people thrive.

The Autistic community comprises an extraordinary diversity of experience, ability, and potentiality. Many Autistic people have key strengths, such as intense focus, attention to detail, memory, efficiency,[111] honesty, creativity, and dedication.[112] Autistic people are less likely to engage in unethical or hypocritical behaviour and more likely to challenge misconduct.[113] Contrary to stereotypes of Autistic people as lacking empathy, many Autistic people describe intense, overwhelming, and sometimes distressing experiences of hyper-empathy and heightened concern for others.[114] Many derive similarly profound joy from engagement in interests and hobbies, which can span numerous domains: toys, machines, animals and nature, TV, art, music, history, science, and more.[115]

“Neurotypical people pity autistics. I pity neurotypicals. I pity anyone who cannot feel the way that flapping your hands *just so* amplifies everything you feel and thrusts it up into the air. I pity anyone who doesn’t understand how beautiful the multiples of seven are, anyone who doesn’t get chills when a shadow falls *just so* across a solitaire game spread out on the table. I pity anyone who is so restrained by what is considered acceptable happiness that they will never understand when I say that sometimes being autistic in this world means walking through a crowd of silently miserable people and holding your happiness like a secret or a baby, letting it warm you as your mind runs on the familiar tracks of an obsession and lights your way through the day."

Julia Bascom[116]

[111] Cope et al (2022); Russell et al (2019)
[112] Cope et al (2022); Russell et al (2019)
[113] Hartman & Hartman (2024); Hu et al (2021); Peterson & Wellman (2022)
[114] Kimber et al (2023); Shaw et al (2023)
[115] Frisch et al (2023); Spackman et al (2023); Uljarević et al (2022)
[116] Bascom (2011)

Autistic people can also experience joyful engagement from social interaction.[117] Indeed, although autism has traditionally been seen as a social-communication deficit, recent research suggests — as Autistic people have long argued[118] — that the problem is bidirectional, with non-autistic people's difficulties understanding, interacting with, and accepting Autistic people[119] contributing to Autistic people's social isolation and un-/under-employment.[120] This is just one of the numerous and varied ways[121] in which the marginalisation of Autistic people can reflect intentional or unintentional discrimination in a world dominated by non-Autistic people

Despite the many joys and strengths to be found in autism, discrimination against and exclusion of Autistic people has caused or exacerbated many of the issues that are herein identified as increasing the risk of suicide in autism, such as bullying, loneliness, and mental health distress.

The high rates of suicide in autism are not only a grave public health issue, but a crucial equity concern that demands action.

In this brief, we have laid out the overwhelming evidence demonstrating the dramatically elevated risk of suicide within the Autistic population. As we have set out above, this heightened risk arises from a complex mix of transdiagnostic and autism-specific risk factors, paired with systemic and individual barriers that impede access to crucial suicide prevention services and supports. Despite an increased research focus on Autistic suicidality over the past 10 years, the evidence base remains sparse. Key questions – regarding, for example, the contribution of intersectional marginalisation to suicide risk; strategies for efficient translation of research to practice; and whether/how appropriate interventions may aid in preventing death by suicide of Autistic Australians - remain unanswered. It is clear that dramatic systemic reform is urgently needed, with a systemwide approach required to deliver healthcare professionals who are better-trained, and healthcare environments that are better-adapted, to meet Autistic people's needs.

Far from an academic or policy-making exercise, these glaring gaps in knowledge and practice can give rise to dire consequences, as epitomised by the heartbreaking experience of one Western Australian family devastated by the loss of two Autistic children to suicide. Stories like this are all too common within the Autistic community. This policy brief represents an **urgent call to action**. We call upon the Australian Government and peak suicide prevention organisations to **formally recognise the Autistic community as a population at significantly increased risk of death by suicide.** We further call upon the Government and peak bodies to **join with the Autistic and autism communities in working to reduce the burden of suicidality and prevent suicide death among Autistic Australians.**

[117] Heasman et al (2024)
[118] Sinclair (1989); Grant (1993); Milton (2012)
[119] Crompton et al (2020a; 2020a); Heasman & Gillespie (2018)
[120] Whelpley et al (2023)
[121] Brandsen et al (2024); Botha & Frost (2018); Jones et al (2022); Lim et al (2022); Tan et al (2024)

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OTARC is a dedicated Autism Research Centre located within La Trobe University, Melbourne, Australia. Our vision is for a world where Autistic people, their families and their carers thrive. Our research is internationally recognised as making an impact not just in Australia but globally.

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