LA TROBE UNIVERSITY

Olga Tennison Autism Research Centre

La Trobe University response to the Select Committee on Mental Health and Suicide Prevention

March 2021

Inquiry into Mental Health and Suicide Prevention in Australia

ENQUIRIES
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INTRODUCTION

La Trobe University welcomes the opportunity to provide a submission to the Select Committee on Mental Health and Suicide Prevention. At La Trobe, we have the first dedicated autism research centre in Australia – the Olga Tennison Autism Research Centre (OTARC), established in 2008. OTARC has a dedicated Co-occurring conditions research theme led by Professor Amanda Richdale. La Trobe University is an essential participant in the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC), established in 2013. The OTARC Director was part of the original bid team for the Autism CRC, with three of our staff leading projects in the CRC.

OTARC's research aims to:

- Enable autistic people to realise their full potential, participate in the community, education, and employment, to enjoy life and to actively and meaningfully contribute, throughout their life.

AUTISM SPECTRUM DISORDER[1,2] is a neurodevelopmental condition characterised by challenges with social communication and interaction and engagement in restricted, repetitive behaviours, interests and activities. In 2018, 205,200 Australians reported a diagnosis of autism. Autism is the largest primary disability category for the NDIS (29%).

Autistic people are at exceptionally high risk of **CO-OCCURRING MENTAL HEALTH CONDITIONS**[3] with current rates of clinical anxiety or depression in autistic adults ranging from 23% to 46% and lifetime rates for anxiety and depression 42% and 37%, respectively. This significantly exceeds the Australian general population rates of 26.3% and 15%. Sleep difficulties are also very common, occurring in more than half of autistic adults. In the general population, a diagnosis of insomnia with a co-occurring mental health condition increases suicide risk **18-fold** compared to that of people who do not have insomnia.

90% of autistic people who attempt or die by suicide have had a mental health condition in their lifetime[4]

SUICIDE[5] is the leading cause of premature death in people with autism of average IQ or above. In Australia, 4.6% of males who died by suicide were autistic far exceeding the estimated prevalence of autism of ~2% (all sexes). Autistic people face a 3-9 times higher risk of premature death by suicide. Autistic people who die by suicide are more likely to die violently (73%;), less likely to use a firearm, and tend to be younger than suicides in the general population (e.g., 32 vs. 41 years).

Up to **9** times higher **risk** of premature death by **suicide**

Autistic people are at also at an increased risk of suicide *behaviour* including[6] thoughts of suicide (36%; ideation), planning for suicide, and non-fatal suicide attempt. There is an emergent suicide risk in young autistic children with the autistic community in Victoria recently impacted by the suicide death of a 14-year-old autistic [7]. Research currently underway at OTARC has found that autistic children under 8-years of age have attempted suicide, with first suicide attempts not unusual during the early teenage years [8].

[1] Please note that we use a mixture of identity-first (e.g., 'autistic person') and person-first (e.g., 'person with autism') language, to reflect the diversity of preferences in the autism community.
[2] APA, 2013; ABS, 2018; NDIA, 2018
[3] Murray et al., 2019; Kent et al., 2017; Thomas et al., 2017; Uljarević et al., 2019; Hollocks et al., 2019; ABS 2008; Lin et al., 2018
[4] Kõlves et al., 2021
[5] Hill et al., 2021; Dietz et al., 2020; Kõlves et al., 2021; Kirby et al., 2019
[6] Hedley & Uljarević, 2018; Hirvikoski et al., 2016; Kirby et al., 2019
[7] News.com.au., 2020
[8] Fellowship - Understanding and Preventing Suicidal Behaviour in Individuals with Autism Spectrum Disorder

The focus of this submission is to provide evidence-based, community-driven recommendations that will benefit autistic Australians. In making these recommendations we will be drawing on evidence from national and international published works and from the following four research studies and collaborators:

- **Study of Australian School Leavers with Autism (SASLA)[9] –**aims to identify and describe the comprehensive profiles of autistic Australian school leavers (including mental health), and to compare them with non-autistic school leavers (aged 15-25 years). We surveyed four populations: (1) autistic people without an intellectual disability, (2) autistic people with an intellectual disability (parent report), (3) non-autistic people, and (4) parents of autistic children.
- **Understanding and Preventing Suicidal Behaviour in Individuals with Autism Spectrum Disorder** – Suicide Prevention Australia National Suicide Prevention Research Fellowship awarded to Dr Darren Hedley. This study aims to identify predictors, underlying causal mechanisms and protective factors of suicidal behaviours in autism (section 3.3.1)
- **Sleep Intervention for Autistic Adults Presenting with Insomnia (SLEAPI) –** a pilot Acceptance and Commitment Therapy (ACT) and Behavioural Therapy (BT) intervention developed by La Trobe researchers, Dr Eric Morris, Dr Lauren Lawson and Prof Amanda Richdale, as an insomnia intervention for autistic adults with examination of concurrent effects on mental health. (section 2.5).
- **Supporting a Neurodiverse Workforce: A mental health and well-being resource and training package -** OTARC, in collaboration with DXC Technology and ANZ Bank, has developed a mental health resource and training package that specifically targets the mental health and wellbeing of autistic employees and those who support them. This package is being further developed into in-person and online training with support from Untapped Holdings (section 3.3.2).
- **The Melbourne Clinic** - Autism Spectrum Assessment and Mental Health Treatment at The Melbourne Clinic. A qualitative study of assessment acceptability and therapeutic directions in consumers and clinical staff (section 2.6).
- **Mindful -The University of Melbourne (UoM)** as an example of an effective system-wide strategy to improve mental health literacy and capacity across Victoria (section 3.3.3).

A summary of recommendations to the committee are provided on pages 3-6 of this submission.

The terms of reference addressed in this submission are:

[9] Funded by the Cooperative Research Centre for Living with Autism (Autism CRC) and led by Prof Amanda Richdale

SUMMARY OF RECOMMENDATIONS

1. All suicide and self-harm events should be mandatorily reported at a federal level and as part of that a specific question about autism status should be included.

2. There should be implementation and adequate funding for effective strategies that can drive down the costs of clinical services and supports. For example, by providing appropriate and effective outpatient services that minimize repeat use of emergency/high-cost services (see also the need for related research, recommendations 18-19).

3. Include autism as a group of interest in any policy or implementation of the Productivity Commissions Inquiry Report into Mental Health due to their very high rates of co-occurring mental health conditions, critically low labour participation rates and an elevated risk of death by suicide.

Informed service provision for autistic people

4. Services should be co-designed with the autistic community. Co-designed services are far more likely to meet the needs of consumers, thus increasing utilisation and reducing stigma around help-seeking[10].

5. The focus should be on prevention across the lifespan due to the high rates of co-occurring mental health difficulties and suicide risk experienced by autistic people. This should include early intervention, teaching life skills, and awareness of the problem in children, particularly as our research[11] and that of others shows that autistic adolescents report more anxiety and depression symptoms than non-autistic adolescents[12] and more disturbingly, our finding that first suicide attempts are often in autistic children aged 13-14 years. This identifies a potentially critical period for intervention, and a time when autistic children may become increasingly aware of their differences from others, and there is increased salience and complexity in social relationships[86].

6. The heterogeneity of presentations and needs of those on the autism spectrum must be recognised by clinicians and service providers. An autistic person's unique needs and requirements must be understood and accommodated - not all autistic people require changes to practice but, other practices may be required for some autistic people.

7. Due to difficulties in using instruments to measure mental health problems and suicidality in autistic populations, a clinical interview conducted by a professional trained in autism, mental health problems, and in suicide risk is critically important.

8. Education and training of mental health practitioners about autism and mental health is required and should be incorporated in basic training, as well as ongoing professional development. Training must also include known mental health and suicide risk factors:

    - extent of autistic characteristics and how autism can influence the presentation of mental health symptoms and vice versa,
    - emerging evidence of suicide risk in young autistic children,
    - later age of autism diagnosis,
    - gender differences,
    - increased risk of co-occurring conditions (intellectual disability, anxiety, depression, eating disorders, psychosis, insomnia, fatigue, and bullying),
    - maladaptive self-regulation behaviours,
    - autistic burnout,

[10] Maple et al., 2018
[11] Richdale et al., 2014
[12] van Steensel et al., 2017; Rai et al., 2018a

- the importance of feeling connected to others (loneliness, social acceptance and supports).

9. Public, adult diagnostic services need to be made available for all health regions across Australia. These services should have an emphasis on multidisciplinary assessment and differential diagnosis.

10. Accurate identification and quantification of the impact of autism on mental health services - use, cost, etc. This is likely to be higher than current estimates due to difficulties faced by clinicians and autistic people in:

    - accessing a diagnosis of autism in childhood or adulthood,
    - complications due to diagnostic overshadowing,
    - lack of accessibility of current services for autistic people,
    - lack of validated interventions available to autistic people, and
    - a need for greater funding into autism specific mental health and suicide prevention services.

Accommodations and adjustments to usual practice for autistic people

11. Services need to take account of and provide for the different needs of autistic people regarding sensory, executive functioning and communication needs. Doing so will promote initial access to services and reduce premature service drop-out. Required accommodations include:

    - Provision of alternative ways of making and being reminded of appointments.
    - Provision of quiet spaces and spaces designed to reduce the impact of potential sensory sensitivities within service provision facilities.
    - Provision of quiet, low sensory waiting areas and minimising waiting time within the facility (e.g., ability to wait in the car until called).
    - Tools such as written instructions to assist autistic people to follow advice and instructions (e.g., regarding filling and taking prescriptions).
    - Provision of alternative forms for communicating between the autistic person and the service provider, such as written or other visual means.
    - Provision of treatment and therapies adapted and tailored to the needs of the individual.

Specialist service availability, development, and expansion

12. There must be correct and consistent application of best practice in working with autistic consumers in all aspects of service provision.

13. Transition support services must be made more accessible to autistic people in Australia. This includes transition services for entering and exiting education, employment and living arrangements.

14. More education for autistic teens and adults about available services for mental health, building social networks and managing health concerns would be beneficial.

15. Each public mental health service should have access to specialist autism advisors with expertise in autism and mental health. Such advisors should be available for crisis and emergency department presentations of suicidal autistic patients (or those who may be autistic) as well as for those autistic individuals (or those who may be autistic) who present with other severe mental

health episodes/concerns (e.g., psychosis, bipolar, eating disorders), and for advice on ongoing management.

Education and training of service providers

16. Expand work of the Mindful Centre for Training and Research in Developmental Health to a national level through additional federal funding to produce a well-trained multidisciplinary workforce in both the state-funded and private sector.

17. Mental health and other health providers generally do not receive training about autism in their basic training and have very limited understanding of autism, including the relationship between autism and mental health. Training about autism should be mandatory for all mental health practitioners given the high incidence of co-occurring mental health conditions for autistic people, their over-representation as users of mental health services, high rates of misdiagnosis and the common experience of health practitioners failing to recognise autism in mental health clients. Training should encompass:

    - Understanding and managing the social communication, sensory and executive functioning issues associated with autism and how they can impact service access and treatment.
    - Understanding co-occurring conditions in autism, their presentation and treatment. Mental health practitioners need to understand how to assess for and differentially diagnose psychiatric conditions in autistic users of mental health services.
    - Recognition of autism (including formal screening) in adolescent and adult mental health service clients, particularly in groups that may not display “classic” signs of autism, such as girls and women, culturally diverse groups, and people with different levels of cognitive ability.
    - Education about next steps to take if a practitioner suspects autism in a mental health client.
    - Training in assessment and diagnosis of autism in adolescents and adults for appropriate practitioners in each health region. Not all mental health practitioners need this skill, but there needs to be availability of publicly funded diagnostic services in each region.

Research

18. Fund the first adult autism specific integrated training, service, and research clinic in Australia at La Trobe University. Creating a federal benchmark for the creation of science informed, accessible and equitable intervention for autistic adults, co-developed *with* autistic people *for* autistic people.

19. Establish a dedicated Australian research funding pool for both applied and basic research on autism through the life course.

20. Research priorities:

    - Identification of what constitutes best practice, both for diagnosing autism and differential diagnosis of co-occurring conditions.
    - Identification of the barriers Australian autistic people face in accessing and using mental health services.
    - Identification of factors that particularly impact on the mental health, and the escalation of mental ill-health, in autistic persons and how these factors can be better managed. This should include investigation of the concept of “autistic burnout”.
    - Research related to treatment efficacy and effectiveness, including cost-effective treatment modes such as telehealth and group psychological interventions (e.g., Cognitive Behaviour Therapy, Acceptance and Commitment Therapy, SLEAPI).

- Identification and development of self-help strategies and resources for preventing and managing mental ill-health for autistic people. Resources for autistic people should be widely promoted and available. (e.g., available online and promoted by health practitioners, autism forums and organisations).

RESPONSE TO THE TERMS OF REFERENCE

1. The findings of the Productivity Commission Inquiry Report into Mental Health.

La Trobe University was disappointed that autistic Australians were not considered a group of interest in this report. As this submission will describe, and as we have detailed in previous submissions to State and Federal government (Appendix 1), autistic people are at far greater risk of co-occurring mental health conditions; at a significantly elevated risk of premature death by suicide than the general Australian population; and have very low labour participation rate (38%), which is lower than non-autistic individuals with (53%) and without a disability (84%)[13]. We believe this to be a critical oversite of the report.

Recommendation

3. To include autism as a group of interest in any policy or implementation of the Productivity Commissions Inquiry Report into Mental Health due to their very high rates of co-occurring mental health conditions, critically low labour participation rates and an elevated risk of death by suicide.

2. Emerging evidence-based approaches to effective early detection, diagnosis, treatment and recovery across the general population and at-risk groups, including drawing on international experience and directions.

The Study of Australian School Leavers with Autism (SASLA) community[14] rated mental health as the most important area of focus in SASLA (January 2020) and are consistently telling us this needs to have a dedicated focus - not only in research but at the State and Federal level in terms of service development and provision. Mental health was a key inclusion after an Adult Forum[15], and extensive consultation with the autistic community. Several publications described in this section use a pooled data set with another Autism CRC study – Australian Longitudinal Study of Adults with Autism (ALSAA) (aged 25-80 years) of which Prof Richdale is an investigator – to span the entire adult lifespan.

2.1 Risk markers for suicidality and mental health problems in the autistic population

2.1.1 Extent of Autistic Characteristics

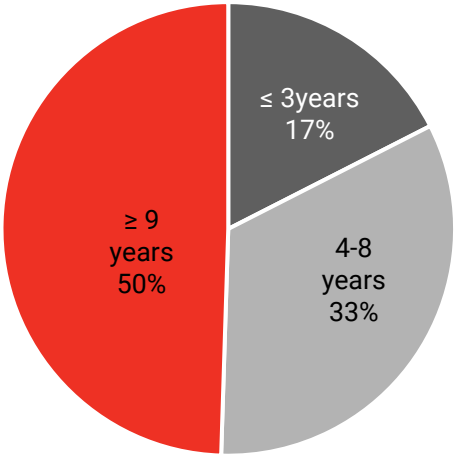
Autistic individuals who express a greater extent of autistic traits may be at greater risk of mental health problems[16] and subsequent suicidality[17]. The core social-communication challenges associated with autism may lead to difficulties recognising and communicating thoughts or feelings about suicide and seeking help or support - for example, clearly articulating difficulties to health professionals. Higher levels of social communication difficulties are associated with a higher risk of suicidal ideation[18]. For autistic people who are non-verbal, or have limited verbal communication skills, there are likely to be additional challenges detecting correctly diagnosing, and subsequently treating mental health problems. In addition, research suggests that repetitive/behavioural features of autism are associated with suicidal behaviour[19] and predict poorer tolerance of distress (resulting from uncertainty) and higher levels of anxiety[20].

[13] ABS, 2019
[14] is comprised of autistic individuals aged 17–27, their parents/carers, members of autism specific organisations and individuals who work with autistic people.
[15] Consisting of autistic people, their families and community and state organisations
[16] Uljarević et al., 2020
[17] Hedley et al., 2018
[18] Hedley et al., 2021b
[19] Dell'Osso et al., 2019
[20] Uljarević et al., 2017

2.1.2 Later Age of Autism Diagnosis

Suicide risk may also be greater when diagnosis occurs later in life[21]. This may be due to a lack of access to supports and interventions throughout critical developmental periods. SASLA found that the average age of diagnosis was 9.7 years, with 49.5% of participants diagnosed at age 9 years or older (well beyond early diagnosis guidelines[22]), and that only 26% had received early intervention (Figure 1). Several SASLA participants who entered the study as non-autistic subsequently reported an autism diagnosis. The ALSAA study found that 90% of its autistic participants received their diagnosis in adulthood, an average of 6.9 years prior to completing the first ALSAA survey, indicating that many adults in Australia are receiving an autism diagnosis well into adulthood[23]. This delay in diagnosis may also be indicative of a history of diagnostic overshadowing[24] - meaning that while other mental health conditions may be recognised or treated, an underlying diagnosis of autism may be overlooked[25]. In people who are diagnosed with autism, clinicians may fail to fully appreciate the impact of other mental health conditions, or to treat them accordingly.

Figure 1: Age of diagnosis for Autistic participants in the SASLA study (15-25 years).



Finally, there is very little research about being diagnosed during adulthood or in later life (e.g., over 50). This over 50s group commonly report a high degree of co-occurring diagnoses (e.g., depression and anxiety) and are left feeling isolated and 'alien' throughout their lives[26]. At this point in time very few supports exist not only for the newly diagnosed autistic adult but also for carers, clinicians, and front-line medical practitioners to ensure people in this age group receive adequate care. More research is required to assess the needs of this population.

2.1.3 Female Gender

Being female is a protective factor for suicide in the general population[27] however, this is not the case for autistic females. Autistic females are three times more likely to die by suicide then their non-autistic peers[28].

Potential reasons for heightened risk of suicide for autistic females:

- Greater number of psychiatric diagnoses.
- Greater risk of traumatic experiences.
- Diagnosed later/less likely to receive a formal diagnosis.
- Experience identity conflict.
- Increased camouflaging.
- More likely to report non-binary gender descriptions.

[21] Cassidy et al., 2014
[22] Whitehouse et al., 2018
[23] Arnold et al., 2019
[24] Reiss et al., 1982
[25] Andrea et al., 2014
[26] Stagg & Belcher, 2019
[27] Centers for Disease Control and Prevention, 2020
[28] The Interagency Autism Coordinating Committee, 2018

Autistic females are more likely than autistic males to experience symptoms of anxiety and/or depression and reach clinical cut-off criteria for anxiety and/or depression across the lifespan[29] and being an autistic female is also a risk factor for sleep difficulties[30].

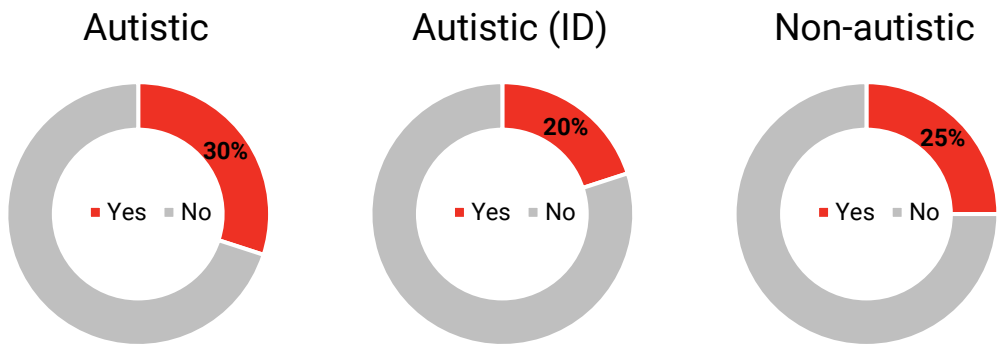
A comparatively high number of autistic females also report a non-binary gender preference or minority sexual orientation[31]. A miss-match between sex and gender can have flow on impacts on mental health and wellbeing[32] so is an important consideration for support services. Non-suicidal self-injury (NSSI) may also be more prevalent in autistic females and is associated with suicide[33]. It is critical for clinicians to consider if self-harming behaviours are NSSI or suicidal in nature in an autistic client for best practice in suicide prevention.

In addition to increased risks associated with being an autistic female, autistic females are being diagnosed later than males in Australia. Young autistic female SASLA participants were significantly less likely than autistic males to be diagnosed at 3 years of age or under (4.9% vs 26.2%) and far more likely to be diagnosed at 9 years or older (65.9% vs 37.7%).

2.1.4 Co-occurring Conditions

Autistic people with a co-occurring **INTELLECTUAL DISABILITY** (ID) have a lower relative risk for death by suicide compared to autistic individuals without co-occurring ID [34]. However, a co-occurring ID is associated with a greater risk of suicide *attempt* or self-inflicted injury[35]. In the SALSA study, around one-quarter of autistic participants with an ID experienced suicidal ideation "several days", "more than half of days" or "nearly every day" in the preceding two weeks (Figure 2).

Figure 2: Percentage of SASLA participants who reported that they had suicidal thoughts - "would be better off dead or hurting yourself in some way?" - (suicidal ideation) in the past two weeks.

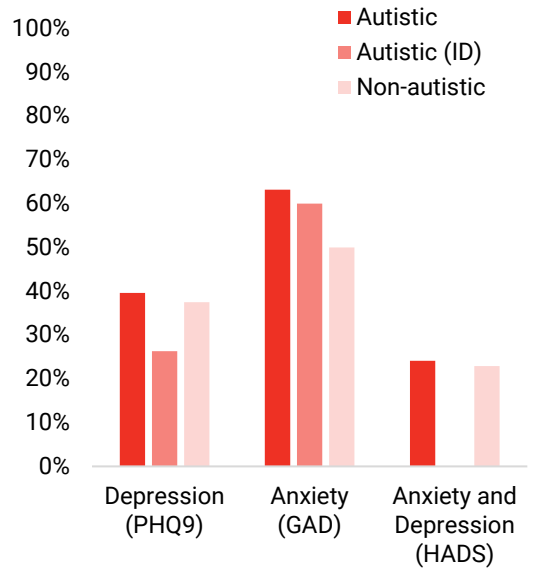


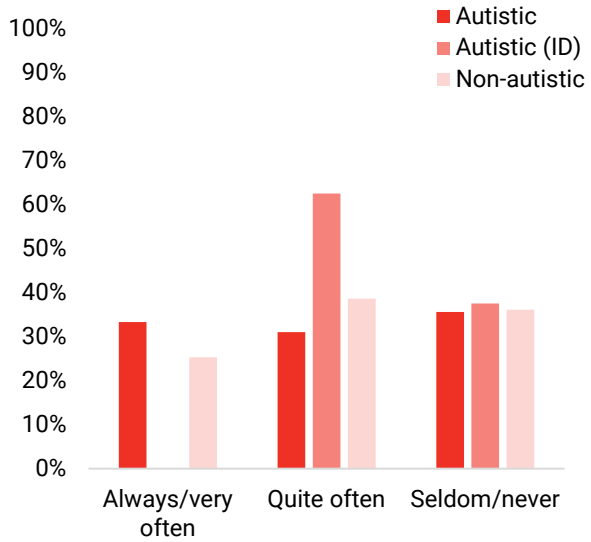
There is a higher prevalence of **ANXIETY AND/OR DEPRESSION** among autistic people than in the general population. An Australian study found that "injury and poisoning" was the leading cause of death for autistic people, risk increased with the presence of a comorbid mental health condition[36]. Depression can impair autistic people's social skills and adaptive behaviours, with diagnostic overshadowing due to the overlapping symptomology of autism and depression (e.g., social withdrawal) making a diagnosis of depression more difficult for clinicians[37]. Figure 3 shows the proportion of autistic, autistic with an ID and non-autistic SASLA

[29] Uljarević et al., 2020; Hedley et al, 2018
[30] Jovevska et al., 2020
[31] George & Stokes, 2018a
[32] George & Stokes, 2018b
[33] Maple, Wayland, Pearce, & Hua, 2018
[34] Hirvikoski et al., 2016
[35] Hand et al., 2019
[36] Hwang, et al., 2019
[37] The Interagency Autism Coordinating Committee

participants who met the clinical threshold for depression and/or anxiety. All groups also experienced "negative feelings, such as blue mood, despair, anxiety, depression" a significant proportion of the time (Figure 4). Autistic SASLA participants were also significantly more likely to be taking medication for 'anxiety/nerves', 'antidepressants', 'mood stabilisers', or 'other medication for mental health' then their non-autistic peers.

Figure 3 (left): Percentage of SASLA participants who met clinical cut-off for anxiety, depression, or concurrent anxiety and depression.
Figure 4 (right): Percentage of SASLA participants frequency of negative feelings.





Anxiety is also a common problem for school-aged autistic children. A recent systematic review of interventions for anxiety in mainstream school-aged children with autism spectrum disorder showed that interventions, particularly Cognitive Behaviour Therapies (CBT), had a statistically significant, moderate to high effect in reducing anxiety compared to waitlist and treatment-as-usual control conditions at post-treatment[38]. This outcome was dependent on who provided the report on the child:

- Clinician = very high statistically significant effect.
- Parent = high significant effect.
- Self-report = moderate significant effect.

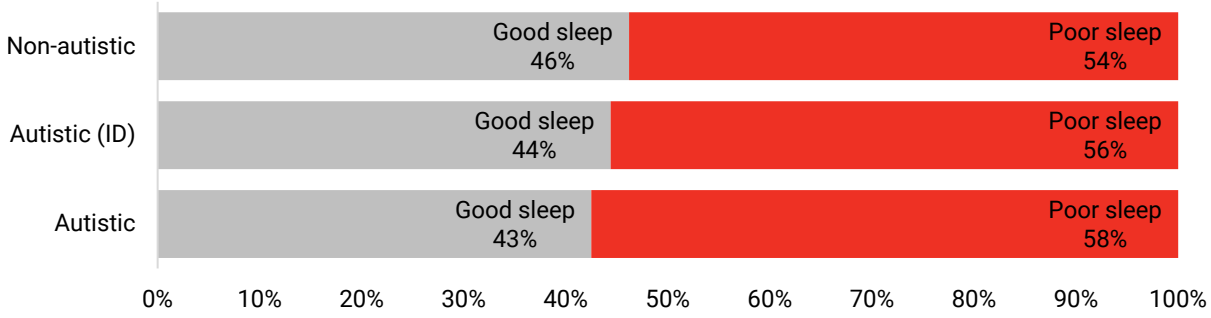
Due to the lack of blinding in these studies and lack of adequate methodological description in several of the published studies there is certainly a need to undertake larger scale, methodologically robust research in this area.

EATING DISORDERS are also a common co-occurring mental health condition in the autistic population. Research suggests that the up to 30% of people with a diagnosis of anorexia show high levels of autistic traits or are autistic[39]. Suicide is up to 31 times more likely to occur for someone with an eating disorder[40]. In terms of treatment options this is very important as treatments for autistic people often require modification to be efficacious.

[38] Hillman et al., 2020
[39] Brown and Stokes et al., 2020
[40] Preti et al., 2011

POOR SLEEP QUALITY was more common for Australian autistic individuals (63.7%) than non-autistic individuals (46.4%), with difficulty getting to sleep, night waking and shortened night sleep (i.e., insomnia) being the most common difficulties (Figure 5)[41]. More Australian autistic adults meet diagnostic criteria for insomnia (28%) than non-autistic adults (6%)[42]. While sleep difficulties appear to peak in adolescence in the general population, in autistic individuals sleep difficulties peak in early and middle adulthood and persist across the lifespan[43]. It is noteworthy that sleep difficulties in autism begin around 2-years and, unlike in the general population, generally do not tend to lessen in childhood and there is evidence that poor sleep is a chronic problem[44].

Figure 5: Percentage of SASLA participants who reached cut-off for good and poor sleep quality on the PSQI.



Insufficient sleep can have a negative effect on multiple aspects of physical and mental health, can impair daytime functioning, and is strongly associated with suicide behaviours[45], even when mental health problems are accounted for[46]. In general population samples, suicide risk increases dramatically when insomnia occurs with a mental health condition (Figure 6)[47]. The type of sleep difficulties may also be important, with trouble getting to sleep (the most common sleep problem in autism[48]), waking too early (common in autism[49]) and hypersomnia all increasing suicide risk[50].

Fatigue and daytime functioning are related to both poor sleep and mental health. Autistic adolescents and adults report increased daytime fatigue and increased daytime dysfunction compared with non-autistic peers, while poor sleep, anxiety and depression predict poorer daytime functioning in autistic adolescents[51]. In the general population, daytime fatigue is both a symptom of poor sleep and depression and independently associated with poor sleep and mental health, particularly anxiety and depression[52]. A third of autistic SASLA participants without an ID reported feeling distressed by fatigue 'moderately' to 'extremely'. Very recently SASLA investigated the impact of poor sleep quality, fatigue, sense of contribution to community and depression. We found that fatigue and lack of sense of contribution to one's community impact significantly on depressive symptomatology in older adolescents and young autistic adults in Australia[53].

[41] Jovevska et al., 2020; (SASLA and ALSAA)
[42] Baker & Richdale, 2015
[43] Jovevska et al., 2020
[44] Humphreys et al., 2013; Verhoeff et al., 2018
[45] E.g., Bernert & Joiner, 2007; Bernert, Kim, Iwata, & Perlis, 2015
[46] Geoffroy et al., 2020
[47] Lin et al., 2018
[48] Jovevska et al., 2020; Richdale & Schreck, 2009
[49] Richdale & Schreck, 2009
[50] Geoffroy et al., 2020
[51] Baker et al., 2013; Baker & Richdale, 2015; Richdale et al., 2014
[52] McCallum et al., 2019
[53] Richdale et al., 2021

Figure 6: Risk of suicide for people experiencing insomnia and a mental health condition compared to those without a co-occurring diagnosis[54].

Across autistic and non-autistic Australian youth and adults, we found that poor sleep quality was significantly related to[55]:

- greater extent of autistic traits (section 2.1),
- current use of medication,
- female gender (section 2.1), and
- having a current mental health condition.

When SASLA participants were asked to *subjectively* rate their overall sleep quality, autistic participants (with and without an ID) were significantly more likely to report having 'very good' sleep and less likely to report having 'fairly bad' sleep than their non-autistic peers. This suggests there is a disparity between *perceived and actual* sleep quality for autistic individuals. Our autistic participants without an ID also reported problems in keeping "keep up enough enthusiasm to get things done" in the past month (44%) indicating daytime disfunction. Medication for sleep was taken at least weekly by 12.6% of autistic youth without an ID.

PSYCHOSIS AND SCHIZOPHRENIA are common co-occurring conditions for autistic people[56]. An early-onset first-episode psychosis is a significant risk factor for suicide[57] as is schizophrenia, with the lifetime risk of suicide associated with schizophrenia around 5%[58]. Depression, hopelessness, and suicidal behaviour are associated with autistic traits and positive symptoms of schizophrenia for people experiencing their first episode of psychosis[59]. In clinical terms, the assessment of autistic traits, psychosis, and positive symptoms of schizophrenia are essential for comprehensive care and where autism is diagnosed in conjunction with these conditions, suicidal behaviour needs to be seriously considered[60]. Psychosis is also related to sleep problems[61] which are a common co-occurring conditions in autistic people. Australian research suggests that Cognitive Behavioural Therapy for Insomnia (CBTI) improves sleep and daytime functioning and can be a successful intervention for psychosis[62].

2.1.5 Maladaptive Self-Regulation Behaviours

Mental health problems and suicidality are related to one's style or strategies of responding to stressful events. The strategies used by autistic people to regulate emotions and behaviour might not be conducive to overall psychological well-being. For instance, **SUBSTANCE USE** is thought to affect over a third of the autistic population[63], double that of the general population[64]. Substance dependence is associated with a higher

[54] Han-Ting et al., 2018
[55] Jovevska et al., 2020
[56] Chisholm et al., 2015; Upthegrove et al., 2018
[57] Sanchez-Gistau et al., 2013
[58] Hor & Taylor, 2010
[59] Upthegrove et al., 2018
[60] Hedley at al., 2021 in press,
[61] Reeve et al., 2018
[62] Waters et al., 2020
[63] Lugo-Marín et al., 2019
[64] Butwicka et al., 2017

likelihood of death by suicide, particularly involving opioids and alcohol[65], and for those who have a co-occurring substance use disorder[66]. When autistic SASLA participants were asked how they typically deal with problems, we found that 6% were using alcohol or other drugs to make themselves feel better and 5% used alcohol or other drugs to help get through 'it'. The SASLA study also surveyed parents about the behaviours of their autistic children and found that 4% believed their child had "problems with cigarettes, alcohol or caffeine" and/or 2% had "problems with the illegal use of drugs". **CAMOUFLAGING**, the concealment of autistic traits, is also a common coping mechanism that accounts for 3.5% of the variance in suicidal behaviour[67].

Furthermore, autistic individuals have more difficulties with emotion regulation and use more maladaptive **EMOTION REGULATION STRATEGIES** than non-autistic peers. Greater use of maladaptive strategies has been associated with mental health problems in the autistic population. OTARC research, including from the SASLA and ALSAA cohorts, found that:

- Greater use of expressive suppression (I.e., avoiding uncomfortable emotions) relative to reappraisal (I.e., reframing a situation to change its emotional meaning) was associated with more anxiety and depression symptoms in autistic people[68].
- Dampening (e.g., reminding yourself that feelings are temporary) and blaming others reduced mood in autistic people[69].

Nevertheless, our research suggests that supporting autistic people to implement more constructive emotion regulation strategies may protect against mental health problems, that result from maladaptive strategy use. Specifically, we found that:

- Savouring (I.e., enjoying the moment) and emotion acceptance strategies improved mood in autistic people[70].
- The negative effects of suppression usage on depression and mental wellbeing were lessened by concomitant the use of reappraisal[71].

Further, research shows that intervention can improve emotion regulation in autistic individuals[72].

RUMINATION is another self-regulation strategy engaged in more often by autistic than non-autistic individuals[73]. Rumination among autistic adults is associated with emotional dysregulation[74], depression and suicidal behaviour[75]. Almost half of SASLA autistic participants (without an ID) reported "worrying thoughts go through my mind" either *a lot* (22%) or *great deal* (22%) of the time.

2.1.6 Autistic burnout[76]

This is a state of mental exhaustion that autistic people report experiencing when cognitive and social demands exceed their coping resources over time. This condition is well-known within the autistic community but has only recently begun to receive research attention. Early investigations indicate that autistic burnout is

[65] Esang & Ahmed, 2018
[66] Poorolajal et al., 2016
[67] Cassidy et al., 2018
[68] Cai et al., 2018
[69] Cai et al., 2019a
[70] Cai et al., 2019b
[71] Cai et al, 2019a
[72] Mennin et al., 2009
[73] Crane et al., 2013
[74] Samson et al., 2014
[75] Dell'Osso et al., 2019; Arwert et al., 2020
[76] Mantzalas et al., 2021; Raymaker et al., 2020

a risk factor for poor mental health outcomes among autistic adults and can contribute to suicidal ideation; however, more work is needed to better understand its potential impact.

Episodes of autistic burnout typically last 3 or more months, and recovery can be protracted and difficult. So far, research has explored burnout among autistic adults, but self-reports suggest that first episodes commonly occur during adolescence and recur throughout the lifespan. The cumulative impact of autistic burnout may be long-lasting and irrevocable.

[…] experiencing burnout so severe and for so long that you wish you could just not be here anymore […] (autistic adult on Twitter)

Autistic adults differentiate between autistic burnout and depression, seeing them as separate but possibly related conditions where the personal impact is particularly detrimental if they co-occur. For details of contributing factors and consequences for autist people see Table 1.

Table 1: Autism-related and societal factors that contribute to autistic burnout and the consequences for autistic people.

CONTRIBUTING FACTORS	CONSEQUENCES FOR THE AUTISTIC PERSON
Autism-associated Factors: 1. Camouflaging or masking autistic traits to pass as non-autistic. 2. Sensory hyper-sensitivity. 3. Developmental transitions and stressful life events.	1. Inability to function (e.g., work, study).
Societal-associated Factors: 1. Stigma and discrimination towards autistic people. 2. Lack of awareness in non-autistic individuals about autism. 3. Unreasonable expectations of the autistic person.	2. Loss of previously acquired skills (e.g., self-care, speech).
	3. Poor emotion regulation 4. Heightened sensitivity to sensory stimuli 5. Poor mental health and suicidality

2.1.7 Connectedness to Others

Autistic Australians (aged 15-80 years) experience significantly higher levels of **LONELINESS** than non-autistic individuals, which is associated with elevated depression symptoms[77]. Living alone was associated with higher depressive symptoms[78] in the SASLA study. Those who have fewer social supports and lack satisfaction with their social supports were more likely to have elevated depressive symptoms[79]. The SASLA study found that autistic youth without an ID felt disconnected from others:

[77] Heldley et al, 2018a (SASLA and ALSAA data)
[78] Uljarević et al., 2020
[79] Heldley et al, 2018a

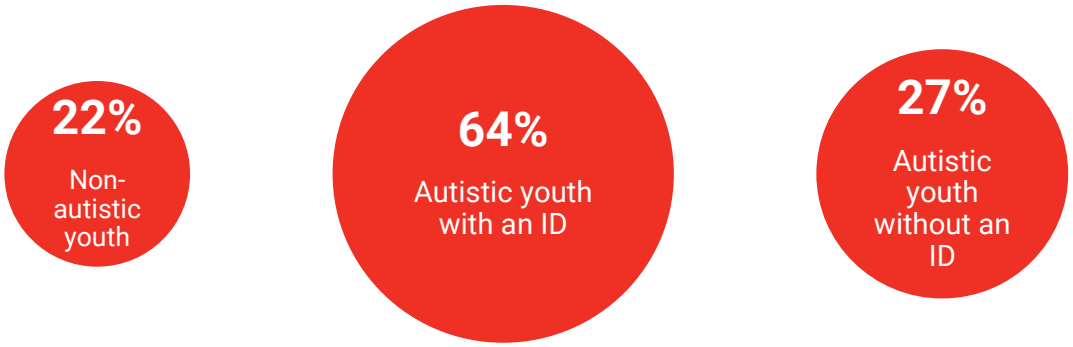
- Rarely (or not at all) felt "close to other people" (28%),
- Often felt that "people are around me but not with me" (30%),
- Often or sometimes felt that there was no one to turn to (38%),
- Were twice as likely to have often felt "isolated from others" (30%) and "left out" (31%) than non-autistic youth, and
- Were almost 3 times as likely to report a lack of companionship (28%) than non-autistic youth.

The core social-communication difficulties of autism can contribute to poor social relationships and support, loneliness, and depression[80]. Loneliness is a transdiagnostic risk factor for suicide[81], and our own research has demonstrated that loneliness and poor social support are risk factors for suicide in the autistic population [82]. The SASLA study asked about **SOCIAL ACCEPTANCE AND SUPPORTS;** only 33% of autistic youth with an intellectual disability reported feeling 'satisfied' or 'very satisfied' with support from their friends compared to autistic youth without an intellectual disability (62%) or non-autistic youth (58%), and approximately 30% of autistic youth without an ID reported that they did not seek emotional support from others.

2.1.8 Bullying

Research has found that, in general population youth, bullying is associated with higher depression symptoms, suicidal ideation, and suicide attempts, and this is consistent across primary and secondary school settings[83]. A recent study from the UK found that autistic adolescents receiving treatment for a mental health difficulty, who also reported bullying in their first month, were twice as likely to go on to develop suicidal behaviours and thoughts[84]. Bullying was very common in the Australian SASLA sample, with 58% of autistic youth without an ID, 50% of autistic youth with an ID and 44% of non-autistic participants reporting having been bullied or picked on at school. Teasing was the most common form of bullying from our survey. Two thirds of autistic youth had been teased on called names at school. Autistic youth also reported having "Had things stolen from a locker, desk, or other places at school" (40%). Of particular concern is the rates of physical attacks or fighting involvement reported by our participants (Figure 7). Autistic youth with an ID were significantly more likely to be physically attacked or involved in fights at school (or to and from school) then autistic youth without an ID or non-autistic youth.

Figure 7: Rates of physical attack or involvement in fights at, to or from school in Australia



We asked our participants how they coped with bullying at school. Autistic youth with an ID were least likely to seek help from friends (5%) compared to their autistic pears without an ID (12%). Autistic youth without an ID were more likely to get help from family/parents (28%) compared to non-autistic (18%) and autistic youth with an ID (19%). Only 20% of youth in the study sort help for bullying from a teacher.

[80] Mazurek, 2014; Rai, et al., 2018a; Rai, et al., 2018b
[81] Glenn et al., 2017; Glenn et al., 2018
[82] Hedley et al., 2018b; Hedley et al., 2018b; Hedley et al., 2017
[83] Klomek et al., 2011
[84] Holden et al., 2020

The statistics presented in this section reveal a concerning pattern of multiple and interrelated risk markers for suicidal thoughts and behaviours in the autistic population. This increase in risk is apparent from childhood and associated with how autistic traits are expressed and managed in clinical settings, as well as the experience of co-occurring conditions, and less adaptive personal and interpersonal functioning. It is very likely that these factors have a significant impact on the quality of life experienced by autistic Australians.

2.2 Quality of life (QoL)[85]

All the risk factors listed above contribute to a person's QoL. A study of Australian teens and adults (15-80 years of age) found that autistic people experienced lower QoL on all four dimensions of QoL measured (detailed in Table 2) compared to non-autistic Australians. This table also shows the predictors of each QoL dimension. While mental health affects QoL in both autistic and non-autistic individuals with depression being a predictor for both Physical and Psychological QoL, depression was also a unique predictor of environmental QoL for autistic Australians. Additionally, a dependent living situation (e.g., living with parents) was related to poorer psychological QoL, while older age and being male were related to poorer social QoL for the autistic group.

QoL did not improve for autistic participants over a 2-year period, with psychological and social QoL staying the same and physical and environmental QoL declining. The biggest predictor for QoL for autistic Australians over two years was baseline QoL which was already significantly lower than non-Autistic Australians to begin with. Examination of other predictors showed that psychological well-being, depression and sleep 2-years earlier continued to have an impact on psychological QoL 2-years later. Therefore, current supports and strategies in place from 2015 until 2020 do not seem to have improved the QoL of autistic Australians.

Table 2: Unique predictors of quality of life for autistic and non-autistic Australians

	AUTISTIC AUSTRALIANS	NON-AUTISTIC AUSTRALIANS
1. Physical (E.g., Activities of daily life, dependence on medication, mobility, pain)	• Autism traits • Depression symptoms • Autonomic symptoms • Sleep quality	• Gender (male)[86] • Depression symptoms • Autonomic symptoms • Sleep quality
2. Psychological E.g., Negative and/or positive feelings, thinking, learning	• Living situation • Depression symptoms • Well-being	• Depression symptoms • Well-being
3. Social E.g., Personal relationships, social support, sexual activity	• Age • Gender (male) • Well-being	• Well-being
4. Environmental E.g., Financial resources, freedom, physical safety and security	• Depression symptoms	• Well-being

Nevertheless, opportunities do exist for improving QoL for autistic Australians. The results of this study support the treatment of both mental health problems and sleep problems to assist in improving QoL and may lead to improved psychological wellbeing for autistic adolescents and adults. For example, as sleep

[85] Lawson et al., 2020 (SASLA and ALSAA data)
[86] Male and female only as the sample size was too small for analysis for other gender options.

challenges (e.g., insomnia) are related to mental health, an intervention addressing both insomnia and mental health may be most useful in helping improve the QoL for autistic Australians.

2.3 COVID-19

The COVID-19 pandemic has impacted autistic Australians, and this is likely to be stronger than for Australians in general because autistic Australians[87]:

- have a higher risk of co-occurring mental health problems (as previously detailed in this submission), and
- because the measures taken to reduce the spread of COVID-19 affect social functioning and the maintenance of everyday routines.

"I could feel the rush of adrenaline circulate throughout my body every time there was a stressor. It would just build up and build up and build up each day. I was finding it really hard to get to sleep at night and my sleep quality was terrible and every morning was the same. Every time something happened unexpectedly, or any time an additional 'pressure' was felt, my whole body would feel this rush. I persisted and persisted. I had to work. I had to parent. I had to domesticate. Then the crying started. I was the only one in my family working. It got to a point where my workplace suggested I take some time off. It was such a relief and I felt supported. Although I wasn't going to get paid for taking time off, I needed it. I spent two full days sleeping to start the recovery process." (autistic person describing the compounding impact of COVID-19)88

Survey data from Belgium, the Netherlands, and the UK (*N* = 1044) found that compared to the general population, autistic people showed both positive and negative impacts of COVID-19 (Table 3)[89].

Table 3: Positive and negative impacts of COVID-19 on a European autistic population

	IMPACT
Significantly greater increase in:	• Anxiety and depression symptoms compared to non-autistic people. • worry about pets, work, getting medication and food, and their own safety/security.
Felt:	• Loss of social contact. • More relieved of social stress. • Greater stress by the loss of routine. • An increase in solidarity. • Reduced sensory load.

In April 2020, the SASLA study introduced a series of questions about the impact of COVID-19 on young Australian adults. Sixteen participants responded the COVID-19 general questions and nine responded with extended qualitative responses[90]. Autistic participants were twice as likely to describe the pandemic as

[87] Oomen et al., 2021
[88] Hedley et al., 2021 in press
[89] Oomen et al., 2021
[90] Our final 65 (autistic *n* = 22/20%, non-autistic *n* = 43/66%) participant complete the final survey during the pandemic.

having a very negative impact on their lives. A thematic analysis of written responses (Autistic *n* = 4 [19 individual item responses], non-autistic *n* = 5 [17 individual item responses]) can be found in Table 4. Three themes were identified from the autistic responses (change, sleep, and stress). The cumulative life stress is likely to impact suicide risk and development of mental health problems.

Table 4: Themes identified from text responses to the SASLA survey relating to COVID-19.

AUTISTIC		NON-AUTISTIC	
1. Change	*"Depression came back, unsurprisingly rapid changes and uncertainty did not mesh well with my brain"* *"Reduced hours, affted honours project timeline signifcantly, changed style of workload and assessments" (sic)*	**1. Online**	*"Everything was closed and moved online. My hours at work changed so I couldn't go to the online youth groups even when they didn't change thir hours."* *"TAFE moved online which has impacted my willingness to study and attend sessions."*
2. Sleep	*"Anxiety worsening sleep patterns."* *"Sleep: Stress levels have made it harder to fall asleep on time, means I get less overall sleep"*	**2. Work**	*"I quit my job when it began due to stress and anxiety and have a new job but I have reduced hours"* *"Working in retail resulted in increased stress from anxious customers. Work shifts are longer increasing stress."*
3. Stress	*"Stress levels have increased significantly more than expected."*		

2.4 Validated scales for measuring anxiety, depression, and suicide risk in autistic adults.

Evidence-based assessments are a cornerstone of evidence-based clinical practice. Most existing tools to assess anxiety, depression and suicide risk were originally developed and validated for use with the general (non-autistic) population. We have investigated the psychometric properties of several such tools for autistic people:

2.4.1 The Hospital Anxiety and Depression scale (HADS)[91]

The HADS questionnaire measures anxiety and depression symptoms in the past week. Using a pooled sample of 45 SASLA (Australian sample) + 151 UK Transition longitudinal study (UK sample) autistic adolescents and young adults we found that[92]:

- The HADS demonstrated statistically similar properties in the autistic sample to a non-autistic sample, with good internal consistency (Cronbach's alpha [α] = .83) and good convergent and divergent validity.

[91] Zigmond, & Snaith, 1983
[92] Uljarević et al., 2018

2.4.2 Patient Health Questionaire-9 (PHQ-9)[93]

The PHQ-9 measures depression symptom severity and functional impairment in the past two weeks. Using an Australian sample of 346 autistic + 235 community comparison participants from the SASLA and ALSAA studies (aged 15-80 years) we found that[94]:

- The PHQ-9 demonstrated statistically similar properties in the autistic sample to a non-autistic sample, with excellent internal consistency for autistic and community comparison samples (α = .91) and good convergent validity.

2.4.3 Suicide Ideation Attributes Scale (SIDAS)[95]

The SIDAS screens for suicide ideation in the past four weeks. We worked with the original instrument authors and a panel of experts to modify the SIDAS for use by autistic people, including through improved clarity of language and incorporation of "Easy English", visual analogue scales, and provision of response exemplars. We found that[96]:

- The SIDAS-M had a comparable factor structure to the original SIDAS and showed excellent internal consistency (omega = .923) and convergence with related measures.

There are currently no comprehensive clinical assessments of suicidality validated for use with autistic individuals. However, a psychometric evaluation of a modified version of the Australian **Suicide Assessment Kit Risk Screener (SAK)** for autistic individuals (SAK-M) is currently underway.

In addition to evidence-based symptom evaluation, it is imperative to equip clinicians of autistic people with evidence-based tools for treatment planning and outcome assessments.

2.4.4 The Brief COPE[97]

The Brief COPE assesses dispositional coping (general coping style). A representative Australian sample (*n* = 255 aged 15 to 80 years of age [SASLA + ALSAA data]) were used to validate and investigate the psychometric properties of the scale in the autistic population. We found [98]:

- Six-factors - engagement coping, support-seeking coping, disengagement coping, substance-use coping, humour coping, and religious coping - best represented the use of coping strategies in the autistic adult sample. High reliabilities and good convergent and divergent validities for the conceptually relevant coping factors were found.

2.5 Effective treatments - SLEAPI

Treating sleep difficulties, primarily insomnia symptoms, is important for autistic people; autistic individuals are highly susceptible to poor sleep quality. Better sleep quality is associated with better mental health, and thus sleep difficulties may be positively influenced by the treatment of mental health conditions and vice versa. Insomnia is a significant lifespan health problem in autism, but current sleep intervention research almost exclusively addresses children and adolescents. However, Australian and international studies show 54-64% of autistic individuals from mid-adolescence to old age have poor sleep quality or insomnia on standardised sleep questionnaires (PSQI, ISI), while UK autistic adults included sleep in their top 5 priority areas for research. Consultation with our Australian autism communities in 2018 and 2020 also identified

[93] Kroenke et al., 2001
[94] Arnold et al., 2020
[95] Van Spijker et al., 2014
[96] Hedley et al., 2021
[97] Carver, 1997
[98] Muniandy et al., 2021 in press

sleep as a priority research area. Currently there is no published psychological insomnia intervention research for autistic adults.

SLEAPI, also referred to earlier in the submission (section 2.1), is a novel combination of Acceptance and Commitment Therapy (ACT) and Behavioural Therapy (BT) that addresses insomnia in autistic adults. Due to the core and comorbid features of autism, cognitive behavioural therapy for insomnia (CBTI) which is generally the first-line psychological intervention for insomnia, may not always be a suitable treatment in autism. ACT is an alternative approach that has empirical support for insomnia treatment in non-autistic populations. An ACT/BT pilot program[99] was implemented with 8 autistic adults and improvements occurred for self-reported, clinical levels of insomnia in majority of participants; improvements in self-reported anxiety also occurred for some adults who entered the program with clinical levels of anxiety. Participants attended four, 2-hour group sessions (4 people per group) of an ACT/BT intervention promoting sleep and training in mindfulness and acceptance to reduce over-control, worry, experiential avoidance and arousal. An intervention based on ACT/BT was both efficacious and acceptable in reducing insomnia symptoms in autistic adults, and gains were maintained at a 2-month follow-up. Participants wrote:

"Helping with strategies for better sleep and general state of mind."
"Great study in an area that badly needs more research."

SLEAPI is the result of autism community consultation; it is based on our successful ACT/BT pilot intervention, which was informed by feedback from autistic adults, and post-intervention feedback from our pilot study autistic participants. SLEAPI is led by Dr Eric Morris, Director of the La Trobe University Psychology Clinic, in association with OTARC. **SLEAPI will be offered and evaluated within our Psychology Clinic in 2021; we are currently seeking funding to support a randomised clinical trial for a full evaluation of SLEAPI.**

2.6 Autism Spectrum Assessment and Mental Health Treatment at The Melbourne Clinic.

This is a qualitative study of assessment acceptability and therapeutic directions in consumers and clinical staff. The Melbourne Clinic Neuropsychology service has recently commenced a project in Adult Autism Spectrum Disorder (ASD) with two aims:

1. Evaluate the acceptability of the ASD diagnostic assessment process provided by the neuropsychology service, from the perspective of consumers.
2. Gain information from both consumers, and staff who have worked with clients on the spectrum, to inform the development of a day program focused on the treatment of improving mental health functioning in clients with ASD.

The aims of the project are to make the assessment process safe and helpful to consumers, and to design a safe, inclusive, and effective outpatient program through client and clinician co-design. The Melbourne Clinic currently runs several day-programs, including for the treatment of adult ADHD and other conditions. However, there are no group problems specifically designed for clients on the autism spectrum to assist with mental health wellness, and no published evidence-based group therapy frameworks that we are aware of. Through the co-design process the study team hope to identify which mental health issues autistic adults are most interested in gaining assistance with, and therapy frameworks they have found helpful and unhelpful in the past. Recommendations will also be sought for ways to set up the group in a manner that is safe and inclusive for the participation of autistic people. The project has a qualitative study design, involving

[99] Richdale et al., 2019

consumer and staff interviews. The plan for phase two will be client and staff co-design workshops, when establishing a group program therapy framework.

Recommendations – informed service provision for autistic people

4. Services should be co-designed with the autistic community. Co-designed services are far more likely to meet the needs of consumers, thus increasing utilisation and reducing stigma around help-seeking[100].

5. The focus should be on prevention across the lifespan due to the high rates of co-occurring mental health difficulties and suicide risk experienced by autistic people. This should include early intervention, teaching life skills, and awareness of the problem in children, particularly as our research[101] and that of others shows that autistic adolescents report more anxiety and depression symptoms than non-autistic adolescents[102] and more disturbingly, our finding that first suicide attempts are often in autistic children aged 13-14 years. This identifies a potentially critical period for intervention, and a time when autistic children may become increasingly aware of their differences from others, and there is increased salience and complexity in social relationships[86].

6. The heterogeneity of presentations and needs of those on the autism spectrum must be recognised by clinicians and service providers. An autistic person's unique needs and requirements must be understood and accommodated - not all autistic people require changes to practice but, other practices may be required for some autistic people.

7. Due to difficulties in using instruments to measure mental health problems and suicidality in autistic populations, a clinical interview by a professional trained in autism, mental health problems, and in suicide risk is critically important.

8. Education and training of mental health practitioners about autism and mental health is required within their basic training as well as ongoing professional development. Training must also Include known mental health and suicide risk factors:

    - extent of autistic characteristics and how autism can influence the presentation of mental health symptoms and vice versa,
    - emerging evidence of suicide risk in young autistic children,
    - later age of autism diagnosis,
    - gender differences,
    - increased risk of co-occurring conditions (intellectual disability, anxiety, depression, eating disorders, psychosis, insomnia, fatigue, and bullying),
    - maladaptive self-regulation behaviours,
    - autistic burnout,
    - the importance of feeling connected to others (loneliness, social acceptance and supports).

9. Public, adult diagnostic services need to be made available for all health regions across Australia. These services should have an emphasis on multidisciplinary assessment and differential diagnosis.

10. Accurate identification and quantification of the impact of autism on mental health services - use, cost, etc. This is likely to be higher than current estimates due to difficulties faced by clinicians and autistic people in:

[100] Maple et al., 2018
[101] Richdale et al., 2014
[102] van Steensel et al., 2017; Rai et al., 2018a

- accessing a diagnosis of autism in childhood or adulthood,
- complications due to diagnostic overshadowing,
- lack of accessibility of current services for autistic people,
- lack of validated interventions available to autistic people, and
- a need for greater funding into autism specific mental health and suicide prevention services.

Accommodations and adjustments to usual practice for autistic people

11. Services need to take account of and provide for the different needs of autistic people regarding sensory, executive functioning and communication needs. Doing so will promote initial access to services and reduce premature service drop-out. Required accommodations include:

- Provision of alternative ways of making and being reminded of appointments.
- Provision of quiet spaces and spaces designed to reduce the impact of potential sensory sensitivities within service provision facilities.
- Provision of quiet, low sensory waiting areas and minimising waiting time within the facility (e.g., ability to wait in the car until called).
- Tools such as written instructions to assist autistic people to follow advice and instructions (e.g., regarding filling and taking prescriptions).
- Provision of alternative forms for communicating between the autistic person and the service provider, such as written or other visual means.
- Provision of treatment and therapies adapted and tailored to the needs of the individual.

3. Effective system-wide strategies for encouraging emotional resilience building, improving mental health literacy and capacity across the community, reducing stigma, increasing consumer understanding of the mental health services, and improving autistic community engagement with mental health services.

3.1 Access to support services for autistic adults

In several of our studies of autistic individuals and their parents/carers, participants have expressed concern about the availability and cost of services across the lifespan[103]. For example, a thematic analysis of data from the SASLA community survey in 2020 identified significant problems with accessibility and adequacy of services (Table 2).

Table 2: Problems with accessibility and adequacy of support services in Australia raised by SASLA community members.

	THEME
Difficulty:	• locating available services, particularly after high school • navigating the system if you do not fit typical categories of support
Lack of:	• adaptation of the curriculum to cater for individual needs of autistic students in education settings

[103] Flower et al, 2019

- support to acquire employability and upskilling
- day programs
- practical supports and accommodations at university
- supports in fostering decision making, living skills and self-advocacy
- post diagnosis supports

"It's frustrating to find the scarce gold nuggets of information for adults on how to manage themselves. It's even more frustrating to see information targeted for the more physical, typically presenting symptoms, and not knowing what I can do to help myself. My only source of information, my only community, cannot help me. I'm left to go to blog posts and information I cannot trust, hoping for something to be true, and hoping it's not detrimental, because that's all that's left. I need this community to guide me. I don't want to hurt myself through ignorance." (Autistic individual)[104]

The lack of support services for autistic young people in transitioning from high school to further study, employment or a vocation is very concerning for their long-term mental wellbeing, particularly as unmet support needs have been flagged as a suicide risk for autistic adults[105]. Analysis also identified inadequacies in knowledge of autism and associated difficulties in front-line service providers, including many psychologists and psychiatrists, police and support workers, making interactions between autistic persons and service providers unnecessarily stressful and difficult.

"There is insufficient support and understanding of an autism diagnosis. For example, in paperwork from Centrelink they ask how long he will (sic) have Autism." (Family of an autistic individual and works with autistic individuals)[106]

A submission to the Royal Commission into Victoria's Mental Health System[107] by AMAZE, with content provided by OTARC researchers, identified a population of autistic people in crisis:

1. Mental health professionals felt unqualified to work with autistic people,
2. Autism specialists lacked training in mental health treatment.

Clearly, systemic changes are needed to better support autistic clients. An international scoping review (including Australian studies) of patient-service provider interactions with autistic individuals in healthcare settings, undertaken in 2019, found six themes that would inform improvement of services[108]. These were:

1. The complexity of working with autistic patients was beyond service providers' usual role.
2. Limited knowledge and resources negatively affected service provision to autistic patients and their families.
3. A lack of training or prior experience with autistic patients was a barrier to care.

[104] Dissanayake et al, 2020
[105] Cassidy et al., 2018
[106] Dissanayake et al, 2020
[107] AMAZE, 2019
[108] Morris et al (2019)

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

The above illustrates why co-designed and developed service provision is so important to the autistic population. These services are far more likely to[109]:

- Meet the needs of consumers,
- Increase utilisation, and
- Reduce stigma around help-seeking.

Differences in gender identity and sexual orientation, which are relatively common in the autistic population[110], are also important to consider as they can negatively influence help seeking behaviour[111].

3.2 Knowledge of available supports

SASLA Participants were asked about their knowledge of supports, including those for mental health, disability specific funded programs, disability supports post-school, disability employment services, federal government payments, relationship building advice on a Likert-scale ('know a lot', 'know a little' or 'don't know' response options). Autistic participants reported less knowledge regarding finding and making new friends after leaving school, romance and dating, and managing health compared to non-autistic participants. When asked about disability specific services, 63% of autistic participants were unaware of after school programs, 34% had no knowledge of disability supports available in TAFE and universities and 35% had no knowledge of job assistance services. This gap between knowledge of supports for autistic people in Australia needs addressing to improve accessibility and prevention of mental health difficulties and suicide.

A list of freely available resources from la Trobe University and from the SASLA study can be found in Appendix 2.

Recommendations - specialist service availability, development, and expansion

12. There must be correct and consistent application of best practice in working with autistic consumers in all aspects of service provision.

13. Transition support services must be made more accessible to autistic people in Australia. This includes transition services for entering and exiting education, employment and living arrangements.

14. More education for autistic teens and adults about available services for mental health, building social networks and managing health concerns would be beneficial.

15. Each public mental health service should have access to specialist autism advisors with expertise in autism and mental health. Such advisors should be available for crisis and emergency department presentations of suicidal autistic patients (or those who may be autistic) as well as for those autistic individuals (or those who may be autistic) who present with other severe mental health episodes/concerns (e.g., psychosis, bipolar, eating disorders), and for advice on ongoing management.

[109] Maple et al., 2018
[110] George & Stokes, 2018a, 2018b
[111] Pinder-Amaker, 2014

3.3 Improving wellbeing and mental health literacy and capacity across the community

3.3.1 Outcomes of the Understanding and Preventing Suicidal Behaviour in Individuals with Autism Spectrum Disorder Suicide Prevention Australia National Suicide Prevention Research Fellowship

This research aims to identify predictors, underlying causal mechanisms and protective factors of suicidal behaviours in autism using a longitudinal sample, and identify the nature, availability, use and appropriateness of supports for autistic individuals experiencing mental health distress/suicidal behaviour. This is a co-designed study that includes autistic researchers, academics and higher degree students and a partner organisation - Untapped.

Outcomes:

- development of new screening and clinical suicide assessment instruments (SIDAS-M, SAK-M),
- a conference (Dec 9, 2021) on mental health and suicide prevention in autism,
- first longitudinal study to explicitly examine suicidal risk and behaviour in Australian autistic adults,
- the launching an inclusive (e.g., autism, LGBTQI+ etc) suicide prevention website including information for professionals, family members, and people at risk, and
- policy recommendations and advisory services at State and federal level.

3.3.2 Mental health and wellbeing in the workplace – Industry collaboration to improve workforce literacy in mental health and wellbeing

Mental health conditions pose significant barriers to participation in the workforce and further education for autistic people. There is evidence that workplace-based support services (e.g., EAP) are limited in their ability to provide appropriate support to autistic people, due partly to a lack of expertise in working with autistic people by health professionals working in this sector. This has significant knock-on limiting labour force engagement, thereby excluding a proportion of the Australian population who can otherwise contribute to the Australian GDP (autistic adults represent about 2% of the population[9]).

OTARC, in collaboration with DXC Technology, ANZ Bank, and Untapped Holdings, has developed a mental health resource and training package that specifically targets the mental health and wellbeing of autistic employees and those who support them[112]. Available as a training and resource package, we have also developed and delivered face-to-face training sessions, and are in the middle of developing a workforce targeted online training platform (due for release in mid- 2021). Similar to Mental Health First Aid, and in addition to better supporting autistic employees, this work is intended to increase the mental health literacy of the broader workforce.

3.3.3 Mindful Centre for Training and Research in Developmental Health[113]

The Mindful Centre for Training and Research in Developmental Health is the state-wide unit in Victoria responsible for the delivery of postgraduate courses, training programs, professional development and research programs in child and adolescent mental health. Mindful is auspiced by The University of Melbourne and is part-funded by a Victorian Department of Health grant.

Mindful has a comprehensive Autism Training Calendar and is the largest provider of Autism Spectrum Disorder (ASD) training in Victoria [and possibly Australia] and attracts participants from across Australia,

[112] Bury et al., 2020
[113] The content in this section was written by Mindful. Mindful uses the term Autistic Spectrum Disorder (ASD).

New Zealand and Asia. This training calendar has been developed and is managed by the State-wide ASD Coordinator.

A key element contributing to well-being and good outcomes for Autistic people and their families is access to mental health care across the lifespan. This is needed for 1) diagnostic clarification, 2) identifying and treating co-occurring mental health problems, and 3) assisting with challenging and distressing symptoms including suicidal ideation, self-harming behaviours and suicide risk. Autistic people are at greater risk of suicide and this risk is further increased in the presence of unrecognised or inadequately treated mental illness and psychological distress.

What is urgently needed is a well-staffed and well-trained multidisciplinary workforce in both the state-funded and private sectors.

The following describes a successful model of capacity building across Victoria [targeting the public and private sector child and adolescent mental health providers] that has been expanded over the last 10 years and which should be considered in other States and Territories. Further, Mindful is now being approached by services and professionals from across Australia and in order to meet this demand, significant further investment in training at a Commonwealth level, needs to be prioritised.

This is a highly successful model that could be scaled up at a National level in partnership with existing mental health services across Australia.

Developing and maintaining a skilled ASD workforce in Child and Adolescent/Youth Mental Health (CAMHS/CYMHS) in Victoria has three components

1. The development of a high quality ASD training calendar in areas of ASD assessment and identification & treatment of mental health comorbidities, that is accessible and affordable for clinicians in both public mental health, and private sector services. See Appendix 3 for the autism training pamphlet from 2020.

2. Providing recurrent funding for ASD coordinators in each CAMHS to facilitate best practice ASD assessment and treatment approaches, raise awareness and assist clients & families to access the care that they need [ideally] in their region.

3. Funding of a **Statewide** ASD coordinator to support the networking and development of the ASD coordinator group that has been important in having a state-wide overview, collecting data, identifying gaps and making recommendations to government and supporting & maintaining the ASD coordinator workforce.

Training and skill development

It is critical to have a skilled and well-trained mental health workforce knowledgeable in ASD and comorbid mental health conditions. The current estimates of ASD prevalence in Australia is 1– 2.5 in 100[114]. Mental Health comorbidity in ASD is high[115] and is increasingly the reason for clients with ASD presenting to Child and Adolescent/Youth Mental Health Services (CAMHS/CYMHS).

Increasing numbers of children, young people and adults are presenting with an underlying ASD that has not previously been identified. For a significant number of these children, and young people with an undiagnosed ASD, their first contact with mental health services are at the Emergency Departments of hospitals, where they present with significant mental health concerns including self-harm, suicidal ideation and attempted suicide.

[114] Randall et al., 2016
[115] Brookman-Frazee etal., 2018

Mindful received funding from the Victorian Health Department's 2009 Autism State Plan, to establish a training program of ongoing Professional Development Workshops in Assessment and Treatment of ASD and Neurodevelopmental Disorders. This has made a significant impact on the capability and capacity of Victorian professionals, in both public and private sectors, to diagnosis and treat children, young people and adults with ASD and comorbid mental illness and psychological distress.

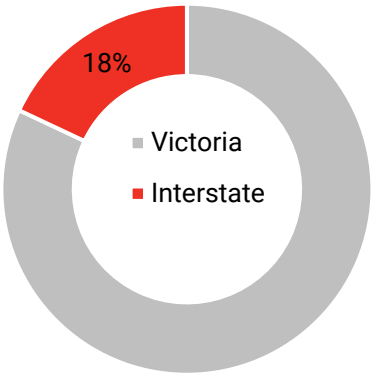


Figure 8: Percentage of training places for interstate participants of online training

In **2020** Mindful moved to an online platform and provided **1200 t**raining places for professionals offering subsidized places for publicly employed mental health professionals in Victoria. **Eighteen percent** of participants were from interstate (Figure 8).

In 2021 we can already see that the demand from interstate is growing and we currently have requests from State-funded mental health organisations to train their workforce [WA, NT, ACT] as well as requests from individuals across Australia.

Whilst we are trying to respond to these requests this demand for training is stretching our current capacity to the limit. This demonstrates a huge gap and a critical unmet need.

Training for Child and Adolescent Mental Health Professionals

The program continues to expand and includes:

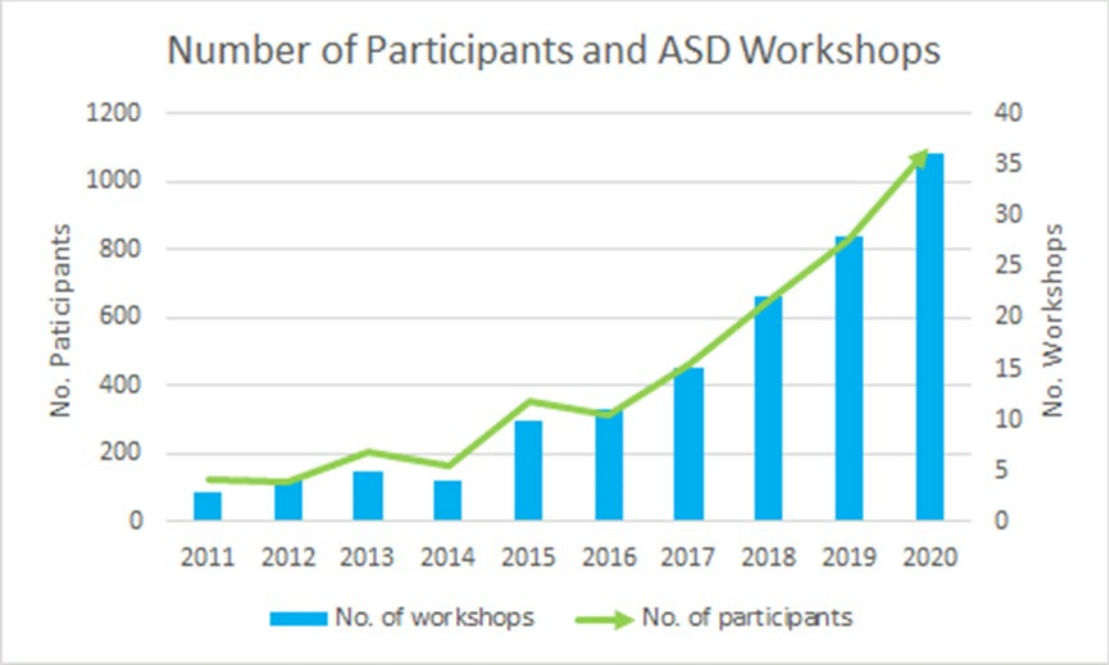
- Core training in the fundamentals of ASD assessment and positive behaviour support
- Specialised training in specific Autism assessment tools such as:
  - Autism diagnostic observation Schedule 2 - ADOS-2
  - Autism Diagnostic Interview Revised – ADI-R
  - Developmental, Dimensional and Diagnostic Interview, an ASD Computer Based Diagnostic Interview -3Di
- ASD Skill Development Workshop cover topics such as Gender Dysphoria, Emotional Regulation, Sleeping and Eating Issues, Attachment & Trauma; School Refusal; Anxiety, Sexual Development. These workshops are delivered by expert clinicians.

Training for Adult Mental Health Clinicians

- Due to high demand, training in assessment and understanding ASD in Adults with comorbid mental health conditions has been developed and added to the training calendar in 2020. This is being expanded in 2021.
- 12-month Pilot -Autism Coordinators in 6 Victorian Adult Mental health Services trained and supported by the Mindful statewide ASD co-ordinator based on the very successful model outlines above.

Analysis of the 2019 training data shows that now **50% of our participants come from outside of CAMHS/CYMHS.** These include paediatricians, psychologists, speech pathologists, occupational therapists, teachers, nurses, and others from the private sector and also from other public institutions such as Hospitals, Community Health Centres, Department of Education & Training, DHHS and family support services. For a nine-year overview of participant access to training see Figure 9.

Figure 9: Number of participants and ASD workshops undertaken by Mindful 2011-2020



Note: 2011 -2014 CAMHS/CYMHS only 2015-2020 CAMHS/CYMHS + Headspace, Public Health Services+ Private Practitioners

Impact of establishing regional ASD coordinators with CAMHS

Under the implementation of the Autism State Plan each Child & Adolescent Mental Health Service (CAMHS)/ Child & Youth Mental Health Service (CYMHS) and Orygen Youth Health were allocated ongoing funding for an ASD Coordinator to coordinate the ASD assessment and diagnostic process, oversee the delivery of quality early intervention and ongoing clinical care within the mental health service and facilitate referral pathways to appropriate support services.

In addition to coordinating services and demonstrating leadership within the mental health service system regarding ASD, the local coordinators also link in with key service providers in their local areas such as paediatricians, disability services, early childhood services and student support services from the Department of Education and Early Childhood Development.

These coordinators provide a network of services for children and young people with ASD who have a complex presentation or are difficult to diagnose. Many present with additional mental health disorders such as anxiety and depression. In addition, these children and young people may also have experienced trauma, family breakdown, non-attendance at school; homelessness, criminal justice system, socio economic hardship and /or CALD Background. There is also an increase in the number of girls referred for ASD assessment, which has previously been a largely unrecognised cohort.

Through this ASD CAMHS/CYMHS network many of our most vulnerable and disadvantaged children and young people with suspected ASD have access to tertiary ASD diagnostic and treatment services.

We have begun to see the long-term impact of the accessibility of ASD training and having key ASD specialists situated in CAMHS. Capacity building in the child and adolescent mental health sector can be demonstrated by the significant increases in the number of high-quality assessments conducted without increases in staffing.

- These ASD/Neurodevelopmental specialist teams provided 667 assessments in 2018/19 representing a 20% increase in assessments, with no increase in EFT, compared with 3 years earlier (557), 2015/16.

- An additional 345 assessments occurred within the CAMHS/CYMHS outpatient and inpatient teams demonstrating the wide impact of these specialist teams within their services.
- The total number of ASD assessments 2018/19 =1012 which represents almost 50% increase capacity across CAMHS in Victoria

ASD State-wide coordinator mental health

Also as part of the implementation of the Autism State Plan funding was provided for the establishment of a dedicated state wide ASD coordinator whose role was to support regional ASD coordinators, to develop practice guidelines, (*A Guide to Identification, Diagnosis and Treatment of Autism Spectrum Disorders in Victorian Mental Health Services*; Kerry Bull & Sandra Radovini, April 2013) and establish a high quality ongoing training calendar to facilitate a CMYHS workforce skilled in ASD treatment and diagnosis.

The ASD State-wide coordinator regularly collects data provided by regional coordinators regarding regional waiting lists, and regional issues and challenges to the provision of quality services, as well as local training needs. This role also provides mentoring and supervision to newly appointed ASD coordinators and facilitating regular peer network meeting where coordinator address common issue and share knowledge further increasing the capacity of this expert group. In addition, statewide data is provided to government to assist with planning.

Further areas for development

- Inequity of access to services with significantly longer waiting lists in areas of lower socio-economic disadvantage and rural areas.
- Young adults with ASD, discharged from mental health services experience limited access to appropriate services at a time of increased risk.
- Very limited or no access within adult mental health services to ASD assessments.

Issues specific to rural areas include:

- Lack of access to allied health disciplines, particularly speech pathology. The latter is currently being address with new funding to recruit Speech Pathologist in rural areas.
- Limited access to private or public services for ongoing care and treatment and long waiting lists.
- Few Paediatricians and Child & Adolescent Psychiatrists in rural areas.
- Maintenance of a skilled workforce.
- Effective utilisation of the skilled ASD workforce in regional areas. Understaffing of rural mental health teams often means clinicians with specialised training in ASD are not able to offer these assessments due to high demands related to other work such as risk and crisis assessments.

These issues identified in the Victorian context are likely to be similar to other rural parts of Australia.

Recommendations - Education and training of service providers

16. Expand the work of Mindful Centre for Training and Research in Developmental Health to a national level through additional federal funding to produce a well-trained multidisciplinary workforce in both the state-funded and private sector.

17. Mental health and other health providers generally do not receive training about autism in their basic training and have very limited understanding of autism, including the relationship between autism and mental health. Training about autism should be mandatory for all mental health practitioners given the high incidence of co-occurring mental health conditions for autistic people, their over-representation as users of mental health services, high rates of misdiagnosis and the

common experience of health practitioners failing to recognise autism in mental health clients. Training should encompass:

- Understanding and managing the social communication, sensory and executive functioning issues associated with autism and how they can impact service access and treatment.
- Understanding co-occurring conditions in autism, their presentation and treatment. Mental health practitioners need to understand how to assess for and differentially diagnose psychiatric conditions in autistic users of mental health services.
- Recognition of autism (including formal screening) in adolescent and adult mental health service clients, particularly in groups that may not display "classic" signs of autism, such as girls and women, culturally diverse groups, and people with different levels of cognitive ability.
- Education about next steps to take if a practitioner suspects autism in a mental health client.
- Training in assessment and diagnosis of autism in adolescents and adults for appropriate practitioners in each health region. Not all mental health practitioners need this skill, but there needs to be availability of publicly funded diagnostic services in each region.

4. Any related matters

4.1 Vision for an autism specific integrated training, service, and research clinic at La Trobe University

At least 10% of those seeking mental health support are autistic. Since autistic adults comprise approximately 2% of the population, they are significantly overrepresented amongst those seeking support. Autistic adults are often overlooked in research, which primarily focuses on children and families, and face significant barriers to receiving adequate healthcare. There is a clear community driven need for mental health research in autism, evidenced by both national[116] and international[117] surveys.

The establishment of a research-orientated, bulk-billed psychological clinic for autistic adults would be a major step forward in delivering accessible and effective psychological intervention for mental health difficulties in Australia. The overarching aims of the research clinic are outlined in Figure 10.

Figure 10: The aims of a research orientated bulk-billed psychological clinic for autistic adults

1. Provide low-cost psychological support to autistic adults
2. Embed clinical research into the service
3. Provide training and education opportunities to postgraduate clinical psychology students

La Trobe is committed to researching "A healthy, safe and equitable life course for everyone" (one of five priority research areas linked to the United Nation's Sustainable Development Goals), by conducting research with national and international impact, that is equitable, focused, and consumer-informed to improve the life course of autistic adults. This clinical research program will guide clinicians in making informed decisions on intervention options for autistic clients.

[116] Australian Autism Research Council, 2019
[117] Benevides et al., 2020

Autistic adults will see improvements in their quality of life, workforce participation and most importantly, be able to live the life they want to live.

This clinical research program will:

- Investigate the efficacy of psychological interventions such as the SLEAPI study (section 2.5) and modified ACT and CBT.
- Validate clinical measures for autistic adults. As mentioned previously in the submission (section 2.4), many tools used to measure mental health difficulties have not been validated for this population.
- Use our existing connections and build new relationships - La Trobe/OTARC has the capacity to undertake community consultation to identify and address barriers accessing psychological support. This clinical research program's goal to provide equitable access to evidence-based mental health support for autistic adults can be realised on an international scale and aligns with La Trobe University's values.
- Use co-production principles to develop clinician and client manuals for evidence-based psychological interventions (e.g., SLEAPI).
- Train a new generation of clinicians who will develop skills not only in undertaking evidence based mental health treatment but will understand the influence of autism on those treatments.
- Provide professional development seminars aimed at mental health clinicians to promote the practical outcomes of the research and provide recommendations for intervention with autistic adults.
- Share the results of the research clinic's work using connections with national autism organisations (e.g., Amaze, Aspect, Autism CRC) to share with the autism community, through short videos, webinars, and infographics. E.g., https://www.youtube.com/watch?v=wNQAvVa-Ge8

4.2 Autism Research Funding

Despite the systemic lack of funding in Australia for autism research, Australian autism researchers have made significant contributions to autism science internationally, beginning with the research of Professor Margot Prior back in the early 1970s. It was no accident that she was recognized with a Lifetime Achievement Award by the International Society for Autism Research in 2018.

With the conclusion of the Autism CRC funding in 2021, there is no federal autism-specific research funding available.

To continue Australia's contribution to both basic and applied autism research within the current competitive international environment, more funds are needed which are specifically directed to researching a condition that is prevalent in around 2% of people[118].

There is a severe gap in research exploring the autistic experience in adulthood. There is a lack of large-scale longitudinal studies which are important in assisting us to predict pivotal outcomes for autistic adults and the impact of co-occurring conditions, accessibility to services and adequacy of supports. There are few available evidence-based, psychological interventions for autistic adults that have the capacity to improve their physical and mental well-being; funding is needed to progress the necessary research to develop and test these interventions which will ultimately improve and even save lives.

[118] Dietz et al., 2020

Recommendations - Research

18. Fund the first adult autism specific integrated training, service, and research clinic in Australia at La Trobe University. Creating a federal benchmark for the creation of science informed, accessible and equitable intervention for autistic adults, co-developed *with* autistic people *for* autistic people.

19. Establish a dedicated Australian research funding pool for both applied and basic research on autism through the life course.

20. Research priorities:

    - Identification of what constitutes best practice, both for diagnosing autism and differential diagnosis of co-occurring conditions.
    - Identification of the barriers Australian autistic people face in accessing and using mental health services.
    - Identification of factors that particularly impact on the mental health, and the escalation of mental ill-health, in autistic persons and how these factors can be better managed. This should include investigation of the concept of "autistic burnout".
    - Research related to treatment efficacy and effectiveness, including cost-effective treatment modes such as telehealth and group psychological interventions (e.g., Cognitive Behaviour Therapy, Acceptance and Commitment Therapy, SLEAPI).
    - Identification and development of self-help strategies and resources for preventing and managing mental ill-health for autistic people. Resources for autistic people should be widely promoted and available. (e.g., available online and promoted by health practitioners, autism forums and organisations).

Acknowledgements

La Trobe University

La Trobe University undertakes world-class, high-impact research that addresses the major issues of our time. La Trobe placed in the top 400 in all three major global rankings and is now ranked the top 1.2 per cent of universities worldwide. La Trobe's broad fields of research are rated by the Federal Government at above or well above world standard.

Website: **https://www.latrobe.edu.au/**

The Olga Tennison Autism Research Centre

The Olga Tennison Autism Research Centre (OTARC) is Australia's first centre dedicated to autism research. It has a strong focus on research translation through the development of evidence-based tools, and collaborates with other autism research centres and institutes both in Australia and internationally.

OTARC is situated in the School of Psychology and Public Health within the College of Science, Health and Engineering (SHE) at La Trobe University in Melbourne, Australia.

Website: **https://www.latrobe.edu.au/otarc**
Blog: **http://otarc.blogs.latrobe.edu.au/**
Facebook: **https://www.facebook.com/search/top/?q=otarc**
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The Cooperative Research Centre for Living with Autism (Autism CRC) – The Study of Australian School Leavers with Autism (SASLA)

The authors acknowledge the financial support of the Autism CRC, established and supported under the Australian Government's Cooperative Research Centre Program. The authors would like to acknowledge the research participants who dedicated their time to the project. We further acknowledge Dr Mirko Uljarevic and Dr Ru Ying Cai for project establishment and data collection, and members of the Autism CRC Program 3 team who contributed to project content and recruitment, in particular the ALSAA team. Staff and non-staff in-kind support, including recruitment, was also provided by the Autism CRC and Other participants (**here**), other autism associations, a Victorian Secondary School, and many other individuals.

SASLA Website: **https://www.autismcrc.com.au/our-programs/adulthood/study-australian-school-leavers-autism-sasla-15-25-years**
SASLA Email: **SASLA@latrobe.edu.au**

Suicide Prevention Australia National Suicide Prevention Research Fellowship

Dr Darren Hedley is supported by a Suicide Prevention Australia National Suicide Prevention Research Fellowship. The Suicide Prevention Research Fund was established by the Federal Government to support research into suicide prevention. The aim of the fund is to support world-class Australian research and facilitate the rapid translation of knowledge into more effective services for individuals, families and communities.

DXC Technology, ANZ Bank, and Untapped Holdings

The authors would like to acknowledge DXC Technology, ANZ Bank and Untapped for their funding of the "Supporting a Neurodiverse Workforce: A Mental Health and Wellbeing Resource and Training Package". Dr Darren Hedley and Dr Simon Bury declare that they have received funding support and consultancy fees from these organisations.

The Melbourne Clinic

The Melbourne Clinic is Australia's largest private mental health service providing 203 inpatient beds, standalone Day Program centre, an Outreach Program, consulting suites at three locations and a Consultation Liaison service.

Nationally and internationally renowned for our quality mental health care services, their focus is to provide patients with the support and expertise from a comprehensive multi-disciplinary team of over 200 accredited Psychiatrists, Addiction Medicine specialists, Pain Medicine specialists and experienced registered mental health nurses, Allied Health Staff (Psychologists, Social Workers, Dietitians, Exercise Physiologist, Art Therapist and Pastoral Care Worker) in conjunction with several key support services such as Administration and Housekeeping services.

The Melbourne Clinic delivers Patient Centred Care; health care that is respectful of, and responsive to, the preferences, needs and values of patients. Their programs and care are based on the recovery model.

Website: https://themelbourneclinic.com.au/
Phone: +61 (0)3 9429 4688

Mindful Centre for Training and Research in Developmental Health

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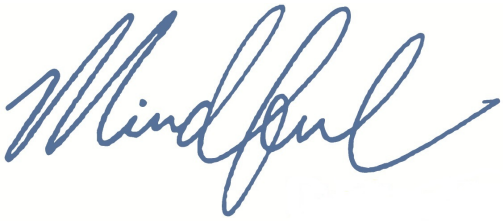

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Citation: Richdale, A.L., Hedley, D., Haschek, A., Chetcuti, L., Radovini, A., Saunders, F., Ball, R., Bury, S., Mantzalas, J., Fisher, C.A., Stokes, M., Lawson, L.P., & Morris, E. (2021). *La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the Select Committee on Mental Health and Suicide Prevention.* Bundoora. La Trobe University.

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APPENDIX 1 – OTARC/SASLA POLICY SUBMISSIONS

1. Dissanayake, C., Richdale, A., Haschek, A., Ihsen, E., Barbaro, J., Hedley, D., Bury, S., Flower, R., Hayward, S.M., Sadka, N., & Denham, M. (2020). La Trobe University Olga Tennison Autism Research Centre (OTARC) response to the **Select Committee on Autism**. La Trobe. https://doi.org/10.26181/5f20f14745abe
2. Richdale, A. L., Haschek, A. & Chetcuti, L. (2021). Feedback on the **Productivity Commission Report on Mental Health**. Olga Tennison Autism Research Centre, La Trobe University, Melbourne.
3. Haschek, A., Richdale, A., Lawson, L., Abdullahi, I., Flower, R., Unwin, K., Hedley, D., & Bury, S. (2020). The Longitudinal Study of Australian School Leavers with Autism's (SASLA) response to the **inquiry into access to TAFE for learners with a disability Victoria**, Australia. La Trobe. https://doi.org/10.26181/5f890479948c5
4. Richdale, A., Haschek, R., & Flower, R. The Longitudinal Study of Australian School Leavers with Autism's (SASLA) response to the **Royal Commission into Victoria's Mental Health System**. https://rcvmhs.vic.gov.au/submissions
5. Richdale, A. L., Dissanayake, C., Haschek, A., Ihsen, E., Hedley, D., Bury, S., Flower, R., Hayward, S. M., Denham, M. La Trobe University Olga Tennison Autism Research Centre (OTARC) **response to the Education and Employment Legislation Committee:** Comment on the Higher Education Support Amendment (Job-Ready Graduates and Supporting Regional and Remote Students) Bill 2020's potential impact on autistic higher education students. Bundoora. La Trobe University. https://doi.org/10.26181/5f585f483a2e2

APPENDIX 2 - EXISTING EDUCATION AND TRAINING MATERIALS

1. A Neurodiversity Toolkit for Higher Education[119]

A series of seven factsheets developed by the Neurodiversity Project Officer at La Trobe University, Elizabeth Radulski (A PhD student at La Trobe University co-supervised by OTARC), in November 2020 which are suitable for university and other higher education staff planning events with an inclusive focus. Each of the factsheets contains tips and guidance for ensuring that higher education activities accommodate neurodiverse students.

Full Neurodiversity toolkit **https://doi.org/10.26181/5fc833aebbd88**

1. Crash Course Neurodiversity 101
2. Neurodiversity Placemaking DIY Sensory Room
3. Neurodiversity Cultural Sensitivity: Language, Symbols and Culture
4. Neurodiversity Accessibility Checklist: Guided Tours
5. Neurodiversity Accessibility Checklist: Online Teaching and Events
6. Neurodiversity Accessibility Checklist: Large Events and Festivals
7. Neurodiversity Accessibility Checklist: Classroom/ Lecture Theatre Events

2. Clinical - Supporting mental health: What young Australian autistic adults tell us

This document for clinicians, summarises the SASLA findings so far in supporting autistic Australians facing mental health difficulties and co-produced with feedback from the autistic community. It covers the unique issues facing autistic people including emotion regulation, psychological inflexibility, suicide ideation, sleep, quality of life indicators and validated scales for mental health condition measurement. This is freely available as an online presentation (https://sway.office.com/8lt8IxNRZepuMCFd?ref=Link) or to download https://doi.org/10.26181/5fdc10c56879a (934.21 KB).

3. Pamphlets for autistic people

- **Anxiety, depression and autism -** This pamphlet is a free resource for autistic adults, family and friends regarding depression and anxiety prevalence, risk factors and practical strategies for managing these. The information presented is based on research findings from the Study of Australian School Leavers with Autism. https://doi.org/10.26181/5fdc0c5939471
- **Sleep and Young Autistic Adults -** with that around 60% of SASLA participants on the autism spectrum (age 15-25 years) reporting poor sleep quality this brochure offers some simple things young autistic adults can do to get better sleep. https://www.autismcrc.com.au/knowledge-centre/resource/sleep-and-young-autistic-adults

[119] **http://otarc.blogs.latrobe.edu.au/tag/neurodiversity/**

APPENDIX 3

MINDFUL CENTRE FOR RESEARCH AND TRAINING IN DEVELOPMENTAL HEALTH

STATEWIDE AUTISM TRAINING 2020

mindful.org.au/Autism-Training.aspx

CORE TRAINING

The core training workshops are designed for Psychologists, Speech Pathologists, Social Workers, Occupational Therapists, Psychiatric Nurses, Teachers, Early Intervention Workers, Headspace clinicians, Paediatric Fellows, and Psychiatry Trainees.

COMPLEXITIES OF ASD ASSESSMENT WORKSHOP

Two Day Seminar
$275 ($121 for CYMHS/CAMHS*)

This workshop provides clinicians with knowledge and skills for engaging in a comprehensive ASD assessment, including taking a developmental history, consideration of collateral information, issues of comorbidity, differential diagnosis and formulation of complex cases.

DATES (9.00am - 4.30pm)
Thurs 13th + Fri 14th February
Tuesday 17 & 24 March 2020 (CANCELLED)
Thurs 7th + Fri 8th May (CANCELLED)
Thurs 23rd + Fri 24th July (online, FULL)
Thurs 10th + Fri 11th September (FULL)

ASD POSITIVE BEHAVIOUR SUPPORT WORKSHOP

One Day Seminar
$198 ($99 for CYMHS/CAMHS*)

This workshop aims to provide practical strategies for professionals working with children and young people with ASD. Participants are advised to bring a case to the seminar for discussion and planning.

DATES (9.00am - 4.30pm)
Thursday 30th April (CANCELLED)
Friday 5th June (CANCELLED)
Thursday 22nd October

ASD & ADULT MENTAL HEALTH

Part 1: One Day Seminar
$198 ($99 for CYMHS/CAMHS*)
Part 2: Half-day Seminar
$99 ($55 for CYMHS/CAMHS*)

This training will focus on practical approaches to diagnosis and treatment

DATES
Pt 1: 13th March (9am - 4:30pm)
Pt 1: 29th May (RESCHEDULE IN PROGRESS)
Pt 2: Friday 14th August (9am - 12:30pm)

Please note:

Fees listed include the Goods and Services Tax (GST).

*Subsidised rates are available to Victorian CYMHS/CAMHS Clinicians, Headspace staff, Take Two staff, and Victorian publicly employed mental health clinicians.

Where are we?

Mindful – Centre for Training and Research in Developmental Health
Department of Psychiatry, University of Melbourne
Building C, 50 Flemington St, Travancore , VIC 3032

Enquiries

Please direct enquiries to Frances Saunders, Statewide Autism Training Coordinator at mindful-asd@unimelb.edu.au or (03) 9371 0200

ADVANCED ASSESSMENT

The advanced assessment skills workshops provide clinicians with training in ASD assessment tools for use in clinical practice.

AUTISM DIAGNOSTIC OBSERVATION SCHEDULE SECOND EDITION (ADOS-2)

Two Day Training
$770 ($385 for CYMHS/CAMHS*)
Presenter: Deborah Sweeney

This two-day workshop provides an introduction to the ADOS-2 as an assessment tool of communication, social interation and play. Training does not include the toddler module.
Prerequisite: Complexities of ASD Assessment.

DATES (9.00am - 4.30pm)
Monday 3rd + Tuesday 4th February (training in BENDIGO: $869 / $385 CYMHS/CAMHS*)
Thursday 27th + Friday 28th February
Thursday 16th + Friday 17th April (CANCELLED)
Thursday 21st + Friday 22nd May (CANCELLED)
Wednesday 8th + Thursday 9th July (online, FULL)
Thursday 17th + Friday 18th September (FULL)
Monday 7th + Tuesday 8th December (FULL)

ADOS-2 ADVANCED COURSE

Two and a Half Day Training
$1265 ($660 for CYMHS/CAMHS*)
Presenter: Deborah Sweeney
Prerequisite: ADOS-2 Workshop

DATES (8.45am - 4.30pm)
Wednesday 9th to Friday 11th December

ADOS-2 TODDLER MODULE

One Day Training
$385 ($187 for CYMHS/CAMHS*)
Presenter: Deborah Sweeney

DATE (9am - 3:30pm)
Friday 10th July (RESCHEDULE IN PROGRESS)

AUTISM DIAGNOSTIC INTERVIEW REVISED (ADI-R)

Two and a Half Day Training
$1540 ($770 for CYMHS/CAMHS*)
Presenter: Deborah Sweeney

Participants observe and discuss an administration of the ADI-R, conduct part of a ADI-R interview and receive feedback on their administration and scoring of the ADI-R

DATES (8.45am - 4.30pm)
Thursday 18th to Saturday 20th June (CANCELLED)
Thursday 26th to Saturday 28th November

3DI: DEVELOPMENTAL, DIMENSIONAL AND DIAGNOSTIC INTERVIEW

Two Day Training
$1540 ($770 CYMHS/CAMHS*)
Presenter: Richard Warrington

3Di is a computer-based programme used to diagnose ASD and related disorders in children. This course includes installation of the 3Di system and a single-user licence.

DATES (9am - 4.30pm)
2nd + 3rd July (RESCHEDULE IN PROGRESS)
6th + 7th July (RESCHEDULE IN PROGRESS)

SKILL DEVELOPMENT

Skill development workshops are designed for professionals working with clients with ASD. They focus on practical skill development for delivering a wide range of ASD interventions.

Half Day Training $99 ($55 for CYMHS/CAMHS*)
Full Day Training $198 ($110 for CYMHS/CAMHS*)

ASD TRACKING BETTER
MANAGING STRESS & EMOTIONAL REGULATION
Presenter: Dr Deeta Kimber, Child and Adolescent Psychiatrist
Friday 21st February, 9am - 4pm

ASD AND SCHOOL REFUSAL (NEW)
Presenters: Chrystie Mitchell and Leonie Wilson, Mental Health Clinicians
Friday 15th May (RESCHEDULE IN PROGRESS)

ANXIETY AND ASD
Presenter: Dr Fiona Zandt, Clinical Psychologist
Friday 12th June (RESCHEDULE IN PROGRESS)

ATTACHMENT AND ASD
Presenter: Dr Jenny Harrison, Child and Adolescent Psychiatrist
Friday 31st July, 9am - 12.30pm

ASD TRACKING BETTER
FEELING SAFE & STRONG WITH SENSORY CALMING AND TELLING FUTURE STORIES OF COPING BETTER
Presenter: Dr Deeta Kimber, Child and Adolescent Psychiatrist
Friday 21st August, 9:30am - 4:15pm (online)

ASD AND CORMORBIDTY IN YOUNG PEOPLE
Presenter: Johanna Rouse, ASD Coordinator, Orygen
Friday 28th August, 9am - 12.30pm

EATING DISORDERS IN ASD
Presenter: Dr Claire Burton, Clinical Psychologist
Thursday 3rd September, 9am - 12.30pm

ASD & FORENSIC ISSUES (NEW)
Presenter: Dr Teresa Flower, Consultant Child & Adolescent Psychiatrist
Monday 14th September, 9am - 12.30pm

SEXUAL DEVELOPMENT IN ASD (NEW)
Presenter: Dr Belinda Gargaro, Clinical Neuropsychologist
Friday 16th October, 9am - 12.30pm

ASD AND GENDER DYSPHORIA
Presenter: RCH Gender Clinic, RCH Specialist Autism Team, and Orygen
Thursday 5th November, 9am - 12.30pm

ASD AND SLEEPING ISSUES
Presenter: Dr Deborah Marks, Paediatrician
Friday 13th November, 9am - 12.30pm

Mindful

Register online at mindful.org.au/Autism-Training.aspx

Disclaimer:
All information correct at time of printing (20/12/2019). Mindful reserves the right to make changes to the training calendar or any general or specific information published in this calendar. Mindful reserves the right to cancel courses that do not achieve minimum participation, in which case, course fees will be refunded.

THE UNIVERSITY OF MELBOURNE