



Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:

Hedley, D;Hayward, SM;Clarke, A;Uljarević, M;Stokes, MA

Title:

Suicide and Autism: A Lifespan Perspective

Date:

2022-01-01

Citation:

Hedley, D., Hayward, S. M., Clarke, A., Uljarević, M. & Stokes, M. A. (2022). Suicide and Autism: A Lifespan Perspective. Stancliffe, R (Ed.). End of Life and People with Intellectual and Developmental Disability Contemporary Issues Challenges Experiences and Practice, (1), pp.59-94. Springer International Publishing.

Persistent Link:

<https://hdl.handle.net/11343/278744>

Suicide and Autism: A Lifespan Perspective

Darren Hedley, PhD¹

Susan M. Hayward, PhD¹

Alison Clarke, B.A., MSc^{2,3}

Mirko Uljarević, MD, PhD³

Mark A. Stokes, PhD⁴

¹Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe

University, VIC, Australia

²Orygen, VIC, Australia

³University of Melbourne, VIC, Australia

⁴Deakin University, VIC, Australia

Correspondence concerning this chapter should be addressed to:

Darren Hedley, PhD

Olga Tennison Autism Research Centre, School of Psychology and Public Health

La Trobe University, Melbourne, Victoria 3086, Australia

Phone: +61 03 9479 3704, Email: D.Hedley@latrobe.edu.au

Abstract

People with Autism Spectrum Disorder (ASD) are at increased risk of suicidal behaviour compared to the general population; the largest population-based study to date demonstrates a sevenfold increased risk of premature death by suicide. This chapter provides an overview of: a) the current literature regarding risk and prevalence of suicide behaviour in autism; b) the role of intellectual disability/intellectual developmental disorder in suicide in autism; c) correlates, risk and protective factors; d) dimensional constructs of suicide, including autistic traits; e) current approaches to suicide assessment, including potential modifications and; f) suicide prevention and service access. We consider these topics by drawing on state-of-the-art research, the perspective of lived experience, and consideration of the potential impacts of major events such as the coronavirus (COVID-19) pandemic.

Keywords: Autism Spectrum Disorder; developmental disability; intellectual developmental disorder; intellectual disability; suicide; suicide prevention.

Suicide and Autism: A Lifespan Perspective

Suicide accounts for 1.4% of deaths worldwide, is ranked as the 14th leading cause of death across all ages, and the second leading cause of death among 15 to 29-year-olds (Casey et al., 2008; Roth et al., 2018). Suicide has a significant impact on individuals, families, and society; in Australia suicide and the associated mental health impacts cost the economy in excess of AUD \$51 billion annually (Productivity Commission, 2019). Compared to people in the general population, people with a diagnosis of Autism Spectrum Disorder (ASD; henceforth ‘autism’)¹ are at increased risk of suicide behaviour, including thoughts of suicide (ideation), planning for suicide, non-fatal suicide attempt, and death by suicide (Hedley & Uljarević, 2018; Hirvikoski et al., 2016; Kirby et al., 2019). In this chapter we provide a detailed overview of the current knowledge concerning suicide behaviour in autistic people, supported by examples from people with lived experience.

“It [the thought of suicide] isn’t always present, thanks largely to medication and other factors such as exercise and therapy, but it is always at the back of my mind, lurking, like a burglar waiting for his opportunity to steal my levity.”

Will Attwood, autistic author²

Autism

The Centers for Disease Control and Prevention (CDC) estimates 1 in 54 children are diagnosed with autism in the United States (US; Maenner et al., 2020). Autism is a lifelong neurodevelopmental condition that is more prevalent in males than females (i.e., 2:1 to 4:1); at least 30% of autistic individuals have a co-occurring intellectual developmental disorder

¹ Consistent with the most recent edition of the Publication Manual of the American Psychological Association (2019), and the preferences of individuals with lived experience of autism (Bury, Jellet, Spoor, & Hedley, 2020), we utilise identity first language.

² Permission to be identified and quoted in this chapter provided by W.A. via personal communication with author D.H., June 28, 2020

(IDD; Maenner et al., 2020). Autism is hallmarked by varying degrees of impairment in social interaction and communication, restricted, repetitive behaviours and interests (RRBI), and can include hypo- or hyper-sensory sensitivities (American Psychiatric Association, 2013). Cognitive profiles are often uneven, reflecting relative areas of strength and weakness (Oliveras-Rentas, Kenworthy, Roberson, Martin, & Wallace, 2012; Rabiee et al., 2019). Specific cognitive domains may also be impacted (e.g., cognitive control, emotional regulation, executive functioning; Geurts, Verte, Oosterlaan, Roeyers, & Sergeant, 2004; Karalunas et al., 2018).

Autism is marked by significant heterogeneity; however, symptoms are often pervasive across all aspects of development, affecting treatment options and response (Masi, DeMayo, Glozier, & Guastella, 2017). Treatment response, as well as health and wellbeing, are particularly confounded by a high number of co-occurring neuropsychiatric conditions (Lai et al., 2019; Rodriguez-Seijas et al., 2020). This chapter specifically considers depression, anxiety, sleep disorders, substance use, and psychosis, due primarily to their association with suicidal behaviour in the general population (Joiner, Brown, & Wingate, 2005; Kessler, Berglund, Borges, Nock, & Wang, 2005). We also review the evidence concerning suicidal behaviour in IDD due to its high prevalence in autism.

a) Risk and prevalence of suicide behaviour in autism

There is robust evidence of increased risk of suicidal behaviour in the autistic population, with suicides rates ranging from 0.17% to 0.31% (Hirvikoski et al., 2016; Kirby et al., 2019). In a large population-based study, Hirvikoski et al. (2016) reported a sevenfold increased risk of premature death by suicide amongst autistic people compared to the general population. Risk may be impacted by degree of intellectual impairment with a lower relative risk in autistic people with co-occurring IDD (Hirvikoski et al., 2016). Kirby et al. (2019) found 73% of suicides by autistic people were violent (e.g., hanging/strangulation, blunt force

injury; non-violent means included asphyxiants or intoxication, including drug overdose), a rate similar to the non-autistic comparison group. However, autistic people were less likely than non-autistic people to use firearms. Autistic males and females did not differ significantly on the method used; in the general population males are more likely to use violent means than females (Ajdacic-Gross et al., 2008).

Lifespan perspective. The average age of those who die by suicide may be lower in autistic groups than in the general population (e.g., 32 vs. 41 years; Kirby et al., 2019). There is also a higher incidence of suicide amongst younger autistic (0.16%) than non-autistic (0.07%) people (Kirby et al., 2019). Suicide risk may be greater when diagnosis is deferred until later in life, possibly as individuals diagnosed during early childhood may be more likely to access supports and interventions throughout critical developmental periods. For example, of 374 people diagnosed with autism in adulthood, 66% reported suicidal ideation and 35% reported having made suicide plans or attempts (Cassidy et al., 2014). When diagnosis is delayed until adulthood there may also be a history of diagnostic overshadowing (Reiss, Levitan, & Szyszko, 1982), leading to other mental health conditions being treated without considering autism (Andrea et al., 2014). Finally, there is a growing portion of people diagnosed with autism in their fifties and beyond, with this group commonly reporting other psychiatric diagnoses (e.g., depression, anxiety), feeling isolated and ‘alien’ throughout their lives (Stagg & Belcher, 2019).

Below we present a case study of ‘Max’³ as a way of illustrating the early age that suicidal behaviour can present, difficulties navigating the healthcare system, and the complex interrelationship between autism symptoms, mental health, social relationships, and suicide attempts.

³ Not their real name. Gender neutral (they/their) pronouns are applied when referring to Max.

CASE EXAMPLE: Max

Max is an Indigenous Australian who was diagnosed with autism at 13 years following a series of suicide attempts. Max is verbal but struggles with social/pragmatic communication and expressive and receptive language. Max experiences difficulties with changes and surprises, attention, sensory regulation, and becomes easily overwhelmed by auditory information. Max was diagnosed with severe anxiety, childhood depression, and Post Traumatic Stress Disorder (PTSD) prior to receiving their autism diagnosis. Max faces significant mental health challenges and sleep difficulties. These were unsuccessfully treated with medication and affect access to services. Max is currently 21 years of age and presents with a primary diagnosis of autism and several additional co-occurring diagnoses.

As a child Max was active in sports but was regularly excluded from group activities. Max struggled throughout childcare and school, was in conflict with teachers, and was the victim of bullying. Max was unsuccessful in attempts to make friends and experienced social isolation. By the sixth grade Max had attended numerous schools, struggled with exclusion from school programs, and displayed high levels of non-attendance. Max's parents returned home one day to find that Max had attempted suicide by strangulation.

Despite seeking professional assistance, Max's parents state that "no one took the suicide attempt seriously; they labelled it as attention seeking". Max's suicide attempts continued, resulting in an attempt by strangulation at a public location. The family sought help from a local hospital where they were instructed to go home and initiate a 24-hour suicide watch. About six months after hospital presentation Max was diagnosed with autism. Max's suicide attempts continued, including at school. The school developed a plan to manage Max's behaviour, however, the family reported neither they nor Max were consulted in this process. Following Max's 14th birthday the family were informed the school could no longer support

Max. Max's mother reported feeling dismissed by professionals and unprepared to provide the high level of care that Max required.

During visits to the local mental health service Max struggled with the noise of the waiting room, which led to sensory overload and escape attempt. He also had difficulty with changes to staff and long wait times to see specialists. Max's anxiety increased with each visit. Max's mother describes a cycle of being admitted to a service, often receiving additional diagnoses, followed by referral elsewhere due to Max's complex needs. They failed to develop an effective solution to Max's challenges; at times Max was engaging in suicide behaviour on a weekly basis. Attempts were violent and unplanned. Max increasingly withdrew from the outside world deeming it to be "unsafe". Max slept more and began engaging in non-suicidal self-injurious behaviour, including severe head banging. At 16 years of age Max had completely withdrawn from the outside world.⁴

Subthreshold symptomatology. Little is understood or reported about suicidal behaviour in people who are autistic but remain undiagnosed, or who exhibit high autistic traits but whose symptoms do not reach the diagnostic threshold. Although speculative, these people may face similar challenges to those who receive a formal diagnosis. They may also face added challenges due to not understanding or knowing the underlying cause of their difficulties or failing to access treatments that consider the influence of autistic traits.

Gender. Autistic females are at a significantly higher risk of suicide than non-autistic females (Hirvikoski et al., 2016; Kirby et al., 2019). In the general population, being female is a protective factor for suicide (Centers for Disease Control and Prevention, 2020).

⁴ At the time of writing Max is supported by a multidisciplinary team. Team members have experience with autism and are willing to learn about Max's needs and wishes for the future. Max has an Assistance Dog and is beginning to venture outside again. While suicide attempts have now stopped, Max continues to experience suicidal ideation to varying degrees.

Compared to autistic males, autistic females report a relatively higher number of psychiatric diagnoses (Hedley, Uljarević, Foley, Richdale, & Trollor, 2018; Lai et al., 2019; Sedgewick, Leppanen, & Tchanturia, 2020). Females may be more likely to be diagnosed with autism in adulthood (Kirby et al., 2019) or may not receive a formal autism diagnosis (Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015). Females may also be at greater risk of traumatic experiences, including sexual abuse (Kirby et al., 2019), and could experience identity conflict (Bargiela, Steward, & Mandy, 2016; Cassidy, Bradley, Shaw, & Baron-Cohen, 2018). Concealing autistic traits (“camouflaging”) is more common in autistic females and has been found to account for 3.5% of the variance in suicidal behaviour (Cassidy et al., 2018). A relatively high portion of autistic females report non-binary gender preference or minority sexual orientation (George & Stokes, 2018b). Incongruence between sex and gender can have subsequent impacts on mental health and well-being (George & Stokes, 2018a).

b) Intellectual disability/intellectual developmental disorder and suicide risk

Risk of suicide may be greater in autistic individuals without co-occurring IDD (Hirvikoski et al., 2016); however, co-occurring IDD has been found to be associated with greater risk of suicide attempt or self-inflicted injury (e.g., intentional suffocation, drowning, firearm wounds, poisoning, injuries from objects, and other mechanisms of self-injury; Hand, Benevides, & Carretta, 2019). Overall, there is a very limited amount of research concerning suicide risk in autistic people with IDD. Similarly, suicide in people with IDD in the absence of autism remains under-explored and poorly characterised (Ludi et al., 2012; Wark, McKay, Ryan, & Müller, 2018), with similar (Erlangsen et al., 2020) or lower (Patja, Iivanainen, Raitasuo, & Lönnqvist, 2001) rates of suicide reported than in the general population. Frequent risk factors for suicidal behaviour include concurrent mental health difficulties and *severity* of IDD, with those with milder IDD at greater risk (Dodd, Doherty, & Guerin, 2016).

However, in adolescents with borderline intellectual impairment, a recent study reported no clear association between suicidal thoughts and behaviours and level of IDD (King et al., 2019).

Reported methods of suicide by people with mild or moderate IDD, who were mostly in psychiatric institutions, included hanging, drowning, intoxication by eating cigarettes or medication, and lying on a train track or jumping under a train (Patja et al., 2001). Males in this study were at a lower risk of suicide compared to males in the general population, but risk for females was similar. People with borderline or mild intellectual functioning may be at increased risk compared to those with moderate to profound IDD (Weinheimer, 2018). However, suicidal intent can be difficult to assess in people with profound levels of intellectual impairment. Other factors associated with suicidal behaviour in IDD include younger age, history of abuse or self-harm, trauma, and familial psychopathology, a prior visit to an emergency department, a history of psychiatric hospitalisation, and co-occurring physical disability (Lunsky, Raina, & Burge, 2012; Weinheimer, 2018). Female sex may be a risk factor in those who attempt suicide (Lunsky et al., 2012). People with IDD also report low levels of social support, high levels of loneliness, stress, anxiety, and depression, which may present as additional risk factors for suicide in this population (Lunsky, 2004).

c) Correlates, risk and protective factors

Suicide rates are elevated across a wide range of psychiatric disorders and are compounded by the presence of multiple conditions (Joiner et al., 2005; Kessler et al., 2005). In autism there is a higher prevalence of co-occurring mental health diagnoses than in the general population (Hudson, Hall, & Harkness, 2018; Lai et al., 2019). Due to their relevance to suicide we focus on depression, anxiety, and sleep disorders, substance use and psychosis.

Depression. Lifetime rates of depressive disorders are high in the autistic population, ranging from around 28% to 49% (Uljarević, Hedley, Cai, Hardan, & South, 2020; Uljarević,

Hedley, Foley et al., 2020), about four times that observed in the general population (11% to 17%; Hudson et al., 2018; Lai et al., 2019). This is notable given a strong positive association between depression and suicidal behaviour in autistic people (Dell'Osso et al., 2019; Hand et al., 2019). Risk of depression may be higher in individuals without co-occurring IDD; however, depression may present differently in people with IDD (Hudson et al., 2018; Rai, Heuvelman, et al., 2018). Psycho-social risk factors that may be symptomatic of the social communication difficulties experienced in autism, such as loneliness and reduced social support, predict depressive scores (Mazurek, 2014) and suicidal ideation (Hedley et al., 2018). Bullying is also prevalent and a risk factor for depression in autistic children (Rai, Culpin, et al., 2018).

Anxiety. Anxiety has been shown to increase suicide risk in non-autistic populations (De La Vega, Giner, & Courtet, 2018; Kanwar et al., 2013). Anxiety disorders are more prevalent and may have greater symptom severity in autistic compared to clinical and non-clinical populations (Uljarević, Hedley, Cai et al., 2020). Although the prevalence of anxiety in autism varies considerably across studies, the majority of large scale studies and meta-analytic reviews indicate that at least 40% of children and adolescents (van Steensel, Bogels, & Perrin, 2011) and up to 60% of adults meet the diagnostic threshold for anxiety disorders (Lever & Geurts, 2016; Uljarević, Hedley, Foley et al., 2020). However, it is important to emphasise that anxiety can present atypically in autism (Kerns et al., 2014; Lau, Leung, & Lau, 2019). Thus, it can be missed by standardised screening and diagnostic instruments suggesting likely underestimation of prevalence and impact.

Research to date has mainly focused on exploring the effects of sex, age, cognitive functioning and core autism symptoms on the presentation and severity of anxiety in the autistic population. There is some evidence that female sex (Hedley et al., 2018; Lai et al., 2019), higher IQ (Hallett et al., 2013), and severity of autism symptoms (Wigham, Rodgers,

South, McConachie, & Freston, 2015) are associated with higher prevalence and severity of anxiety, although not all studies report significant results (Duvekot et al., 2017; Hollocks, Pickles, Howlin, & Simonoff, 2016). In autism, relationships have been identified between anxiety and both emotion regulation (Cai, Richdale, Dissanayake, Trollor, & Uljarević, 2019) and intolerance of uncertainty (Cai, Richdale, Dissanayake, & Uljarević, 2018; Maisel et al., 2016). These are consistent with findings in non-autistic samples (Aldao, Nolen-Hoeksema, & Schweizer, 2010).

Sleep disorders. Sleep problems are prevalent in autism and may include short sleep duration, low sleep quality and efficiency, insomnia, daytime sleepiness, and circadian sleep desynchronization (Carmassi et al., 2019; Mazzone, Postorino, Siracusano, Riccioni, & Curatolo, 2018; Reynolds et al., 2019). In both general and non-autistic clinical populations there is strong support of an association between suicide behaviour and sleep complaints (Bernert & Joiner, 2007; Bernert, Kim, Iwata, & Perlis, 2015; Malik et al., 2014). Sleep disorders are modifiable with treatment (Bernert et al., 2015; Lovato, Lack, & Kennaway, 2016) and some sleep medications may reduce suicidal ideation (e.g., zolpidem-CR; McCall et al., 2019). Studies have yet to examine relationships between sleep problems and suicide in autistic people, although autistic traits (and shorter sleep duration) have been found to predict suicidal ideation in a non-autistic sample (Hochard, Pendrous, Mari, & Flynn, 2020).

Alcohol and other drugs. Relatively little research has examined substance use amongst autistic people, which is thought to affect from 0.7% to 36% of the autistic population (Arnevik & Helverschou, 2016; Lugo-Marín et al., 2019). It was once thought that substance use was rare amongst autistic people, or primarily associated with co-occurring attention deficit hyperactivity disorder (Butwicka et al., 2017). Currently, however, the risk of substance use-related problems in autistic people is thought to be double that of the general population (Butwicka et al., 2017). Substance dependence significantly increases risk of

death by suicide with a high portion of suicide deaths involving alcohol and opioids (Esang & Ahmed, 2018)—risk may be more than doubled in the presence of substance use disorder (Poorolajal, Haghtalab, Farhadi, & Darvishi, 2016). Substance use clearly needs to be considered as a potential risk factor for suicide in autism in both research and applied settings.

Psychosis. Autism often co-occurs with psychosis and schizophrenia (Chisholm, Lin, Abu-Akel, & Wood, 2015; Upthegrove et al., 2018), with evidence of shared genetic susceptibility (Ruzzo & Geschwind, 2016). Suicide is a significant risk for people with early-onset first-episode psychosis (Sanchez-Gistau et al., 2013), and there is a high overlap between schizophrenia and suicide, returning a lifetime risk of suicide around 5% (Hor & Taylor, 2010). In patients with first episode psychosis, a high level of autistic traits and positive symptoms of schizophrenia have been found to be associated with depression, hopelessness, and suicidal behaviour (Upthegrove et al., 2018). Clinicians should therefore assess for psychosis or other positive symptoms of schizophrenia in addition to autism. Where psychotic symptoms are present in conjunction with high autistic traits or autism diagnosis, depression and suicidal behaviour needs to be seriously considered. However, it is also important to acknowledge that similar to autism itself, psychosis is phenotypically and etiologically complex, with a number of domains within both positive and negative symptom dimensions that are at least partially distinct in terms of correlates, outcomes and underpinning mechanisms (Strauss et al., 2018). Research that combines dimensional frameworks with fine-grained latent variable approaches is required in order to understand how transdiagnostic interactions between specific, precisely defined symptom domains that occur across autism, psychosis, and the schizophrenia spectrum give rise to suicide risk.

There has been a recent and significant shift towards consideration of transdiagnostic or dimensional constructs that might underlie suicidal risk and behaviour (Glenn, Cha,

Kleiman, & Nock, 2017; Glenn et al., 2018; O'Connor & Portzky, 2018). In the next section we identify potential transdiagnostic factors associated with autism that might increase suicide risk in both autistic and non-autistic populations.

d) Dimensional constructs

Dimensional constructs represent basic, biologically meaningful dimensions of functioning that span the full range of human behaviour, from normative to atypical functioning (Cuthbert & Insel, 2013). These dimensions represent building blocks of normative functioning, and if disrupted, can result in specific behaviors/traits/characteristics or symptoms seen across a range of disorders. Therefore, studying specific dimensional constructs, and cross-dimensional interactions, measured across different levels, from genes and neurocircuitry to observable behaviors, has been proposed as a better way of defining and understanding mental disorders than symptom-based classification systems (Cuthbert & Insel, 2013). In the context of this chapter, dimensional constructs are important as they offer a way to understand common risk factors across clinically diverse populations.

Autistic traits. Autistic traits are normally distributed in the general population (Ruzich et al., 2015). There is emerging evidence that autistic traits are risk markers for suicide in non-autistic (Pelton & Cassidy, 2017; Stanley et al., 2020; Upthegrove et al., 2018) and autistic (Cassidy et al., 2014; Hedley et al., 2018) populations. Autistic trait severity has been found to directly (Cassidy et al., 2014) or indirectly (through mediator variables including loneliness, low perceived social support, burdensomeness, belonging; Hedley et al., 2018; Pelton & Cassidy, 2017) predict increased suicide risk. Thus, autistic traits may serve as a useful marker for suicide risk across clinically diverse populations.

Social communication. Social communication difficulties contribute to poor social relationships and support, loneliness and depression (Mazurek, 2014; Rai, Culpin, et al., 2018; Rai, Heuvelman, et al., 2018) and are identified as important transdiagnostic risk

factors for suicide (Glenn et al., 2017; Glenn et al., 2018). In non-autistic populations, impairments in different domains of social and communication functioning are associated with increased risk of suicidal ideation and behaviour (Stanley et al., 2020). In autistic people, social communication challenges 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. For autistic people who are non-verbal, or have limited verbal communication skills, there are likely to be additional challenges detecting and correctly diagnosing mental health problems.

Restricted, repetitive behaviours and interests (RRBI). Cognitive rigidity and rumination are associated with suicidal behaviour in both general (Fazakas-DeHoog, Rnic, & Dozois, 2017; Smith, Alloy, & Abramson, 2006) and autistic (Dell'Osso et al., 2019) populations. As it relates to RRBI, autistic people may have difficulties with broad cognitive domains including cognitive control and executive function (Geurts et al., 2004; Karalunas et al., 2018). These cognitive challenges likely underpin cognitive and behavioural rigidity and social communication difficulties (Bos et al., 2019). Emotional dysregulation is another transdiagnostic dimension characteristic of autism (Cai et al., 2018, 2019) that is strongly associated with RRBI (Samson et al., 2014). Emotion dysregulation is associated with both depressive symptoms and suicidal behaviour in non-autistic people (Crandall, Allsop, & Hanson, 2018); however, it may also serve as a protective measure against lethal self-harm (Anestis, Bagge, Tull, & Joiner, 2011). People who have difficulty with emotional regulation, low distress tolerance, and high negative urgency exhibit higher levels of suicidal *desire* (i.e., perceived burdensomeness, thwarted belongingness), but may also have a lower *capability* for suicide (Anestis et al., 2011).

e) Risk assessment and instruments

There is a general paucity of mental health and other instruments designed specifically for autistic people; thus, instruments designed for the general population are typically substituted for this population (Uljarević et al., 2018). Cassidy, Bradley, Cogger-Ward, and Shaw et al. (2020) examined the psychometric properties of the Suicidal Behaviors Questionnaire-Revised (SBQ-R; Osman et al., 2001) in autistic adults. The SBQ-R is a four-item instrument assessing lifetime ideation and attempts, frequency of ideation over 12 months, threat of a suicide attempt, and likelihood of future suicidal behaviour. In the study, autistic participants scored higher on all items than participants from the general population. However, SBQ-R items loaded differently in the two populations suggesting the instrument may perform differently for each group. Autistic participants reported difficulty interpreting and responding to questions and cited response options as lacking relevance or not adequately capturing their experience; for example, some autistic participants reported difficulty understanding the concept of a suicide plan (Cassidy, Bradley, Cogger-Ward, Shaw et al., 2020). A modified version of the SBQ-R for use by autistic people has been developed for research use, returning improved psychometric characteristics in autistic people (although predominantly females diagnosed in adulthood) compared to the original version (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2020).

The Interpersonal Needs Questionnaire-10 (INQ-10; Van Orden, Cukrowicz, Witte, & Joiner, 2012) measures thwarted belonging and perceived burden; important constructs in Joiner's (2005) interpersonal-psychological theory of suicidal behaviour. However, the INQ-10 may function differently in autistic than general populations, possibly due to inclusion of items requiring awareness of mental states of others, which may be a challenging concept for autistic respondents (Pelton et al., 2020). The Acquired Capability for Suicide Scale—Fearlessness About Death (ACCS-FAD) is a scale that assesses suicidal capability (Ribeiro et al., 2014). Although the use of non-concrete language and negatively worded responses

affected performance, there is some support for its psychometric properties in autistic populations with one item removed (Pelton et al., 2020).

Notably, these studies have, to date, excluded autistic participants with co-occurring IDD who may have experienced additional difficulties understanding and responding to the questionnaire. Instruments designed for use by people with co-occurring IDD may need to be adapted by simplifying question wording and providing less complex response options (Nicolaidis et al., 2020).

Given problems associated with instruments that are not specifically designed for use in autistic populations, it may be important to combine validated instruments with a clinical interview conducted by professionals experienced with both suicide risk assessment and autism. Two tools developed in Australia, the Suicidal Ideation Attributes Scales (SIDAS; Van Spijker et al., 2014) and the Suicide Assessment Kit (SAK; Deady, Ross, & Darke, 2015) are examples of instruments that can be used as part of a clinical risk assessment by trained and suitably qualified health practitioners. The chapter authors are currently developing these two instruments for use in the autistic population.

Non-suicidal self-injury (NSSI). NSSI in autistic people contributes to reduced quality of life and difficulty accessing services (Steenfeldt-Kristensen, Jones, & Richards, 2020). NSSI is highly prevalent in the autistic population, including in those with and without co-occurring IDD, with an estimated prevalence around 42% (Steenfeldt-Kristensen et al., 2020). Hand-hitting, skin picking, and hitting self or objects are amongst the most common forms of self-injury; rubbing self on surfaces, self-pinching, and self-cutting are less common (Steenfeldt-Kristensen et al., 2020). Due to lack of research, it is difficult to evaluate the influence of intellectual impairment on behaviour; although one study found similar rates in adults with average cognitive ability (31%) and severe IDD (32%) (Ballaban-Gil, Rapin, Tuchman, & Shinnar, 1996). NSSI is associated with suicide risk in the autistic population

(Moseley, Gregory, Smith, Allison, & Baron-Cohen, 2020), and may be more prevalent in autistic women than men (Maddox, Trubanova, & White, 2017). In the general population, NSSI often precedes suicide attempts (Olfson et al., 2017).

Suicide attempts may be mis-diagnosed as NSSI in the autistic population. Because NSSI can be predictive of suicide attempt, whether harming behaviour is a suicide attempt or NSSI is an important consideration for suicide prevention. It is therefore critically important that health professionals carefully evaluate autistic people who present with NSSI for suicide risk, including in the presence of IDD.

f) Prevention and service access

Autistic people describe significant difficulties accessing mental health support with lack of appropriate treatment and support options as significant barriers to their health and wellbeing (Camm-Crosbie, Bradley, Shaw, Baron-Cohen, & Cassidy, 2019), reflecting a general paucity of specialised services for this population (Marrus et al., 2014). The problem is particularly common in older autistic adults (Vogan, Lake, Tint, Weiss, & Lunskey, 2017). Families of younger children also report difficulties accessing mental health services (Jackson, Keville, & Ludlow, 2020), suggesting mental health challenges begin early in autism. It is therefore essential for policy makers and clinicians to improve their understanding of co-occurring mental health conditions and suicidal behaviour in autistic people in order to appropriately inform suicide management, treatment, and prevention (Camm-Crosbie et al., 2019; Hedley & Uljarević, 2018).

Currently there is a dearth of quality research examining mental health and other interventions for autistic adolescents and adults (Foley & Trollor, 2015). Interventions for mental health and wellbeing with some efficacy include social skills programs (Reichow, Steiner, & Volkmar, 2013), CBT (Wood et al., 2020), and peer-mediated approaches (Crane, Hearst, Ashworth, Davies, & Hill, 2020). Interventions that target key risk factors (e.g., social

isolation, social support, sleep concerns, depression) may prove beneficial but require research (Hedley & Uljarević, 2018). Treatments that directly target suicide risk should be prioritised (Office of the Surgeon General and the National Action Alliance for Suicide Prevention, 2012).

Programs informed by lived experiences of autistic people with suicidal behaviour may be important for improving service access (Maple, Wayland, Pearce, & Hua, 2018). Co-design and development create better informed services that are more likely to meet the needs of consumers, increase utilisation, and reduce stigma around help-seeking (Maple et al., 2018). Given that differences in gender identity and sexual orientation are relatively common within the autistic population (George & Stokes, 2018a, 2018b), supports are needed for autistic youth in relation to their sexual identity and development (Vanbergeijk, Klin, & Volkmar, 2008). Concerns or confusion regarding gender identity and sexual orientation may also negatively influence help-seeking behaviour (Pinder-Amaker, 2014).

Lack of knowledge and difficulty navigating services are identified as significant barriers to accessing appropriate mental health services by autistic people (Lake, Perry, & Lunsky, 2014). Adjustments that may improve access include provision of quiet rooms, removal of potential sensory distractions, and allowance for additional time to articulate problems and concerns (Lunsky, Tint, Weiss, Palucka, & Bradley, 2018). Multi-disciplinary service models incorporating health professionals who have autism knowledge, who are willing to listen and patiently develop a therapeutic alliance with the autistic person, that are co-developed with autistic people, and that take a holistic and lifespan approach are recommended and urgently needed. Training healthcare providers in autism generally, and specifically in the management of mental health conditions in autistic people, will be essential in developing effective suicide prevention strategies in this population.

Coronavirus (COVID-19) pandemic

There is no doubt the current global coronavirus (COVID-19) pandemic is negatively impacting the health and wellbeing of people across the globe, particularly those with neuropsychiatric conditions (Fontenelle & Miguel, 2020). Australian researcher and autistic advocate, Dr Jaelyn den Houting (2020) describes this impact on autistic people associated with restrictions on activity, changes to work routine, disturbing media coverage, and uncertainty that may enhance pre-existing anxiety. Restrictions to movement and extended lockdowns may further affect access to regular health services and social supports (Cassidy, Nicolaidis, et al., 2020). These experiences may also be common among non-autistic people; the significant impact of the pandemic on the mental health of society is only beginning to be felt. The following excerpt was written by an autistic person describing the compounding impact of COVID-19 for her as news of the pandemic worsened and people were losing their jobs.

“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.”

Anonymous

Summary

The prevailing evidence strongly suggests increased risk of suicidal behaviour among autistic people. There is a critical need for research that seeks to better understand the phenomena of suicide in autism, particularly among those with IDD, to enable the development of effective prevention strategies. As we have outlined in the sections above, many of the risk and protective factors associated with suicidal behaviour are similar for autistic and non-autistic people (e.g., depression, anxiety, sleep, substance use, psychosis). However, there are also factors that may be uniquely characteristic to autism or that have yet to be identified. Taking a transdiagnostic and dimensional approach, autistic traits align and overlap with mental health symptomology and other factors that may heighten vulnerability to suicide. Service access remains a significant barrier. It is critical that healthcare professionals consider the possibility of suicide as well as the presence of other psychiatric conditions (e.g., depression, psychosis) in autistic people. Adopting a transdiagnostic approach may also benefit those who exhibit high autistic traits but are not formally diagnosed and may offer insights into suicide risk and behaviour in non-autistic populations. Finally, programs adapted and informed by the lived experiences of autistic people with suicidal behaviour may be necessary for improving service accessibility, screening, intervention, and ultimately suicide prevention.

Scenario

Michael is a 15-year old male who has been referred to you due to difficulties with schoolwork. Michael lives with his father on a small rural farm and attends a local school. Michael's father reports that as a child Michael was generally happy but liked to play alone rather than with other children. Michael reports he currently does not have any close friends. In his spare time he likes to watch the trucks that pass the farm. During the interview

Michael's father tells you that he has seen Michael lying down in the middle of the road. Although the road is not overly busy, he is concerned about the behaviour as it could be dangerous for Michael. He has not talked to Michael about it though, and is not sure how to bring it up. It is likely that Michael has a mild intellectual disability and, although he has not been assessed for it, it is possible that he may have autism.

Reflection questions

1. How might Michael's provisional diagnoses of mild intellectual disability and possibly autism influence the approach taken when supporting Michael and his family?
2. Would you have any concerns for suicidal behaviour based on the information provided here? Why/why not?
3. What additional information or questions might be helpful to determine whether Michael is at risk of suicide?
4. Reflect on how you might discuss Michael's behaviour with him and his family.
5. How might you help to build a comprehensive system of supports around Michael to a) reduce risk and b) increase quality of life experiences?

List of quality assessments

Presently there are no clinically available suicide risk assessment instruments that have been developed specifically for use by autistic people. When using instruments developed for non-autistic populations, the interpretation of specific items should be verified through follow-up questions and a clinical interview. Importantly, if there is any clinical concern, it is important to ask directly about the presence of any suicidal behaviour or risk (e.g., thoughts or plans about suicide or self-harm) as well as to determine available supports.

Interviews should ideally be conducted by a health professional with expertise in mental health and intellectual and developmental disabilities.

The list below is not intended to be extensive, but describes four instruments that have either been used in research involving autistic adults, or are in development for use in this population. It is recommended that all instruments listed below be administered by a healthcare professional or someone with training in the administration and interpretation of health questionnaires.

1. The *Suicide Behaviors Questionnaire-Revised* (SBQ-R) is a four question self-report instrument designed to assess risk factors for suicide. The instrument provides cut-off scores to indicate risk of suicidal behaviour in the general population and in people with clinical diagnoses. The original SBQ-R has been used in research settings with autistic people and a revised version for autistic people has been developed (SBQ-ASC). The revised version is only recommended for use in research settings and is not recommended for assessing risk of future suicide attempts or self-harm. The SBQ-ASC has not been tested in people with co-occurring intellectual disability. Readers interested in the SBQ-ASC are referred to Cassidy, Bradley, Cogger-Ward, and Rodgers (2020; please refer to the References).

2. The *Suicidal Ideation Attributes Scale* (SIDAS) is a five question web-based measure of the severity of suicidal ideation and the *Suicide Assessment Kit* (SAK) is a comprehensive assessment and policy package designed to assess and manage suicide risk, which incorporates an 11 question suicide risk screen. Both instruments are included here as they are currently being developed for use by autistic people by the chapter authors in collaboration with the authors of the original instruments. The original versions of these instruments are available through the Australian National University (SIDAS;

<https://rsph.anu.edu.au/research/tools-resources/suicidal-ideation-attributes-scale-sidas>) and

the University of New South Wales (SAK; <https://ndarc.med.unsw.edu.au/suicide-assessment-kit>). Because SIDAS and SAK have not yet been tested with autistic people caution is recommended if they are to be used in this population. At the time of writing the modified instruments are under development and therefore not yet available for general use.

3. The *Patient Health Questionnaire-9* (PHQ-9) includes a single question concerning potential for self-harm/suicidal ideation. In the absence of alternative instruments, the PHQ-9 provides a useful, brief screening tool for suicide risk in autistic people that has been used in research settings. The PHQ-9 is widely available online.

Resources

1. *International Association for Suicide Prevention (IASP)* provides a worldwide directory of resources and hotlines for suicide support, as well as a forum for academics, mental health professionals, crisis workers, and suicide survivors. www.iasp.info
2. *Suicide Prevention Australia* is the peak body for suicide prevention in Australia. Provides information on suicide prevention policy and advocacy, resources, webinars, research and publications. www.suicidepreventionaust.org
3. *Autism Speaks - Eight Critical Measures to Counter Suicide*. A list of tips for talking about and preventing suicide in autistic people. www.autismspeaks.org/blog/8-critical-measures-counter-suicide
4. *National Autistic Society – Suicidality in autism: risk and prevention*. Practical suggestions for assessment and prevention of suicide for autistic people. network.autism.org.uk/good-practice/evidence-base/suicidality-autism-risk-and-prevention

Acknowledgements

We would like to thank Will Attwood and Lachlan Dummigan for their insights which helped shape the writing of this chapter, and Melissa Dummigan for reading and commenting on a draft version. We would especially like to thank the contributors of the case studies and quotes presented in this chapter for so freely sharing their very personal stories. D.H. and S.M.H. contributed equally to the writing of this chapter.

Funding

The writing of this chapter was supported by a Suicide Prevention Australia National Suicide Prevention Research fellowship awarded to D.H. M.U. is supported by the Australian Research Council Discovery Early Career Researcher Award (DE180100632). D.H. also receives research funding to examine suicide prevention in autism from Untapped Holdings Pty Ltd.

References

- Ajdacic-Gross, V., Weiss, M. G., Ring, M., Hepp, U., Bopp, M., Gutzwiller, F., & Rössler, W. (2008). Methods of suicide: International suicide patterns derived from the WHO mortality database. *Bulletin of the World Health Organization*, *86*, 657-736.
- Aldao, A., Nolen-Hoeksema, S., & Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review*, *30*, 217-237.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: American Psychiatric Publishing.
- American Psychological Association. (2019). *Publication manual of the American Psychological Association (7th ed.)*. United States: American Psychological Association.
- Andrea, T., Katharine, D., Katharine, D., Nicole, K., Nicole, K., Thomas, O., . . . Susan, W. (2014). Under-identification of ASD in females: A case series illustrating the unique presentation of ASD in young adult females. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, *2*, 66-76.
- Anestis, M. D., Bagge, C. L., Tull, M. T., & Joiner, T. E. (2011). Clarifying the role of emotion dysregulation in the interpersonal-psychological theory of suicidal behavior in an undergraduate sample. *Journal of Psychiatric Research*, *45*, 603-611.
- Arnevik, E. A., & Helverschou, S. B. (2016). Autism Spectrum Disorder and co-occurring Substance Use Disorder: A systematic review. *Substance Abuse: Research and Treatment*, *10*, 69-75.
- Ballaban-Gil, K., Rapin, I., Tuchman, R., & Shinnar, S. (1996). Longitudinal examination of the behavioral, language, and social changes in a population of adolescents and young adults with autistic disorder. *Pediatric Neurology*, *15*, 217-223.

- Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders, 46*, 3281-3294.
- Bernert, R. A., & Joiner, T. E. (2007). Sleep disturbances and suicide risk: A review of the literature. *Neuropsychiatric Disease and Treatment, 3*, 735-743.
- Bernert, R. A., Kim, J. S., Iwata, N. G., & Perlis, M. L. (2015). Sleep disturbances as an evidence-based suicide risk factor. *Current Psychiatry Reports, 17*, 554.
- Bos, D. J., Silverman, M. R., Ajodan, E. L., Martin, C., Silver, B. M., Brouwer, G. J., . . . Jones, R. M. (2019). Rigidity coincides with reduced cognitive control to affective cues in children with autism. *Journal of Abnormal Psychology, 128*, 431-441.
- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It Defines Who I Am" or "It's Something I Have": What language do [Autistic] Australian adults [on the Autism Spectrum] prefer? *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04425-3
- Butwicka, A., Långström, N., Larsson, H., Lundström, S., Serlachius, E., Almqvist, C., . . . Lichtenstein, P. (2017). Increased risk for substance use-related problems in Autism Spectrum Disorders: A population-based cohort study. *Journal of Autism and Developmental Disorders, 47*, 80-89.
- Cai, R. Y., Richdale, A. L., Dissanayake, C., Trollor, J., & Uljarević, M. (2019). Emotion regulation in autism: Reappraisal and suppression interactions. *Autism, 23*, 737-749.
- Cai, R. Y., Richdale, A. L., Dissanayake, C., & Uljarević, M. (2018). Inter-relationship between emotion regulation, intolerance of uncertainty, anxiety, and depression in youth with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 48*, 316-325.

- Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*, 1431-1441.
- Carmassi, C., Palagini, L., Caruso, D., Masci, I., Nobili, L., Vita, A., & Dell'Osso, L. (2019). Systematic review of sleep disturbances and circadian sleep desynchronization in Autism Spectrum Disorder: Toward an integrative model of a self-reinforcing loop. *Frontiers in Psychiatry, 10*, 366-366.
- Casey, P., Dunn, G., Kelly, B. D., Lehtinen, V., Dalgard, O. S., Dowrick, C., & Ayuso-Mateos, J. L. (2008). The prevalence of suicidal ideation in the general population: Results from the Outcome of Depression International Network (ODIN) study. *Social Psychiatry and Psychiatric Epidemiology, 43*, 299-304.
- Cassidy, S., Bradley, L., Cogger-Ward, H., & Rodgers, J. (2020). *Development and validation of the Suicide Behaviours Questionnaire-Autism Spectrum Conditions in autistic, possibly autistic and non-autistic adults*. Research Square.
doi:10.21203/rs.3.rs-48455/v1
- Cassidy, S., Bradley, L., Cogger-Ward, H., Shaw, R., Bowen, E., Glod, M., . . . Rodgers, J. (2020). Measurement properties of the Suicidal Behaviour Questionnaire-Revised in autistic adults. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04431-5
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism, 9*, 42.
- Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: A clinical cohort study. *Lancet Psychiatry, 1*, 142-147.

Cassidy, S., Nicolaidis, C., Davies, B., Rosa, S. D. R., Eisenman, D., Onaiwu, M. G., . . .

Waisman, T. C. (2020). An expert discussion on autism in the COVID-19 pandemic. *Autism in Adulthood, 2*, 106-117.

Centers for Disease Control and Prevention. (2020). *Web-based Injury Statistics Query and Reporting System (WISQARS) fatal injury data 1999-2018*. Atlanta, GA: Centers for Disease Control and Prevention (CDC).

Chisholm, K., Lin, A., Abu-Akel, A., & Wood, S. J. (2015). The association between autism and schizophrenia spectrum disorders: A review of eight alternate models of co-occurrence. *Neuroscience and Biobehavioral Reviews, 55*, 173-183.

Crandall, A., Allsop, Y., & Hanson, C. L. (2018). The longitudinal association between cognitive control capacities, suicidality, and depression during late adolescence and young adulthood. *Journal of Adolescence, 65*, 167-176.

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2020). Supporting newly identified or diagnosed autistic adults: An initial evaluation of an autistic-led programme. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04486-4

Cuthbert, B. N., & Insel, T. R. (2013). Toward the future of psychiatric diagnosis: The seven pillars of RDOC. *BMC Medicine, 11*, 126.

De La Vega, D., Giner, L., & Courtet, P. (2018). Suicidality in subjects with anxiety or obsessive-compulsive and related disorders: Recent advances. *Current Psychiatry Reports, 20*, 26.

Deady, M., Ross, J., & Darke, S. (2015). *Suicide Assessment Kit (SAK): A comprehensive assessment and policy development package*. Sydney, NSW: National Drug and Alcohol Research Centre.

- Dell'Osso, L., Carpita, B., Muti, D., Morelli, V., Salarpi, G., Salerni, A., . . . Maj, M. (2019). Mood symptoms and suicidality across the autism spectrum. *Comprehensive Psychiatry, 91*, 34-38.
- den Houting, J. (2020). Stepping out of isolation: Autistic people and COVID-19. *Autism in Adulthood, 2*, 103-105.
- Dodd, P., Doherty, A., & Guerin, S. (2016). A systematic review of suicidality in people with intellectual disabilities. *Harvard Review of Psychiatry, 24*, 202-213.
- Duvekot, J., van der Ende, J., Verhulst, F. C., Slappendel, G., van Daalen, E., Maras, A., & Greaves-Lord, K. (2017). Factors influencing the probability of a diagnosis of autism spectrum disorder in girls versus boys. *Autism, 21*, 646-658.
- Erlangsen, A., Stenager, E., Conwell, Y., Andersen, P. K., Hawton, K., Benros, M. E., . . . Stenager, E. (2020). Association between neurological disorders and death by suicide in Denmark. *JAMA, 323*, 444-454.
- Esang, M., & Ahmed, S. (2018). A closer look at substance use and suicide. *American Journal of Psychiatry Residents' Journal, 13*, 6-8.
- Fazakas-DeHoog, L. L., Rnic, K., & Dozois, D. J. A. (2017). A cognitive distortions and deficits model of suicide ideation. *Europe's Journal of Psychology, 13*, 178-193.
- Foley, K., & Trollor, J. (2015). Management of mental ill health in people with autism spectrum disorder. *Australian Family Physician, 44*, 784-790.
- Fontenelle, L. F., & Miguel, E. C. (2020). The impact of coronavirus (COVID-19) in the diagnosis and treatment of obsessive-compulsive disorder. *Depression and Anxiety, 37*, 510-511.
- George, R., & Stokes, M. A. (2018a). A quantitative analysis of mental health among sexual and gender minority groups in ASD. *Journal of Autism and Developmental Disorders, 48*, 2052-2063.

- George, R., & Stokes, M. A. (2018b). Sexual orientation in Autism Spectrum Disorder. *Autism Research, 11*, 133-141.
- Geurts, H. M., Verte, S., Oosterlaan, J., Roeyers, H., & Sergeant, J. A. (2004). How specific are executive functioning deficits in attention deficit hyperactivity disorder and autism? *Journal of Child Psychology and Psychiatry, 45*, 836-854.
- Glenn, C. R., Cha, C. B., Kleiman, E. M., & Nock, M. K. (2017). Understanding suicide risk within the Research Domain Criteria (RDoC) Framework: Insights, challenges, and future research considerations. *Clinical Psychological Science, 5*, 568-592.
- Glenn, C. R., Kleiman, E. M., Cha, C. B., Deming, C. A., Franklin, J. C., & Nock, M. K. (2018). Understanding suicide risk within the Research Domain Criteria (RDoC) framework: A meta-analytic review. *Depression and Anxiety, 35*, 65-88.
- Hallett, V., Lecavalier, L., Sukhodolsky, D. G., Cipriano, N., Aman, M. G., McCracken, J. T., . . . Scahill, L. (2013). Exploring the manifestations of anxiety in children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*, 2341-2352.
- Hand, B. N., Benevides, T. W., & Carretta, H. J. (2019). Suicidal ideation and self-inflicted injury in Medicare enrolled autistic adults with and without co-occurring intellectual disability. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-019-04345-x
- Hedley, D., & Uljarević, M. (2018). Systematic review of suicide in Autism Spectrum Disorder: Current trends and implications. *Current Developmental Disorders Reports, 5*, 65-76.
- Hedley, D., Uljarević, M., Foley, K.-R., Richdale, A., & Trollor, J. (2018). Risk and protective factors underlying suicidal ideation in Autism Spectrum Disorder. *Depression and Anxiety, 35*, 648-657.

- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry, 208*, 232-238.
- Hochard, K. D., Pendrous, R., Mari, T., & Flynn, S. (2020). Examining the relationship between autism traits and sleep duration as predictors of suicidality. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04405-7
- Hollocks, M. J., Pickles, A., Howlin, P., & Simonoff, E. (2016). Dual cognitive and biological correlates of anxiety in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46*, 3295-3307.
- Hor, K., & Taylor, M. (2010). Suicide and schizophrenia: A systematic review of rates and risk factors. *Journal of Psychopharmacology, 24*, 81-90.
- Hudson, C. C., Hall, L., & Harkness, K. L. (2018). Prevalence of depressive disorders in individuals with Autism Spectrum Disorder: A meta-analysis. *Journal of Abnormal Child Psychology, 1-11*.
- Jackson, L., Keville, S., & Ludlow, A. K. (2020). Mothers' experiences of accessing mental health care for their child with an Autism Spectrum Disorder. *Journal of Child and Family Studies, 29*, 534-545.
- Joiner, T. E. (2005). *Why people die by suicide*. Cambridge, MA: Harvard University Press.
- Joiner, T. E., Brown, J. S., & Wingate, L. R. (2005). The psychology and neurobiology of suicidal behavior. *Annual Review of Psychology, 56*, 287-314.
- Kanwar, A., Malik, S., Prokop, L. J., Sim, L. A., Feldstein, D., Wang, Z., & Murad, M. H. (2013). The association between anxiety disorders and suicidal behaviors: A systematic review and meta-analysis. *Depression and Anxiety, 30*, 917-929.

- Karalunas, S. L., Hawkey, E., Gustafsson, H., Miller, M., Langhorst, M., Cordova, M., . . . Nigg, J. T. (2018). Overlapping and distinct cognitive impairments in Attention-Deficit/Hyperactivity and Autism Spectrum Disorder without intellectual disability. *Journal of Abnormal Child Psychology, 46*, 1705-1716.
- Kerns, C. M., Kendall, P. C., Berry, L., Souders, M. C., Franklin, M. E., Schultz, R. T., . . . Herrington, J. (2014). Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*, 2851-2861.
- Kessler, R. C., Berglund, P., Borges, G., Nock, M., & Wang, P. S. (2005). Trends in suicide ideation, plans, gestures, and attempts in the United States, 1990-1992 to 2001-2003. *JAMA, 293*, 2487-2495.
- King, T. L., Milner, A., Aitken, Z., Karahalios, A., Emerson, E., & Kavanagh, A. M. (2019). Mental health of adolescents: Variations by borderline intellectual functioning and disability. *European Child & Adolescent Psychiatry, 28*, 1231-1240.
- Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20-year study of suicide death in a statewide autism population. *Autism Research, 12*, 658-666.
- Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., . . . Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry, 6*, 819-829.
- Lai, M.-C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/gender differences and autism: Setting the scene for future research. *Journal of the American Academy of Child and Adolescent Psychiatry, 54*, 11-24.

- Lake, J. K., Perry, A., & Lunsky, Y. (2014). Mental health services for individuals with high functioning autism spectrum disorder. *Autism Research and Treatment, 2014*, e502420.
- Lau, W. K. W., Leung, M.-K., & Lau, B. W. M. (2019). Resting-state abnormalities in Autism Spectrum Disorders: A meta-analysis. *Scientific Reports, 9*, 3892.
- Lever, A. G., & Geurts, H. M. (2016). Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders, 46*, 1916-1930.
- Lovato, N., Lack, L., & Kennaway, D. J. (2016). Comparing and contrasting therapeutic effects of cognitive-behavior therapy for older adults suffering from insomnia with short and long objective sleep duration. *Sleep Medicine, 22*, 4-12.
- Ludi, E., Ballard, E. D., Greenbaum, R., Pao, M., Bridge, J., Reynolds, W., & Horowitz, L. (2012). Suicide risk in youth with intellectual disabilities: the challenges of screening. *Journal of Developmental and Behavioral Pediatrics, 33*, 431-440.
- Lugo-Marín, J., Magán-Maganto, M., Rivero-Santana, A., Cuellar-Pompa, L., Alviani, M., Jenaro-Rio, C., . . . Canal-Bedia, R. (2019). Prevalence of psychiatric disorders in adults with autism spectrum disorder: A systematic review and meta-analysis. *Research in Autism Spectrum Disorders, 59*, 22-33.
- Lunsky, Y. (2004). Suicidality in a clinical and community sample of adults with mental retardation. *Research in Developmental Disabilities, 25*, 231-243.
- Lunsky, Y., Raina, P., & Burge, P. (2012). Suicidality among adults with intellectual disability. *Journal of Affective Disorders, 140*, 292-295.
- Lunsky, Y., Tint, A., Weiss, J. A., Palucka, A., & Bradley, E. (2018). A review of emergency department visits made by youth and adults with autism spectrum disorder from the parent perspective. *Advances in Autism, 4*, 10-18.

- Maddox, B. B., Trubanova, A., & White, S. W. (2017). Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder. *Autism, 21*, 412-422.
- Maenner, M. J., Shaw, K. A., Baio, J., Washington, A., Patrick, M., DiRienzo, M., . . . Patricia M. Dietz, P. M. (2020). Prevalence of Autism Spectrum Disorder among children aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *MMWR Surveillance Summaries, 69*, 1-12.
- Maisel, M. E., Stephenson, K. G., South, M., Rodgers, J., Freeston, M. H., & Gaigg, S. B. (2016). Modeling the cognitive mechanisms linking autism symptoms and anxiety in adults. *Journal of Abnormal Psychology, 125*, 692-703.
- Malik, S., Kanwar, A., Sim, L. A., Prokop, L. J., Wang, Z., Benkhadra, K., & Murad, M. H. (2014). The association between sleep disturbances and suicidal behaviors in patients with psychiatric diagnoses: A systematic review and meta-analysis. *Systematic Reviews, 3*, 18.
- Maple, M., Wayland, S., Pearce, T., & Hua, P. (2018). *Services and programs for suicide prevention: An evidence check rapid review*. NSW, Sydney: SAX Institute.
- Marrus, N., Veenstra-Vanderweele, J., Hellings, J. A., Stigler, K. A., Szymanski, L., King, B. H., . . . Pruetz, J. R., Jr. (2014). Training of child and adolescent psychiatry fellows in autism and intellectual disability. *Autism, 18*, 471-475.
- Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of Autism Spectrum Disorder, heterogeneity and treatment options. *Neuroscience Bulletin, 33*, 183-193.
- Mazurek, M. O. (2014). Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism, 18*, 223-232.
- Mazzone, L., Postorino, V., Siracusano, M., Riccioni, A., & Curatolo, P. (2018). The relationship between sleep problems, neurobiological alterations, core symptoms of

Autism Spectrum Disorder, and psychiatric comorbidities. *Journal of Clinical Medicine*, 7, 102.

McCall, W. V., Benca, R. M., Rosenquist, P. B., Youssef, N. A., McCloud, L., Newman, J. C., . . . Krystal, A. D. (2019). Reducing suicidal ideation through insomnia treatment (REST-IT): A randomized clinical trial. *American Journal of Psychiatry*, 176, 957-965.

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. (2020). Links between self-injury and suicidality in autism. *Molecular Autism*, 11, 14.

Nicolaidis, C., Raymaker, D. M., McDonald, K. E., Lund, E. M., Leotti, S., Kapp, S. K., . . . Zhen, K. Y. (2020). Creating accessible survey instruments for use with autistic adults and people with intellectual disability: Lessons learned and recommendations. *Autism in Adulthood*, 2, 61-76.

O'Connor, R. C., & Portzky, G. (2018). Looking to the future: A synthesis of new developments and challenges in suicide research and prevention. *Frontiers in Psychology*, 9, 2139-2139.

Office of the Surgeon General and the National Action Alliance for Suicide Prevention. (2012). *National Strategy for Suicide Prevention: Goals and Objectives for Action: A Report of the U.S. Surgeon General and of the National Action Alliance for Suicide Prevention. Strategic Direction 3: Treatment and Support Services*. Washington, DC.

Olfson, M., Wall, M., Wang, S., Crystal, S., Gerhard, T., & Blanco, C. (2017). Suicide following deliberate self-harm. *American Journal of Psychiatry*, 174, 765-774.

Oliveras-Rentas, R. E., Kenworthy, L., Roberson, R. B., 3rd, Martin, A., & Wallace, G. L. (2012). WISC-IV profile in high-functioning autism spectrum disorders: Impaired processing speed is associated with increased autism communication symptoms and

- decreased adaptive communication abilities. *Journal of Autism and Developmental Disorders*, 42, 655-664.
- Osman, A., Bagge, C. L., Gutierrez, P. M., Konick, L. C., Kopper, B. A., & Barrios, F. X. (2001). The Suicidal Behaviors Questionnaire-Revised (SBQ-R): Validation with clinical and nonclinical samples. *Assessment*, 8, 443-454.
- Patja, K., Iivanainen, M., Raitasuo, S., & Lönnqvist, J. (2001). Suicide mortality in mental retardation: a 35-year follow-up study. *Acta Psychiatrica Scandinavica*, 103, 307-311.
- Pelton, M. K., & Cassidy, S. A. (2017). Are autistic traits associated with suicidality? A test of the interpersonal-psychological theory of suicide in a non-clinical young adult sample. *Autism Research*, 10, 1891-1904.
- Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). A measurement invariance analysis of the Interpersonal Needs Questionnaire and Acquired Capability for Suicide Scale in autistic and non-autistic adults. *Autism in Adulthood*. Advance online publication. doi:10.1089/aut.2019.0055
- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22, 125-137.
- Poorolajal, J., Haghtalab, T., Farhadi, M., & Darvishi, N. (2016). Substance use disorder and risk of suicidal ideation, suicide attempt and suicide death: a meta-analysis. *Journal of Public Health*, 38, e282-e291.
- Productivity Commission. (2019). *Mental Health, Draft Report*. Canberra, ACT.
- Rabiee, A., Samadi, S. A., Vasaghi-Gharamaleki, B., Hosseini, S., Seyedin, S., Keyhani, M., . . . Ranjbar Kermani, F. (2019). The cognitive profile of people with high-functioning autism spectrum disorders. *Behavioral Sciences*, 9, e20.

- Rai, D., Culpin, I., Heuvelman, H., Magnusson, C. M. K., Carpenter, P., Jones, H. J., . . . Pearson, R. M. (2018). Association of autistic traits with depression from childhood to age 18 years. *JAMA Psychiatry, 75*, 835-843.
- Rai, D., Heuvelman, H., Dalman, C., Culpin, I., Lundberg, M., Carpenter, P., & Magnusson, C. (2018). Association between Autism Spectrum Disorders with or without intellectual disability and depression in young adulthood. *JAMA Network Open, 1*, e181465.
- Reichow, B., Steiner, A. M., & Volkmar, F. (2013). Cochrane Review: Social skills groups for people aged 6 to 21 with autism spectrum disorders (ASD). *Evidence-Based Child Health: A Cochrane Review Journal, 8*, 266-315.
- Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: Diagnostic overshadowing. *American Journal of Mental Deficiency, 86*, 567-574.
- Reynolds, A. M., Soke, G. N., Sabourin, K. R., Hepburn, S., Katz, T., Wiggins, L. D., . . . Levy, S. E. (2019). Sleep Problems in 2- to 5-Year-Olds With Autism Spectrum Disorder and Other Developmental Delays. *Pediatrics, 143*, e20180492.
- Ribeiro, J. D., Witte, T. K., Van Orden, K. A., Selby, E. A., Gordon, K. H., Bender, T. W., & Joiner, T. E., Jr. (2014). Fearlessness about death: the psychometric properties and construct validity of the revision to the acquired capability for suicide scale. *Psychological Assessment, 26*, 115-126.
- Rodriguez-Seijas, C., Gadow, K. D., Rosen, T. E., Kim, H., Lerner, M. D., & Eaton, N. R. (2020). A transdiagnostic model of psychiatric symptom co-occurrence and autism spectrum disorder. *Autism Research, 13*, 579-590.
- Roth, G. A., Abate, D., Abate, K. H., Abay, S. M., Abbafati, C., Abbasi, N., . . . Murray, C. J. L. (2018). Global, regional, and national age-sex-specific mortality for 282 causes of

- death in 195 countries and territories, 1980: A systematic analysis for the Global Burden of Disease Study 2017. *The Lancet*, *392*, 1736-1788.
- Ruzich, E., Allison, C., Smith, P., Watson, P., Auyeung, B., Ring, H., & Baron-Cohen, S. (2015). Measuring autistic traits in the general population: a systematic review of the Autism-Spectrum Quotient (AQ) in a nonclinical population sample of 6,900 typical adult males and females. *Molecular Autism*, *6*, e2.
- Ruzzo, E. K., & Geschwind, D. H. (2016). Schizophrenia genetics complements its mechanistic understanding. *Nature Neuroscience*, *19*, 523-525.
- Samson, A. C., Phillips, J. M., Parker, K. J., Shah, S., Gross, J. J., & Hardan, A. Y. (2014). Emotion dysregulation and the core features of autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *44*, 1766-1772.
- Sanchez-Gistau, V., Baeza, I., Arango, C., González-Pinto, A., de la Serna, E., Parellada, M., Graell, M., Paya, B., Llorente, C., & Castro-Fornieles, J. (2013). Predictors of suicide attempt in early-onset, first-episode psychoses: a longitudinal 24-month follow-up study. *The Journal of Clinical Psychiatry*, *74*, 59-66.
- Sedgewick, F., Leppanen, J., & Tchanturia, K. (2020). Gender differences in mental health prevalence in autism. *Advances in Autism*. Advance online publication. doi:10.1108/aia-01-2020-0007
- Smith, J. M., Alloy, L. B., & Abramson, L. Y. (2006). Cognitive vulnerability to depression, rumination, hopelessness, and suicidal ideation: Multiple pathways to self-injurious thinking. *Suicide and Life-Threatening Behavior*, *36*, 443-454.
- Stagg, S. D., & Belcher, H. (2019). Living with autism without knowing: receiving a diagnosis in later life. *Health Psychology and Behavioral Medicine*, *7*, 348-361.
- Stanley, I. H., Day, T. N., Gallyer, A. J., Shelef, L., Kalla, C., Gutierrez, P. M., & Joiner, T. E. (2020). Autism-related traits and suicide risk among active duty U.S. military

service members. *Psychological Services*. Advance online publication.

doi:10.1037/ser0000418

Steenfeldt-Kristensen, C., Jones, C. A., & Richards, C. (2020). The prevalence of self-injurious behaviour in autism: A meta-analytic study. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-020-04443-1

Strauss, G. P., Nuñez, A., Ahmed, A. O., Barchard, K. A., Granholm, E., Kirkpatrick, B., Gold, J. M., & Allen, D. N. (2018). The latent structure of negative symptoms in schizophrenia. *JAMA Psychiatry*, *75*, 1271–1279.

Uljarević, M., Hedley, D., Cai, R.-Y., Hardan, A. Y., & South, M. (2020). Anxiety and depression from adolescence to old age in Autism Spectrum Disorder. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders*. New York: Springer.

Uljarević, M., Hedley, D., Foley, K. R., Magiati, I., Cai, R. Y., Dissanayake, C., . . . Trollor, J. (2020). Anxiety and depression from adolescence to old age in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *50*, 3155-3165.

Uljarević, M., Richdale, A. L., McConachie, H., Hedley, D., Cai, R. Y., Merrick, H., . . . Le Couteur, A. (2018). The Hospital Anxiety and Depression scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research*, *11*, 258-269.

Upthegrove, R., Abu-Akel, A., Chisholm, K., Lin, A., Zahid, S., Pelton, M., . . . Wood, S. J. (2018). Autism and psychosis: Clinical implications for depression and suicide. *Schizophrenia Research*, *195*, 80-85.

van Orden, K. A., Cukrowicz, K. C., Witte, T. K., & Joiner, T. E. (2012). Thwarted belongingness and perceived burdensomeness: construct validity and psychometric

- properties of the Interpersonal Needs Questionnaire. *Psychological Assessment*, *24*, 197-215.
- van Spijker, B.A.J., Batterham, P.J., Calear, A.L., Farrer, L., Christensen, H., Reynolds, J. & Kerkhof, A.J.F.M. (2014). The Suicidal Ideation Attributes Scale (SIDAS): Community-based validation study of a new scale for the measurement of suicidal ideation. *Suicide and Life-Threatening Behavior*, *44*, 408-419.
- van Steensel, F. J., Bogels, S. M., & Perrin, S. (2011). Anxiety disorders in children and adolescents with autistic spectrum disorders: a meta-analysis. *Clinical Child and Family Psychology Review*, *14*, 302-317.
- Vanbergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: college and beyond. *Journal of Autism and Developmental Disorders*, *38*, 1359-1370.
- Vogan, V., Lake, J. K., Tint, A., Weiss, J. A., & Lunskey, Y. (2017). Tracking health care service use and the experiences of adults with autism spectrum disorder without intellectual disability: A longitudinal study of service rates, barriers and satisfaction. *Disability and Health Journal*, *10*, 264-270.
- Wark, S., McKay, K., Ryan, P., & Müller, A. (2018). Suicide amongst people with intellectual disability: An Australian online study of disability support staff experiences and perceptions. *Journal of Intellectual Disability Research*, *62*, 1-9.
- Weinheimer, L. A. (2018). *A mixed method exploration of suicidality in clients with intellectual disability*. (Doctor of Psychology). University of Toronto, Canada.
Retrieved from <http://hdl.handle.net/1807/91979>
- Wigham, S., Rodgers, J., South, M., McConachie, H., & Freeston, M. (2015). The interplay between sensory processing abnormalities, intolerance of uncertainty, anxiety and

restricted and repetitive behaviours in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45, 943-952.

Wood, J. J., Kendall, P. C., Wood, K. S., Kerns, C. M., Seltzer, M., Small, B. J., . . . Storch, E. A. (2020). Cognitive behavioral treatments for anxiety in children with Autism Spectrum Disorder: A randomized clinical trial. *JAMA Psychiatry*, 77, 474-483.