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Suicide and Autism: A Lifespan Perspective

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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 amongst 15 to 29-year-olds (Casey et al., 2008; Roth et al., 2018).

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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 author.[2]

Autism

The Centers for Disease Control and Prevention (CDC) estimates 1 in 54 children are diagnosed with autism in the United States (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 (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

[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 et al., 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.

include hypo- or hyper-sensory sensitivities (American Psychiatric Association, 2013). Cognitive profiles are often uneven, reflecting relative areas of strength and weakness (Oliveras-Rentas et al., 2012; Rabiee et al., 2019). Specific cognitive domains may also be impacted (e.g., cognitive control, emotional regulation, executive functioning; Geurts et al., 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 et al., 2017). Treatment response, as well as health and well-being, 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 et al., 2005; Kessler et al., 2005). We also review the evidence concerning suicidal behaviour in intellectual and developmental disability due to its high prevalence in autism.

Risk and Prevalence of Suicide Behaviour in Autism

There is robust evidence of increased risk of suicidal behaviour in the autistic population, with suicide rates ranging from 0.17% to 0.4% (Hirvikoski et al., 2016; Kirby et al., 2019; Kõlves et al., 2021). In a large population-based study from Sweden, Hirvikoski et al. (2016) reported a sevenfold increased risk of premature death by suicide amongst autistic people compared to the general population. In a large cohort study from Denmark, Kõlves et al. (2021) reported a threefold higher rate of both suicide attempt and suicide in the autistic sample. Risk may be impacted by degree of intellectual impairment, with a lower relative risk in autistic people with co-occurring intellectual and developmental disability (Hirvikoski et al., 2016). Kirby et al. (2019) reported 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 et al., 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 story about "Max" 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.

Max's Story* 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 programmes, 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-hours 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 attempts. Max 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.[3]

* Assumed names are used in this story.

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; Kõlves et al., 2021). In the general population, being female is a protective factor for suicide (Centers for Disease Control & Prevention, 2020). Compared to autistic males, autistic females report a relatively higher number of psychiatric diagnoses (Hedley et al., 2018; Lai et al., 2019; Sedgewick et al., 2021). 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 et al., 2015). Females may also be at greater risk of traumatic experiences, including sexual abuse (Kirby et al., 2019), and could experience identity conflict (Bargiela et al., 2016; Cassidy et al., 2018). Concealing autistic traits ("camouflaging") is more common in autistic females and has been reported 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

[3] 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. Whilst suicide attempts have now stopped, Max continues to experience suicidal ideation to varying degrees.

gender can have subsequent impacts on mental health and well-being (George & Stokes, 2018a).

Intellectual Disability/intellectual Developmental Disorder and Suicide Risk

Risk of suicide may be greater in autistic individuals without co-occurring intellectual and developmental disability (Hirvikoski et al., 2016); however, co-occurring intellectual and developmental disability 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 et al., 2019). Overall, there is a very limited amount of research concerning suicide risk in autistic people with intellectual and developmental disability. Similarly, suicide in people with intellectual and developmental disability in the absence of autism remains under-explored and poorly characterised (Ludi et al., 2012; Wark et al., 2018), with similar (Erlangsen et al., 2020) or lower (Patja et al., 2001) rates of suicide reported than in the general population. Frequent risk factors for suicidal behaviour include concurrent mental health difficulties and *severity* of intellectual and developmental disability, with those with milder intellectual and developmental disability at greater risk (Dodd et al., 2016). However, in adolescents with borderline intellectual impairment, a recent study reported no clear association between suicidal thoughts and behaviours and level of intellectual and developmental disability (King et al., 2019).

Reported methods of suicide by people with mild or moderate intellectual and developmental disability, 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 intellectual and developmental disability (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 intellectual and developmental disability 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 et al., 2012; Weinheimer, 2018). Female sex may be a risk factor in those who attempt suicide (Lunsky et al., 2012). People with intellectual and developmental disability 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).

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 et al., 2018; Lai et al., 2019). The association between autism and suicide deaths, as well as higher prevalence of self-harm, may be explained by the presence of co-occurring psychiatric conditions (Jokiranta-Olkoniemi et al., 2021), with one study reporting that over 90% of autistic people who died by suicide had at least one other co-occurring condition (Kõlves et al., 2021). 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, with estimates ranging from 28 to 49% (Uljarević, Hedley, Cai et al., 2020a, 2020b; Uljarević, Hedley, Foley et al., 2020a, 2020b), 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 intellectual and

developmental disability; however, depression may present differently in people with intellectual and developmental disability (Hudson et al., 2018; Rai, Culpin, et al., 2018; Rai, Heuvelman, et al., 2018). Psychosocial 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 et al., 2018; Rai, Heuvelman, et al., 2018).

Anxiety. Anxiety has been shown to increase suicide risk in non-autistic populations (De La Vega et al., 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., 2020a, 2020b). 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 et al., 2011) and up to 60% of adults meet the diagnostic threshold for anxiety disorders (Lever & Geurts, 2016; Uljarević, Hedley, Foley et al., 2020a, 2020b). However, it is important to emphasise that anxiety can present atypically in autism (Kerns et al., 2014; Lau et al., 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 et al., 2015) are associated with higher prevalence and severity of anxiety, although not all studies report significant results (Duvekot et al., 2017; Hollocks et al., 2016). In autism, relationships have been identified between anxiety and both emotion regulation (Cai et al., 2019) and intolerance of uncertainty (Cai et al., 2018; Maisel et al., 2016). These are consistent with findings in non-autistic samples (Aldao et al., 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 desynchronisation (Carmassi et al., 2019; Mazzone et al., 2018; Reynolds et al., 2019). In both general and non-autistic clinical populations, there is a strong support of an association between suicide behaviour and sleep complaints (Bernert & Joiner, 2007; Bernert et al., 2015; Malik et al., 2014). Sleep disorders are modifiable with treatment (Bernert et al., 2015; Lovato et al., 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 et al., 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 than 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 et al., 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 et al., 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 et al., 2017, 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.

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 behaviours/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 behaviours, 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., 2021; 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, 2018). In non-autistic populations, impairments in different domains of social and communication functioning are associated with increased risk of suicidal ideation and behaviour (Hedley, Batterham, et al., 2021; Hedley, Uljarević, et al., 2021; Stanley et al., 2021). 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 et al., 2017; Hedley, Batterham, et al., 2021; Hedley, Uljarević, et al., 2021; Smith et al., 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 et al., 2018); however, it may also serve as a protective measure against lethal self-harm (Anestis et al., 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).

Risk Assessment and Instruments

There is a general paucity of mental health and other instruments designed specifically for autistic people (see also Chapter 16); thus, instruments designed for the general population are typically substituted for this population (Uljarević et al., 2018). Cassidy, Bradley, et al. (2020), Cassidy, Nicolaidis, et al. (2020)) examined the psychometric properties of the Suicidal Behaviours 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 et al., 2020; Cassidy, Nicolaidis, 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, et al., 2021).

The Interpersonal Needs Questionnaire-10 (INQ-10; van Orden et al., 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 intellectual and developmental disability who may have experienced additional difficulties understanding and responding to the questionnaire. Instruments designed for use by people with co-occurring intellectual and developmental disability 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 et al., 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 have developed and are currently evaluating modified versions of these two instruments for use in the autistic population (Hedley, Batterham, et al., 2021; Hedley, Uljarević, et al., 2021).

Non-Suicidal Self-Injury (NSSI). NSSI in autistic people contributes to reduced quality of life and difficulty accessing services (Steenfeldt-Kristensen et al., 2020). NSSI is highly prevalent in the autistic population, including in those with and without co-occurring intellectual and developmental disability, 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 intellectual and developmental disability (32%) (Ballaban-Gil et al., 1996). NSSI is associated with suicide risk in the autistic population (Moseley et al., 2020), and may be more prevalent in autistic women than men (Maddox et al., 2017). In the general population, NSSI often precedes suicide attempts (Olfson et al., 2017).

Suicide attempts may be misdiagnosed 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 intellectual and developmental disability.

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 well-being (Camm-Crosbie et al., 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 et al., 2017). Families of younger children also report difficulties accessing mental health services (Jackson et al., 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 well-being with some efficacy include social skills programmes (Reichow et al., 2013), CBT (Wood et al., 2020), and peer-mediated approaches (Crane et al., 2021). 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).

Programmes informed by lived experiences of autistic people with suicidal behaviour may be important for improving service access (Maple et al., 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 et al., 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 et al., 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 et al., 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 that the current global coronavirus (COVID-19) pandemic is negatively impacting the health and well-being of people across the globe, particularly those with neuropsychiatric conditions (Fontenelle & Miguel, 2020). Australian researcher and autistic advocate, Dr Jaclyn 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, Bradley, et al., 2020; Cassidy, Nicolaidis, et al., 2020). These experiences may also be common amongst 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 amongst autistic people. There is a critical need for research that seeks to better understand the phenomena of suicide in autism, particularly amongst those with intellectual and developmental disability, to enable the development of effective prevention strategies. As we have outlined in this chapter, 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, programmes 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.

Reflection

Michael's Story* 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.

*Assumed names are used in this story.

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 three 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. *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 (Arnold et al., 2019). The PHQ-9 is widely available online.
2. *Suicide Behaviours 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).
3. *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 have been modified 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 are currently being evaluated for use with autistic people, caution is recommended if they

are to be used in this population. At the time of writing, the modified instruments are not yet available for general use (enquiries can be directed to the lead author of this chapter).

Resources

1. *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
2. *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
3. *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.
4. *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
5. *Suicide Response Project* is an evidence-based free suicide prevention educational toolkit and resource that provides information about how to detect and respond to people at risk of suicide, including neurodivergent and sex/gender diverse people. www.suicideresponseproject.com

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