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Advancing our understanding of self-harm, suicidal thoughts and behaviours in autism.

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Abstract:	Until recently, self-harm, suicidal thoughts and behaviours have not received extensive attention in autism research. The extant research evidence indicates high rates of self-harm and suicidality in autistic people, but little research exploring why, or how this could be prevented. This special issue brings together a guest editorial team of autism, self-harm and suicide researchers, to enable researchers internationally to present scientific developments on the topic of self-harm, suicidal thoughts and behaviours in autistic people. Here we present the most recent advances in this important topic, and recommendations for future research in light of the autism community's priorities for suicide prevention.

Advancing our understanding of self-harm, suicidal thoughts and behaviours in autism.

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Advancing our understanding of self-harm, suicidal thoughts and behaviours in autism.

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2 Until recently, self-harm, suicidal thoughts and behaviours have not received extensive attention in
3 autism research (Cassidy, 2020; Cassidy & Rodgers, 2017). The extant research evidence indicates
4 high rates of self-harm in autistic people, but this work has primarily focused on self-harm in the
5 context of challenging and/or repetitive behaviour associated with intellectual disability (Minshawi et
6 al., 2014). Although extremely important work, this research does not explore whether autistic people
7 who self-harm also experience intent to end one's life, or whether self-harm increases risk of
8 subsequent suicidal behaviours (as in the general population; Rebeiro et al., 2016). More recent
9 research has explored self-harm and suicidality, as defined in the general population, in autistic
10 people. Early work showed that 66% of adults recently diagnosed with Asperger Syndrome had
11 contemplated suicide in their lifetime, and 35% had planned or attempted suicide (Cassidy et al.,
12 2014). Autistic adults are also significantly more likely to experience non-suicidal self-injury (NSSI)
13 compared to the general population, and NSSI is associated with increased risk of suicidality in this
14 group (Cassidy et al., 2018a; Maddox et al., 2017; Moseley et al., 2019; 2020). Large-scale population
15 studies have followed, showing that autistic people are significantly more likely to die by self-harm
16 and suicide compared to those in the general population (Hirvikoski et al., 2016; Hwang et al., 2019;
17 Kirby et al., 2019).

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21 Importantly, the majority of available research has focused on prevalence (Hedley & Uljarevic, 2018).
22 This has been instrumental in raising awareness of these critical life and death issues in the autistic
23 community. However, there is relatively little research into *why* autistic people are at increased risk of
24 self-harm and suicide, to inform treatment and prevention strategies (Cassidy, 2020; Cassidy &
25 Rodgers, 2017). To make progress, it is crucial for different stakeholders to listen and learn from one
26 another. This includes autism researchers, self-harm and suicide researchers, autistic people, and those
27 who support them. Members of the guest editorial board for this special issue have developed
28 international forums involving these stakeholder groups to support these efforts, including an
29 international priority setting exercise which identified the top 10 autism community priorities for
30 suicide prevention research (Cassidy et al., 2019; Table 1). This special issue brings together a guest
31 editorial team of autism, self-harm and suicide researchers, to enable researchers internationally to
32 present scientific developments on the topic of self-harm, suicidal thoughts and behaviours in autistic
33 people. Here we present the most recent advances in this important topic, and recommendations for
34 future research in light of the autism community's priorities for suicide prevention.

Assessment and measurement

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40 Three papers explored *assessment and measurement* of self-harm, suicidal thoughts and behaviours in
41 autistic people, in research and clinical practice – a top 10 community priority.

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43 Jager-Hyman et al. (2020) surveyed 121 clinicians who felt significantly less confident in screening
44 for suicide risk, and rated safety planning as significantly less acceptable, for their autistic compared
45 to their non-autistic clients (JADD-D-19-00604). Howe et al. (2020) conducted a systematic review of
46 tools used to measure suicidality among children and youth with and without ASD diagnosis. Results
47 showed that no suicidality assessment tool has yet been validated in autistic children and young
48 people (JADD-D-19-00619). Cassidy et al. (2020) explored whether a widely used suicidality
49 assessment tool validated in the general population, (the Suicide Behaviours Questionnaire – Revised;
50 SBQ-R, Osman et al., 2001), operates similarly in autistic compared to non-autistic adults. Analysis of
51 online survey data in 371 participants showed that the structure of the SBQ-R was not equivalent in
52 autistic compared to non-autistic adults. Autistic adults also reported difficulties interpreting and
53 responding to the SBQ-R items, due to difficulties with abstract questions, complex language and
54 response options, and lack of items relevant to autistic people's unique experience of suicidality
55 (JADD-D-19-00598).

1 Together these results further emphasise the crucial need for future research to identify the most
2 effective ways of assessing self-harm, suicidal thoughts and behaviours in autistic people. This will
3 enable crucial high-quality research to establish prevalence, understand risk and evaluate intervention.

4 *Prevalence and Risk Markers*

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6 A group of papers focused on *prevalence* and broad *risk markers* for self-harm, suicidal thoughts and
7 behaviours in autistic people – another community priority, under-explored in previous research.
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10 Three papers explored both prevalence and risk markers for self-harm, suicidal thoughts and
11 behaviours. Hand et al., (2020) report data from large representative sample of 21,792 Medicare
12 enrolled autistic adults, with or without co-occurring intellectual disability - 4% met criteria for
13 suicidal ideation or suicide attempts/self-injury. Young age and co-occurring psychiatric conditions
14 increased risk of suicide ideation and suicide attempts/self-injury. Co-occurring intellectual disability
15 was associated with increased risk of suicide attempts/self-injury, but not of suicide ideation, which
16 could indicate difficulties in assessment of suicide ideation in autistic with intellectual disability
17 (JADD-D-19-00512). Hunsche et al., (2020) report results from a longitudinal study of suicidal
18 ideation, self-injury/suicidal behaviour in 178 autistic children aged 7-11 years. Parent reported
19 suicidal ideation occurred in 9.6%, and self-injury/suicidal behaviours in 14.6% of children using the
20 Child Behaviour Checklist. Oliphant et al., (2020) report results from a systematic literature review
21 exploring the prevalence of self-harm in autistic children and young people under 18 years. Only 9
22 studies were identified, with prevalence estimates of self-harm, suicidal ideation or suicidal behaviour
23 ranging between 11-73%. No studies had used a tool with evidence of validity to assess self-harm in
24 autistic children or young people (JADD-D-19-00558).
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28 A number of papers explored whether known risk markers for suicide in the general population can
29 help explain increased risk in autistic people. DiBlasi et al., (2020) report results from the first
30 preliminary genetic study of suicidal behaviour in autistic people, suggesting overlap between the
31 genes involved in autism and increased risk of suicidal behaviour (JADD-D-19-00573). In 481
32 autistic youth, McDonnell et al. (2020) report correlates of suicidal ideation and self-harm/suicide
33 behaviours, notably child age, parental education, restricted and repetitive behaviours, IQ and
34 adaptive behaviour, affective and conduct problems, and medical concerns (JADD-D-19-00575).
35 Conner et al., (2020) showed significantly increased risk of suicidality in autistic youth from the
36 community and psychiatric inpatient samples, and emotion regulation was associated with increased
37 risk of suicidality (JADD-D-19-00651). Licence et al., 2020 showed a 24% parent reported
38 prevalence of self-harm in autistic children and adults. Low mood and overactivity/impulsivity
39 predicted the presence of self-harm, with the model correctly classifying a majority (82.9%) of cases
40 (JADD-D-19-00554).
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44 Hochard et al., (2020) report online survey data from 650 general population adults, assessing
45 associations between autistic traits, sleep duration and suicidality. Results suggest that autistic traits
46 and short sleep duration are separately associated with suicidal ideation, but do not interact (JADD-D-
47 19-00561). Costa et al., (2020) showed in 150 autistic and 189 non-autistic adults, self-reported
48 autistic traits, depressive symptomatology, and antidepressant intake significantly predicted
49 suicidality. In those with high autistic traits, alexithymia was associated with further increased risk of
50 suicidality (JADD-D-19-00592). Arwert & Sizoo (2020) showed in 75 autistic adults, self-esteem was
51 significantly associated with current suicidal ideation, and rumination with history of suicide attempts.
52 Neither self-esteem or rumination were significantly associated with severity of suicidality after
53 controlling for depression (JADD-D-19-00557). South et al. (2020) report on 74 women with
54 significant social difficulties and high autistic traits. Self-reported imagination and repetitive
55 behaviours were associated with suicidality, suggesting that feeling sad, alongside not being able to
56 see a way out of one's current circumstances may increase risk of suicide in autistic people regardless
57 of diagnostic status (JADD-D-19-00581).
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1 These studies suggest overlap between the characteristics of autism and risk markers for suicidality in
2 autistic people, from the biological (DiBlasi et al., 2020) to the cognitive, affective and behavioural
3 level. Studies identified common risk markers, such as low mood (e.g. Licence et al., 2020; South et
4 al., 2020; Arwet & Sizoo, 2020), age (Hand et al., 2020; McDonnell et al., 2020), repetitive
5 behaviours and rumination (South et al., 2020; McDonnell et al., 2020; Arwet & Sizoo, 2020). Other
6 potential risk markers include impulsivity (Licence et al., 2020), alexithymia (Costa et al., 2020) and
7 self-esteem (Arwet & Sizoo, 2020). Many of these are common risk markers for suicide in the general
8 population (O'Connor & Kirtely, 2018). However, the characteristics of autism could amplify the risk.
9 Increased tendency to perseverate on a particular train of thought or behaviour and difficulty
10 imagining alternatives could increase risk of feeling entrapped with suicide as the only possible
11 escape route (South et al., 2020; Arwet & Sizoo, 2020).
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13 *Theoretical models*

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15 Two papers explored how a widely cited model of suicide – the Interpersonal Theory of Suicide (ITS)
16 – could help explain increase risk of suicidality in autistic and non-autistic people. Pelton et al.,
17 (2020) showed that autistic people were significantly more likely to experience thwarted belonging
18 and perceived burdensomeness compared to non-autistic people, and both mediated associations
19 between autistic traits and suicidality. The predictions of the ITS were broadly upheld in both groups,
20 but associations were significantly attenuated in autistic compared to non-autistic adults (JADD-D-19-
21 00617). Cassidy et al., (2020) explored how the ITS could be expanded for autistic people, exploring
22 the role of camouflaging one's autistic traits in experiences of thwarted belonging and suicidality.
23 Results suggest that those with high autistic traits attempt to camouflage these in order to fit in in
24 social situations, which is associated with increased feelings of thwarted belongingness and suicidality
25 (JADD-D-19-00597).
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29 These studies show that there are likely unique as yet unknown risk markers for suicide in autistic
30 people, which need to be included in existing suicide theories developed for the general population.
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32 *Recommendations for future research*

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34 This special issue represents a step change in relation to self-harm, suicidal thoughts and behaviours
35 in autistic people, across childhood, adolescence and adulthood. However, there are clear avenues for
36 future research.
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39 First, it is crucial given the early stage of the research cycle, that we meaningfully involve autistic
40 people and those who support them in developing high quality, useful and ethical self-harm and
41 suicide research with and for autistic people. This special issue illustrates welcome overlap between
42 the priorities of the autism community and research being undertaken, particularly in relation to
43 understanding the best ways of assessing self-harm, suicidal thoughts and behaviours, identifying risk
44 markers, explore how suicide theories developed for the general population could apply to and be
45 adapted for autistic people, and explore the contribution of poor sleep to suicidality in autistic people.
46 However, there was a lack of studies exploring other important aspects of suicidality, such as
47 personalised interventions, and help seeking behaviour – only one study reported on the potential of
48 suicide safety planning for autistic people from the perspective of clinicians (Jager-Hyman et al.,
49 2020). Second, assessment and measurement of self-harm, suicidal thoughts and behaviours in autism
50 are in their infancy (Howe et al., 2020; Cassidy et al., 2018b). It is essential to evaluate the most
51 effective ways of identifying and assessing self-harm, suicidal thoughts and behaviours in future
52 research and clinical practice. Third, research exploring self-harm, suicidal thoughts and behaviours in
53 autism has tended not to be theoretically driven, and only two studies in this special issue explored
54 how suicide theory in the general population could apply to autistic people (Cassidy et al., 2020;
55 Pelton et al., 2020). Suicide models developed for the general population include many risk markers
56 which are relevant to autistic people and identified in this special issue (e.g. social connections,
57 rumination and impulsivity), and attempt to identify factors that distinguish those who contemplate
58 suicide from those who go onto attempt suicide (Cassidy, 2020; O'Connor & Kirtley, 2018). Self-
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1 harm and suicide research for autistic people needs to take these important next steps, in order to
2 better understand and prevent suicide and reduce the distress experienced by autistic members of our
3 community.

4 References:

5
6 Arwert, T. G., & Sizoo, B. B. (2020). Self-reported suicidality in male and female adults with autism
7 spectrum disorders: rumination and self-esteem. *Journal of Autism and Developmental Disorders*, 1-
8 8.

9
10 Cassidy, S. (2020). Suicidality and self-harm in autism spectrum conditions. In S. White, B. Maddox
11 & C. Mazefsky (Eds.), *Oxford handbook of autism and co-occurring psychiatric conditions*. Oxford:
12 Oxford University Press.

13
14 Cassidy, S. A., Bradley, L., Bowen, E., Wigham, S., & Rodgers, J. (2018b). Measurement properties
15 of tools used to assess suicidality in autistic and general population adults: A systematic review.
16 *Clinical Psychology Review*, 62, 56–70.

17
18 Cassidy, S. A., Bradley, L., Cogger-Ward, H., Shaw, R., Bowen, E., Glod, M., ... & Rodgers, J.
19 (2020). Measurement properties of the suicidal behaviour questionnaire-revised in autistic
20 adults. *Journal of Autism and Developmental Disorders*, 1-12.

21
22 Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M., & Baron-Cohen, S. (2014). Suicidal
23 ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist
24 diagnostic clinic: A clinical cohort study. *The Lancet Psychiatry*, 1(2), 142–147.

25
26 Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018a). Risk markers for suicidality in autistic
27 adults. *Molecular Autism*, 9(1), 42.

28
29 Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2019). Is
30 camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the
31 interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism
32 and Developmental Disorders*, 1-11.

33
34 Cassidy, S., & Rodgers, J. (2017). Understanding and prevention of suicide in autism. *The Lancet
35 Psychiatry*, 4(6), e11.

36
37 Cassidy, S.A., Cogger-Ward, H., Goodwin, J., Roberston, A., Rodgers, J. (2019). Autism Community
38 Priorities for Suicide Prevention. [https://sites.google.com/view/mentalhealthinautism/projects/insar-
39 policy-briefing](https://sites.google.com/view/mentalhealthinautism/projects/insar-policy-briefing)

40
41 Conner, C. M., Golt, J., Righi, G., Shaffer, R., Siegel, M., & Mazefsky, C. A. (2020). A Comparative
42 Study of Suicidality and Its Association with Emotion Regulation Impairment in Large ASD and US
43 Census-Matched Samples. *Journal of Autism and Developmental Disorders*, 1-16.

44
45 Costa, A. P., Loor, C., & Steffgen, G. (2020). Suicidality in Adults with Autism Spectrum Disorder:
46 The Role of Depressive Symptomatology, Alexithymia, and Antidepressants. *Journal of Autism and
47 Developmental Disorders*, 1-13.

48
49 DiBlasi, E., Kirby, A. V., Gaj, E., Docherty, A. R., Keeshin, B. R., Bakian, A. V., & Coon, H. (2020).
50 Brief Report: Genetic Links Between Autism and Suicidal Behavior—A Preliminary
51 Investigation. *Journal of Autism and Developmental Disorders*, 1-6.

52
53 Hand, B. N., Benevides, T. W., & Carretta, H. J. (2019). Suicidal ideation and self-inflicted injury in
54 Medicare enrolled autistic adults with and without co-occurring intellectual disability. *Journal of
55 Autism and Developmental Disorders*, 1-7.

56
57 Hedley, D., & Uljarević, M. (2018). Systematic review of suicide in autism spectrum disorder:
58 Current trends and implications. *Current Developmental Disorders Reports*, 5(1), 65–76.

59
60 Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016).
61 Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232-238.

- 1 Hochard, K. D., Pendrous, R., Mari, T., & Flynn, S. (2020). Examining the relationship between
2 autism traits and sleep duration as predictors of suicidality. *Journal of Autism and Developmental*
3 *Disorders*, 1-10.
- 4 Howe, S. J., Hewitt, K., Baraskewich, J., Cassidy, S., & McMorris, C. A. (2020). Suicidality among
5 children and youth with and without autism spectrum disorder: a systematic review of existing risk
6 assessment tools. *Journal of Autism and Developmental Disorders*, 1-15.
- 7 Hunsche, M. C., Saqui, S., Mirenda, P., Zaidman-Zait, A., Bennett, T., Duku, E., ... & Ungar, W. J.
8 (2020). Parent-reported rates and clinical correlates of suicidality in children with autism spectrum
9 disorder: a longitudinal study. *Journal of Autism and Developmental Disorders*, 1-14.
- 10 Hwang, Y. I., Srasuebkul, P., Foley, K. R., Arnold, S., & Trollor, J. N. (2019). Mortality and cause of
11 death of Australians on the autism spectrum. *Autism Research*, 12(5), 806-815.
- 12 Jager-Hyman, S., Maddox, B. B., Crabbe, S. R., & Mandell, D. S. (2020). Mental health clinicians'
13 screening and intervention practices to reduce suicide risk in autistic adolescents and adults. *Journal*
14 *of Autism and Developmental Disorders*.
- 15 Kirby, A. V., Bakian, A. V., Zhang, Y., Bilder, D. A., Keeshin, B. R., & Coon, H. (2019). A 20- year
16 study of suicide death in a statewide autism population. *Autism Research*, 12(4), 658-666.
- 17 Licence, L., Oliver, C., Moss, J., & Richards, C. (2019). Prevalence and risk-markers of self-harm in
18 autistic children and adults. *Journal of Autism and Developmental Disorders*, 1-14.
- 19 McDonnell, C. G., DeLucia, E. A., Hayden, E. P., Anagnostou, E., Nicolson, R., Kelley, E., ... &
20 Stevenson, R. A. (2019). An exploratory analysis of predictors of youth suicide-related behaviors in
21 autism spectrum disorder: implications for prevention science. *Journal of Autism and Developmental*
22 *Disorders*, 1-14.
- 23 Maddox, B. B., Trubanova, A., & White, S. W. (2017). Untended wounds: Non-suicidal self-injury in
24 adults with autism spectrum disorder. *Autism*, 21(4), 412-422.
- 25 Minshawi, N. F., Hurwitz, S., Fodstad, J. C., Biebl, S., Morriss, D. H., & McDougle, C. J. (2014). The
26 association between self-injurious behaviors and autism spectrum disorders. *Psychology Research and*
27 *Behavior Management*, 7, 125.
- 28 Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. J. M. A. (2019). A 'choice',
29 an 'addiction', a way 'out of the lost': exploring self-injury in autistic people without intellectual
30 disability. *Molecular Autism*, 10(1), 1-23.
- 31 Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. (2020). Links between self-
32 injury and suicidality in autism. *Molecular Autism*, 11(1), 1-15.
- 33 Oliphant, R. Y., Smith, E. M., & Grahame, V. (2020). What is the prevalence of self-harming and
34 suicidal behaviour in under 18s with ASD, with or without an intellectual disability?. *Journal of*
35 *Autism and Developmental Disorders*, 1-15.
- 36 Osman, A., Bagge, C. L., Gutierrez, P. M., Konick, L. C., Kopper, B. A., & Barrios, F. X. (2001). The
37 Suicidal Behaviors Questionnaire-Revised (SBQ-R): validation with clinical and nonclinical
38 samples. *Assessment*, 8(4), 443-454.
- 39 Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020).
40 Understanding suicide risk in autistic adults: Comparing the Interpersonal Theory of Suicide in
41 autistic and non-autistic samples. *Journal of Autism and Developmental Disorders*, 1-18.
- 42 Ribeiro, J. D., Franklin, J. C., Fox, K. R., Bentley, K. H., Kleiman, E. M., Chang, B. P., & Nock, M.
43 K. (2016). Self-injurious thoughts and behaviors as risk factors for future suicide ideation, attempts,
44 and death: a meta-analysis of longitudinal studies. *Psychological Medicine*, 46(2), 225-236.
- 45 South, M., Beck, J. S., Lundwall, R., Christensen, M., Cutrer, E. A., Gabrielsen, T. P., ... & Lundwall,
46 R. A. (2019). Unrelenting depression and suicidality in women with autistic traits. *Journal of Autism*
47 *and Developmental Disorders*, 1-14.
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Table 1: Autism community's top 10 priorities for suicide prevention 2019

1. What barriers do autistic people experience when seeking help which may put them at greater risk of suicide?
2. What are the risk and protective factors for suicide in autism across the lifespan?
3. To what extent are autistic people not believed about the severity of their distress?
4. How can we further understand suicide where mental health is not a factor, across the lifespan?
5. How can we best identify and assess suicidal thoughts and suicidal behaviours in autistic people, in research and clinical practice?
6. How should interventions be adapted for autistic people and individual presentations?
7. What is the experience of suicidality in autistic people? Is this experience different to the general population?
8. How do autistic people seek help when they are in a crisis?
9. How well do existing models of understanding suicide apply to autistic people?
10. What is the impact of poor sleep on suicide risk in autistic people, and how can this be measured?

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