University of Exeter

BRIEFING PAPER

ESMI Evidence Synthesis & Modelling for Health Improvement

Exeter Policy Research Programme Evidence Review Facility: November 2024

What research exists which examines the effectiveness and cost-effectiveness of strategies to reduce the risk of autistic people dying by suicide?

Autistic or potentially autistic people (i.e., those with elevated autistic traits) are at a higher risk of experiencing suicidality (suicidal ideation, suicide plans, suicide attempts, dying by suicide) than the general population.[1] Recent estimates indicate over a third of autistic and possibly autistic people without co-occurring intellectual disability experienced suicidality; considerably higher than estimates of 9% in the general population experiencing suicidal ideation.[1] The NHS Long Term Plan and Building the Right Support have committed to increasing the availability and accessibility of community mental health support, including crisis support, for autistic people to reduce the need for inpatient mental health care and 'preventable deaths'. The Department of Health & Social Care (DHSC) identified autistic people as a priority group in the National Suicide Prevention Strategy for England and committed to building the evidence on preventing suicidality for autistic people to develop policy and guidance.[2, 3, 4]

The University of Exeter PRP Evidence Review Facility was independently commissioned by the National Institute of Health and Care Research to undertake a scoping review to better understand the quantity and nature of existing primary research evaluating interventions to support autistic people experiencing suicidality.

Findings highlighted:

- 27 studies (28 articles) included; 16 articles represented completed studies published as journal articles, 6 trials in progress and 6 abstracts. None of these included possibly autistic participants, despite being within the inclusion criteria.
- Studies focused on evaluating or developing interventions to reduce suicidality (n=17) or evaluating/developing screening procedures to identify individuals with autism who may be at risk of dying by suicide (n=9). One study belonged to both categories.
- Intervention categories supported by the highest quantity of evidence included safety planning (n=4, all completed) and DBT (n=4, 2 completed).
- The number of completed studies using robust methods (e.g. randomised controlled trials (RCTs)), was small. Where RCTs were present they tended to represent smaller, feasibility trials and were distributed between the six different categories of intervention identified. Thus, at this stage of the research cycle, the level of RCT evidence supporting each type of intervention/screening procedure is limited.
- Few studies used robust effectiveness methods to evaluate similar interventions/ screening programmes. The review found no cost-effectiveness evidence.
- Limited UK-specific evidence. Little explanation of theoretical basis for interventions.
- Small sample sizes, with limited representation of minority ethnic groups and cultures.

Despite commitments to reduce avoidable mortality and improve support available in the community, there is a lack of evidence on effective interventions to treat suicidality, with autistic people reporting that they receive interventions that have been designed for other groups and are inappropriate for their needs

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Why did we do this review?

Given the commitments made by the DHSC in the Suicide Prevention Strategy to developing the evidence base on preventing suicidality in people with autism, a greater understanding of existing evidence in this field is needed to support the commissioning of future research.

Research Question:

What is the quantity, range and nature of studies on the effectiveness, cost-effectiveness and experiences of interventions to reduce suicidality for autistic, and potentially autistic, people?

How did we do this review?

We searched bibliographic databases, including trial registries, conducted backwards citation chasing on all studies which met our inclusion criteria and searched reference lists of topically relevant reviews, alongside a selection of relevant websites.

Eligibility criteria:

Quantitative and/or qualitative studies which evaluated the effectiveness, cost-effectiveness of experiences of intervention or screening tool intended to reduce suicidality in people with autism or potential autism. Outcomes needed to include: a reduction in attempted suicides, completed suicides or suicidal thoughts and behaviour in autistic/potentially autistic people or explore patient, clinician or carer/family experiences of interventions/screening tools.

Study selection, data extraction and quality appraisal:

Study selection was completed independently by two reviewers. Data extraction and quality appraisal of completed studies were carried out by one reviewer and checked by a second, Quality appraisal of completed studies was undertaken using the Mixed-Methods Appraisal Tool (MMAT).

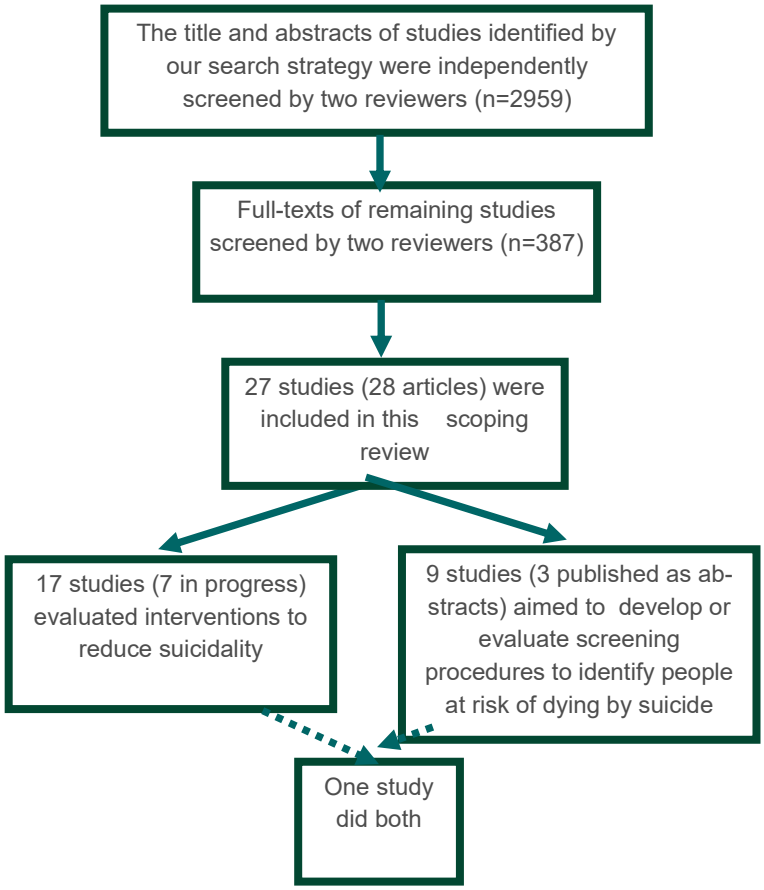

Figure 1: Identification of the evidence

What did we find?

Ten studies evaluated suicide screening procedures:

Ask Suicide Screening Questions (n=5)	Two journal articles, and three abstracts focused on using the Ask Suicide Screening Questions (ASQ). Four quantitative studies evaluated the effectiveness of the five-item ASQ in identifying youth at risk of suicide within the emergency department. One study explored the feasibility of using the ASQ in a medical setting, and one study described implementation of a screening programme in an emergency department and factors influencing engagement. Three studies collected data via retrospective chart review, two administered ASQ via cross-sectional surveys.
Universal screening tools (n=3)	Three studies published as journal articles evaluated the useability or feasibility of a different universal risk screening tool for people with autism, including the revised Suicidal Behaviours Questionnaire, and the Kiddie-Computerized Adaptive Test Suicide-Scale. The third study explored attitudes towards the non-suicide specific revised Mental Health Crisis Assessment Scale, which appraises the severity of 13 mental health related externalising behaviours, which encompassed suicidal thoughts/behaviour, and parental self-efficacy in managing these. Setting: emergency department or outpatient psychiatric, behavioural or psychiatric clinic in ASD specialty centres.
Attitudes (n=2)	Two studies published as journal articles explored broader experiences/attitudes, not specific to a particular tool, towards screening practices to identify autistic people at risk of suicide.

Studies evaluating interventions

Studies were primarily from high-income, western countries. The most common country represented was the USA (n=14). Three studies were conducted within the UK.

The 18 studies focusing on evaluating or developing interventions could be categorised into one

Safety Planning (n=5)	Four studies (published as eight articles) were completed, with findings published for three, and one is a trial in progress. Two of these were RCTs with a preliminary qualitative study, one a mixed methods, and one cross-sectional study. Three of the interventions evaluated by the completed studies were based on the structure of the original Stanley–Brown Safety Plan (Stanley & Brown, 2012). This comprises a list of hierarchical steps which are: warning signs; internal coping strategies; social contacts and locations; family members or friends that may offer help; professionals or agencies to help; and how to keep the environment safe.[5]
Dialectical behaviour therapy (n=4)	Four studies evaluated dialectical behaviour therapy (DBT) interventions which aimed to decrease emotion dysregulation and maladaptive coping, and improve depression, hopelessness, anxiety, alexithymia and the frequency and intensity of self-harm and suicidal ideation for autistic adults. Two studies were mixed methods, one of which is in progress, and two were RCTs (one of which was in progress).
Cognitive Behaviour Therapy (n=2)	Two RCTs (one in progress) evaluated the effects of cognitive behaviour therapy (CBT) on self -reported symptoms of depression and on self-harm and suicidality in autistic adolescents and young people.
Psychosocial Therapy: other (n=2)	The two interventions in this category, both reported in journal articles, used narrative therapy or targeted social skills development to reduce stress-related problems and potentially reduce depression for autistic adolescents. One study was an RCT, the other a before-and-after study.
Training (n=3)	Three studies, one cross-sectional study reported in a journal article, and two cross-sectional studies as abstracts focused on training to improve quality of care for autistic young people by increasing clinician confidence in recognising and diagnosing ASD, screening for and identifying suicide risk, and managing and intervening on suicide risk;(28) encouraging clinicians to implement routine suicide risk screening with autistic young people; and increasing trainee (e.g. child and adolescent psychiatry fellows and psychology interns) confidence in assessing and addressing suicidal thoughts and behaviours in young people presenting in hospital emergency departments.
ECT/rTMS (n=2)	Two studies evaluated electroconvulsive therapy (ECT) and rTMS to alleviate self-injurious behaviour and aggression and to reduce depression in autistic children and young people and PDD-NOS (pervasive developmental disorder-not otherwise specified). The first was a retrospective chart review reported in a journal article, and the second is a RCT in progress reported on a trial registry.

What are the implications of this review?

This scoping review aimed to better understand the quantity and nature of existing primary research evaluating interventions to support autistic people experiencing suicidality, provides an overview of the research evidence currently available in this area.

- **Implications for future research:**

◊ Larger RCTs will be required in the future to better establish the effectiveness of interventions and screening procedures included in this review.

◊ Trials should be accompanied by a qualitative element to explore patient, carer and clinician experiences of the intervention, to generate insights into factors which influence patient engagement and longer-term efficacy.

◊ Efforts should be made to improve the integration of quantitative and qualitative research evidence within mixed-methods studies.

◊ Development of future interventions should be designed with and for autistic people to allow them to fully engage with the intervention process and content. The content of future interventions should also address the characteristics of autistic people which increase their risk of experiencing suicidality.

◊ A systematic review of the large body of primary evidence exploring relationship between different characteristics/experiences of people with autism and increased suicidality could help better understand the specific challenges associated with living with autism linked to increased risk of suicide which are amenable to intervention. Identifying challenges which are amenable to earlier intervention prior to "crisis" point, e.g. anxiety and depression, may be useful.

◊ Randomised controlled trials evaluating use of screening tools outside of emergency or hospital settings will also be needed.

◊ Efficacy and experience of completing such screening tools with people who do not have a formal autism diagnosis is necessary.

◊ Future research should involve people with autism/potential autism and those who support them.

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