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"Picking the best of a bad bunch": exploring stakeholder perspectives of self-harm assessment tools for autistic adults

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Ethical considerations

Ethical approval was granted by the University of Nottingham's School of Psychology (ref: S1508).

Data availability statement

The data are not publicly available because of the sensitive nature of the research topic and information that could compromise participant privacy.

Plain language summary

The perspectives of autistic adults and professionals on existing self-harm assessment tools

Self-harm is defined as when someone intentionally hurts or poisons themselves, regardless of the reason. This can include suicide attempts as well as behaviours such as cutting, hitting, or burning as a way to express or manage difficult feelings. Concerningly, autistic people are more likely to self-harm than non-autistic people, but there are currently no tools specifically designed to assess self-harm in this group. This makes it harder for researchers and service providers to identify autistic people who self-harm and offer the right support or treatment. Previous studies have suggested that three existing self-harm assessment tools could be adapted for autistic people, but it is unclear what autistic adults and professionals think about these tools. We conducted two focus groups: one with autistic adults who have self-harmed and another with professionals who work with autistic people who self-harm. Both groups felt that none of the three tools were suitable for autistic people. They explained that some questions might be harder for autistic people to answer, such as those requiring them to remember specific details or identify their emotions. They also noted the tools missed out on important aspects of the autistic experience, like managing sensory and social overload. Both groups highlighted that self-harm is complex and discussed the overlap with behaviours such as stimming (e.g., repetitive movements or sounds). They emphasised the importance of a supportive approach to self-harm that considers the role of co-occurring conditions, like ADHD or intellectual disabilities, and ensures researchers and professionals prioritise participant safety. These findings suggest that instead of adapting existing tools, a new one should be developed specifically with and for autistic people. A tailored tool could help identify self-harm earlier and lead to better support for autistic adults.

Abstract

Autistic people are at greater risk of self-harm than non-autistic people, yet no tools exist specifically for assessing self-harm in this population. We therefore conducted two focus groups with autistic adults (n = 5) and professionals (n = 4) to examine their perspectives on three existing self-harm assessment tools (Non-Suicidal Self-Injury – Assessment Tool, Inventory of Statements About Self-Injury, and Questionnaire for Non-Suicidal Self-Injury). Using reflexive thematic analysis, we found one overarching theme – “picking the best of a bad bunch” – where participants acknowledged some strengths of the tools, but multiple limitations outweighed these. Subthemes included cognitive considerations (e.g., complexity, length, working memory demands, introspection), missing elements (e.g., broader self-harm behaviours, functions, context, support) and challenges in conceptualising self-harm, particularly around intentionality and stimming. Participants also stressed the importance of addressing stigma, considering co-occurring conditions like ADHD and ID, and upholding a duty of care. Overall, findings show that existing self-harm assessment tools are not appropriate or acceptable for autistic adults who self-harm, indicating a clear need for a new self-harm assessment tool developed with and for autistic people.

Background

The UK's National Institute for Health and Care Excellence (2022) defines self-harm as any act of intentional self-poisoning or self-injury, regardless of underlying motivation. This definition includes actions intended to end life, such as suicide attempts (Hawton et al., 2012) and those without suicidal intent, such as non-suicidal self-injury (NSSI; Nock & Favazza, 2009). Self-harm behaviours may include self-cutting, self-hitting, self-burning, self-biting, and skin picking (Klonsky, 2011; Pompili et al., 2015), and serve various intra- and interpersonal functions, such as emotion regulation, self-punishment, or communication of distress (Hepp et al., 2020; Peel-Wainwright et al., 2021; Taylor et al., 2018). In the general population, self-harm is linked to poor mental health and psychosocial outcomes (Beckman et al., 2019; Borschmann et al., 2017) and represents one of the strongest predictors of suicide (Favril et al., 2022; Hawton et al., 2020; Runeson et al., 2016). Given its link to adverse outcomes, addressing self-harm in clinical and research settings is critical.

Concerningly, autistic people are at a significantly increased risk of self-harm, with studies indicating they are three to five times more likely to self-harm than their non-autistic counterparts (Blanchard et al., 2021; Stark et al., 2022). Estimates suggest that up to 54.4% of autistic individuals engage in NSSI during their lifetime (Maddox et al., 2017; Schwartzman et al., 2024), and adults with high autistic traits report more self-harm than those with lower autistic traits (Stewart et al., 2023). Despite this, self-harm in autism has been historically subsumed within “challenging” or “restrictive and repetitive” self-injurious behaviour (SIB), such as headbanging or self-biting (Duerden et al., 2012; Matson & Turygin, 2012). While both SIB and self-harm involve hurting oneself, SIB is more commonly observed in autistic children or those with co-occurring intellectual disabilities (ID) and is typically understood to serve sensory, behavioural or communicative functions (Goldfarb et al., 2021; Matson & Turygin, 2012; Minshawi et al., 2014). Consequently, self-harm presentations resembling those in the general population (i.e., NSSI) are often overlooked or misattributed as SIB, rather than being recognised and treated as distinct indicators of psychological distress, particularly in autistic adults without co-occurring ID (Cassidy, 2020; Maddox et al., 2017). However, research indicates that NSSI is similar in autistic and non-autistic adults in terms of age of onset, methods used, and underlying function (e.g., emotion regulation; Goldfarb et al., 2021; Maddox et al., 2017; Moseley et al., 2019). As in the general population, self-harm in autism is also associated with heightened suicide risk (Cassidy et al., 2018; Moseley et al., 2020; Nyrenius et al., 2023), with theories of suicide suggesting NSSI may serve as a precursor to suicidal behaviours (Moseley et al., 2022). Given the already elevated rates of suicidality and mental health challenges among autistic individuals (Lai et al., 2019; Newell et al., 2023), recognising and understanding self-harm in this population is essential.

Robust assessment tools are therefore necessary to accurately identify autistic people who self-harm. However, a recent systematic review using COSMIN (the COnsensus-based Standards for the selection of health Measurement Instruments; Mokkink et al., 2018; Prinsen et al., 2018; Terwee et al., 2018) highlighted a lack of instruments designed specifically to assess self-harm in autism (Newell et al., 2024). Of eight self-harm assessment tools identified, only one – the Non-Suicidal Self-Injury - Assessment Tool (NSSI-AT; Whitlock et al., 2014) – had been used in three studies involving autistic adults. Two other tools, the Inventory of Statements About Self-injury (ISAS; Klonsky & Glenn, 2009) and the Questionnaire for Non-Suicidal Self-Injury (QNSSI; Turner et al., 2012), showed promising measurement properties in the general population. Yet, none were specifically developed or validated for autistic individuals, leaving uncertainty about their suitability and the potential need for adaptation.

There are also limitations to using existing self-harm assessment tools with autistic individuals. Research indicates that autistic adults interpret and respond to measures developed for the general population differently than intended by tool designers (Cassidy et al., 2020; Pelton et al., 2020). This may stem from challenges identifying and describing emotions (i.e., alexithymia; Kinnaird et al., 2019), ability to remember past experiences (episodic memory) and imagine future scenarios (episodic future thinking; Lind et al., 2014; Lind & Bowler, 2010), or a tendency to interpret information literally (Vicente & Falkum, 2023). Autistic people may also experience unique presentations of self-harm that are not captured by the existing tools, such as those related to sensory processing differences (Marsden et al., 2024; Moseley et al., 2019). Complex or insensitive language, vague response options, and a lack of autism-specific items can therefore make existing instruments inaccessible to autistic people (Nicolaidis et al., 2020), where using such tools may yield inaccurate results that fail to reflect the construct of interest.

Addressing these limitations requires meaningful collaboration between researchers and autistic individuals to ensure that self-harm assessment tools are reliable, valid, and suitable for use in this population (Nicolaidis et al., 2020). Additionally, research should align with the priorities of the autistic community, which includes identifying risk factors for suicide prevention (e.g., self-harm, Cassidy et al., 2018; Cassidy, Cogger-Ward, et al., 2021) and understanding the mental health needs of autistic individuals (Roche et al., 2021). There is evidence that measures can be successfully adapted in this way with and for autistic people, as shown with the Suicidal Behaviours Questionnaire – Autism Spectrum Conditions (Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021) and the Autistic Depression Assessment Tool – Adult (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021). Despite the notable lack of instruments to assess self-harm in autism, no studies have yet explored key stakeholder perspectives regarding the appropriateness and acceptability of existing tools.

Therefore, this study sought to explore the perspectives of autistic adults with lived experience of self-harm and professionals who work with them on the three existing self-harm assessment tools (ISAS, NSSI-AT, QNSSI) identified in a prior COSMIN review (Newell et al., 2024). Specifically, we aimed to identify: 1) which tool, if any, would be most appropriate for use with autistic adults; and 2) whether these tools were clear, relevant, and inclusive of autism-specific items.

Methods

Participants

Nine participants were recruited to take part in two separate focus groups: one with autistic adults with lived experience of self-harm (n = 5) and another with professionals who have worked with autistic people who self-harm (n = 4). See Table 1 for demographics. Participants for both groups were recruited using purposive sampling via social media (e.g., X), as well as professionals from a local third-sector organisation. The professional group included early career professionals and those with experience supporting autistic individuals with co-occurring ID, across one or more roles such as team leader (n = 2), clinical support worker (n = 2) and specialist mentor (n = 1). Given the sensitive research topic, participants were required to be over 18 years old and live in the United Kingdom for safeguarding purposes.

Table 1.

Participant demographics for each focus group.

Demographics	**Autistic adults (n = 5)** *n (%)/Mdn (range)*	**Professionals (n = 4)**
Age*	39 (27 – 42)	24 (23 – 44)
Gender identity		
Female	3 (60)	3 (75)
Male	0	1 (25)
Non-binary/ non-conforming	1 (20)	0
Questioning	1 (20)	0
Autism		
Formal diagnosis	5 (100)	1 (25)
Self-identified	0	1 (25)
Not autistic	0	2 (50)

**Missing data for one participant.*

Note. Data on ethnicity, socioeconomic status and educational attainment levels were not collected.

Materials and measures

Participants were provided with the three self-harm assessment tools identified in a recent COSMIN systematic review (Newell et al., 2024): the ISAS (Klonsky & Glenn, 2009), NSSI-AT (Whitlock et al., 2014), and QNSSI (Turner et al., 2012). See Table S1 in the supplementary materials for descriptions of the self-harm assessment tools. An agenda was developed for each focus group (autistic adults and professionals), outlining the aims, schedule, and questions for discussion (see S2 in the supplementary materials). Questions were based on the COSMIN methodology for evaluating content validity (Terwee et al., 2018), covering comprehensibility (are the items understood as intended?), relevance (are all items relevant for the construct of interest within a specific population and context of use?) and comprehensiveness (are any key aspects of the construct missing?). Participants were also asked which tool they would be most and least likely to recommend for use with autistic people who self-harm and why.

Procedure

Interested participants contacted the research team, who provided information about the research and answered any questions. Autistic adults were required to have an online introductory meeting with the first author to complete a well-being plan adapted from previous self-harm and suicide research with autistic adults (Goodwin et al., 2024; Pelton et al., 2025; see S3 in the supplementary materials). The plan included emergency contact information, accessibility needs, and how best to support the participant should they become distressed. This was password-protected, shared with the participant, stored securely, and deleted two weeks after participation. The introductory meeting was optional for professionals who already had access to safeguarding procedures. Participants provided informed consent electronically via Qualtrics, and study materials were shared a week before focus groups to allow for preparation time.

Two focus groups were conducted in line with guidance on saturation and sample size parameters for qualitative research, suggesting one group per demographic of interest (autistic adults and professionals) to identify key issues in the data, and 2-3 groups in total to achieve approximately 80% thematic saturation. This saturation threshold is considered acceptable for capturing the most prevalent themes, where any additional discoveries are unlikely to add further insights, and complete saturation is rarely possible (Hennink et al., 2019). Owing to the sensitive research topic, group size was also limited to 4-5 participants to encourage in-depth discussions and ensure adequate safeguarding was possible (Barbour, 2018). Focus groups were run online using a semi-structured format facilitated by two researchers who followed the agenda. Several measures were implemented to support participant well-being (e.g., mood checks before and after, a virtual breakout room) and improve accessibility (e.g., verbal or typed contributions, frequent breaks).

All introductory meetings and focus groups were held via Microsoft Teams to enable greater geographical reach and convenience. Sessions were recorded, transcribed verbatim, and anonymised for analysis.

Participatory Methods

This study is part of a larger project to co-develop a new self-harm assessment tool with and for autistic adults, aligning with community and stakeholder priorities in suicide prevention (e.g., identifying risk factors) and mental health (Cassidy, Cogger-Ward, Robertson, et al., 2021; Roche et al., 2021). A mix of autistic and non-autistic academic researchers and participants contributed to this study. Participants acted as community advisors, contributing lived experience and actively shaping the direction of the research. Following community-based participatory research guidelines for adapting and validating instruments for autistic populations, participants directly informed key decisions about the acceptability and appropriateness of existing self-harm assessment tools (Newell et al., 2024), or determined that a new measure was needed (Nicolaidis et al., 2020). This approach aimed to redistribute power and centre autistic perspectives within the research process. Participants were compensated in line with the UK's National Institute for Health and Care Research (NIHR, 2022) guidance, which outlines recommended payment rates for public involvement to ensure fair recognition of individuals' time, expertise and contribution.

Analysis

Reflexive thematic analysis was conducted using Braun & Clark's (2006) six-phase framework, which consisted of: 1) familiarising yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report. This method was selected to identify patterns of information and perspectives on the underexplored topic of self-harm assessment in autism. To ensure rigour and transparency, Braun & Clarke's (2021) tool for evaluating thematic analysis quality informed the methodological approach and analytic process (see Table S4 in supplementary materials).

The first author transcribed each focus group verbatim and summarised initial thoughts on the content. Following this, they familiarised themselves with the data and generated initial codes using the comments function in Microsoft Word. These initial codes were reflected on by revisiting the data to refine or add new ones as needed. Codes were then collated into groups describing similar concepts, forming the basis for potential themes and subthemes. This process was conducted in Microsoft Excel, as a widely available and cost-effective aid for analysis (Bree & Gallagher, 2016). Potential themes were reviewed and refined against the codes and original data. Lastly, clear definitions and names for the final themes were generated. The first author discussed themes with co-authors, who offered feedback and helped ensure an accurate interpretation of the data (Braun & Clarke, 2006, 2021).

Both focus groups were analysed together to triangulate viewpoints due to similarities in participant perspectives. This approach has been taken by previous research that found uniformity in themes across stakeholder groups (French & Cassidy, 2024; Goodwin et al., 2024). Quotes are presented both verbatim and as excerpts integrated throughout the text

(Bradley et al., 2021; Camm-Crosbie et al., 2019), with square brackets to add context where needed. Participants are identified by group (autistic adult [A], professional [P]) and participant number (e.g., A1, P2) to maintain anonymity.

Positionality Statement

This research was informed by the neurodiversity paradigm, reflecting our commitment to embracing diversity and promoting autistic voices (Kapp, 2020; Pellicano & den Houting, 2022). We adopted an essentialist theoretical standpoint, interpreting participants' experiences as direct expressions of their lived reality. A primarily deductive approach was taken, where data were open-coded but also guided by the COSMIN methodology for evaluating content validity (Terwee et al., 2018) to ensure themes were meaningful to the research aims. Codes were identified at the semantic level, reflecting explicit or surface meanings of the data. The authors brought a range of lived and professional experiences to the study and acknowledged the potential influence of personal biases on knowledge production. Reflexivity was embedded throughout the research process via notetaking and team discussions, to critically reflect on how our identities, assumptions, and disciplinary backgrounds may have shaped interpretation of the data and theme development.

Results

The analysis generated one overarching theme: “picking the best of a bad bunch”. This included seven subthemes, which explored perspectives on the three self-harm assessment tools. See Figure 1 for a thematic map.

Figure 1.

Thematic map of themes and subthemes.

1. Picking the best of a bad bunch

This theme centred on the consensus that none of the three self-harm assessment tools were considered “fit for purpose” (P4), and as a result, participants felt they had to “pick the best of a bad bunch” (A3). This was reflected in the acknowledgement that the tools had some strengths, but many limitations outweighed these. The nuances of this theme are discussed within the relevant subthemes below.

> *“At this moment of time, all three [tools] are so off on its own thing, that I don't think there's one that can be really used.”* (P3)

1.1. Strengths

Participants highlighted that within the tools, there were “one or two elements that you think, you know, that's quite well laid out, it could be adapted” (P4) or “something you can take from each [tool]" (P3). For example, the NSSI-AT and QNSSI were described as more comprehensive and relevant. The NSSI-AT included extra "detail and options to select" and "granularity" (A3), along with self-harm behaviours and functions that were "inclusive" (A4) or that "autistic people may not have thought about were self-harm" (P4).

> *"This [NSSI-AT] had things on it that the others didn't, such as a friend suggesting it and seeing it on TV [self-harm] and things like that. I just think it adds more situation."* (A4)

Likewise, the QNSSI "recognise[s] there are some benefits to self-harm behaviours" (A5) and included response options relevant to autistic people's experiences of self-harm, such as "decreasing tension" (A5) or "head-banging and scratching" (P2).

> *"It [QNSSI] was the only one that looked at kind of, head banging and scratching as methods of self-harm, and from just my own client base, those are the methods I've seen the most commonly with autistic people."* (P2)

Several participants reported on what made the tools more user-friendly. The NSSI-AT provided "guidance" (A2) on how to answer questions, and the "strongly agree, somewhat disagree [etc]" Likert scaling was "easier to fill out" and "less overwhelming" (A2). The ISAS was generally favoured in terms of its "layout" (P3), "presentation" (A2), and "shortness" (P4). It also provided references, where this "basis in fact" was "reassuring" (P4). Moreover, participants appreciated having lists of response options, which were common to all three tools.

> *"I think often, I find it difficult to locate the answer, but if I have a menu, I can often see what I agree with or what I don't agree with."* (A1)

1.2. Cognitive considerations

Conversely, participants found the tools to be "really long" (A3), "overcomplicated" (P2) and "overwhelming" (P3), especially the NSSI-AT and QNSSI. Scale explanations were "wordy and high-minded" (P4), which resulted in participants feeling "agitated" (P1) or "frustrated"

(A2) with having to go back and forth to make sense of things. Multiple autistic participants said they would struggle to complete the tools on their own, but “it would be okay” (A3), or they would “stick with it” (A4) and ”ask more [for help]” (A2) if they were being supported. However, they also acknowledged that if a professional makes a mistake when using a complex tool with someone in crisis, it could have harmful consequences – “does that person just go, yeah, this [professional] doesn't know what they're doing. I'm not trusting them or telling them that I'm feeling a certain way” (P4).

> *“You know, you go through this list that keeps saying this, and how do you feel about this? How do you feel about that? And it is a process where they have to really think about what's going on, where they are.”* (P3)

Consequently, participants thought it was important that the tools had “considered and quality formatting that's well spaced and clear” (A1), “a balance between including relevant items, but then not having a list that's longer than it needs to be” (P1), and that “things go in quite a logical order, and they make sense for someone to follow” (P2).

> “*Short, simple, you know, layout. Good font, easy to read. You know, those sorts of things are really, really important, aren’t they? And quite often overlooked when we're looking at clinical tools, you know, that actually, is it just an easy read?”* (P4)

Moreover, problems with Likert scales were flagged by multiple participants. “Each of the measures had loads of different types of scales” (P2), and scale options were considered “really hard to differentiate [often vs seldom]” (A4) or inappropriate where “it doesn't feel like agreeing or disagreeing really captures what it's [the question] asking about” (A4). Other participants found “numerical scales really difficult to respond to” (A1), leading to a preoccupation with how to answer the question and wanting to “get it right even though it's not necessarily a right or wrong thing” (P1).

> *“I'd be sitting there for ages trying to think what number it [response] would fit in. Like, how I would quantify that in my head is quite confusing.*” (A4)

It was suggested that Likert scales could be improved by providing “something that is more illustrative” (A1) or “another kind of scale next to it” (A4). Other participants reported that a neutral option would help them “move on [from the question] in a way that might not have been possible otherwise” (A1) and reducing the number of options to something like “never, sometimes, always… might be a bit more approachable” (P1).

Participants also described challenges when estimating over a time period or determining how much time had passed. For example, the ISAS item regarding how many times a person engaged in different self-harm behaviours over their lifetime was highlighted as particularly “difficult” (P1). Autistic participants spoke of being “time blind” (A1) and the impact of one’s emotional state or not being in their “wise mind” (A4) on their ability to remember. The questions also did not give space for variability in self-harm, where an individual may have “periods where it is quite intense, and then periods where it's kind of not present at all” (A1).

> *“I would struggle to remember how many occasions because something blocks it out, and I'm not really, like my awareness and my memory of it is not good, because like you say, the distress and the kind of, not being as aware or as in control at the time. Which then makes it difficult to estimate things like that, doesn't it?”* (A3)

Additionally, the tools had high demands on working memory. For Likert scales, “holding that information [scale options] and processing the question is really challenging” (A1). Multiple participants also noted the QNSSI items that required ranking statements were “really hard” (A1) and “almost impossible” (A3) as a result of “the cognitive load of trying to deal with that [long list] and make those decisions [ranking]” (P2).

> *“Working memory is a problem that I think would affect my answering of a lot of these questionnaires, having to remember different responses and manipulate them and work out and compare them in my head.”* (A3)

There were shared concerns that the language used across tools was not appropriate or clear. Participants described ambiguous wording such as “creating a boundary between yourself and others [ISAS]” (A3), wanting clarity on “occasions” vs “times” (A3), and specific types of “therapy” and “medical care” (A3). Some questions were confusing (e.g., Who knows/suspects about it [self-harm] and has not talked with you about it? [NSSI-AT]) – “How would I know that?” (A1). Others could be answered in multiple different ways (e.g., Do or did you want to stop self-harming? [ISAS]) where “do you, and did you, are two different questions” (A3) and the answer could be “both [yes and no]” (A1). Similarly, participants might interpret things literally, such as “bloodletting” [QNSSI] as “some medieval practice, and not really understand that it meant cutting” (P4), or “as a way to practice suicide” [NSSI-AT] in that “the more I practice self-harm, is that gonna make me more likely to ‘be successful’ dying by suicide?” (P1). The language was also described as “outdated and probably quite complex for people who aren't academic or clinical staff” (P4).

> *“They [the tools] need definitions or explanations so it’s clear how to answer them. Also, a few questions I can read too literally and answer differently than reading the question again, which suggests they're actually wanting.”* (A5)

Further, all three tools require introspection, such as on one’s emotional state or perception of pain. The NSSI-AT module on personal reflections was “confusingly weighted towards the impact of scars” (A1) and required “an understanding of myself or autism to make this information meaningful” (A2). Participants also described having “a really terrible range of emotions” (A2) or “alexithymia” (A4), which made it challenging to identify the reason for their progression from “reasonably okay, to just can't cope, need to let it out” (A5). This was complicated further by tools including emotional states that become “more and more nuanced as you go along” (P4), such as “euphoric”, “relieved”, and “positively aroused”. Participants reported similar issues for questions about physical pain, where they “might feel pain (or not) differently” (A3) and that “the idea of pain itself can be relatively abstract” (P4).

“I don't really know how I feel a lot of the time. Especially in heightened distress, like I'll just describe it as URGHH I feel awful, but I can't actually say whether that's sadness, anxiety, disappointment.” (A4)

1.3. Missing elements

Participants discussed a variety of elements they felt were missing from the tools. A broader range of behaviours “not normally considered self-harm” (A3) were highlighted, such as “smoking and drinking” and “using substances” or “medication” (A3), “putting yourself in an unsafe situation” (A4), “self-neglect” (A4), “intentionally ingesting or exposing yourself” to something you are allergic/ have a reaction to (A3), and “looping thoughts and rumination” (A4).

“Self-neglect probably is my biggest form of self-harm. I won’t eat or eat the wrong things knowing it's bad for me, and none of these measures really address this.” (A5)

Likewise, self-harm was reported as having additional functions to “block other uncomfortable feelings” (A3) and “regulate distress or to address dysregulation” (A3), which could result from “sensory or social overload” (A1). Some participants also described an element of self-harm “management” (A1), where they reported doing “less than [usual]” (A1) or a behaviour they “wouldn't usually engage in” (A4) if they wanted to self-harm but avoid involving or dealing with medical services. Moreover, none of the tools included “sensory seeking” (P2) or being “under-stimulated” (P4) as a reason for self-harm.

Understanding contextual and environmental factors was considered essential to “capturing the real reason why” (A5) someone self-harms, helping to identify “patterns” and “stop it [self-harm] in the future” (A5). Participants described their own experiences as “extremely situational” (A4), where “things stack on top of each other” (A4), and it depends on “what the trigger was to begin with; was it sensory, was it something someone said, is it you’re just having a bad day, and you don't feel well cause it's that time of the month?” (A5). This should also include “outside challenges that people might be experiencing”, such as “sexual abuse, sexual assault” (A1), that are not covered by the tools.

> “I *think a questionnaire that focuses on the situational motivations would be beneficial for me, because it would allow me to go, oh okay, in this situation I self-harmed because of this. In future, when I'm in this situation, maybe I could do this instead of self-harming, and I think that's a good thing to focus on.”* (A4)

Moreover, participants suggested a need for items like “Have you put any adjustments in place to support yourself?” (A2) or “What have you tried before or what do you try to stop self-harming” (A5), which could indicate “potentially why doesn't it [the adjustment] always work” (A2).

> “*If you're autistic and you've tried to talk to somebody, or you have ADHD and they've rejected you or they don't understand you, because the double empathy problem or whatever, then that's another layer of additional challenge and complication to get around.”* (A3)

1.4. Conceptualising self-harm is not straightforward

Participants found it challenging to identify certain behaviours as self-harm. The “issue of intentionality” (A3) was key to this, particularly with self-stimulatory (i.e., stimming) behaviours (e.g., skin picking, biting nails, hitting oneself) where an individual is “not doing it intentionally to cause harm” (A3) or “it doesn't necessarily feel like that [self-harm]” (A4). Instead, the purpose of the behaviour is to “ground or put something back in” (P4) and “regulate [my] feelings” (A4). This distinction was important to participants who reflected that you do not want to “take something away from somebody that actually is really helpful for them, their wellbeing and their mental health” (P4).

> *“Like picking skin or biting nails, you know, for some people that could be self-harm because you're literally destroying the nail, but for others it could be stimming.”* (A2)

Additionally, self-harm was discussed in a stratified manner. Participants distinguished acute episodes (e.g., cutting) as “you do something in the moment, it happens at that time” (A3) versus chronic (e.g., neglecting self-care, not eating properly) where “the cumulative effect of all of that is really bad for your health” (A3). This was also referred to as “impulsive active self-harm and then more long-term passive self-harm” (A4).

It was also important to acknowledge the complexity of self-harm as having both “positives and negatives” (A1). Participants reported the tools as missing how self-harm “helps you cope and it helps you survive a rough time” (A3), which may be particularly relevant for those hurting themselves if it “is not the place where we're experiencing the most harm” (A1).

> *“The positives are particularly around like, you know, it supported me to survive, it enabled me to process difficult things, it supported me to stay grounded, it supported me to avoid other things.”* (A1)

1.5. Perpetuating and addressing stigma

The use of stigmatising language was common across all three tools. In particular, the word “mutilated” [NSSI-AT] was described as “harsh”, “aggressive” (P2), “offensive” and “uncomfortable” (A1). Certain items and response options also “didn’t sit right” (A4) with participants, such as “because my friends hurt themselves” [NSSI-AT], which made them “feel quite infantilised as if, like, oh my pal's doing it. So, I'm just gonna give it a go” (A4).

Participants reported that some language could be misinterpreted with potentially harmful implications. For example, the response options [NSSI-AT] “as a way to practice suicide” and “as an attempt to commit suicide”, where “we know self-harm isn't suicidal behaviour, they're not the same thing, but that implies that they are” (P2). Likewise, self-harm is described in the QNSSI as a “commonly occurring symptom among (female) patients with borderline personality disorder”, which perpetuates “the stigma around personality disorders” (P1) and self-harm “being a symptom and not a coping mechanism” (P1).

Instead, self-harm and the language we use should be approached from a position of “kind curiosity rather than feeling that it's like bad or wrong” (A1). Tools should also provide an explicit and supportive place for specific self-harm (i.e., genital), which may otherwise have “associations of different kinds of shame and unspeakability” (A1).

> *“I think these [tools] could be much more gently reframed, in a way that feels less judgmental and more, like even neutral would be welcome. I think for me, it would impact how open I felt able to be.”* (A1)

1.6. The role of co-occurring conditions

A shared narrative was that using the same tool for everyone does not work. Co-occurring conditions “may be playing a role in the way that you answer questions or your ability to interact with what's going on” (A2). For example, one participant with ADHD described “having the attention span of a gnat” and “reading every other word” (A2).

> *“The majority of autistic people also have additional neurodivergence where they may be dyslexic, there may be kind of visual processing or something, or you know, ADHD, where somebody might just get bored half the way through that and just not really do it.”* (P4)

Moreover, for those with ID or a learning difficulty, “completing it [the tool] and understanding what it's asking would be a huge barrier” (A3), which then “changes the tools that we've got to use, the language that we use, the words that we use” (P4) to get the same information. Participants referred to other clinical tools which have short versions, such as the “Clinical Outcomes in Routine Evaluation” (P4) and “Autism Quotient” (P2), and the utility of these, even “for somebody without a learning difficulty, who was just maybe in a space of being completely overwhelmed” (P4). Demand avoidance may also complicate things further due to “the amount of demand that questions are placing on people” (P2) or that “the minute you're scoring anything, it starts to feel like it's a performative task” (P4), where “the majority of autistic people probably wouldn't do it [the tool], especially if there's a PDA [Pathological Demand Avoidance] element or profile” (P4).

1.7. Duty of care

Lastly, the content of the tools was described as “so overwhelming to sort of sit with, and then have nothing afterwards” (P1), and there was not “really anything around gentleness or self-care in relation to the questions” (A1). Consequently, participants stressed that researchers and professionals in this area have “a degree of responsibility to check that people are safe” (A1).

> *“It does concern me a little bit if someone’s doing this on their own, dredging through those [questions] and not being supported properly. That’s something I might do with a client over the course of three weeks, exploring those kind of things, and then it’s boiled down to quite a small questionnaire. I think it could lead to some really interesting answers and knowledge, but I think from my perspective, it concerns me about them being properly cared for within that.”* (P2)

It was suggested that the tools also need to be explicit around confidentiality so individuals can “either be honest” or “know that I don’t want to answer” (A1). This should also include an opportunity to check if they need help “to take a different action and to be safe in other ways” (A1), which can be followed up with appropriate support and validation.

> *“Like, you know, an encouragement to take a break, to look after yourself, to complete it with someone else if you need to, to not complete it if that's what feels best. Um, I think some like acknowledgement of how challenging this is, and that it can be like triggering or distressing for people to think about and talk about, could be really validating and supportive.”* (A1)

Discussion

This study explored the views of autistic individuals with lived experience of self-harm and professionals who support them on three existing self-harm assessment tools (ISAS, NSSI-AT, QNSSI). While some of the tools' strengths were acknowledged, these were largely overshadowed by concerns, with participants describing the process as "picking the best of a bad bunch". Subthemes explored a variety of cognitive considerations related to complexity, length, working memory demands, and introspection, along with missing elements such as broader self-harm behaviours, additional functions, contextual and environmental factors, and support. Further challenges arose around how self-harm was conceptualised, particularly regarding intentionality and stimming, as well as the need to address stigma. Participants also highlighted the role of co-occurring conditions (e.g., ADHD, ID) and the importance of upholding a duty of care. Ultimately, none of the tools were considered appropriate or acceptable for autistic adults who self-harm. This is significant given the high prevalence of self-harm in autism and the current lack of suitable assessment tools (Newell et al., 2024), indicating a clear need for the development of a new tool.

Consistent with previous research, the present findings highlight ongoing limitations with instrument accessibility and reinforce the importance of co-developing measures with the autistic community. Participants reiterated known concerns with Likert scales, complex language, vague response options, and challenges in identifying and describing emotions (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021; Nicolaidis et al., 2020). Additional feedback included processing differences for items requiring time perception (Casassus et al., 2019) or that place greater demands on working memory (Wang et al., 2017). Moreover, participants indicated the tools were missing key elements relevant to autistic experiences of NSSI (e.g., sensory processing differences; Marsden et al., 2024; Moseley et al., 2019), alongside broader non-recreational risk-taking (Hawton et al., 2012) or self-damaging behaviours (Nock, 2010), and factors that precede a self-harm episode (Pelton et al., 2025). Our findings also echo what autistic individuals who self-harm consider important to understanding and supporting them, such as reasons for self-harm, challenging assumptions and responding appropriately (Moseley et al., 2019). Moving forward, collaboration with autistic people is therefore key to improving the clarity and relevance of measurement tools, a process shown to enhance both accessibility and construct sensitivity (Cassidy, Bradley, Cogger-Ward, Graham, et al., 2021; Cassidy, Bradley, Cogger-Ward, & Rodgers, 2021). Such efforts must carefully balance the inclusion of diverse self-harm experiences with the potential need for individualisation (e.g., for co-occurring conditions), while ensuring tools remain practical and accessible to users and professionals alike.

Additionally, terms and definitions for self-harm are known to vary widely across research and clinical settings (Nock, 2010). This was also reflected in participant narratives, particularly concerning self-stimulatory behaviours (i.e., stimming) and intentionality. While stimming can serve as a helpful self-regulatory mechanism (Kapp et al., 2019), participants noted that it may sometimes result in inadvertent harm (e.g., skin picking, hitting oneself). Likewise, a qualitative study of online forum posts revealed that a disproportionate amount of self-harm among autistic individuals was related to stimming, often performed unconsciously to alleviate anxiety or sensory overload (Marsden et al., 2024). However, this behaviour does not fit traditional, non-autistic definitions of self-harm, potentially leading to misclassification as SIB in autistic adults without co-occurring ID (Goldfarb et al., 2021; Matson & Turygin, 2012). Therefore, self-harm assessment tools for autistic individuals should incorporate these behaviours to better identify and understand self-harm in this population.

Strengths and limitations

This study is the first to examine the perspectives of autistic individuals with lived experience of self-harm and the professionals who support them regarding existing self-harm assessment tools. A key strength of this research lies in the involvement of multiple stakeholders to address a priority in autism research (Cassidy, Cogger-Ward, et al., 2021; Roche et al., 2021). This approach allowed us to triangulate viewpoints, revealing shared perspectives across groups (French & Cassidy, 2024; Goodwin et al., 2024). However, it is important to note that autistic individuals often report a lack of autism-specific knowledge among professionals as a barrier to mental health support (Adams & Young, 2021). Therefore, our sample may have included a more neuro-affirming group of professionals, potentially resulting in perspectives better aligned with those of the autistic group.

On the other hand, our sample was relatively small and homogeneous, mainly comprising female-identifying and cognitively able autistic individuals. Autism in females, particularly those without co-occurring ID, is often under-recognised or misdiagnosed, leading to a lack of appropriate support (Kirkovski et al., 2013; Loomes et al., 2017; Mandy & Lai, 2017). Likewise, females in the general population are also more likely to engage in NSSI than males (Bresin & Schoenleber, 2015). While it is unclear whether these gender differences extend to autism, autistic females may face unique challenges that contribute to a qualitatively different experience of self-harm. Additionally, the study did not collect further demographic data (e.g., ethnicity, co-occurring conditions), limiting the generalisability of findings. Future research to develop new self-harm assessment tools for autistic people should strive to include a more representative demographic.

Conclusion

Our findings indicate that current self-harm assessment tools are not appropriate or acceptable for use with autistic adults who self-harm. Participants emphasised the need to address various cognitive considerations, include autism-specific items, and take a broader, more inclusive view of self-harm. They also highlighted the importance of addressing stigma, recognising the role of co-occurring conditions, and maintaining a duty of care. While issues of clarity, relevance, and lack of autism-specific items are common in tools not validated for autistic populations, evidence suggests these tools can be adapted successfully. Findings from this study underscore the need for a new self-harm assessment tool, specifically co-developed with autistic individuals.

References

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436–453. https://doi.org/10.1007/s40489-020-00226-7

Barbour, R. (2018). Sampling. In *Doing Focus Groups* (pp. 65–82). SAGE Publications Ltd. https://doi.org/10.4135/9781526441836

Beckman, K., Lysell, H., Haglund, A., & Dahlin, M. (2019). Prognoses after self-harm in youth: Exploring the gender factor. *Social Psychiatry and Psychiatric Epidemiology*, *54*(4), 437–444. https://doi.org/10.1007/s00127-018-1618-7

Borschmann, R., Becker, D., Coffey, C., Spry, E., Moreno-Betancur, M., Moran, P., & Patton, G. C. (2017). 20-year outcomes in adolescents who self-harm: A population-based cohort study. *The Lancet Child & Adolescent Health*, *1*(3), 195–202. https://doi.org/10.1016/S2352-4642(17)30007-X

Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic Adults' Experiences of Camouflaging and Its Perceived Impact on Mental Health. *Autism in Adulthood: Challenges and Management*, *3*(4), 320–329. https://doi.org/10.1089/aut.2020.0071

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352. https://doi.org/10.1080/14780887.2020.1769238

Bree, R. T., & Gallagher, G. (2016). Using Microsoft Excel to code and thematically analyse qualitative data: A simple, cost-effective approach. *All Ireland Journal of Higher Education*, *8*(2), Article 2. https://doi.org/10.62707/aishej.v8i2.281

Bresin, K., & Schoenleber, M. (2015). Gender differences in the prevalence of nonsuicidal self-injury: A meta-analysis. *Clinical Psychology Review*, *38*, 55–64. https://doi.org/10.1016/j.cpr.2015.02.009

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: The International Journal of Research and Practice*, *23*(6), 1431–1441. https://doi.org/10.1177/1362361318816053

Casassus, M., Poliakoff, E., Gowen, E., Poole, D., & Jones, L. A. (2019). Time perception and autistic spectrum condition: A systematic review. *Autism Research*, *12*(10), 1440–1462. https://doi.org/10.1002/aur.2170

Cassidy, S. A. (2020). Suicidality and Self-Harm in Autism Spectrum Conditions. In S. W. White, B. B. Maddox, & C. A. Mazefsky (Eds.), *The Oxford Handbook of Autism and Co-Occurring Psychiatric Conditions* (p. 0). Oxford University Press. https://doi.org/10.1093/oxfordhb/9780190910761.013.18

Cassidy, S. A., Bradley, L., Cogger-Ward, H., Graham, J., & Rodgers, J. (2021). *Development and Validation of the Autistic Depression Assessment Tool – Adult (ADAT-A) in Autistic Adults.* https://doi.org/10.21203/rs.3.rs-358997/v1

Cassidy, S. A., Bradley, L., Cogger-Ward, H., & Rodgers, J. (2021). Development and validation of the suicidal behaviours questionnaire—Autism spectrum conditions in a community sample of autistic, possibly autistic and non-autistic adults. *Molecular Autism*, *12*(1), 46. https://doi.org/10.1186/s13229-021-00449-3

Cassidy, S. A., Bradley, L., Cogger-Ward, H., Shaw, R., Bowen, E., Glod, M., Baron-Cohen, S., & Rodgers, J. (2020). Measurement Properties of the Suicidal Behaviour Questionnaire-Revised in Autistic Adults. *Journal of Autism and Developmental Disorders*, *50*(10), 3477–3488. https://doi.org/10.1007/s10803-020-04431-5

Cassidy, S. A., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, *9*(1), 42. https://doi.org/10.1186/s13229-018-0226-4

Cassidy, S. A., Cogger-Ward, H., Robertson, A. E., Goodwin, J., & Rodgers, J. (2021, April). *Autism Community Priorities for Suicide Prevention: An International Society for Autism Research Policy Brief* [Research Reports or Papers]. International Society for Autism Research. https://www.autism-insar.org/page/PolicyBriefs

Duerden, E. G., Oatley, H. K., Mak-Fan, K. M., McGrath, P. A., Taylor, M. J., Szatmari, P., & Roberts, S. W. (2012). Risk Factors Associated with Self-Injurious Behaviors in Children and Adolescents with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *42*(11), 2460–2470. https://doi.org/10.1007/s10803-012-1497-9

Favril, L., Yu, R., Uyar, A., Sharpe, M., & Fazel, S. (2022). Risk factors for suicide in adults: Systematic review and meta-analysis of psychological autopsy studies. *BMJ Ment Health*, *25*(4), 148–155. https://doi.org/10.1136/ebmental-2022-300549

French, B., & Cassidy, S. (2024). “Going Through Life on Hard Mode”—The Experience of Late Diagnosis of Autism and/or ADHD: A Qualitative Study. *Autism in Adulthood*. https://doi.org/10.1089/aut.2024.0085

Goldfarb, Y., Zafrani, O., Hedley, D., Yaari, M., & Gal, E. (2021). Autistic adults’ subjective experiences of hoarding and self-injurious behaviors. *Autism*, *25*(5), 1457–1468. https://doi.org/10.1177/1362361321992640

Goodwin, J., Gordon, I., O’Keeffe, S., Carling, S., Berresford, A., Bhattarai, N., Heslop, P., Nielsen, E., O’Connor, R. C., Ogundimu, E., Pelton, M., Ramsay, S. E., Rodgers, J., Townsend, E., Vale, L., Wilson, C., & Cassidy, S. (2024). Adapting Safety Plans for Autistic Adults with Involvement from the Autism Community. *Autism in Adulthood*. https://doi.org/10.1089/aut.2023.0124

Hawton, K., Bale, L., Brand, F., Townsend, E., Ness, J., Waters, K., Clements, C., Kapur, N., & Geulayov, G. (2020). Mortality in children and adolescents following presentation to hospital after non-fatal self-harm in the Multicentre Study of Self-harm: A prospective observational cohort study. *The Lancet Child & Adolescent Health*, *4*(2), 111–120. https://doi.org/10.1016/S2352-4642(19)30373-6

Hawton, K., Saunders, K. E., & O'Connor, R. C. (2012). Self-harm and suicide in adolescents. *The Lancet*, *379*(9834), 2373–2382. https://doi.org/10.1016/S0140-6736(12)60322-5

Hennink, M. M., Kaiser, B. N., & Weber, M. B. (2019). What Influences Saturation? Estimating Sample Sizes in Focus Group Research. *Qualitative Health Research*, *29*(10), 1483–1496. https://doi.org/10.1177/1049732318821692

Hepp, J., Carpenter, R. W., Störkel, L. M., Schmitz, S. E., Schmahl, C., & Niedtfeld, I. (2020). A systematic review of daily life studies on non-suicidal self-injury based on the four-function model. *Clinical Psychology Review*, *82*, 101888. https://doi.org/10.1016/j.cpr.2020.101888

Kapp, S. K. (Ed.). (2020). *Autistic Community and the Neurodiversity Movement: Stories from the Frontline*. Springer Nature. https://doi.org/10.1007/978-981-13-8437-0

Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*, *23*(7), 1782–1792. https://doi.org/10.1177/1362361319829628

Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry*, *55*, 80–89. https://doi.org/10.1016/j.eurpsy.2018.09.004

Kirkovski, M., Enticott, P. G., & Fitzgerald, P. B. (2013). A Review of the Role of Female Gender in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *43*(11), 2584–2603. https://doi.org/10.1007/s10803-013-1811-1

Klonsky, E. D. (2011). Non-suicidal self-injury in United States adults: Prevalence, sociodemographics, topography and functions. *Psychological Medicine*, *41*(9), 1981–1986. Scopus. https://doi.org/10.1017/S0033291710002497

Klonsky, E. D., & Glenn, C. R. (2009). Assessing the functions of non-suicidal self-injury: Psychometric properties of the Inventory of Statements About Self-injury (ISAS). *Journal of Psychopathology and Behavioral Assessment*, *31*(3), 215–219. https://doi.org/10.1007/s10862-008-9107-z

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & 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*(10), 819–829. https://doi.org/10.1016/S2215-0366(19)30289-5

Lind, S. E., & Bowler, D. M. (2010). Episodic memory and episodic future thinking in adults with autism. *Journal of Abnormal Psychology*, *119*(4), 896–905. https://doi.org/10.1037/a0020631

Lind, S. E., Williams, D. M., Bowler, D. M., & Peel, A. (2014). Episodic memory and episodic future thinking impairments in high-functioning autism spectrum disorder: An underlying difficulty with scene construction or self-projection? *Neuropsychology*, *28*(1), 55–67. https://doi.org/10.1037/neu0000005

Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, *56*(6), 466–474. https://doi.org/10.1016/j.jaac.2017.03.013

Maddox, B. B., Trubanova, A., & White, S. W. (2017). Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder. *Autism: The International Journal of Research and Practice*, *21*(4), 412–422. https://doi.org/10.1177/1362361316644731

Mandy, W., & Lai, M.-C. (2017). Towards sex- and gender-informed autism research. *Autism*, *21*(6), 643–645. https://doi.org/10.1177/1362361317706904

Marsden, S. J., Eastham, R., & Kaley, A. (2024). (Re)thinking about self-harm and autism: Findings from an online qualitative study on self-harm in autistic adults. *Autism*, 13623613241271931. https://doi.org/10.1177/13623613241271931

Matson, J. L., & Turygin, N. C. (2012). How do researchers define self-injurious behavior? *Research in Developmental Disabilities*, *33*(4), 1021–1026. https://doi.org/10.1016/j.ridd.2012.01.009

Minshawi, N. F., Hurwitz, S., Fodstad, J. C., Biebl, S., Morriss, D. H., & McDougle, C. J. (2014). The association between self-injurious behaviors and autism spectrum disorders. *Psychology Research and Behavior Management*, *7*, 125–136. https://doi.org/10.2147/PRBM.S44635

Mokkink, L. B., de Vet, H. C. W., Prinsen, C. A. C., Patrick, D. L., Alonso, J., Bouter, L. M., & Terwee, C. B. (2018). COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. *Quality of Life Research*, *27*(5), 1171–1179. https://doi.org/10.1007/s11136-017-1765-4

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., & Baron-Cohen, S. (2019). A ‘choice’, an ‘addiction’, a way ‘out of the lost’: Exploring self-injury in autistic people without intellectual disability. *Molecular Autism*, *10*(1), 18. https://doi.org/10.1186/s13229-019-0267-3

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*(1), 14. https://doi.org/10.1186/s13229-020-0319-8

Moseley, R. L., Gregory, N. J., Smith, P., Allison, C., Cassidy, S., & Baron-Cohen, S. (2022). Non-suicidal self-injury and its relation to suicide through acquired capability: Investigating this causal mechanism in a mainly late-diagnosed autistic sample. *Molecular Autism*, *13*(1), 45. https://doi.org/10.1186/s13229-022-00522-5

National Institute for Health and Care Research. (2022). *Payment guidance for researchers and professionals*. https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392

Newell, V., Phillips, L., Jones, C., Townsend, E., Richards, C., & Cassidy, S. (2023). A systematic review and meta-analysis of suicidality in autistic and possibly autistic people without co-occurring intellectual disability. *Molecular Autism*, *14*(1), 12. https://doi.org/10.1186/s13229-023-00544-7

Newell, V., Townsend, E., Richards, C., & Cassidy, S. (2024). Measurement properties of tools used to assess self-harm in autistic and general population adults. *Clinical Psychology Review*, *109*, 102412. https://doi.org/10.1016/j.cpr.2024.102412

NICE. (2022, September 7). *Self-harm: Assessment, management and preventing recurrence [NG225]*. National Institute for Health and Care Excellence (NICE). https://www.nice.org.uk/guidance/ng225

Nicolaidis, C., Raymaker, D. M., McDonald, K. E., Lund, E. M., Leotti, S., Kapp, S. K., Katz, M., Beers, L. M., Kripke, C., Maslak, J., Hunter, M., & 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*(1), 61–76. https://doi.org/10.1089/aut.2019.0074

Nock, M. K. (2010). Self-Injury. *Annual Review of Clinical Psychology*, *6*(1), 339–363. https://doi.org/10.1146/annurev.clinpsy.121208.131258

Nock, M. K., & Favazza, A. R. (2009). Nonsuicidal self-injury: Definition and classification. In *Understanding nonsuicidal self-injury: Origins, assessment, and treatment* (pp. 9–18). American Psychological Association. https://doi.org/10.1037/11875-001

Nyrenius, J., Waern, M., Eberhard, J., Ghaziuddin, M., Gillberg, C., & Billstedt, E. (2023). Autism in adult psychiatric out-patients: Self-reported suicidal ideation, suicide attempts and non-suicidal self-injury. *BJPsych Open*, *9*(5), e167. https://doi.org/10.1192/bjo.2023.553

Peel-Wainwright, K.-M., Hartley, S., Boland, A., Rocca, E., Langer, S., & Taylor, P. J. (2021). The interpersonal processes of non-suicidal self-injury: A systematic review and meta-synthesis. *Psychology and Psychotherapy*, *94*(4), 1059–1082. https://doi.org/10.1111/papt.12352

Pellicano, E., & den Houting, J. (2022). Annual Research Review: Shifting from ‘normal science’ to neurodiversity in autism science. *Journal of Child Psychology and Psychiatry*, *63*(4), 381–396. https://doi.org/10.1111/jcpp.13534

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: Challenges and Management*, *2*(3), 193–203. https://doi.org/10.1089/aut.2019.0055

Pelton, M., Newell, V., French, B., Townsend, E., & Cassidy, S. (2025). *Exploring patterns of self-harm in autistic adults using the Card Sort Task (CaTs)*.

Pompili, M., Goracci, A., Giordano, G., Erbuto, D., Girardi, P., Klonsky, E. D., & Baldessarini, R. J. (2015). Relationship of non-suicidal self-injury and suicide attempt: A psychopathological perspective. *Journal of Psychopathology*, *21*(4), 348–353. Scopus.

Prinsen, C. A. C., Mokkink, L. B., Bouter, L. M., Alonso, J., Patrick, D. L., de Vet, H. C. W., & Terwee, C. B. (2018). COSMIN guideline for systematic reviews of patient-reported outcome measures. *Quality of Life Research*, *27*(5), 1147–1157. https://doi.org/10.1007/s11136-018-1798-3

Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, *25*(2), 336–348. https://doi.org/10.1177/1362361320967790

Runeson, B., Haglund, A., Lichtenstein, P., & Tidemalm, D. (2016). Suicide Risk After Nonfatal Self-Harm: A National Cohort Study, 2000-2008. *The Journal of Clinical Psychiatry*, *77*(2), 20475. https://doi.org/10.4088/JCP.14m09453

Schwartzman, J., Mcmorris, C., Williams, Z., Brown, C., Trollor, J., Uljarevic, M., Stokes, M., & Hedley, D. (2024). *Elevated Suicidal Thoughts and Behaviors and Self-injury in Autism Across the Lifespan: A Multinational Study*. https://doi.org/10.13140/RG.2.2.11256.66568

Stewart, G. R., Corbett, A., Ballard, C., Creese, B., Aarsland, D., Hampshire, A., Charlton, R. A., & Happé, F. (2023). Self-harm and Suicidality Experiences of Middle-Age and Older Adults With vs. Without High Autistic Traits. *Journal of Autism and Developmental Disorders*, *53*(8), 3034–3046. https://doi.org/10.1007/s10803-022-05595-y

Taylor, P. J., Jomar, K., Dhingra, K., Forrester, R., Shahmalak, U., & Dickson, J. M. (2018). A meta-analysis of the prevalence of different functions of non-suicidal self-injury. *Journal of Affective Disorders*, *227*, 759–769. https://doi.org/10.1016/j.jad.2017.11.073

Terwee, C. B., Prinsen, C. a. C., Chiarotto, A., Westerman, M. J., Patrick, D. L., Alonso, J., Bouter, L. M., de Vet, H. C. W., & Mokkink, L. B. (2018). COSMIN methodology for evaluating the content validity of patient-reported outcome measures: A Delphi study. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation*, *27*(5), 1159–1170. https://doi.org/10.1007/s11136-018-1829-0

Turner, B. J., Chapman, A. L., & Layden, B. K. (2012). Intrapersonal and Interpersonal Functions of Non suicidal Self-Injury: Associations with Emotional and Social Functioning. *Suicide and Life-Threatening Behavior*, *42*(1), 36–55. https://doi.org/10.1111/j.1943-278X.2011.00069.x

Vicente, A., & Falkum, I. L. (2023). Accounting for the preference for literal meanings in autism spectrum conditions. *Mind & Language*, *38*(1), 119–140. https://doi.org/10.1111/mila.12371

Wang, Y., Zhang, Y., Liu, L., Cui, J., Wang, J., Shum, D. H. K., van Amelsvoort, T., & Chan, R. C. K. (2017). A Meta-Analysis of Working Memory Impairments in Autism Spectrum Disorders. *Neuropsychology Review*, *27*(1), 46–61. https://doi.org/10.1007/s11065-016-9336-y

Whitlock, J., Exner-Cortens, D., & Purington, A. (2014). Assessment of nonsuicidal self-injury: Development and initial validation of the Non-Suicidal Self-Injury-Assessment

Tool (NSSI-AT). *Psychological Assessment*, *26*(3), 935–946. https://doi.org/10.1037/a0036611