Adapting safety plans for autistic adults with involvement from the autism community

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Authorship contribution statement

JR is Chief Investigator, and SC is Principal Investigator at Nottingham University. JR leads governance and reporting. JR and SC co-designed the AASP and co-supervise the research team. PH, RO, EO, SR, ET, LV, and CW are co-investigators and research management group members. JG, IG, EN and MP are researchers on the team. JG and EN were responsible for the day-to-day assessment and recruitment of participants. NB is responsible for the health economics component. AB and SC are student researchers and contributed to transcription. Data analysis was conducted by JG, IG and SOK. All authors contributed to the development of the manuscript. The authors read and approved the final manuscript.

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Abstract

Background: Autistic adults are at greater risk of self-harm and suicide than the general population. One promising intervention in the general population is safety planning. We aimed to seek advice from autistic adults and others in the autism community on how to adapt safety plans for autistic adults.

Methods: We conducted focus groups with autistic adults (n=15), family members (n=5) and service providers (n=10), about their views of the Autism Adapted Safety Plan (AASP). We also conducted interviews about the acceptability of the AASP with autistic adults who had developed an AASP (n=8) and service providers who had supported them (n=8). We analysed the focus group and interview transcripts using thematic analysis.

Results: Theme one highlights conditions needed to make the process of creating the AASP acceptable for autistic adults. This included creating the AASP with someone they could trust and at the right place and time, when they were not in distress or in crisis. Theme two describes how safety planning needed to be a creative, flexible, and iterative process. Autistic adults may need help in expressing their emotions and identifying coping strategies, which can be supported through visual resources and suggestions from the service provider. To ensure the AASP is accessible in times of crisis, it needs to meet the autistic adults' preferences in terms of formatting and how it is stored (i.e., hard copy or electronic).

Conclusion: The AASP is a potentially valuable intervention for autistic adults, provided that the process of creating it is flexible and sensitive to individual needs. Further testing of the AASP to assess its clinical effectiveness in reducing suicidal behaviour could provide a life-saving intervention for autistic adults.

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Keywords: Autism, qualitative research, safety plan, self-harm, suicide, thematic analysis.

Community brief

Why is this an important issue?

Autistic adults are at risk of self-harm and suicide, yet there are no approaches specifically for autistic adults to reduce their risk of self-harm and suicide.

What was the purpose of this study?

We wanted to explore how developing a document called a safety plan might be useful for autistic people if it was designed with advice from autistic adults and others in the autism community. A person creates their own safety plan document. This safety plan includes a person's own list of steps that can be used when they are in distress or crisis. The steps are: (1) Warning Signs that a crisis may be about to occur; (2) Coping Strategies that might help; (3) Social Contacts and Locations that might help; (4) Family Members or Friends that might help; (5) Professional support that might help; and (6) How to Keep the Environment Safe.

What did the researchers do?

We conducted interviews and group discussions with autistic adults, family members and service providers about what they thought of an Autism Adapted Safety Plan and how it could be improved to make it more helpful for autistic people.

What were the results of the study?

We learnt that it was important that autistic adults had a supporter they felt able to trust to help them to develop their safety plan. The safety plan needed to be done at the right time, when they were not in distress or in crisis. The safety plan also needed to be flexible, based on the autistic adult's needs and preferences. Autistic adults told us they sometimes needed help identifying things that they could do that they could include in their plan to help them to feel less distressed. They told us that using pictures and symbols might help them express their needs, and that people supporting them could make suggestions to help them identify things that might help. It was important for the safety plan to fit the person's preferences for layout,

colour, text and images, and options for either paper or electronic format, to make the safety plan accessible in times of crisis.

What do these findings add to what was already known?

Our findings suggest that an Autism Adapted Safety Plan may help autistic adults who are experiencing self-harm and suicidal thoughts.

What are potential weaknesses in the study?

We don't know whether the views of participants in this study are the same as the views of other autistic people. This means further work will be needed with more autistic people to see whether these views are shared.

How will these findings help autistic adults now or in the future?

These findings will allow the Autism Adapted Safety Plan to be further refined based on the feedback provided by participants in this study. Then the plan could be used in future studies to find out if it helps autistic adults who are experiencing distress.

Background

Suicide is a significant concern for public health globally[1] and autistic adults have been identified as a high-risk group.[2,3,4] Self-harm is defined as intentional self-poisoning or self-injury, irrespective of suicidal intent.[4] Self-harm is a key risk marker for suicidal thoughts and behaviours[5], including in autistic adults.[6] Autistic adults have a three-fold increase in odds of self-harm and suicidality.[7] Identifying effective self-harm and suicide prevention interventions is therefore an urgent public health priority. [8, 9,10].

Interventions used in the general population often fail to meet the needs of autistic adults.[11] A UK survey reported that clinicians often lack knowledge and awareness of autism[12] and 30% have been found to be unwilling to treat autistic individuals as they felt they lacked sufficient knowledge to do so.[13] Despite the need for suicide prevention interventions for autistic adults, no interventions have been developed specifically for this population.[11,14] Research shows that interventions that are adapted for autistic individuals are more effective than standard approaches.[15] It is crucial to address this gap to identify effective approaches for autistic adults who experience self-harm and suicidality.

In the general population, a promising suicide prevention intervention is the Safety Planning Intervention, commonly referred to as safety plans. Safety plans are a brief intervention that is co-produced to provide a personalised plan for managing distress.[16] Safety plans consist of a list of hierarchical steps that can be used in times of crisis, and are tailored to the individual, to mitigate risk. The steps are: (i) Warning Signs; (ii) Internal Coping Strategies; (iii) Social Contacts and Locations; (iv) Family Members or Friends; (v) Professionals or Agencies; and (vi) How to Keep the Environment Safe.[16] Safety plans can be implemented in any setting and the person doing the safety plan can be supported by another person. A meta-analysis found safety planning was associated with a 43% reduction in suicidal behaviour in adults presenting to hospital with suicidal distress or following a suicide attempt.[17] A recent systematic review of 26 studies found safety plans were associated with

reduction in suicidal ideation and behaviour and decreases in depression, hopelessness and hospitalisations, in both general population and veteran samples.[18]

To date, safety plans have not been evaluated specifically with autistic adults although the concrete steps involved in safety planning may appeal to the learning style of many autistic adults.[19] Even so, safety planning is likely to require adaptation. For example, autistic adults frequently report difficulty in recognising when they are approaching a crisis and seeking help during a crisis.[12,20] This is a crucial step in safety planning, so steps for recognising a crisis may require concrete explanations of signs or behaviours.[15] Common coping strategies in safety plans may include calling a friend, which may be a source of anxiety for autistic adults, so coping strategies must be tailored to their individual needs.[15] Nevertheless, safety plans do have the potential to reduce self-harm and suicide in autistic adults. The aim of this study was to gather autism community guidance on how to adapt safety plans for autistic adults.

Methods

We collected data as part of the Autism Adapted Safety Plans study.[21] Further details of the overall study are available at https://doi.org/10.1186/s40814-023-01264-8.[21] Data collection took two forms: focus groups and semi structured interviews.

Participants

Adults aged 18 years and older were eligible for participation if they were:

1. Autistic adults with experience of self-harm, suicidal thoughts or behaviours;
2. Family members of autistic adults who have experienced self-harm, suicidal thoughts or behaviours; or

3. Service providers who support autistic adults who have experiences of self-harm, suicidal thoughts or behaviours in non-National Health Service (NHS) settings in the UK (e.g., health and social care professionals and charity support workers).
4. Sufficient spoken English to take part in the assessments;

Autistic adults were not eligible if they were currently experiencing psychotic symptoms.

Recruitment

We recruited autistic adults via the Autistica Network, a volunteers database where autistic adults have registered their interest in being contacted with opportunities to assist with research studies. Autistica is a UK charity that focuses on research which is meaningful to autistic people and their families (https://www.autistica.org.uk/). We also recruited autistic adults, family members, and service providers through other third sector organisations that partnered with the research team, including local councils, suicide prevention charities, and services supporting autistic adults. All participants lived in England and Wales. Some autistic participants withdrew from the study prior to participation due to mental health difficulties (n=2 from focus groups and 3 from the interviews) or COVID related issues (n=2 from focus groups and 2 from interviews).

Materials and measures

Autism Adapted Safety Plan

In patient and public involvement work with adults from the autism community, safety planning was suggested as a potentially valuable intervention for autistic adults to prevent self-harm and suicide. The research team subsequently co-produced an initial adapted safety plan template with adults from the autism community. In the current study, the research team refined this initial template for use in the focus groups, including shortening its length, simplifying the design, reducing distractions (e.g., funder logo removed from all but first

page) and adding examples to help answer questions, such as possible coping strategies. Following input from the focus groups, the research team further developed the safety plan into the Autism Adapted Safety Plan (AASP). A resource kit was included with tools to help autistic adults determine the content of their AASP and a list of support services. More explanation about the AASP and how to complete it, and larger text boxes with a visual scale at the side to indicate varying degrees of emotional intensity were included. Section headings were made into subjective questions and some language changed e.g., "reasons for living" to "what is important to me?" and with each step there was more explanation, examples of what to put in and practical reminders e.g., to note when people are/are not available. Language explaining each step was also simplified. Additional steps were added about who the person might share their AASP with and where to store it.

A topic guide was developed for all focus groups to explore opinions of the drafted AASP and possible facilitators and barriers to using AASPs and acceptability and feasibility of the AASP. Topics asked about included participants' views of the study information and measures, the draft AASP and what could be adapted, what the study should find out about, their experiences of taking part and services autistic people could access for support. In addition, service providers were asked about their views of the AASP training workshops, supporting an autistic person to do an AASP and any changes they would make to the AASP.

Procedure

Focus groups

The Autistica Network and partner organisations shared study information with contacts whom they thought might be willing to take part. Potential participants contacted the research team who explained the research and answered any questions. If interested, participants completed and returned an electronic consent form. With the exception of

participants who could not attend appointments due to ill health or situational difficulties, participants completed a "wellbeing plan" to provide information about communication needs and how the research team could best support them during discussions on this sensitive topic.

Six focus groups (two with autistic adults, two with family members and two with service providers) were convened between October 2020 and January 2021. Three autistic adults and one service provider completed individual interviews with a researcher due to preference. The focus groups and interviews were facilitated by two researchers, who presented the study design and draft AASP to each focus group. The researchers followed a topic guide, which explored how the draft AASP could be refined and adapted to better meet the needs of autistic adults, proposed adaptations to the draft AASP, barriers to the use of the AASP, and acceptability of the proposed study design and materials.

Interviews

Service providers attended training workshops on how to support autistic people to develop an AASP, delivered by the research team. Service providers subsequently identified autistic adults in their organisations who met the inclusion criteria and gave them information about the study. Potential participants returned an expression of interest form, either via their service provider or independently. The research team then contacted the autistic adult to explain the research and answer any questions. A meeting was arranged with a researcher to obtain informed consent and undertake baseline assessments. The researcher met with the autistic adult's service provider to obtain their informed consent and complete a demographic questionnaire. After consent and baseline assessment were complete, the service provider and autistic adult arranged a mutually convenient time to develop the AASP. One month after completing the AASP, the researcher contacted the autistic adult and service provider separately to complete the interviews included in this study. The interviews were conducted

by a researcher who followed a topic guide, which explored the participants' views of the AASP.

Data collection

Focus groups and interviews were held via Microsoft Teams, Zoom, or telephone to enable greater geographical reach and comply with COVID-19 restrictions. They were recorded and transcribed verbatim, except for one interview which was excluded from this study as the conversation was unrelated to the research questions. One autistic adult did not consent to be recorded, so their responses were noted by the interviewer, and these were included in the analysis.

Analysis

Reflexivity and Trustworthiness

A reflexive approach to thematic analysis was undertaken as outlined by Braun and Clarke, which recognises that while the analysis process is "grounded" in the data, it can also be interpreted through the "lens" of existing research and theory.[22] As such, focus group and interview data sets were initially analysed separately with codes and themes deriving directly from the data, then compared to see how far they fitted together. Themes generated from the development of codes were discussed with members of the research team (JG, IG, SOK), who had worked on the AASP project for varying lengths of time and had different levels of experience in the field of autism and suicide prevention research. This meant each researcher brought a different perspective to interpretation of the data. Discussion between the researchers enabled consensus to be reached, and interpretations were modified and expanded where necessary.

We used descriptive statistics to describe the sample. Reflexive thematic analysis was used to explore the qualitative data.[23] Audio files were transcribed and coded without the use of coding software. JG, IG and SOK read all the transcripts to familiarise with the data. Transcripts were coded by JG for focus groups and IG for interviews. To confirm validity, SOK acted as a second coder for 25% of the transcripts. The group met to review their coding and reached consensus as to how to apply the codes to the data. JG, IG and SOK then individually grouped the codes into themes and met to triangulate their findings and reach consensus over the final themes. The themes were presented to the wider team for discussion and refinement. Quotes were selected to illustrate each of the themes.

Community Involvement

Autistic adults and their families were involved and informed all stages of the research. The research team consists of autistic and non-autistic researchers, scholars, and advocates. A steering committee, composed of autistic adults with lived experience, advised on ethical issues, participant-facing documentation, interpretation of findings and dissemination. Members of the autism community were involved in the research in all stages as participants and provided feedback on the research materials and design.

Ethical Considerations

The study received ethical approval from NHS Health Research Authority and Wales Research Ethics Committee (Wales REC 5; REC Reference: 20/WA/0101; IRAS Project ID: 280742). Participants are referred to by their role to protect their anonymity.

Results

15 autistic adults, 5 family members (all mothers), and 10 service providers took part in the focus groups. 8 autistic adults and 8 service providers took part in semi structured

interviews. Their demographic details are provided in Table 1. Participants shared similar perspectives across both data collection methods, so the results reflect our findings from all participants across the whole data corpus of focus group and interview data. We acknowledge any instances where participants perspectives diverge in the results.

Table 1. Demographic characteristics for participants

	Focus Groups			**Interviews**	
	Autistic adults n = 15	**Family members** n = 5	**Service providers** n = 10	**Autistic adults** n = 8	**Service providers** n = 8
Gender					
Female	9	5	5	5	5
Male	2	0	2	2	3
Other	1	0	0	1	0
Missing	3	0	3	0	0
Age					
18-24 years	1	0	0	4	0
25-34 years	3	0	0	4	0
35-44 years	1	2	3	0	2
45-54 years	5	1	3	0	5
55-64 years	1	1	1	0	0
65+ years	1	1	0	0	0
Missing	3	0	3	0	1
Ethnicity					
White British	9	4	5	6	7
White (other)	2	0	2	0	0
Non-White[a]	0	0	0	2	1
Missing	4	1	3	0	0

Employment type	N/A	N/A		N/A	
Higher education			2		2
Third sector charity			2		3
Company			2		1
Voluntary sector			1		2
Missing			3		0
Years of experience	N/A	N/A		N/A	
0-10			1		0
11-20			2		4
21+			1		2
Missing			5		2

Note. 'Missing' refers to participants who did not provide answers for particular questions. 'N/A' means the question was not asked to this group of participants.
[a] Participants provided their ethnicity but we have noted them as "Non-White" to avoid identifying them.

Table 2: Summary of themes and sub themes

Themes	Subthemes
Creating the right conditions for safety planning	The right supporter The right place and time Advance Preparation
Creative process to be flexible and evolving	A flexible process Identifying new and creative solutions An iterative process

1. Creating the right conditions for developing an AASP

Autistic adults and service providers identified contextual factors that influenced the acceptability of the process of creating an AASP. These conditions needed to be considered for each person before and during the process of creating their AASP.

> *So there is a real sense about a safety plan, it is only as good as the process that it is embedded in and making those connections for those people and reaching out (Service provider 06, focus group)*

The right supporter

The service provider (i.e., supporter) needed to have the right skills and qualities, including being able to "realise my real problem" (*Autistic adult 21, focus group*) and to be non-judgemental and trustworthy. They would "sort of help them and go step by step" (*Family member, 10, focus group*) to support the autistic adult in developing the AASP. This was preferably someone outside of a mental health team who was able to support autistic adults to feel comfortable to open up. A trusting relationship was crucial as autistic adults commonly described experiences of being let down by healthcare services. Traumatic events included sensory or autistic needs not being met when accessing services, not feeling understood by professionals or not being believed in relation to self-harm and suicidality. This led many autistic adults to feel let down, rejected, or betrayed and mistrustful in seeking help.

This illustrates an essential need for a trusting relationship between an autistic adult and the supporter helping them to develop their AASP.

> *Invariably our guys are being let down so many times by professionals that have said they're going to bring them back and they never do, make appointments, change them, break them, so they don't have a lot of faith in the system. (Family member 09, focus group)*

Autistic adults told us they needed to trust the supporter enough to open up, show themselves fully and to make a genuine connection. This groundwork was essential for creating an AASP that was meaningful to autistic adults. Successful collaboration required the supporter to listen, understand and pay a real interest in the person.

> *Someone that takes an interest in you, a real interest and doesn't just drop you in it afterwards. That goes a long way. (Autistic adult 10, focus group)*

The supporter not showing distress was important to autistic adults who may themselves become distressed by seeing this reaction or think they are not being a "good client" (*Autistic adult 21, focus group*). The supporter being able to manage difficult and potentially distressing conversations was a quality valued by autistic adults. It was also important for the supporter not to project assumptions onto the person (e.g., assume the need for friendship) and accept them as an individual, so that coping strategies are informed by the person's specific preferences and experiences. This highlights the need for autistic adults to be validated in their autistic experiences, and for supporters to be open-minded about what each autistic adult may or may not find helpful.

> *I can understand why people do want to be with other people and do want to belong. But for me, that would be an absolute nightmare. So, for me it would be just being okay being myself and not being told, I should get out more. (Autistic adult 01, focus group)*

Thus, it was crucial for the supporter to understand how the needs of an autistic adult can differ from those of the general population. This was perceived as more important than the relationship between the supporter and the autistic adult, although if the supporter was someone the autistic adult had not met before, they needed more time to develop the AASP.

The ability of the supporter to help identify solutions and practical steps that the person may not have previously considered taking was considered to be important by autistic adults and supporters. The supporters should be able to offer extra insight and make creative suggestions; for example, to give ideas to make the environment safer. Supporters thought that it was important to get to know the person they were supporting well enough to ensure they were equipped to offer realistic and useful suggestions, rather than presenting the AASP as a blank canvas.

> *Crisis plans or that kind of thing with mental health before it [the AASP] felt like they were just making me think of things without like giving any suggestions, but I didn't really know what they were on about, so I think this was a lot easier (Autistic adult 17, Interview)*

This was in contrast to many past experiences, where autistic adults felt they had been set up to fail by being given advice that felt unachievable.

> *...the solutions that we get or get given are usually like others with were saying, unobtainable. So they're sort of setting you up to fail. (Autistic adult 17, Interview)*

Suggestions from supporters about what to put in their AASP was particularly important for autistic adults who had less experience of doing safety plans or less awareness of their own needs. If this process worked well, autistic adults valued the process of creating the AASP because it increased self-knowledge and provided potential coping strategies.

The right place and time

For most interview participants, appointments were online or by telephone due to COVID restrictions. This was acceptable for some autistic adults and supporters, but some would have preferred face-to-face appointments. It was suggested it was important to find the right time to develop the AASP, ensuring there were minimal environmental distractions and enough time to complete it.

> *So it's about giving it time and the right environment and almost being led, well definitely being led by the individual, not by your own agenda of getting it filled in by 2:00 o'clock to get it off your inbox. (Family member 18, focus group)*

Autistic adults and supporters described fluctuating capacity during appointments and based on what was happening in their lives or environments at the time of appointments. Participants suggested the AASP should not be developed when the person was in distress or in crisis, when they would not have capacity to work through it. For example, autistic adults may often lose the ability to express themselves in times of crisis and "*when you're in that state and someone asks you something you can't tell them" (Autistic adult 02010, focus group).*

Advance preparation

Some anxiety before AASP appointments was reported because it was a new experience. Knowing what to expect beforehand helped. Autistic adults, supporters and family members all reported that it was easier to support people to create their AASP if they had previous knowledge of what safety plans were and/or experience of doing them.

> *...she has a number of behaviour support plans for self-injury and absconding and things like that, so she kind of already knows what she's got to do (Service Provider 01014, interviews)*

It was suggested that creating the AASP might be easier for some autistic adults if they were sent the AASP template in advance, which gave them the option of considering what to put in it prior to AASP appointments.

Some autistic adults initially found it difficult to complete the AASP. This was for different reasons, such as they found the topics distressing or found it difficult to identify and navigate emotions and complex feelings around suicide. Some struggled to identify coping strategies and had less knowledge of strategies that met their autistic and mental health needs.

> *A lot of people that come to our groups seem to really struggle with identifying emotions or feelings or being able to do all that and have a lot of…of shame that goes along with the idea of having those emotions or feelings. (Service provider 01003, focus groups)*

Supporters suggested that providing assistance to help autistic adults identify and express feelings and needs may help them to co-produce a meaningful AASP.

It was important that everyone involved was fully informed beforehand about what the AASP was and that expectations were managed so they were realistic in relation to how it could help the autistic adult. For supporters, this was partly to prevent the autistic adult from feeling like a failure if they did not manage to use their AASP in times of crisis.

> *What if you have all the great intentions of doing this, and so you're in a place of, you know, the right place to fill it in, and you've got all these strategies, but that doesn't work and you find yourself in a serious situation. How do you manage with that sense of failure if, if that's how you perceive it as an individual or as the carer? (Family member 01008, focus group)*

2. Creative, flexible and iterative process to develop a personalised AASP

Creating an AASP should be a flexible and ongoing process, tailored to the individual needs of each autistic adult. There were thought to be several important components to achieve this.

A flexible process

Participants expressed the need for the development of the AASP to be a flexible process, leading to an AASP personalised to the individual's needs, preferences and experiences.

Some autistic adults commented that the process of creating the AASP could be overwhelming, as it could be difficult if they could not think of answers to the questions in the AASP. Participants suggested that the AASP template could be completed non-sequentially, with the option to move on and revisit sticking points later. To support autistic adults to engage with the AASP, supporters acknowledge that they needed to adapt their approach to the individual's needs. For example, some autistic adults may benefit from suggestions of what to put in their AASP, some may prefer yes/no questions and others may prefer more open questions.

> *If the questions are specific enough then I'll probably just give up with it and. And just give up with it and it could like become overwhelming, like for me now I have to really sit and think about all these things, but if I was feeling bad, I probably wouldn't. I wouldn't have like the patience you get what I mean. (Autistic adult 2016, focus group)*

For the AASP to become something that the autistic adult took ownership of, it should meet the person's preferences in terms of colours, layouts, and the use of text and pictures. While some people preferred text, others preferred the use of images to reduce the text in their the AASP, which they felt would be more accessible for them to use in times of crisis. Furthermore, to maximise the accessibility of the AASP in times of crisis, participants thought there should be options for it to be in hard copy or online. Participants also suggested that the AASP could include reminders to prompt the person to use their AASP when needed, such as by placing it somewhere visible in their home.

Identifying new and creative solutions

To create their AASP, an autistic adult may need support to find coping strategies that they may not have identified or thought about previously. Both autistic adults and supporters thought that developing personalised visual resources and communication strategies could increase the engagement of autistic adults in their AASP appointments. During appointments, use of resources such as a feelings wheel to describe emotions and providing examples of coping strategies were considered useful, in helping autistic adults to work through the AASP.

> *I never really know how to answer, so I think something like a, like a feeling wheel, something like that could be great 'cause otherwise I always get stuck on these kind of forms and then they end up being kind of unhelpful in that sense. (Autistic adult 01012, focus group)*

However, these resources needed to be used sensitively to avoid patronising the person, such as using them when an autistic adult was struggling to think of ideas for coping strategies themselves. Use of clear language was needed to support in identifying creative coping strategies.

> *...for me yeah it was fine. A bit kind of weirdly worded some of the questions, but… and some sort of repetitive, but slightly different worded questions (laughs). But other than that yes, fine. I can see how the bit difficult for certain people to answer, but I think the way they were worded, is it okay, and you have to kind of be straight to the point (Autistic adult 01015, interview)*

For some autistic adults the AASP section on "reasons for living" was judged to indicate a fundamental misunderstanding of some autistic adults' experiences when they are suicidal: to be told they have reasons for living could be distressing because sometimes the person knows this and can feel "double disappointment" (Autistic adult 2010, focus groups). They described how assumptions were sometimes made that they were not seeing the positives in their lives or being objective, and one person felt that a discussion on reasons for

living could lead to a decision to die. It was thought this section of the AASP should be reframed to consider positive or meaningful aspects of their lives instead.

> *It's not that we're just going through a bad patch and if we look objectively at our lives it would be surrounded by loving family and friends and, you know, a good life… It's, there's so much needs to be done to give people a real reason for living... if I'd have been confronted with this years ago I would have just thought you do not understand how bad my life is. (Autistic adult 2021, focus group)*

An iterative process

Due to fluctuating health, capacity, and ability of autistic adults to express their emotions and life situations, all participants emphasised that creating the AASP should be an iterative process, updated over time. The AASP should also identify what is "normal" for the autistic adult, to help them identify what sort of experiences may signify change if they are entering a crisis. This process of updating the AASP was needed to articulate changes and fluctuations in strategies and support needed. It was seen as not just for times of crisis, but for different states of wellbeing.

> *And they, they are almost, they are not just a, a kind of passive document that is there for them to draw on, we actually use them very much to think about what should we be doing to support this person? What needs to be in place? And to know when there might be potential times that might put that person in a higher risk category than they are. So it, it's very much as a living document and something that is really informing everything that we do really. (Service provider 2006, focus group)*

Discussion

The aim of this study was to seek advice from the autism community on how to adapt safety plans with autistic adults. Findings indicated that a safety plan, adapted specifically for

autistic adults, is a relevant intervention for autistic adults. Our findings show that to create an AASP that is suitable for autistic adults, several conditions are required during the development process. Autistic adults should create their AASP with a supporter they trust, at the right place and time, with advance preparation to ensure they know what to expect from AASP appointments. Developing an AASP should be a creative, flexible process, iterated over time. Some people may need more support to identify their emotions, warning signs of an impending crisis and potential coping strategies; this can be helped by the use of resources (e.g., feelings wheel) and by the supporter offering suggestions. The AASP template should be adapted according to the person's preferences, to ensure it is accessible in times of crisis. This includes options for formatting (e.g., colours, fonts and use of text and images) and how it is accessed (e.g., hard copy or online).

Our findings indicate that safety plans which have been used as a suicide prevention intervention in the general population [17,18,24] may be helpful to autistic people with suitable adaptations. Given the dearth of suicide prevention interventions specifically for autistic adults [11], despite evidence that autistic adults are significantly more likely to die by suicide than the general population, [2,3] this is an important finding. Our results indicate specific ways in which safety planning can be adapted for autistic adults. Of course, the settings in which safety planning was conducted might affect autistic adults' needs and providers' ability to meet these needs. For example, it may be difficult to establish a trusting therapeutic relationship if the safety planning was conducted during a psychiatric hospitalisation. We would hope to explore these issues in future research.

For the process of creating an AASP to be acceptable, the autistic adult's individual needs must be truly understood and accommodated. The data describe complex influences on this process, for both autistic adults and supporters. Many autistic adults described negative experiences of help seeking in the past, echoing findings from previous studies.[25] This context highlights the importance of the autistic person being given the time to build a trusting

relationship with the supporter, prior to developing the AASP. Autistic adults may experience anxiety in developing therapeutic relationships [26] and may take longer to establish such relationships.[27] Therapeutic relationships are an important factor in psychological interventions both in autistic adults and the general population[28], including in safety planning, so that the autistic adult feels comfortable and able to communicate openly with their supporter.

Building therapeutic relationships may be particularly challenging when developing the AASP remotely, which was the case in this study due to COVID restrictions. Remote appointments were acceptable for some autistic adults, overlapping with findings in the literature that describes potential benefits of remote appointments for autistic people. For example, remote appointments mean the autistic person can attend in a familiar environment, while avoiding potential overstimulation that may be experienced in travelling to appointments or in waiting rooms.[29] However, some autistic adults expressed a preference for face-to-face appointments. Ideally, autistic adults should be given options for how they meet their supporter for AASP appointments, and this may help mitigate against the anxiety felt prior to appointments.

While safety planning is typically regarded as a brief intervention, completed over a single session[16], our findings suggest that some autistic adults may need more time to develop their AASP. Flexibility in the number and duration of appointments was experienced positively by autistic adults in our study, which fits with recommendations for adjustments in healthcare appointments for autistic people.[29] Similarly, one study found autistic adults required interventions to be slower in pace due to the way in which they process information. [26] In addition to taking the time to build a relationship with the supporter, autistic adults can need preparation work prior to developing their AASP. This could include taking time to understand what safety planning is, increasing self-knowledge of their feelings and autistic needs, and being able to communicate these to their supporter. Supporters can assist in this

process by ensuring autistic adults know what to expect prior to AASP appointments, through sending them the AASP template. It was also important for autistic adults not to be in distress or in crisis during AASP appointments, so a check-in at the beginning of appointments to ensure they feel up to the appointment would be useful.

The literature suggests the need for psychological interventions for autistic people to use plain language, to use visual materials and to include help with identifying and labelling emotions.[15,27] These suggestions fit with our findings, as visual aids and resources such as the feelings wheel were perceived as helpful. Autistic adults expressed variation in their ability to work through the AASP, which meant their supporter needed to adapt their approach to each person. Some autistic adults were more able to express themselves and had ideas about their coping strategies, whereas others had fewer ideas of what to put in their AASP and being faced with a blank canvas could be overwhelming. To mitigate this, supporters need to be sensitive and able to assess if an autistic adult is struggling to express themselves or identify coping strategies for their AASP. In such cases the supporter may need to take on a more directive role in offering suggestions. AASP's should be highly personalised and actively recognise a person's autistic needs, adding to the literature on adaptations to interventions for autistic people. [15,30]

A range of options for the way it is formatted should be made available to the person to increase a sense of ownership, in terms of fonts, colours, images and the level of detail, with some people preferring less text. This is crucial to ensure that the AASP feels accessible to the person in times of crisis. Further measures to maximise the chances of it being used in times of crisis included having reminders to use the AASP, such has having it in a place where it is visible, or options for how it is accessed (i.e., in paper format or electronically). The suggestion of an electronic version of the AASP fits with the existing literature. One study found that people found it helpful to have a support plan on their mobile phone. This increased ease of access to the plan and did not rely so heavily on them being able to

remember to go and retrieve a hard copy of the plan. This is especially important during difficult times. [30]

It cannot be assumed that the existence of an AASP means an autistic person will always use it in times of crisis and that it will always help them. However, these findings raise important implications for maximising the likelihood of autistic people using an AASP and its content being best suited to individuals. One study of inpatients recruited from general hospitals found that for those who received a safety plan following a suicidal presentation to hospital, 59% made use of their safety plan in the months post-discharge.[24] Future research is required to explore the extent to which AASP's are used in the lives of autistic adults in the months following the creation of their AASP.

Strengths and Limitations

This is the first study to explore the perspectives of the autism community on how safety planning can be adapted for autistic adults and how best to support the process of developing them. This enabled further refinement of the AASP. Strengths of this study were the inclusion of multiple stakeholders, including autistic adults, carers and service providers. Limitations were that the sample was self-selected and may not be representative of the autistic population more generally. The family members included mothers only. Participants were included if they had a clinical diagnosis of autism, so findings may not be representative of those without a diagnosis who may have less access to formal support. Furthermore 9 Autistic participants withdrew from the study prior to participation due to mental health difficulties (n=5) or COVID related issues (n=4). The ethnic diversity of the sample was low (n=3 non white) perhaps due to requiring a clinical diagnosis of autism in the study inclusion criteria and a historical racism in diagnosis.[31,32] Issues highlighted by these participants could be explored further to increase accessibility of AASPs.

Conclusion

This study highlights the relevance of a suicide safety plan template, the AASP, that is adapted appropriately for autistic adults. It highlights the importance of a flexible, iterative development process which recognises the autistic person's needs and preferences to obtain the best possible content for their safety plan. Autistic adults, family members and supporters all indicated the potential value of safety planning as a suicide prevention intervention, provided it is adapted to the needs and preferences of autistic adults. This includes ensuring that the AASP template is flexible so it can be adapted to the person's preferences to ensure it is accessible at times of crisis. Together, these findings suggest the AASP could be a beneficial intervention for autistic adults. The next step is to conduct a pilot RCT to further test the AASP, and to estimate the parameters for a future definitive RCT that would assess its clinical and cost effectiveness.[21] This future work has the potential to provide a life-saving intervention for autistic adults.

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