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Suicide Prevention in Autism: Autism Adapted Safety Plans.

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Suicide in autistic people

- Increased risk of death by self-harm/suicide in autistic people found across countries (Sweden, Australia, US, Canada) (Hirvikoski et al. 2016; Hwang et al. 2019; Kirby et al. 2019; Lai et al. 2023).

- Autistic men and women both at similarly high risk of suicide, but autistic women at particularly increased risk compared to non-autistic women (Kirby et al. 2024).

- Risk higher in autistic people without intellectual disability (Hirvikoski et al. 2016).

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Suicidality in autistic people

1%

of the population is autistic

11-15% of patients at risk for suicide attempts are autistic
(Takara & Kondo, 2014; Ryden et al. 2008).

41.4% of people who died by suicide in the UK *may* be autistic
(Cassidy et al. 2022).

40.6% of people who have attempted suicide report clinically significant levels of autistic traits
(Richards et al. 2019).

Similarly high rates of suicidality in autistic/possibly autistic people
(Newell et al. 2023).

Autism Community "Top 10" Priorities

Autism Community Priorities for Suicide Prevention

An International Society for Autism Research Policy Brief

April 1, 2021

INSAR
International Society for Autism Research
autism-INSAR.org

THE ISSUE

Suicide in autism is a **hidden crisis,** overlooked by policy makers, clinicians and researchers worldwide. Population-wide studies in the US, Sweden and Taiwan show that autistic people are up to **seven times more likely to die by suicide**[1-2] and **six times more likely to attempt suicide** than the general population.[3] The risk of death by suicide is even greater for autistic people without intellectual disability.[1] It is also greater among autistic women, who are **13 times more likely** than non-autistic women **to die by suicide.**[1]

Despite these powerful statistics, numerous barriers prevent autistic people at risk for suicide from getting the attention, treatment and support they need. These barriers include a lack of evidence-based assessment tools and interventions to identify and treat suicidal thoughts and behaviors;[4-9] a lack of access to mental health services[10-11] and exclusion from conversations about policies and guidelines that affect autistic people.

We must immediately address and remove barriers to effectively identifying, treating and supporting autistic people who are at risk for suicide in order to **save lives now.**

"The lack of knowledge around Autism meant that he did not have the support he needed until his difficulties had impacted on him overwhelmingly."

– Family member

BACKGROUND

We do not fully understand why autistic people are disproportionately at risk for dying by suicide. However, reviews of international suicide prevention policy and research indicate that few countries identify autistic people as a high-risk group for suicide in their suicide prevention policies or clinical guidelines. This may be because autistic people do not share the familiar risk markers for suicide, including mental health problems, which commonly occur in the general population.[12] In autistic people, loneliness,[13-14] feeling burdensome to others,[14] social and communication difficulties, lack of support and trying to fit in by camouflaging autistic behaviors are some of the factors that increase suicide risk.[4-5,12,15-16]

Yet, these factors and their association with suicidality are easily missed or misdiagnosed. This may be because neither clinical practice nor research offers any assessment tools that have been validated to identify suicidal thoughts and behaviors in autistic people.[6-9] Even if these tools did exist, they might not reach autistic people, who report having difficulties accessing mental health services.[10-11] Moreover, their providers often report lack of confidence and expertise in supporting autistic clients, particularly those who feel suicidal.[17] Because many autistic people camouflage their autistic behaviors to fit in, it can be difficult for practitioners to interpret their thoughts and feelings[18] or recognize their true level of distress.[10]

Providing appropriate support to autistic people requires evidence-based policies and guidelines for clinical practice and research. But autistic people and those who support them are typically excluded from research that informs the clinical practice and policy related to the identification and mitigation of risk for suicidality. This has led to the creation of assessment tools and interventions that do not reflect or meet the unique needs and concerns of autistic people.[10-11]

A "one size fits all" approach that is designed to meet the needs of non-autistic people is unlikely to work for autistic people. Fortunately, available treatments can be adapted with and for them. We must **work with autistic people** and those who support them to **identify stopgap solutions to implement** now and develop carefully designed and well-researched solutions over **the longer term.**

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Department of Health & Social Care

Policy paper

Suicide prevention in England: 5-year cross-sector strategy

Published 11 September 2023

- Recognised increased risk in diagnosed and undiagnosed autistic people.
- Improve access to autism diagnosis and mental health support.
- **Consider results of safety planning pilot RCT.**
- More participatory research to inform suicide prevention policy.

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Autism Community "Top 10" Priorities

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Priority Setting Partnerships

What barriers do autistic people experience when seeking help which may put them at greater risk of suicide?

What are the risk and protective factors for suicide in autism across the lifespan?

To what extent are autistic people not believed about the severity of their distress?

How can we further understand suicide where mental health is not a factor, across the lifespan?

How can we best identify and assess suicidal thoughts and suicidal behaviours in autistic people**,** in research and clinical practice**?**

How should interventions be adapted for autistic people and individual presentations?

What is the experience of suicidality in autistic people? Is this experience different to the general population?

How do autistic people seek help when they are in a crisis?

How well do existing models of understanding suicide apply to autistic people?

What is the impact of poor sleep on suicide risk in autistic people, and how can this be measured?

SUPPORTED BY
NIHR | National Institute for Health Research

How should interventions be adapted for autistic people and individual presentations?

"Adapted suicide safety plans to address self-harm, suicidal ideation and suicide behaviours in autistic adults: An interventional single arm feasibility trial and external pilot randomised controlled trial"

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Safety planning in autistic adults

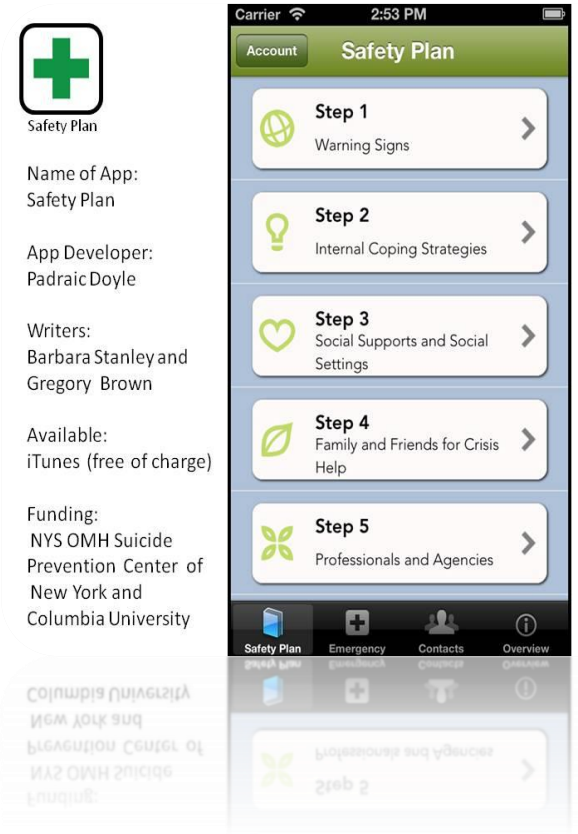
- Lack of appropriate support and treatment for autistic people (Camm-Crosbie et al. 2019; Crane et al. 2019).
- Services are not set up for “people like them”.
- No suicide prevention interventions developed specifically with or for autistic people.
- Safety plans have been recommended to adapted for autistic people (e.g. Schwartzman et al. 2021).
- Research suggests that when people are feeling suicidal the majority do not want end their lives.
- But they feel trapped in a moment of intolerable distress.
- How do we help people to break free of that moment?

Safety planning in autistic adults

Safety Plans are:

- simple, scalable, personalisable, cost-effective suicide prevention interventions.
- can be used with minimal training and in a range of settings and formats.

We adapted safety plans with and for autistic people.



What is typically included in a Safety Plan?

- Reason for living.
- Warning signs.
- Internal coping strategies.
- Social situations and people that can help to distract me.
- People who I can ask for help.
- Professionals or agencies that I can contact during a crisis.
- Making the environment safe.

Safety planning

A Safety Plan

Is…

A written, dynamic document.

A list of internal and social distractions & people to call for help.

Easy to read.

Collaborative.

To fill important gaps in care/ end of care.

About understanding the individual.

Written in the person's own words.

Isn't…

A long-term tool for mood.

For someone at imminent risk of suicide.

For individuals with cognitive impairment (unless adapted).

AASP Pilot Trial Methods

- Stage 1: Refined AASP with focus groups with autistic people and those who support them, and co-produced training for service providers.

- Stage 2: Single arm feasibility pilot with 8 autistic people and 8 service providers who supported the autistic person to complete an AASP.

- Stage 3: Feasibility RCT – AASP+usual care vs. usual care.

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Stage 1/2: Refining AASP

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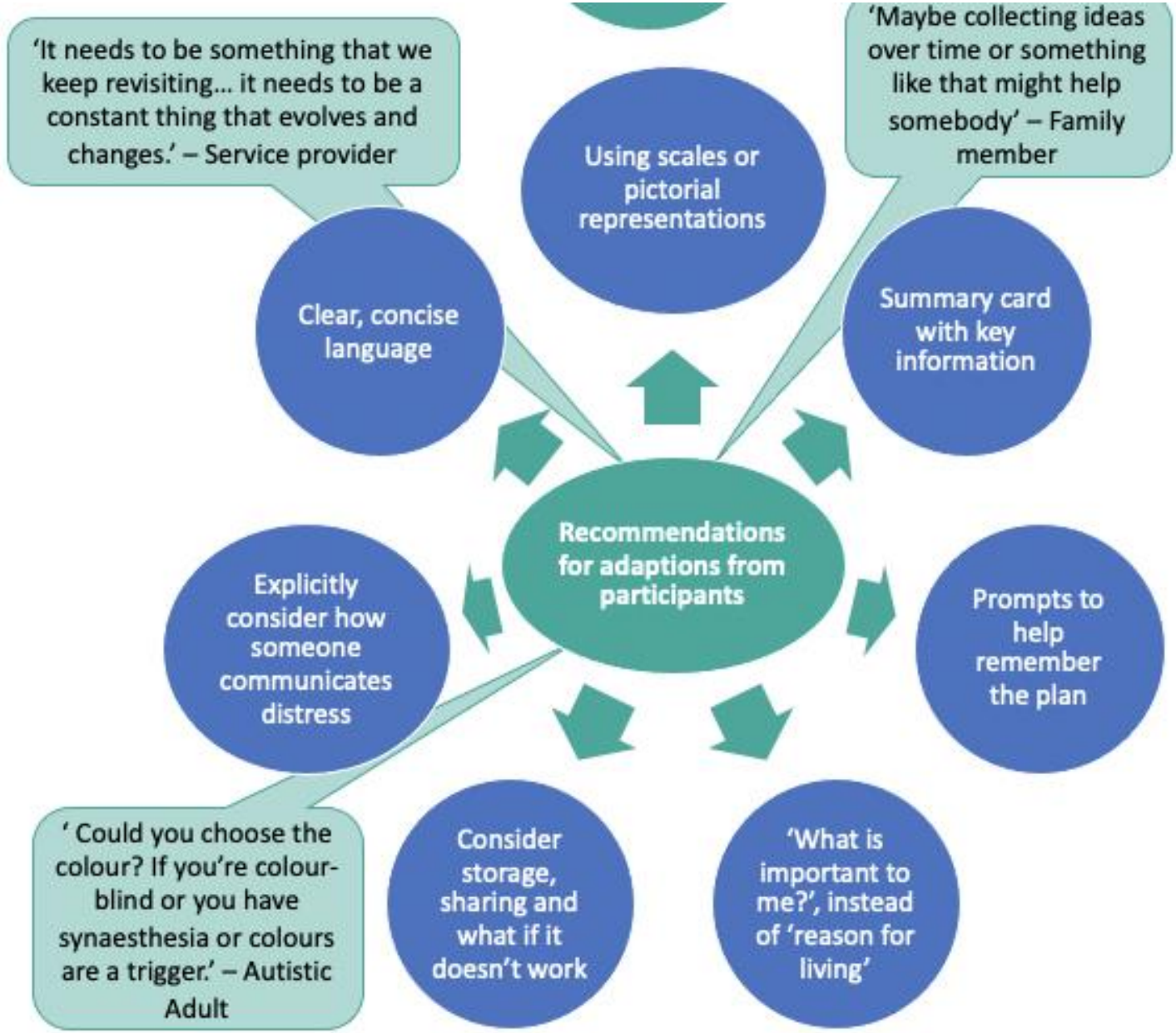
Stage 1/2: Refining AASP



Introducing autism adapted safety plans

- Crises come and go and identifying warning signs is important for acting early to prevent things getting worse.
- In the general population, Safety Plans have been found to help to prevent acting on suicidal feelings. Safety Plan is a series of progressive steps.
- If one step isn't working, go to the next one (although it doesn't have be worked through in a linear manner!).

Autism Adapted Safety Plans have been adapted for, and with, autistic adults and those that support them.

People might not know the answers for each section – important that not knowing isn't the same as not engaging.

What is important to consider for SPs?

- It may be challenging for a non-autistic person to communicate with an autistic person and vice versa, especially when they aren't familiar with each other.
- Be direct: keep language simple and concrete.
- Allow time for the person to process.
- Avoid:
  - Words with double meanings.
  - Double negatives.
  - Too many instructions at once.

- Use prompts and resources – autistic people can find open questions difficult, particularly when describing past experiences.
- Difficult to identify and describe own emotions (Alexythymia).
- Difficult to know when approaching crisis.

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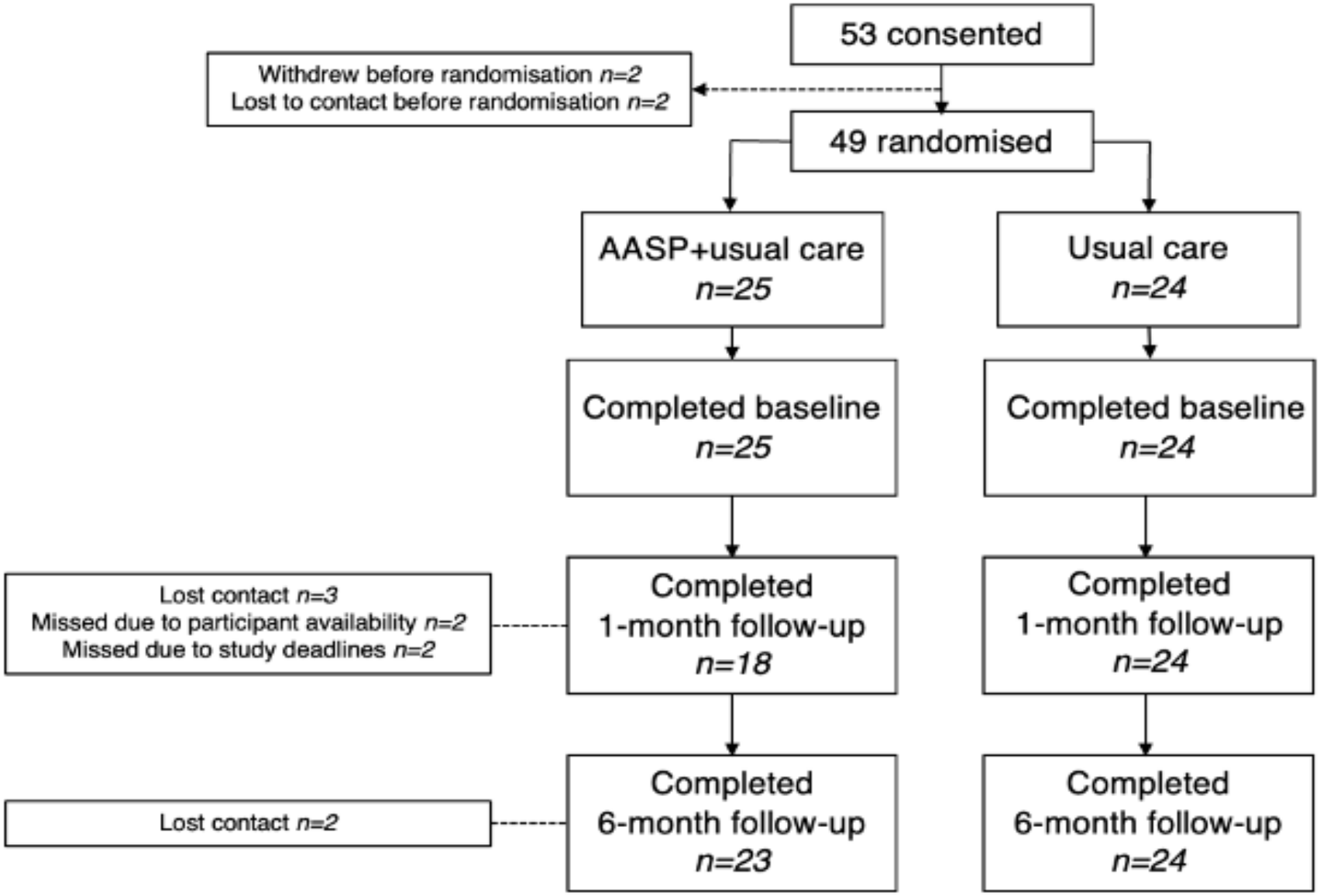
Stage 3: Results of AASP Pilot Trial



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Stage 3: Results of AASP Pilot Trial

- 68% autistic participants were satisfied with AASP.
- 41% rated AASP as usable – however this was because autistic adults reported needing support and on average 3 sessions to complete the AASP.
- Excellent retention to both arms of the trial (92%).
- Excellent fidelity of AASP delivery after training co-produced with autistic people and those who support them.
- No SAE related to study participation.
- All progression criteria met for a fully powered trial.

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Next steps for AASPs?

- Funding for fully powered trial to test clinical and cost effectiveness – need clinical sites to join the study team so please get in touch if your trust are interested in being involved!
- Updated AASP now available on our website.
- AASP is more than the document – training is needed to accompany to enable professionals to support autistic people to complete an AASP successfully.
- **Free training for NHS professionals available in July (in person and online)!**

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Thanks to …

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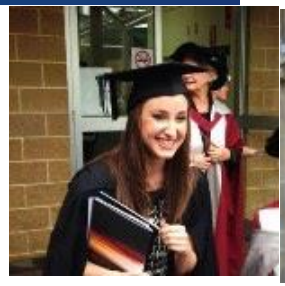


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https://sites.google.com/view/mentalhealthinautism