

Autistic Adults and other Stakeholders Engage Together (AASET) for Suicide Prevention

Organization for Autism Research Webinar
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Objective of this Presentation

To describe effective practices for meaningfully and authentically including autistic individuals and their family members as research partners

We purposefully use identity-first language, as opposed to person-first language, in congruence with preferences expressed by adults on the spectrum.



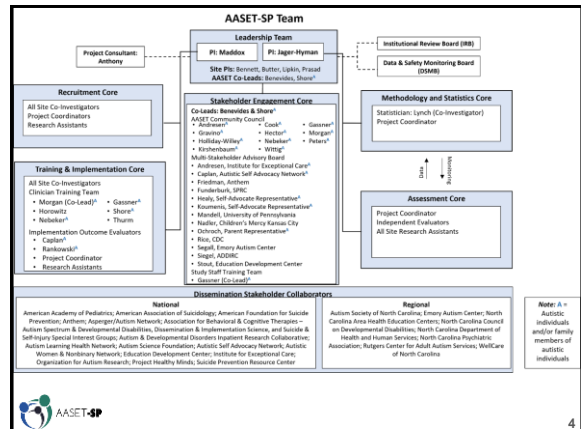
Patient-Centered Outcomes Research Institute (PCORI) Suicide Prevention Study Overview

Study Purpose

- Compare two different approaches to suicide prevention tailored for autistic individuals
- Adapted Suicide Safety Planning Intervention
- Adapted Suicide Safety Planning Intervention + Structured Follow-up

Study Questions

- Which approach results in better outcomes for autistic individuals?
- Which approach leads to better satisfaction for autistic individuals and their providers?
- What factors impact the effectiveness of these interventions?



What is AASET? Autistic Adults & Stakeholders Engaged Together

- AASET Co-Leads comprise autistic and non-autistic individuals



- AASET Community Council includes autistic adults and other stakeholders (e.g. family-care partners)
 - 15 Community Council members joined and contributed
 - Individuals are also involved in other roles



Collaboration between AASET and Suicide Prevention Researchers

- AASET members worked with Principal Investigators to:
 - Revise research questions
 - Identify priority outcomes for the study
 - Create opportunities for authentic autistic involvement in study roles
 - Ensure methods were congruent with autistic priorities
- The process included:
 - Regular Zoom meetings over many months
 - Voting through Google Forms on choices related to study design
 - Email correspondence
 - Brainstorming organizational partners and other members to invite to be a part of the project



Collaboration between AASET and Suicide Prevention Researchers

- **What changed as a result of AASET input?**
 - Outcome assessment now includes a qualitative component
 - Secondary outcomes include priority outcomes identified by AASET prior work
 - Autistic outcome assessors are a part of the team
 - Autistic individuals are involved in qualitative coding and analysis
 - Changes to the method to promote acceptability and feasibility
 - Clinician training and study staff training are co-led by autistic partners
 - Ongoing assessment of engagement practices

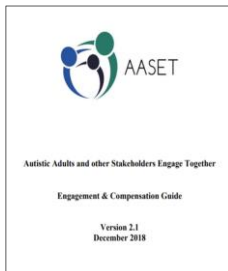


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How? Enhancing Engagement Version 1



Engagement & Compensation Guide for researchers written by autistic adults

- Competence
- Communication
- Compensation
- Considerations

Shore, S. & Benevides, T. W. (Editors).



<https://www.pcori.org/sites/default/files/AASET-Engagement-Guide-122018.pdf>

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How? Enhancing Engagement: Competence

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

1. Non-speaking individuals should be treated as if they understand all verbal language
2. Modify your language
 - Instead of “sensory dysfunction”, describe “sensory differences”
 - The differences may impact function, but aim to not describe the problem as being the individual
1. Teach students, family members, postdocs, and others to communicate **WITH** the person on the spectrum, even if they are a child
 - Do not talk about the child or adult as if they are not listening - they are, and listening to deficit-based language is detrimental to a person’s mental health



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How? Enhancing Engagement: Communication

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

Example Email from the Engagement Guide

Purpose

- To request feedback on Conference Summary

Details:

- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting.

Questions include:

- Are the materials written in a way that is understandable? Clear? Respectful?
- Is there anything missing that you would want to know?

Actions:

- Read the Conference summary
- Use track changes to share edits or comments on the content of the summary
- Send feedback to sampleperson@email.com

Deadline: Wednesday October 4, 2017 at 5pm Eastern Time



Template developed by Elesia Ashkenazy (AASPIRE Representative)

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How? Enhancing Engagement: Compensation

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- All individuals in research and practice should be compensated for their intellectual contributions
- Authentic alliance and respect require compensation as team members, depending on role
- For our project, Community Council members were paid **\$50/hour** for their time in advisory roles
- In recent CER grant applications, we have compensated at a rate of **\$100/hour** for roles such as *outcome assessor*, *intervention manual developer*, and *intervention implementer*
- **Major barrier:** payment can interfere with disability benefits
 - This requires future work to address **how** to best compensate



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How? Measuring Engagement: Considerations

WHAT IS GOOD FOR THE GOOSE IS GOOD FOR THE GANDER

- **Trust**
 - Able to bring up differing ideas and concerns
 - Measurement: Concerns are raised and meaningfully heard
- **Respect**
 - Contributions are valued
 - Measurement: Equality of voices in meetings and decision points
 - Measurement: Contributions are included and recognized in process and products
- **Support**
 - Multiple options for remaining engaged make it easier to participate
 - Measurement: Number of people who prefer or use different options



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How? Enhancing Engagement: Recommendations

1. **Include** autistics in the development, implementation & dissemination of research
2. **Ensure** participation through appropriate accommodation
3. **Presume competence and focus on abilities** in all interactions
4. **Value** autistics as an integral part of the team (avoid tokenism)
5. **Present** research results in several modalities to accommodate different communication styles
6. **Compensate** autistics for time and experience brought to the table
7. **Consult** autistics regarding priorities for research and systems change



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How? Enhancing Engagement: Next Steps

- **Expanded Engagement & Compensation Guide to a broader Governance Document**
 - Vision
 - Principles
 - Personal and professional goals of stakeholder partners
 - Decision-making guide
 - Communication plan
 - Explicit measurement recommendations to ensure we are appropriately engaging autistic people in the study



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Vision

To harness the personal and professional background and knowledge of each team member to contribute fully in the process of a research study in order to reduce the rate of suicide among autistic youth and young adults ages 15-24 years



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Principles

- We value each other's perspectives.
- We prioritize each other's mental health.
- We listen to understand.
- We seek out inclusive and accessible ways to work together.
- We presume competence.
- We strive to learn and grow through mistakes and communicate openly.
- We respect that people may choose to communicate in diverse ways.
- We compensate team members appropriately.
- We continuously evaluate our efforts for authentic engagement.
- We cooperatively implement our inclusive decision-making process and other content of our AASET-SP Governance Document.



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Meeting the Personal and Professional Goals of Stakeholder Partners


Why do people want to be a part of this? Need to ensure their needs and goals are met (in addition to research questions).

- **Raise awareness** and advocacy for suicide prevention and mental health
- **Help** friends and loved ones who live with suicidal ideation and depression
- **Develop** meaningful evidence to be shared with the autism community
- **Show** people that autistic lives are important
- **Ensure** there is an authentic autistic voice in research
- **Contribute to** publication and presentation
- **Strengthen** skills in research and training
- **Learn** from other autistics on the team
- **Create** accessible resources and tools on suicide prevention
- **Increase** quality of life through person-centered outcome research
- **Be a part** of something bigger than myself



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Decision-Making as a Team




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Guiding Principles for Decision-Making:

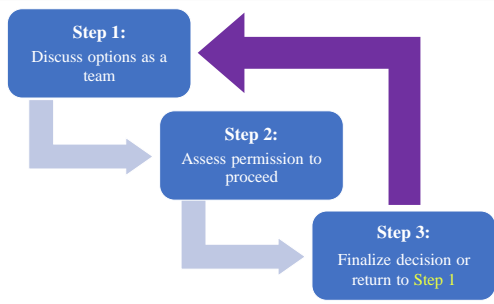
All members of the team commit to:

- Considering the vision, principles, and purpose of the study when making a decision
- Addressing concerns directly in a non-public forum
 - If you feel that you need help talking with someone you are working with in a way that feels safe for you, please speak with Brenna, Shari, Teal, or Stephen so we can assist
- Being open to hearing and incorporating feedback



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Decision Making: Big Picture Process



1. Step 1: Discuss options as a team

2. Step 2: Assess permission to proceed

3. Step 3: Finalize decision or return to Step 1




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Decision Making: Step 1

Step 1: Discuss options as a team	Goal: <ul style="list-style-type: none"> • To obtain input and clarify all possible options • To determine options to eliminate 	Method: <ul style="list-style-type: none"> • Communication via email or virtual meeting
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Example

- **Age:** Discuss various options via email or during a virtual meeting
 - 11
 - 12
 - 13
 - 14




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Decision Making: Step 2

Step 2: Assess permission to proceed	Goal: <ul style="list-style-type: none"> • To ascertain members' preferences for specific options 	Method: <ul style="list-style-type: none"> • Voting via Google Form
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Example

- Vote on whether to lower age to 13
- Vote on whether to lower age to 14




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For each potential option, each AASET-SP Member chooses one of the following responses:

1. I do not have an opinion	2. I prefer for this option to move forward	3. I don't prefer this, but would be okay if it moves forward	4. I don't prefer this, and am uncomfortable moving forward with this choice
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Examples:

- Lowering the eligibility age to 13
 - 4. I don't prefer this and am uncomfortable with this choice moving forward
- Lowering the eligibility age to 14
 - 2. I prefer this option to move forward



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Decision Making: Step 3


Step 3:
Finalize decision or return to Step 1

Goal:

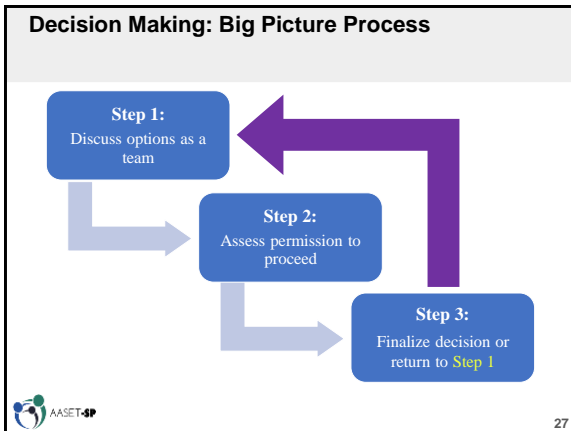
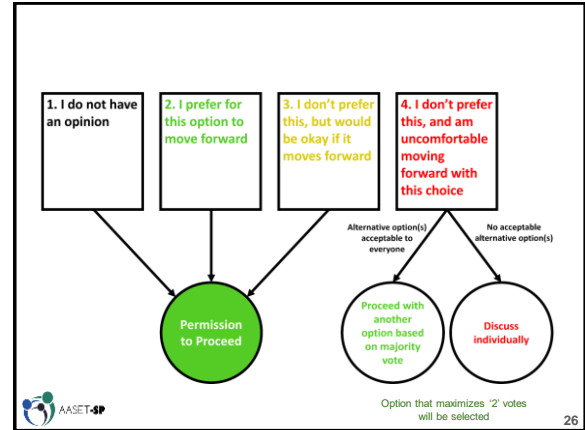
- To select final decision or determine that it is necessary to discuss other options

Method:


- Review of Google Form by Teal & Stephen; sharing of results with Brenna & Shari
- Individual conversations, if needed



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Communication Plan



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Structuring Meetings to Meet Multiple Processing Styles

- Develop and share agenda with preparation **recording** and **transcript** in Zoom
- Allow for **multiple options to engage** with content both during and after the meeting - chat, spoken language, emailed ideas after the meeting after processing time has happened
- Provide **accommodations and supports**:
 - o Closed captioning
 - o Live meeting notes
 - o Someone to manage chat
 - o Powerpoint structure



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Measuring Engagement: Did We Get It Right?

- Adapting existing tools to meet needs of our group

Special Issue Article

Evaluating Stakeholder Engagement: Stakeholder-Centric Instrumentation Process (SCIP)

Jenny Martinez¹, Catherine Verrier Piersol¹, Sherrrie Holloway¹, Lauren Terhorst¹, and Natalie E. Leland¹

Western Journal of Nursing Research 2021, Vol. 45(1) 98-103 © The Author(s) 2021. Article reuse guidelines: sagepub.com/journalsPermissions.nav DOI: 10.1177/0898010120950000 wjnr.sagepub.com/home/wjnr

SAGE

Stakeholder engagement in research: a scoping review of current evaluation methods

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Some Things To Keep In Mind...

- Continuous learning process means it is okay to not be perfect at first
- Being vulnerable and open to feedback is essential
- Spend more time listening to learn
- Spend more time
- Throw out assumptions about “what usually happens”
- Recognize that systems are not created for stakeholder-engaged research, and it is hard to change systems
- Find allies and share good ideas!



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Related Publications

	<p>Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. <i>Autism</i>, 24(4), 822–833. https://doi.org/10.1177/1362361320908410.</p>		
	<p>Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. <i>Autism</i>, 24(6), 1345–1359. https://doi.org/10.1177/1362361320913664</p>		
<p>In progress: A Comparison of Two Brief Suicide Prevention Interventions Tailored for Youth on the Autism Spectrum. Sign up for updates: https://www.pccri.org/research/research/2021/comparison-two-brief-suicide-prevention-interventions-tailored-youth-autism-spectrum</p>	<table border="1"> <tbody> <tr> <td data-bbox="1069 413 1173 540"> </td> <td data-bbox="1181 413 1351 540"> <p>Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lary, B., Morgan, L., Palmer, K., Purkis, J. & Wittig, K. (2018). <i>Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide</i>. https://www.pccri.org/sites/default/files/Engagement-Guide-ss-of-122018-2-1.pdf</p> </td> </tr> </tbody> </table>		<p>Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lary, B., Morgan, L., Palmer, K., Purkis, J. & Wittig, K. (2018). <i>Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide</i>. https://www.pccri.org/sites/default/files/Engagement-Guide-ss-of-122018-2-1.pdf</p>
	<p>Shore, S. & Benevides, T. (Editors) with authored contributions from Ashkenazy, E., Gravino, A., Lary, B., Morgan, L., Palmer, K., Purkis, J. & Wittig, K. (2018). <i>Autistic Adults and other Stakeholders Engage Together: Engagement & compensation guide</i>. https://www.pccri.org/sites/default/files/Engagement-Guide-ss-of-122018-2-1.pdf</p>		



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Contact Us!



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