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

How? Enhancing Engagement Version 1

- Engagement & Compensation Guide for researchers written by autistic adults
  - Competence
  - Communication
  - Compensation
  - Considerations

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

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

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
**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

**How?**

**Enhancing Engagement: Recommendations**

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

**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

**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

**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.

**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
Decision-Making as a Team

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

Decision Making: Big Picture Process

Step 1: Discuss options as a team

Step 2: Assess permission to proceed

Step 3: Finalize decision or return to Step 1

Decision Making: Step 1

Goal:
- To obtain input and clarify all possible options
- To determine options to eliminate

Method:
- Communication via email or virtual meeting

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

Decision Making: Step 2

Goal:
- To ascertain members’ preferences for specific options

Method:
- Voting via Google Form

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

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

1. I do not have an opinion
2. I prefer 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

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
Decision Making: Step 3

**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

### 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

### Communication Plan

- **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:**
  - Closed captioning
  - Live meeting notes
  - Someone to manage chat
  - Powerpoint structure

### Structuring Meetings to Meet Multiple Processing Styles

1. Develop and share agenda with preparation recording and transcript in Zoom
2. 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
3. Provide accommodations and supports:
   - Closed captioning
   - Live meeting notes
   - Someone to manage chat
   - Powerpoint structure

### Measuring Engagement: Did We Get It Right?

- Adapting existing tools to meet needs of our group

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4/20/2022
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!

Related Publications


Contact Us!

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