Meaningful Inclusion of People on the Autism Spectrum

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Objectives

● **Provide** an overview of the AASET (Autistic Adults and other Stakeholders Engage Together) project and lessons learned

● **Discuss** additional key strategies for meaningful inclusion of people on the autism spectrum in multiple settings

● **Support** dialogue between attendees and AASET project leads
Identity-First versus Person-First Language

- We are using identity-first language in place of person-first language.
- Many stakeholders in our project prefer identity-first language that does not separate their experience of autism from who they are.
- This is an acceptable convention self-advocates use in print descriptions.
- It is important to ask the individuals you are working with whether they prefer to be identified as a ‘person with autism’ or as ‘autistic’.
- Our approach values autonomy and identity, and conveys mutual respect.
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The views presented in this presentation are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.
What is AASET?

Autistic Adults and other Stakeholders Engage Together

Autistic adults have multiple, chronic, and potentially preventable healthcare needs as compared to same-aged adults without ASD, but we know very little about why these differences are occurring and how to improve outcomes.

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Two Year Project

Step 1
Establish AASET Team Backbone support
- IRB
- Hiring
- Database of Contacts
- Website & social media
- Communication

Step 2
Build Community Presence
- Contact autism stakeholder groups
- Contact disability advocacy groups
- Contact key researchers
- Contact educational settings

Step 3
Engage Autistic Adults and Family Stakeholders to Solidify Community Input
- Online presence
- Community Council

Step 4
Hold Year 1 Conference to Develop a Results-Oriented Agenda for Future Research Steps
- Logistics
- Speakers
- Agenda

Step 5
Engage in a review of the literature to support identified interventions and outcome measures

Step 6
Develop an Engagement Plan for future PCOR/CER during Year 2 Conference
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Step 1 - What we Learned about Communication within the Project Team

People hear and understand what is said during meetings in different ways.

- It may be helpful to use software such as Zoom or WebEx to keep a record of all meetings so that all members are able to access and review at later times.
- Summary emails should be concise
Step 1 - What we Learned about Communication within the Project Team

For all project team members, determine the best method for communication, which may or may not be written or spoken.

- Aim to ensure email, voice, and text communications are clear.
- Using an email template has been a helpful way to ensure consistent communication.
Example of Email Communication Template

**Courtsy of Elesia Ashkenazy, Community Council Member**

**Purposes of the Email:**
- To share results of the Year 1 meeting
- To request feedback on Conference Summary (short, 3 page summary)

**Details:**
- The Project Team would like feedback on the Year 1 meeting results so that we can provide to the autism community, researchers, organizations, etc.
- We will incorporate feedback from the Community Council prior to sharing with the attendees of the year 1 meeting or posting on Facebook and AASET website.
- 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:**
1. Read the Conference Summary
2. Use track changes to share edits or comments on the content of the summary
3. Send feedback to sampleperson@emai.com

**Deadline:** Wednesday October 4, 2017 at 5pm Eastern Time
Step 1 - What we Learned about IRB

Ethics review boards do not always understand the specific needs of project partners who may not be scientists.

- **Challenges Included:**
  - Lack of understanding of the spectrum - not all autistic adults have ‘diminished capacity’; non-speaking individuals should be presumed competent to consent
  - Lack of understanding of the type of project - participatory nature of initial engagement was not designed as research
  - Lack of accommodation for CITI Training when needed for project partners

- **Strategies to Address Challenges are:**
  - Determine if there is expertise on board for participatory projects
  - Reach out to collaborate with IRB early in the process
  - Educate IRB and others about nature of spectrum
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Step 2 - Build Community Presence

- Contacted autism and other advocacy and educational organizations in Year 1
- Plan in Year 2 to provide more regular updates and involve organizations in project
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Step 3 - Engaging the Community

1. Community Council of Autistic Adults (n=15)
   • Provide input through email, phone, and text-based meetings
   • Project Team ensures opportunities for connection with research community

2. Year 1 Meeting
   • Large stakeholder meetings n>50

3. Future iterative action steps to build knowledge
   • Survey research
   • Face-to-face focus groups
   • Facebook
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Step 4 - Year 1 Meeting (July 2017)

- Large stakeholder meeting: What we Learned
  - Lack of mutual respect & trust inhibits participation and involvement in research activities
  - Undermining actions included lack of…
    - Reporting results in a way useful to autistic individuals
    - Adequate compensation for involvement of research collaborators or participants
    - Involvement in research decisions
    - Strengths based focus in research
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Step 4
Year 1 Meeting
Desired Outcomes

- Physical health outcomes, 32%
- Injury and mortality outcomes, 17%
- Mental health outcomes, 51%
- Obesity outcomes, 0%
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Step 4
Year 1 Meeting

Desired Interventions

- Social well-being, 32%
- Provider & environmental interventions, 21%
- Access to health services, 21%
- Mental health interventions, 25%
Researchers & Other Stakeholders Should:

1. **Include** autistics in the development, implementation & dissemination of research
2. **Ensure** participation through appropriate accommodation
3. **Presume competence and focus on strengths** 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
Examples of How to Support Autistic Engagement

1. **Inclusion Example:**
   a. AASET has 4 members of the project team, 2 are autistic
   b. All communication to community is autistically vetted

2. **Appropriate Accommodation Example:**
   a. Use preferred communication styles employing reduced verbiage, bullets, and other organizing strategies
   b. Modify CITI research training

3. **Compensation Example:**
   a. Example: Pay for autistic community council members is $50/hour
Examples of How to Support Autistic Engagement

4. Presumption of Competence & Strengths Example:

- Non-speaking individuals should be treated as if they understand all verbal language.

- 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.

- Teach students, family members, postdocs, and others to communicate WITH the person on the spectrum, even if they are a child. Try not to 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.
Future Steps for AASET

1. **Continue** working with autistic community to determine priority areas for future research.

2. **Hold** a Year 2 Meeting in Washington DC on Saturday November 10, 2018 to bring together researchers, autistic stakeholders, and others to develop an action plan to address priorities.

3. **Produce** an Engagement Guide for use by stakeholders when planning and implementing future research.
Discussion

1. If you already engage in most of these practices, what success or challenges have you encountered?

2. How can you modify your organizational or research practices to be inclusive?

3. What systems change needs to occur in order to make this a reality?