Meaningful Inclusion of People on the Autism Spectrum in Multiple Settings

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Objectives

- **Discuss** the process of engaging the autistic adult community in defining research priorities.
- **Link** lessons learned in the AASET Project to other research and practice settings.
- **Share** examples of lessons learned to inform research, practice, and policy.
- **Provide** opportunity for discussion.

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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Funding Acknowledgment

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What is AASET?

Autistic **A**dults and other **S**takeholders **E**ngage **T**ogether

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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Methods

Community Council of Autistic Adults (n=15)

- Provides input through email, phone, and text-based meetings

Participatory Action Meetings

- Large stakeholder meetings n>50

- Small community meetings n<15

- Iterative action steps to build knowledge

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Results

- Large stakeholder meeting

  - Lack of mutual respect & trust inhibiting 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

Results

- Preferred allocation of hypothetical research dollars

  - (33%) Mental health interventions and outcomes
  - (24%) Improving social well-being, quality of life
  - (24%) Improving access to services
  - (13%) Addressing knowledge/skills/attitudes of providers and environments where care occurs
  - (10%) Addressing physical health outcomes
  - (5%) Injury and mortality risks

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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

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Examples of How to Support Autistic Engagement

1. **Inclusion Example:**
   a. AASET has 3 project leads, of whom 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

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Example of Email Communication Template
Courtesy 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

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 hearing deficit-based language is detrimental to one's mental health.

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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?