AASPIRE Guidelines to Promote the Successful Inclusion of Autistic Adults as Co-Researchers

1 Be transparent about partnership goals and choose an appropriate approach to match those goals.

- Match the level of engagement best suited to your project (e.g., equal partnership vs. authentic engagement / collaboration vs. consultation) to the participatory approach (e.g., community based participatory research, patient and stakeholder engagement, emancipatory research, other forms of community-engaged research).
- Explicitly communicate what type of engagement community partners can expect from the approach being used.
- Create an infrastructure that supports the type of collaboration you and your community partners have agreed best meets the project goals.

2 Clearly define community partner roles, consider who needs to be included on the team, and partner with people who are likely to help the project succeed.

- Clearly describe roles and expectations, and select partners who can commit to them.
- Consider the expertise the project needs based on different types of lived experience.
- Create a balance between autistic community leaders and other autistic adults.
- Identify partners who have a shared long-term vision and who will prioritize achieving collaborative goals over individual gain.
- If including non-autistic partners (e.g., family members, service providers, other academics) identify people who are willing to share power with autistic partners.

3 Create processes for effective communication and power sharing.

- Jointly create collaboration processes and guidelines.
- Agree on a structured process for making decisions.
- Individually assess accommodation needs, discuss as a group, and re-assess regularly.
- Discuss and address competing accommodations.
- Consider the effects different meeting formats will have on partners' abilities to engage, and consider offering multiple methods for participation (in-person, teleconference, video-conference, text-based chat).
- Present concepts and information using accessible language and formats so partners can make truly informed decisions.
- Allow adequate time and space for partners to process information.
- If using email, provide a structured format to improve clarity (e.g., Purpose; Actions; Deadline; Compensation; Details).
- Provide materials in advance of meetings.
- During meetings, provide strong facilitation, with clear delineation of agenda items, time to catch up, cues to transitioning, and an etiquette for handling digressions.
- Regularly consider the role that power and privilege may play in tensions between academic and community partners and actively work to equalize power.
- Avoid pathologizing autistic partners when trying to understand and address collaboration challenges

4 Regularly focus on building and maintaining trust.

- Engage in a visioning exercise to clarify and solidify shared goals.
- Include exercises to help team members get to know each other. Consider asking community partners to choose and lead such exercises.
- Actively listen to community partners' views and demonstrate that you value the expertise that comes from lived experience.
- Follow through and implement the group's decisions, and regularly report back on progress.
- Celebrate success, and make space for humor and fun.
- Regularly evaluate and improve the collaboration.

5 Collaboratively disseminate findings.

- Collaboratively decide on ways to present findings to minimize stigma or harm.
- Include community partners as co-authors on scientific papers. Doing so may require review and discussion of lay-language or annotated versions of manuscripts.
- Co-create lay-language briefs that can be shared in non-academic venues.
- Jointly find ways to use findings to advance community priorities or goals.
- Encourage community members to find creative venues for dissemination.

6 Actively encourage community capacitation.

- Offer opportunities for autistic individuals to pursue education, participate in internships, and serve as research staff.
- Be aware of the inherent power differentials between faculty and students, trainees, and staff members, and do not assume that such individuals can substitute for collaborations with autistic organizations or leaders.

7 . Fairly compensate community partners for their work.

- Be transparent about project funding.
- Find ways to pay community partners, especially when academic staff or study participants receive payment.

Nicolaidis C, Raymaker D, Kapp SK, Baggs E, Ashkenazy E, McDonald K, Weiner M, Maslak J, Hunter R. AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. Autism. 2019;23(8)2007-2019.

AASPIRE Guidelines to Promote the Successful Inclusion of Autistic Adults as Study Participants

1 Avoid the risk of undue influence and exploitation while maximizing autonomy and inclusion.

- Do not assume that anyone with a diagnosis of ASD needs to undergo an assessment of decisional capacity. Consider the level of risk and the types of decisions the potential participants make on a regular basis.
- In cases where decisional capacity is unclear, consider conducting a brief comprehension assessment after the use of an accessible informed consent process.

2 Make the consent process as accessible as possible.

- Adapt consent forms to increase accessibility (e.g., by making language simpler and more concrete, removing sections that unnecessarily hinder comprehension, adding images, and providing text-to-speech versions of online consent forms).
- Consider partnering with autistic adults to create more accessible consent materials.
- Consider strategies to reduce participant burden (e.g., online consent)

3 If possible, offer multiple modes of participation to maximize inclusion of autistic participants with differing strengths and needs.

- For surveys, consider offering in-person, telephone, and online options. If the survey is only available online, consider using software with read-out-loud capability for participants with low literacy.
- For qualitative interviews, offer both synchronous and asynchronous modes of participation, and allow both oral and written communication. Examples include email (asynchronous, written), telephone or in-person (synchronous oral), and instant messenger chat (synchronous, written).

4 Do not assume that survey instruments validated with general populations, caregivers, or children are valid for use with autistic adults.

- Assess the need for adaptations and, if needed, modify the instrument and retest its psychometric properties.
- Whenever possible, use a participatory process to assess, create, and/or adapt instruments.
- Only change items that would cause significant problems.
- If needed, add prefaces to increase precision or explain context; and modify items to simplify sentence structure, remove the passive voice, and clarify pronouns.
- If needed, substitute difficult vocabulary words, confusing terms, or figures of speech with more straightforward terms. In cases where a substitution is not possible, add hotlinks that define the term or offer examples or clarifications.
- When response options are problematic, consider graphics to increase clarity (e.g., cylinders filled to varying proportions; frowning/smiling faces).

5 Create accessible qualitative interview guides.

- Offer participants the option to review materials in advance.
- Begin with a preface that clearly explains the type of answers you wish to receive. 20
- As much as possible, use concrete questions, asking for stories about specific experiences rather than answers to questions about abstract concepts.
- Work with community partners to ensure that questions are precise enough, and provide enough context, to be answered.
- Use probes to help anchor events and further elaborate on stories or concepts.
- If using email to conduct the interview, include a preface and the first order of questions in the initial email message, and expect 2-4 rounds of responses to obtain complete, rich answers.

6 Use proxy reporters only if direct participation is not possible, even with accommodations and supports.

- Distinguish a "supported participant" (i.e., autistic individual answers questions with help from a supporter) from a "proxy" (i.e., supporter answers questions with minimal input from the individual).
- Provide a way for supporters to offer their own opinions separately from the person they are supporting.
- Create a separate survey for use by proxies. Review and adapt all items, focusing on what the proxy can answer on behalf of the patient versus where the proxy can only provide their own perspective.

https://aaspire.org/collaboration-toolkit/

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