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TIPS FOR ENGAGING WITH AUTISTIC PEOPLE

AS RESEARCH ADVISORY BOARD MEMBERS

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AUTHORS Emily F. Rothman, Sandra Magaña, Megan Bair-Merritt, Megan Sullivan, Leslie CastroAlcina, Huiting M. Chiang, Sequoia Holloway, Ambar Hinojoza, Austin Montgomery, Guillermo Ravelo, Amelia Sanchez, Ti Malice, Charlene Wooten.

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This resource is intended for researchers who would like to meet and work with autistic people as research advisors. It was written collectively by a group of 12 autistic individuals, three researchers, and one occupational therapy student in 2022. We hope that you find it useful.

WELCOME DIVERSE MEETING PARTICIPATION STYLES

Autistic individuals may have differing participation styles and needs. All methods of participation are valid though they may look different than neurotypical participation. It is important to be accommodating and understanding of all engagement styles so your advisors may participate to their fullest extent.

- If you are meeting online, let participants know that they can choose to keep their cameras off and utilize chat features.
 - Do not pressure people to put the camera on by saying you encourage or prefer video to be on.
- Do not require anyone to speak verbally (i.e., using the chat feature online or writing notes in person is OK)
- Break into small groups or utilize breakout rooms online for small group discussions to promote participation.

GIVE ADVANCED NOTICE

Some autistic people can struggle with spontaneity and prefer time to process before answering questions or completing a task. For this reason, it is important to plan ahead and ensure that all materials are available ahead of time. Giving clear instructions and letting your participants know what is coming next is a simple way to avoid surprises and increase the comfort of your advisors.

- Provide a meeting agenda via email ahead of time (ideally one week in advance, and again a day or two before as a reminder) so participants know what to expect.
- If you will be asking questions during the meeting, present discussion questions ahead of time and in writing, if possible. If the meeting is held online, put the discussion question in the chat as well as asking it verbally. Try to give participants extra time to process questions before asking for a response and be prepared for direct or blunt answers.
- If you ask a question and everyone is expected to provide an answer—such as going around for introductions—write out a list of names that is visible to everyone and call on people in that order. That way, participants know who is next and can prepare to be called upon.
- Provide clear instructions on how to access the meeting.
 - If online, provide direct links and send reminder emails to participants ahead of time.

- If in person, give instructions on navigating to the meeting space, including information about parking, security, or other checkpoints.
- If in person, communicate the expectations about dress/attire at meetings or do not require a dress code.
- » Provide clear and detailed information such as, “In general, we dress in business casual attire, but you may choose to wear whatever you please.”

BE FLEXIBLE AND MINDFUL

Because no two autistic people are exactly alike no one accommodation will work for everyone. Maintaining an open mind and practicing flexibility will help to foster a supportive and affirming environment.

- Understand that participants may need to: ask questions more than once, take a moment to process information or transition between topics, take breaks during longer meetings, use more time to explain their points, use fidget toys, etc.
- Be flexible if people need to skip meetings and catch up by watching or listening to a recording after the fact.
- Make deadline extensions easy to ask for and receive.
- Don't make punitive rules (e.g., do not penalize participants for arbitrary reasons such as being late or the way they are dressed). Focus policies on the work that needs to be done as opposed to the compliance of the participants.
- Recognize that your participants may be dealing with prior traumas and be careful about expressing frustration in body language or facial expressions during meetings. This can appear aggressive and be triggering to participants.
- Understand that some participants may be interested in authorship opportunities while others may not.

BE ACCOMMODATING

Accommodations should be freely offered and implemented throughout meetings. While some accommodations will occur on an individual basis, there are practices you can implement to ensure your meeting structure is accessible.

- During the meeting, periodically pause for questions and check for understanding.
- Make presentations and other materials visually simple and printer-friendly with minimal information on each slide.



- Keep bullet points to a minimum (it can be hard to distinguish which things are more or less important when slides are full of information); keep things to the key points and don't 'get in the weeds.'
- Use a sans serif font such as Calibri or Arial as these are the most visually accessible.
- When grant proposals or other materials are single-spaced, they can be hard to read and will need reformatting.
- If an autistic advisor is talking or presenting in an online format, have another person available to monitor the chat so that the presenter may stay on track.
- Multiple acronyms used in one paper or presentation can become confusing and should be avoided or defined clearly.
- Make meetings conversational with minimal pressure and expectations. A low pressure, less formal environment can better encourage participation.
- Try to ensure there are multiple autistic people in the meeting. This can create a sense of comfort and relatedness among participants.
- Treat autistic advisors as individuals and do not tokenize them; they are not all the same and each have unique accommodation needs.
- In between meetings, check in with participants. See if they have questions and solicit feedback on how meetings are going for them.
- Ensure that autistic people who are non-verbal are also included in the recruitment process and accommodate them in meetings.

PAY THE PARTICIPANTS

Advisors provide invaluable lived experience and should be fairly compensated for their work. In general, a rate of \$50-\$100 per hour is reasonable but may vary based on the demands of the project. Be transparent with the project tasks ahead of time so participants understand what they are being paid to do and ensure supports are in place to troubleshoot any payment issues that arise.

- Pay autistic advisors for their work; they are experts!
- Use transparency when discussing compensation with participants. Make it clear what is included in their paid work.
- Provide extra support when setting up payment systems. Designate a clear contact for questions and troubleshooting.
- Avoid payment systems that require the participants to pay a fee to get direct deposit; ensure there are no hidden fees and acknowledge that it is frustrating when there are multiple payment cards across multiple projects.
- Pay participants in a timely manner and acknowledge when university systems are slow. Give an estimated timeline for payment with periodic updates about what to expect and when.
- Ensure autistic advisors are paid a fair rate. They should not be paid a lesser amount than a neurotypical advisor for the same work.



DIVERSITY, EQUITY, AND INCLUSION

There has been a historic exclusion of minoritized populations in autism research both in participant and advisory roles. As such, there are additional considerations when working with autistic people who are Black, Indigenous, and People of Color (BIPOC).

- Many autistic people who are BIPOC and/or identify as women are self-diagnosed. Accepting self-diagnosis will make your advisory board more likely to include these populations. Be flexible and kind, and do not exclude those without a formal diagnosis.
- Be prepared to provide materials in languages other than English.
- Researchers should work to gain an understanding of other cultures social norms through a culturally humble lens.
- Appreciate that BIPOC autistic people have the challenge of learning the norms of more than one culture (American culture, neurodiverse culture, their own cultural background, etc.). Understand that mainstream culture may be difficult to learn in addition to others.
- Do not expect a BIPOC advisor to represent the needs and experiences of their entire culture.

FINDING AUTISTIC ADVISORS

One challenge in compiling an autistic advisory board is finding autistic individuals to fill the roles. Below are some suggested avenues you may take to find advisors.

- Social media can be a powerful tool for finding autistic advisors, particularly those who are BIPOC.
 - Instagram, TikTok, Facebook, and Reddit are some of the social media platforms where the autistic community is active.
 - » It is important to note that researchers should ask group organizers for permission before joining Facebook groups.
 - » Specific hashtags like #actuallyautistic, #autistic, #ADHD, #bipocautism, etc. can be used to reach your target audience.
- Researchers can also ask previous advisors to tap into their social circles as well as asking other autism researchers for referrals.
- Student Disabilities Services at colleges and universities can be a useful place to find advisors.

