



HOW TO FIND AND NAVIGATE AN EXPERT RESEARCH ADVISOR ROLE

ADVICE FOR AUTISTIC INDIVIDUALS

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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 autistic people who would like to meet and work with autism researchers as members of a research advisory board. It was written collectively by a group of 12 autistic individuals, three researchers, and one occupational therapy student in 2022. This document contains information about finding and preparing for an advisory role, logistics of advising, and tips on communicating with researchers and navigating difficulties. We hope that you find it useful.

FINDING ADVISORY BOARD POSITIONS

There are several ways to find available advisory board positions. Some options include:

- The International Society for Autism Research (INSAR) offers the INSAR Community Collaborator Request (ICCR). This system aims to promote participatory autism research by allowing researchers to post ads seeking autistic people to collaborate on research projects. Browse all currently active collaborator requests here - https://www.autism-insar.org/networking/opening_search.asp
- If there is a professor/researcher whose work you are interested in, you may choose to reach out via email and see if they have available positions. An introductory email should include the project(s) you are interested in, your relevant experience, and a preferred way to contact you (see Appendix A).
- If you are interested in joining an advisory board, but are not familiar with any projects or researchers, you may choose to find a university near you and look through their faculty profiles. Faculty pages will typically include a researcher's current projects, recent publications, curriculum vitae (a history of one's academic credentials with a similar purpose as a resume), and an email.

When reaching out via email there are a variety of responses you may receive. You may get an invitation to join an advisory board, be asked to contact again at a later time, receive no response, or anything in between. If you do not hear back from someone, it is appropriate to send one repeat email to follow-up approximately 5-7 days after your initial email. If you still do not hear back, it would be appropriate to stop emailing them.

WHAT TO PREPARE BEFORE JOINING AN ADVISORY BOARD

When applying to advisory boards, or after connecting with researchers, there are several documents you will want to prepare as well as decisions you will need to make regarding your presentation and identification.

RESUME

- The first thing you will need to prepare is a resume. This is typically a one-page summary of your educational and work background, skills, and qualifications. Resources such as Microsoft Word and Canva have resume templates available for free, and resume examples can be found online. Additionally, if you are a student or connected to a university, you may have access to a professional writing center that can assist you in resume creation.

BRIEF BIO

- Depending on the position, you may be asked to create a brief bio which includes your experiences and qualifications written in biography format and catered specifically to the project or role you are applying for. Here is where you can share unique aspects of your background that may be applicable to the area of research such as a late or self-diagnosis, cultural background, sexual orientation, etc. If you are asked for a biosketch, clarify whether they want a brief paragraph biography, or the National Institutes of Health (NIH) format known as an “NIH biosketch.” If they request an NIH biosketch, you may ask for further instructions or support and/or seek out examples online. Formatting guidelines for both types can differ based on the specific organization, but an example brief bio can be found in Appendix B.

SELF-DISCLOSURE

- Before joining an advisory board, you may need to reflect and consider how much

of yourself and your identity you are comfortable sharing. For example, would you be comfortable sharing a photo of yourself, keeping your camera on during virtual meetings, sharing your preferred name and/or pronouns, etc. Setting clear boundaries for yourself before beginning a position may help you to advocate for those needs once the role begins.

- Similarly, joining an autistic advisory board may require you to be public with your identity as an autistic person at least to those present on the board and the research team. If this is something you are not yet comfortable with, you may want to discuss joining at a later date or the possibility of remaining anonymous.

BACKGROUND KNOWLEDGE

- Though not always necessary, it may be useful to have some degree of understanding of the research process. Skills such as learning how to review research papers and understanding the grant and Institutional Review Board processes can broaden your opportunities to engage in research.

HANDLING REJECTION

- As with applying for any job, you need to prepare yourself for the possibility that you will not get the position every time. Researchers are often very specific about the kind of experience they are looking for and it may take a few tries before you find a position that is right for you.



COMMUNICATING ACCOMMODATIONS

Accommodations are something that anyone (neurotypical or neurodiverse) may need to participate fully in a given setting. Researchers may reach out to you specifically asking about accommodations you may need, or you may be provided with a list of possible accommodations. However, if the researcher does not ask, you are still able to reach out and request accommodations. Here are some examples of potential accommodations you can request:

- Printer-friendly materials
- Extra time to complete work
- Meeting reminders
- Closed captioning during meetings
- Use of chat box instead of verbal participation
- Extra information on dress codes, parking, navigating to meeting space, etc.
- Extent to which you may work from home/remotely
- Potential for 1 on 1 meetings instead of groups
- Written as opposed to verbal feedback

If you do not feel your accommodation needs are being met or they are not received in a way that makes you feel comfortable, you may want to send a gentle reminder to the research team. However, you may ultimately decide this project is not a good fit for you and seek out a different advisory board. It may also be possible that you learn to meet expectations of position with assistance, and you may need to have the researcher be very clear about how that will be accomplished. For example, if you are expected to be in person as a part of this Advisory Board, is it possible to slowly transition to in person and figure out how you can do this (e.g., bus schedule, timing, where you perform work, etc.)?

TASKS TO EXPECT

As an expert advisor with your unique lived experience, there are specific tasks you may be asked to do to aid in the research process. These tasks can include, but are not limited to:

- Helping to generate research ideas
- Reviewing research proposals to ensure the scope of the research has relevance to autistic people. I.e., is the aim of this project attempting to solve an issue that matters to autistic people
- Collaborating with researchers to co-construct a study
- Reviewing data collection instruments such as surveys, questionnaires, interview questions, etc. You may be asked to comment on the wording and clarity of questions and the kind of information the instrument is looking to collect.
- Giving feedback on handouts and other deliverables that participants will receive.
- Providing comments on research hypotheses, presentations, papers etc. Researchers may ask you to review materials and provide comments from your perspective.

Tasks will differ from project to project, but in an advisory role you will need to be comfortable voicing your opinion and providing feedback. It is also important to remember that though you are an autistic advisor, you are not able to speak for every member of the autistic community, and the research team should not expect this of you.



VOCABULARY

There is certain vocabulary specific to research that will be consistent across projects. Some terms that may be helpful to know are:

- Principal Investigator
 - The primary individual responsible for the preparation, conduct, and administration of a research project, often referred to as the “PI”.
- Institutional Review Board (IRB)
 - The institutional entity charged with providing ethical and regulatory oversight of research involving human subjects
- Study Design
 - A framework, or the set of methods and procedures used to collect and analyze data on variables specified in a particular research problem
- Research question
 - A question that a research project sets out to answer
 - A sentence that defines what you will examine, within which population, and what the outcome of interest will be
- Recruitment
 - The process of finding, screening, and scheduling suitable candidates to participate in research studies
- Instrument Selection
 - Selection of instruments that will be used to collect data
 - Instruments can be:
 - » Questionnaires
 - » Surveys
 - » Interviews
 - » Observations
 - » Etc.
- Data Analysis
 - Summarizes collected data.
 - Interpretation of data gathered through the use of analytical and logical reasoning to determine patterns, relationships or trends
- Dissemination of Results
 - Spreading information you have learned
 - Getting the findings of your research to the people who can make use of them, to maximize the benefit of the research

PAYMENT

As an expert advisor, you should be paid for your work! Payment rates can differ based on the project and your specific responsibilities, but a generally reasonable rate is \$50-\$100 per hour. There are additionally different ways that payment may be received.

- Check
- Gift cards
- Prepaid card such as a Visa or ClinCard

Your research team will inform you on how and when payments will be received. If specific instructions on setting up the payment system are not provided, this is an additional accommodation you may choose to ask for.

Some projects, however, have no funding which may limit the researchers' ability to pay you. It is important to understand payment up front, so you can make an informed decision about if you would like to participate. You may consider being an unpaid volunteer to gain experience in the work of advisory boards before you would expect payment.

NAVIGATING DISAGREEMENTS

During your work as an advisor, you may be presented with opinions, beliefs, or research topics and methods that you do not agree with. This can create a difficult situation to navigate, but there are several things you may choose to do.

- As an advisor, you have the ability to respectfully disagree with the direction or methods of the research being conducted and voice these opinions at advisory board meetings.
 - If you are aware ahead of time of the issue at hand, you may choose to search and gather relevant evidence to support your points.
- If you do not feel comfortable presenting an opposing point to the larger group, you may choose to reach out to the principal investigator separately. You can do so via email or request a one-on-one meeting to further discuss the issue.
- If you have voiced your opinion and do not feel as if your points were heard or you are not satisfied with the outcome, you must decide if you wish to remain a member of the advisory board. If you believe the research fundamentally goes against your beliefs or you do not feel like you are a respected member of the research team, you may decide this project is not a good fit for you. However, if the disagreement is a matter of opinion and you feel as if you have more to offer the project, it might be in everyone's best interest for you to stay.

APPENDIX A – INTRODUCTORY EMAIL TEMPLATE

Dear Dr./Professor (_____),

My name is (_____). I came across your work through (insert where you heard of their research here – ex. your university webpage, the Autism Research Journal, etc.), and I am very interested in your project, (insert project name, if there is not a specific project you are interested delete this portion). I am wondering if you are looking for individuals to serve as expert research advisors for this project or others you are currently working on.

As a (here is where you can choose how you wish to identify, ex. BIPOC autistic person) I believe that I have unique lived experience that will be of use to your team. I have previously (worked on____/taken classes in____/insert how you gained experience). Additionally, I took part in a project consisting of 12 virtual meetings that aimed to train BIPOC autistic adults to serve as expert research advisors. I have attached my resume below so that you may further review my experience and qualifications.

I hope to hear from you soon. I can be reached at this email address and my phone number is (_____).

Best,

(Your Name)

APPENDIX B – BRIEF BIO EXAMPLE

Marguerite Sampson is a social work student and autistic self-advocate. Marguerite graduated from Lowell University with a degree in accounting, and then spent 12 years working at Freeman, Donovan and Chipp on developing content for workplace trainings. She pursued graduate training in social work in 2012, and since then has been employed by the Minnesota Department of Children and Families as a child trauma specialist. Marguerite presently resides in Minneapolis where she volunteers for a local environmental non-profit and enjoys hiking, cooking, and fostering dogs.



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