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AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as Co-Researchers and Study Participants

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Running Title: Inclusion Guidelines for Adult Autism Research

Keywords: Autism, Adults, Participatory Research, Survey Adaptation, Qualitative Research, Research Ethics

Acknowledgements:

We would like to thank all our current and past team members from the Academic Autism Spectrum Partnership in Research and Education, the Partnering with People with Developmental Disabilities to Address Violence Consortium, and the Pregnancy Decision-Making and Supports for Women with Developmental Disabilities Project.

Funding:

This work was funded, in part by the National Institutes of Health (R34MH111536, R34MH092503, R21MH112038, and R21HD0788300), the Centers for Disease Control and Prevention (RTOI 2009), and the Oregon Clinical and Translational Research Institute (OCTRI), grant number UL1 RR024140 from the National Center for Research Resources (NCRR), a component of the National Institutes of Health (NIH), and NIH Roadmap for Medical Research.

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article are those of the authors and do not necessarily represent the views of the U.S. Department of Veterans Affairs, the National Institutes of Health, or the Centers for Disease Control and Prevention.

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Abstract

As interest in autism in adulthood grows, so does the need for methods to promote the inclusion of autistic adults in research. Our objective was to create practice-based guidelines for the inclusion of autistic adults, both as research team members and study participants. We conducted an institutional ethnography of three closely-related research partnerships that used participatory methods with autistic adults over the years 2006-2018. We used an iterative approach which combined discussions with community and academic partners and artifact review. Guidelines to promote the inclusion of autistic adults as co-researchers focus on being transparent about partnership goals, clearly defining roles and choosing partners, creating processes for effective communication and power-sharing, building and maintaining trust, disseminating findings, encouraging community capacitation, and fairly compensating partners. Guidelines to promote the inclusion of autistic adults as study participants focus on maximizing autonomy and inclusion, creating an accessible consent process, offering multiple modes of participation, adapting survey instruments for use with autistic adults, creating accessible qualitative interview guides, and handling data from proxy reporters. Although these practice-based guidelines may not apply to all research teams, we hope that other researchers can capitalize on these practical lessons when including autistic adults in research.

Despite autism being a lifelong disability, most autism research, advocacy, and services have focused on children. According to the Interagency Autism Coordination Council, adult issues accounted for only 2% of autism research funding in the United States between 2008 and 2015 (Interagency Autism Coordinating Committee, 2017). As the large cohort of children diagnosed with autism in the late 1990s and early 2000s enters adulthood, recognition of the gap in knowledge about adult autism has grown, with multiple international calls for increased research on issues affecting autistic adults (Howlin & Magiati, 2017; Piven & Rabins, 2011; Warner, Parr, & Cusack, 2019).

Filling this gap requires not only a shift in funding priorities, but also attention to research methods and approaches. Whereas some of the methods for conducting research with autistic children may translate to adults, the inclusion of autistic adults in research--as research participants, researcher partners, or both--may require significant changes to existing methods. For example, although parents or guardians commonly participate in studies as proxies for their young autistic children, proxy reporting for adults raises serious ethical and scientific validity concerns (McDonald & Raymaker, 2013). Similarly, whereas some autistic adults may be able to participate directly in research without accommodations or supports, others cannot, limiting the generalizability of findings from studies that don't provide them.

Autistic adults have fought to be included in research as both research participants and research partners, making the case that the disability rights motto "nothing about us without us" applies just as much to research as it does to any other realm (Milton & Bracher, 2013; Robertson, 2010). Although a growing number of autistic individuals are entering academia as scientists, there is also value in the use of participatory methods to include autistic adults outside academia. Participatory approaches to research have existed since the 1940s and have become common in other domains, such as the study of racial and ethnic disparities (Minkler & Wallerstein, 2011). Such approaches, however, have been slow to enter the field of autism research, with early reviews identifying our partnership (the Academic Autism Spectrum Partnership in Research and Education; www.aaspire.org) as one of the only examples (Jivraj, Sacrey, Newton, Nicholas, & Zwaigenbaum, 2014; Pellicano, Dinsmore, & Charman, 2014; Wright, Wright, Diener, & Eaton, 2014). In more recent years, interest in participatory approaches to autism research has blossomed (Crane, Adams, Harper, Welch, & Pellicano, 2018; Fletcher-Watson et al., 2018; Gillespie et al., 2017)) and new participatory research partnerships have emerged (e.g. www.shapingautismresearch.co.uk; www.autismcrc.com.au; www.PARCautism.co.uk; www.research.ncl.ac.uk/adultautismspectrum).

As interest in the inclusion of autistic adults in research grows, the need for practice-informed guidelines becomes more urgent. Our objective was to use our experience from the last 12 years to offer researchers practical recommendations for including autistic individuals as research partners, research participants, or both.

Methods

We wished to ground the guidelines in practical lessons from our experience. As such, we conducted an institutional ethnography (Campbell, 1998) focused on three collaborations that conducted participatory research with autistic adults between 2006 and 2018.

Institutional Context:

The Academic Autism Spectrum Partnership in Research and Education (AASPIRE)

AASPIRE (www.aaspire.org) is an international partnership, based in the United States, that brings together academic researchers, autistic adults, family members, disability services providers, and healthcare providers to conduct research relevant to the needs of adults on the autism spectrum. Since its founding in 2006, our partnership has adhered to the principles of Community Based Participatory Research (CBPR) (Israel et al., 2003), whereby academics and community members share power as equal partners throughout the research process. More details about our collaboration are described elsewhere (Nicolaidis & Raymaker, 2015; Nicolaidis et al., 2011; D Raymaker et al., 2009; Dora Raymaker & Nicolaidis, 2013). We have completed six federally-funded observational and intervention studies using mixed methods (Nicolaidis et al., 2013; Nicolaidis et al., 2016; Nicolaidis, Raymaker, Ashkenazy, et al., 2015; D. M. Raymaker et al., 2016); developed an online healthcare toolkit *(www.autismandhealth.org)*; are actively working on two new federally-funded projects (a mixed-methods intervention study on healthcare and a qualitative study on employment); and are conducting a new exploratory study on autistic burnout. Over the years, we have also offered consultations to multiple other investigators who requested our input to design studies, create research partnerships, or ensure that study materials were accessible to autistic adults.

Partnering to Address Violence Against People with Developmental Disabilities (the Partnering Project)

The Partnering Project was a federally-funded quantitative survey study to assess the relationship between violence and health in people with developmental disabilities. The multi-site partnership (Oregon and Montana, USA) included academic researchers, autistic adults, adults with intellectual disability, family members and disability services providers. Many academic and community partners also had concurrent physical or sensory disabilities. We used a CBPR process to adapt measures to be accessible to autistic adults and adults with intellectual and developmental disabilities (IDD) (Nicolaidis, Raymaker, Katz, et al., 2015); to create an accessible audio computer-assisted self-interview system (ACASI) (Oschwald et al., 2014), and to analyze and disseminate results (Hughes et al., 2019; Platt et al., 2017).

Pregnancy Decision-Making and Supports for Women with Developmental Disabilities (the Pregnancy Project)

The Pregnancy Project was a federally-funded qualitative study to understand the pregnancy experiences of autistic women and women with intellectual disability. The project used a community-partnered approach whereby a community advisory board of autistic women and women with intellectual disability provided feedback at six time points. We used the qualitative study findings to create a set of videos featuring study participants and advisory board members to help women make better-informed pregnancy choices (www.pregnancyanddisability.org).

Each of the original studies were approved by the Institutional Review Boards (IRB) of the related universities.

Guideline Team.

The first two authors led the creation of the guidelines. They have served as the Co-Directors of AASPIRE since its founding and held leadership roles in all 3 collaborations. One is a physician-scientist who had been conducting CBPR with other marginalized communities and developed

an interest in autism after her son's diagnosis. The other is an autistic adult who started as AASPIRE's community lead and has since transitioned to an academic role as a systems scientist (D. M. Raymaker, 2017). Recently active academic and community partners from each of the three collaborations reviewed and refined the guidelines, as described below. This paper's co-authors include seven autistic adults (two with dual roles in academia) and three non-autistic academic researchers. Each of the three partnerships is represented by two or more autistic partners.

Guideline Creation Process

As is expected in institutional ethnographies, we treated both the team's experiences and the artifacts from our projects as data (Campbell, 1998). We used an iterative process with multiple cycles of artifact review, team discussions, feedback, and revision.

Artifact review.

The first two authors systematically reviewed:

- Agendas and minutes from 119 team meetings that included community partners;
- All formal collaboration agreements (e.g., authorship guidelines, meeting ground rules, policies);
- 21 grant proposals and reviewer critiques;
- 17 publications;
- 10 IRB protocols.

They also selectively reviewed additional materials, as needed, to confirm or expand on specific issues related to the guideline discussions. Sources included:

- Personal emails and the AASPIRE and Partnering Project community partner listservs;
- Change logs detailing how materials were revised based on partner feedback;
- Reviewer comments on submitted manuscripts;
- Posters or slides from presentations at professional meetings.

Team discussions and feedback.

The two first authors met to discuss their recollections of the important lessons they had learned over the past decade and drafted an initial set of guidelines. They then shared the draft guidelines with academic partners and autistic adults who had recently participated in each of the three partnerships and made revisions based on their feedback. Academic and community partners later met to discuss their recollections and further refine the guidelines. Co-authors also edited multiple versions of the manuscript.

Results - Lessons Learned and Practice-Based Guidelines

Inclusion of Autistic Adults on the Research Team

Box 1 summarizes our guidelines for the successful inclusion of autistic individuals as partners in research. Examples of our collaboration materials are available at www.aaspire.org.

<Insert Box 1 approximately here.>

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

From the start, AASPIRE aimed to use a CBPR approach, where academic and community partners share power as equal partners through all phases of the research. While this approach worked well for AASPIRE, and later for the Partnering Project, CBPR requires a high level of commitment to community-engagement and may not be the right fit for all projects. Our Pregnancy Project used a consultative model in which a community advisory board provided input throughout the project, but where partners were not as deeply immersed in the research process or decision-making as in the other two partnerships. AASPIRE has also provided consultations to researchers who were seeking input from autistic adults. It has been helpful for teams to openly discuss partnership goals, including when and how partners will be involved, and how much say they will have in decisions. These goals can then drive the team's infrastructure and processes. For example, we have at times chosen to use academic and community co-principal investigators, steering committees, or community councils with decision-making capacities to help support power sharing goals. (For more details see (Nicolaidis & Raymaker, 2015) Regardless of approach, it is important for projects to avoid tokenizing autistic individuals.

Inappropriately calling all participatory projects "CBPR" can have detrimental effects, including frustration, unmet expectations, reduced trust, and wasted resources. For example, one of our community partners described the frustration and anger she experienced working on another project that had been promoted as "CBPR," but where community members were in an advisory role with no decision-making power. She felt her frustration would have been lessened if expectations had been clear from the start. Another partner warned against using the complicated, convoluted language of participatory research, noting that the terminology itself can be difficult and off-putting, convincing potential partners that they will be unable to collaborate because they don't understand the terms.

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.

The core feature of participatory approaches is that members of the population being studied are a *part of the research team*. Assembling such a team can be challenging. We have found that clearly articulated, written descriptions of roles and responsibilities are necessary when recruiting community partners. We have at times seen investigators try to obtain a random or representative sample of autistic individuals to serve as community partners. Such attempts may be appropriate for recruiting study participants, but they devalue the role of community partners; after all, teams need to include academic co-investigators with specific characteristics and expertise, not a random sample of all researchers. We have found that creating a balance between autistic community leaders and other autistic adults is important. We have also sought autistic partners with particular types of lived experience in the same way one might seek an academic co-investigator with specific content expertise. For example, we had to make a special effort to recruit partners who lived in group homes, were transition age, had high support needs, or were people of color. Knowing that there are inherently challenging power dynamics between autistic individuals and stakeholders without disabilities, we have tried to include non-autistic partners who truly value the insights of autistic individuals, will make the necessary accommodations, and are willing to share power.

Long-standing partnerships such as AASPIRE may lose partners over time as their interests and availability change, but adding new partners in the middle of an ongoing study can be challenging. We have found it best to add new partners at the beginning of each new study,

making sure to orient them individually and then including them in a study kick-off meeting with the whole team.

Create processes for effective communication and power-sharing.

Communication and power-sharing are at the very core of all participatory approaches. As is recommended throughout the participatory research literature, it is important to jointly create guidelines and policies related to power-sharing, decision-making, and dissemination. We have found that structured processes for reaching consensus, such as the 5-finger method (Nicolaidis et al., 2011), can help ensure that all partners are included in the decision-making process while increasing efficiency. Ultimately, the goal of almost all of the collaboration guidelines discussed in this paper is to equalize power.

The first author began her career conducting CBPR with communities defined by race/ethnicity and violence victimization. While the theoretical issues related to power-sharing are the same for research with autistic adults, they sometimes played out differently. For example, AASPIRE decided to conduct meetings over text-based instant messenger chat (starting in 2007, when such communication was far less common than it is now). This decision not only improved autistic partners' ability to participate in meetings, but it also helped equalize power and build empathy among non-autistic team members about the experience of communicating in a non-preferred mode (Nicolaidis et al., 2011).

Similarly, we found that accommodations were particularly crucial to successful communication and power-sharing, as was the use of accessible language and formats. Example strategies and accommodations for enabling our partners' participation include multiple formats for participation, individualized alerts and reminders, opportunities to review materials advance, pre-meetings, one-on-one support during meetings, structured email formats, strong meeting facilitation with clear agendas and transitions, communication etiquette guides, sensory supports (e.g. fidgets, natural lighting), and American Sign Language (ASL) or other interpretation. These accommodations have allowed us to authentically include partners with intellectual disability (The Partnering Project and the Pregnancy Project), limited spoken language (AASPIRE), and high support needs (all 3 partnerships). Individual partners made use of varying groups of accommodations. Many accommodations were helpful to partners with varying levels of support needs, while others (e.g. one-on-one support; ASL interpretation; individualized alerts) were only used by a small number of team members. We have found that it is best to assess accommodation needs when a new partner joins the group, and then to regularly reassess needs and adjust processes over time.

Participatory approaches are commonly used – and expected – in research with other marginalized populations, but at least when we started AASPIRE, they were practically unheard of in autism research. Whereas typical reviewer comments on CBPR projects related to racial/health disparities pushed investigators to focus even more on power-sharing, early reviews of our proposals questioned whether autistic adults could even serve as research partners. Alternatively, when we demonstrated our successful inclusion of autistic adults as partners, reviewers often assumed that our partners must not be "truly disabled." In recent years, we have noted a much more positive response from reviewers. However, as participatory methods have become more common in autism research, we have also noticed that autism researchers, many of whom have not been trained to closely consider issues of power and privilege, are often unprepared to meet the demands of working with community partners. For example, in discussions at professional conferences, we have heard researchers describe challenges that are quite typical in academic-community partnerships. However, whereas

academics working with other marginalized populations are trained to interpret such issues as indications of the need for greater attention to power-sharing, autism researchers often attribute challenges to partners' disability-related "impairments" (e.g., their perceptions that autistic adults cannot appreciate other perspectives or be flexible) or to the heterogeneity of the spectrum (i.e., that anyone who can communicate their disagreement with the researchers' perspectives is not disabled enough to represent their study population). We strongly urge academic researchers to continuously consider how their power, privilege, and potential biases may be affecting the collaboration and to avoid pathologizing community partners when disagreements arise.

Regularly focus on building and maintaining trust.

The success of any partnership largely depends on building and maintaining trust. This is an ongoing process of listening, respect, planning, follow-through, willingness to learn from each other, forgiveness, change, and celebrating success. We have found that visioning exercises at the beginning of new projects can help clarify and solidify shared goals. Exercises to help team members get to know each other on a personal level have also been helpful, especially when bringing in new members. Researchers need to actively demonstrate that they value lived experience. As one of our partners commented, "Once I learned that it was not only okay, but highly encouraged for *me* to give opinions to scientists wearing tweed, I was able to relax and bring a lot more to the table than I otherwise would have."

The above strategies can be used in participatory projects with any populations, but we have found that there may be special nuances when working with autistic adults. For example, part of showing respect for community preferences included creating a policy, early on, stating that we would use identity-first language or neutral terms such as "on the autism spectrum" as opposed to person-first language. Similarly, given tensions between the community of autistic adults and parents of autistic children, team members who are parents of autistic individuals sometimes felt they had to work even harder to demonstrate their respect for the perspectives of autistic adults. Finally, we found that our autistic community partners often paid closer attention to detail than the community partners with whom the first author had collaborated in non-autism focused projects. Building trust often depended on academic partners meticulously addressing all feedback (and authentically apologizing when they occasionally missed small details on the first round). Similarly, autistic partners gained the trust of academic partners by consistently participating in meetings and by thoughtfully engaging in discussions.

No collaboration is perfect, and regular evaluations can help teams improve their processes. We have used a variety of evaluation strategies. For example, we regularly reserve the last few minutes of meetings for keep/change exercises where partners indicate what from today's meeting they would like to keep doing and what they would want to change. This information has resulted in countless small but important improvements. We have also conducted larger evaluations at key milestones. In some cases, an academic partner (other than the Principal Investigator) has led the evaluation, soliciting confidential input from each team member and compiling it into recommendations for the group. The Partnering had a formal external evaluation, including a qualitative study of team members' experiences (McDonald & Stack, 2016). Interim findings from the evaluation resulted in a major change in the group's infrastructure to make steering committee meetings more accessible (Nicolaidis & Raymaker, 2015).

Collaboratively disseminate findings.

We have collaboratively tried to decide how to present our findings to minimize stigma or harm, and to use findings to advance community priorities or goals. All individuals who make "substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work" must be offered the opportunity "to participate in the review, drafting, and final approval of the manuscript," and thus meet full authorship criteria (International Committee of Medical Journal Editors, 2017). Since community partners, by definition, make such contributions, all our CBPR projects have authorship guidelines requiring the inclusion of community partners as co-authors on scientific articles. Co-authorship, however, may require additional work when including lay individuals in scientific writing. In AASPIRE, our community partners have been able to review annotated versions of manuscripts, with comments explaining technical sections in lay language, and make suggestions for edits. The Partnering Project, however, included partners with widely varying levels of reading comprehension. As such, we created a document that placed each paragraph of the draft manuscript into one column of a table, with a lay translation in the second column. We then held group or individual meetings where we read and discussed the information in the lay translation column. Partners offered substantive suggestions for revisions of the content and thus met authorship criteria. Dissemination efforts must not be limited exclusively to scientific publications. We have co-created lay language briefs for non-academic venues. Community partners have also often led efforts to disseminate information to practitioners, the lay press, and the autistic community.

Actively encourage community capacitation.

One of CBPR's principles is to foster co-learning and capacity-building among all partners (Israel et al., 2003). In some cases, that has meant hiring autistic partners as research assistants, or supporting autistic adults to obtain advanced degrees and enter academia as insider researchers (i.e., researchers who identify as being a part of the community being researched) (D. M. Raymaker, 2017). That said, recognizing the power differentials between faculty and students, interns, or research assistants is important. Moreover, including only autistic adults who have the potential and interest to become academic researchers leaves out important perspectives. As such, we have found that it is critical both to support the training of autistic academics and to include autistic community leaders and other autistic individuals from non-academic settings. Autistic partners have also used skills they developed as part of the collaboration to obtain jobs outside of academia.

Fairly compensate community partners for their work.

Fairly compensating community partners for their work is important but can be challenging. We have followed the principle that if we have funding to pay study participants, academic co-investigators, or research staff, we also compensate community partners. We have sometimes used discretionary funds to pay partners even when there is no formal funding for a study. In all cases, we have tried to be transparent about funding and compensation. Our structured template for communications includes a category indicating how much compensation partners will receive, if any, for attending a meeting or completing a task. We have found that partners understand funding constraints and make decisions about volunteering for activities that do not offer compensation.

Inclusion of Autistic Adults as Study Participants

Box 2 summarizes our guidelines to promote the successful inclusion of autistic adults as study participants. Example study materials are available upon request.

<Insert Box 2 approximately here.>

Protocols should avoid the risk of coercion and exploitation while maximizing autonomy and inclusion.

Our review identified many internal and external communications (e.g., meeting minutes, email messages) related to human subjects, especially regarding decisional capacity and informed consent. We found successful resolutions to each dilemma by using strategies to avoid risk of undue influence or exploitation, and keeping self-determination and inclusion as the central goal. Questions often revolved around who can offer consent (i.e., the autistic participant versus a legally authorized representative) and who needs to have an assessment of decisional capacity.

As we have clarified with our ethics committee, decisional capacity is affected by study factors (e.g., complexity of the decision; level of risk), participant factors (e.g., cognitive function, communication skills), and the consent process itself (e.g., accessibility of materials, use of accommodations and supports). Researchers must not assume that anyone with a diagnosis of ASD has impaired decisional capacity. Requiring autistic participants to complete an assessment of decisional capacity, simply due to their diagnostic label, is highly offensive to autistic adults and best categorized as discriminatory. In trying to decide when to use such assessments, we have taken into account the level of risk and the types of decisions participants make on a regular basis. For example, our ethics committees have allowed us to forego assessment of decisional capacity in low-risk, online studies. Justification for this approach lies in the assumption that if an individual can access the internet independently, they are regularly making decisions that carry a level of risk at least as high as that of taking part in our survey.

In cases where it is unclear if a participant has decisional capacity, we have used an accessible informed consent process including, when possible, multiple efforts to explain information, and a brief comprehension assessment to confirm understanding of the information. Participants who can answer “yes”/”no” questions correctly about the voluntary nature of the study, what participation entails, and study risks may make their own participation decision. Participants who have challenges with comprehension should be meaningfully included in the decision-making process and provide assent.

Researchers must make the consent process as accessible as possible.

Given that our autistic partners have found standardized consent form templates to be highly inaccessible, we have devoted many community partner meetings to improving their accessibility. In discussions with other investigators, we have found that researchers sometimes believe that they cannot change their institution’s consent form templates. We have successfully asserted that it is necessary to adapt standard consent form templates to increase accessibility, especially to meet the needs of autistic participants who may have challenges with literacy and language pragmatics. We have worked with our autistic partners to make the language on consent forms simpler and more concrete, remove sections that unnecessarily hinder comprehension, add images, and provide text-to-speech or ASL versions of online consent forms. While such changes may not be necessary for all autistic participants, they allow inclusion of participants with a wider range of ability.

We have noticed a misconception that written consent is required in all studies. Printing, signing, and returning a consent form by mail require executive functioning skills and resources and may unnecessarily exclude autistic participants from research. With appropriate justification, we and others have been granted waivers that allowed us to obtain consent and authorization online without need for participants to return a signed document. Our community partners have played a critical role both in creating accessible consent materials and in justifying the modifications to our ethics committees. We believe that more accessible processes can increase autonomy, improve informed consent, increase inclusion, and reduce the need for proxy consent.

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

Throughout this work, we used multiple strategies to increase the proportion of autistic adults who can directly participate in our surveys as research subjects. Such strategies have allowed us to collect data from participants with intellectual disability, little spoken language, challenges with language comprehension, low literacy, high levels of anxiety, or high support needs. We have found that some modes of participation privilege some participants and disadvantage others. From the start, we respected autistic adults' preferences for participating in surveys online rather than via telephone or in person, given challenges with auditory processing, transportation, or social interactions. However, when we offered exclusively text-based, online options for participation, we found that individuals with low educational attainment were under-represented in our sample (Nicolaidis et al., 2013). We have since expanded the educational diversity of our samples by including in-person options or adding read-aloud features for computer-based surveys (Nicolaidis et al., 2016; Nicolaidis, Raymaker, Ashkenazy, et al., 2015).

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

In our experience, autism researchers, like others, may hesitate to modify a "validated instrument" because they are relying on prior studies of the instrument's psychometric properties. However, one cannot assume that instruments validated in general populations, with caregivers, or with autistic children are valid for use with autistic adults. In such cases, one must assess the need for adaptations, and if present, modify the instrument and re-test its psychometric properties.

The use of a participatory process has allowed us to adapt and validate multiple instruments for autistic populations (Nicolaidis, Raymaker, Katz, et al., 2015; Nicolaidis et al., 2013; Nicolaidis et al., 2016; D. M. Raymaker et al., 2016). This process includes several steps: first, we show our autistic partners standardized instruments that measure each construct in question. Partners select which instrument they feel is most accessible and best captures each construct. If they feel the instrument can be used as is, we include that instrument and re-assess psychometric properties in an autistic population. In our experience, however, autistic partners have found most existing instruments inaccessible, often due to imprecise language, confusing terms, or ableist assumptions. We start with the instrument that they select, and work together to improve accessibility, emphasizing the importance of not changing the intended meaning of items, and only changing items that they feel would cause significant problems. With scored scales, to facilitate comparisons with data using the original instrument, we also try to not change the number of items, types of response options, or scoring.

Autistic partners have occasionally found response options problematic, especially when they include vague terms that might be subject to varied interpretations (e.g., “most of the time” vs “some of the time”). Suggestions by some partners to add precision (e.g. “80%-90% of the time”) have raised concern from others who are uncomfortable with mathematical concepts. We obtained consensus by adding graphics to Likert-type scales, such as cylinders filled to varying degrees, so that, for example, the words “most of the time” are accompanied by a cylinder that is 80% full (Nicolaidis, Raymaker, Katz, et al., 2015). Our collaborative process has resulted in similar adaptations over multiple instruments and projects. Adapted instruments have generally had strong psychometric properties.(Nicolaidis, Raymaker, Katz, et al., 2015; Nicolaidis et al., 2013; D. M. Raymaker et al., 2016)

Create accessible qualitative interview guides.

Reviewers of our early grant proposals questioned whether qualitative research was even possible with autistic adults, citing concerns that they may lack the “insight” or “self-reflection” to participate in such studies. Others have raised more appropriate concerns, such as autistic adults’ challenges with open-ended questions or processing information in real time. We have worked with our community partners to find ways to address such challenges and have successfully obtained insightful, rich qualitative data from participants in multiple projects.

From the start, our partners stressed the importance of offering multiple modes of participation in qualitative studies. Participants have strongly echoed this sentiment, with some stating that they would only be willing or able to participate using a specific mode. Based on these experiences, we believe it is important to offer multiple forms of synchronous and asynchronous modes of communication.

Reviewers of early grant proposals also raised concerns that the use of non-traditional interview modes such as email or instant-messenger chat might not produce rich data. Though data collected using different modes has been different in style (e.g., email responses have tended to be more grammatically correct than those collected using spoken modes), all modes have yielded rich, useful data, without significant differences in themes. Thus, we have not felt that stylistic differences precluded the combining of results from multiple modes.

Also based on community partner feedback, we have started qualitative interviews with a detailed preface explaining the type of information we are seeking. An example of a statement included within such a preface is as follows: “Colorful stories are more helpful than short answers. Give us as much detail as you can so you can ‘take us there,’ as though we were watching a movie.”

Our community partners have helped craft interview guides by editing draft questions, often making them more precise or offering greater context about what is wanted. We also learned from trial and error to make questions concrete. For example, one of our original interview guides asked what participants liked or disliked about healthcare and how they felt being on the spectrum influenced their care. While some participants answered such questions with ease, others could not. We revised the interview guide, asking them to describe what happened in each stage of a typical office visit. We found that this format yielded rich data from participants with a wider range of abilities. We have successfully used both autistic and non-autistic interviewers to collect qualitative data.

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

Though we have always tried to collect data directly from autistic adults, some cannot participate directly, even with the accommodations described above. In such cases, we have needed to collect data from supporters. We have learned to distinguish between cases where the supporter is helping a participant in the study (for example, by calling to initiate the process, navigating the computer system, reading items out loud, paraphrasing them, typing the participant's answers, etc.), and when the supporter is answering questions on behalf of the autistic adult with minimal input. We consider the former a "supported participant" and the latter to be a "proxy reporter." We ask supporters to serve as proxy reporters only if it is impossible to support the participant to take part directly. It is important to consider what a proxy reporter can more reliably answer about a participant (e.g., demographic information, facts about diagnosis or service use) versus what they cannot (e.g., questions about the autistic individual's experience or thoughts). We have created separate surveys for proxy reporters, taking care to adapt the language of items so that it is clear when proxy reporters are answering information about the participant, and when they are providing their own perspectives about the participant.

Discussion

We conducted an institutional ethnography of our participatory research projects, focusing on practical lessons learned about the inclusion of autistic adults in research. Our experience over the past twelve years has shown that inclusion of autistic adults on the research team is feasible, important, and beneficial, but requires time and effort, clear processes for inclusion, a desire to learn from the community, and a genuine willingness share power. The inclusion of autistic adults as research partners has improved our ability to include autistic adults as research participants. We do not expect others to replicate our collaboration processes, but hope that the proposed guidelines assist researchers in successfully including autistic adults as team members, research participants, or both.

Our guidelines build on a strong literature and our own experiences conducting participatory research with other communities (Khodyakov et al., 2011; Nicolaidis & Raymaker, 2015; Oetzel et al., 2018). We started our collaborations knowing that issues of power-sharing, trust, communication, and equity would be at the core of our work, as it is with any participatory research project (Jagosh et al., 2015). Implementing participatory approaches with autistic adults bore countless similarities with work in other communities, but also required attention to autism-specific issues. Examples include the importance of understanding and respecting autistic community preferences, prioritizing communication modes (such as instant messenger chat) that privileged autistic partners, offering clear structures while maintaining flexibility, and paying close attention to the need for individualized accommodations. Probably the most notable difference was in how our work was originally received by the autism research community. Whereas it is typical for peer reviewers on grants or manuscripts in other fields that use participatory methods to push investigators to focus, as much as possible, on power sharing and equity, peer reviewers of our early projects expressed concerns about whether inclusion was even possible or desirable. The field has changed dramatically over the past decade, but challenges still remain. Interestingly, in a recent qualitative study of autism scientists' reflections on public engagement, scientists recognized the many potential benefits of participatory research, but attributed a considerable portion of the challenges to "the autistic impairment itself" (Hollin & Pearce, 2018). Our experience suggests that at least a portion of the challenges can be overcome by careful attention to the same power-sharing, trust, communication, and equity issues that are inherent in research with any marginalized community.

We found, both through our own work and in our consultations with other researchers, that transparency is key to successful collaborations. Though the literature describes dozens of different models for participatory approaches, it is helpful to start by considering whether the goal is for 1) input or consultation, 2) authentic inclusion or collaboration, or 3) an equal partnership. CBPR strives for an *equal partnership* between academic and community partners in all phases of the research (Israel, Schulz, Parker, & Becker, 1998). Whereas our AASPIRE and Partnering projects implemented a CBPR approach, CBPR may not be the most appropriate approach for all projects. Other collaborative models, such as the Patient and Stakeholder Engagement model (Sheridan, Schrandt, Forsythe, Hilliard, & Paez, 2017) developed by the Patient Centered Outcomes Research Institute, strive for authentic inclusion of non-academics throughout the research process, without expecting an equal partnership. A growing number of projects are using collaborative approaches to include autistic adults. Prominent examples are the Autistic Adults and Other Stakeholders Engage Together project (www.autistichealth.org) and the Cooperative Research Centre for Living with Autism (Autism CRC; www.autismcrc.com.au). Partnership models may also change over time. For example, while the Adult Autism Spectrum Cohort UK Project started with a consultation model, community partners developed a greater role in decision-making as the project progressed, and later served as co-researchers (Parr, 2018). In some models, such as Emancipatory Research, disabled people control the research, as in the case of a recent study where an autistic researcher engaged autistic members of a Facebook group to conduct a qualitative study on gender identity (Kourti & MacLeod, 2018). Our guidelines are meant to be flexible and can be used with a variety of participatory models.

In recent years, several groups, including the Autism Cooperative Research Center in Australia (Cooperative Research Centre for Living with Autism, 2016) and the Shaping Autism Research in the United Kingdom Seminar Series (http://www.shapingautismresearch.co.uk/) (Fletcher-Watson et al., 2018), have created guides, checklists, and “starter packs” to help inform participatory research with autistic adults. These materials were created in advance of conducting research, and thus were based largely on theoretical considerations and the preferences of potential community partners. Our guidelines align very well with these materials. However, our guidelines add practical experience, depth, and nuance derived from having conducted over a dozen participatory research projects with autistic adults.

Not surprisingly, many of our internal and external communications related to the protection of research participants. Given the historical transgressions against people with disabilities in research settings, ethics boards understandably pay attention to the protection of participants felt to be at risk of exploitation. At the same time, they must balance the risk of coercion and exploitation with the need for autonomy, inclusion, and justice. Unnecessarily excluding participants from research, obtaining information from proxies when it would be possible to obtain it from the participants, and denying individuals the right to make their own decisions are violations of rights (McDonald & Raymaker, 2013). As such, researchers and ethics boards must make every effort to make consent processes and study protocols accessible to a wide range of adults on the autism spectrum. While we have found that ethics boards may vary in their interpretation of ethical standards, focusing discussions on the underlying principles of respect for persons, beneficence, and justice can allow academic researchers, community members, and ethics committees to find mutually satisfactory solutions to common dilemmas.

Although researchers often, by necessity, collect survey data from caregivers in studies of young children, the use of proxies to collect data on behalf of older youth or adults with disabilities may inadvertently challenge a person's autonomy, diminish the validity of data, and raise ethical concerns (McDonald & Raymaker, 2013). As such, collecting data directly from

autistic participants is critical. A great portion of our time in team meetings with community partners focuses on the development or adaptation of survey instruments. Our community partners often feel that instruments developed for general populations are not accessible, usually due to confusing or imprecise language or ableist assumptions. Our process for adapting instruments in collaboration with community partners led to accessible surveys with strong reliability and validity (Nicolaidis, Raymaker, Katz, et al., 2015; Nicolaidis et al., 2013; D. M. Raymaker et al., 2016). McConachie and colleagues used a similar community-engaged process to adapt a quality-of-life measure for use with autistic adults (McConachie et al., 2017).

A small but growing literature reports on qualitative studies that gain in-depth understandings of the experiences of autistic individuals (Kirby, Schneider, Diener, & Henderson, 2018; Nicolaidis, Raymaker, Ashkenazy, et al., 2015; Sosnowy, Silverman, Shattuck, & Garfield, 2018). We spent considerable time in our community partner meetings co-creating qualitative interview guides. Over the course of conducting our own qualitative studies and consulting on other researchers' projects, we have recognized the importance of offering advance access to materials; including prefaces to help participants understand what is wanted; providing enough specificity, even with open-ended questions; and ensuring questions are sufficiently concrete. Our guidelines may help other researchers in the collection of survey and qualitative data from autistic adults.

Our guidelines have several limitations. Although they are created from our experience conducting multiple projects and consulting with a wide range of other researchers, other groups may find the need to adapt, expand, or alter them to meet their needs. We offer them to help others learn from our experiences, not to be prescriptive. Reviewing all communications that occurred over the twelve-year time-period was not possible, so our study relied on available artifacts and team members' recollections. Additional lessons might have been missed in our review. Similarly, we were not able to contact all our former community partners; partners who left the group in the early years may have different perceptions.

Although we are excited by the rapidly growing interest in research on autism in adulthood and in the use of participatory methods, we also recognize the potential risks. Studies with inadequate attention to methods for directly collecting data from autistic participants can have poor internal or external validity. Projects that claim to be participatory but fail to create equitable partnerships can lead to increased mistrust of research by the autistic community, which itself may worsen participation rates and lessen the impact of findings. We created the AASPIRE inclusion guidelines as an attempt to help other researchers capitalize on the practical lessons learned from our experience.

Box 1: 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.

Box 2: 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 re-test 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.

- 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.

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