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

Lay 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 focused on three closely-related research partnerships that used participatory methods with autistic adults over the years 2006-2018. We held discussions with team members and reviewed hundreds of documents from these projects.

Resulting guidelines to promote the inclusion of autistic adults as co-researchers offer recommendations to help academic-community partnerships: 1) be transparent about partnership 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; 3) create processes for effective communication and power sharing; 4) focus on building and maintaining trust; 5) collaboratively disseminate findings; 6) actively support autistic team members’ academic and professional development; and 7) fairly compensate community partners.

Similarly, guidelines to promote the inclusion of autistic adults as study participants offer recommendation to help researchers: 1) avoid the risk of undue influence and exploitation while maximizing autonomy and inclusion; 2) create an accessible informed consent process; 3) maximize inclusion of autistic participants with differing strengths and needs; 4) create accessible survey instruments and qualitative interview guides; and 6) appropriately use 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.