



Strategies for Developing Workshop and Training Materials for Autistic Partners

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Introduction

“Nothing About Us Without Us” is a movement to recognize people with autism spectrum disorder (ASD) as partners through collaboration and by empowering decision-making.

This participatory involvement can improve our communication with the autism community and help create workshops and training material that emphasize abilities rather than disabilities.

Developing teaching materials with autistic people involves many considerations that can be addressed by using strategies for successful collaboration by providing appropriate supports, using effective communication, and developing trust.

There are several research participatory guidelines that detail how to successfully work with someone with autism. These can also be used when collaborating with someone with ASD in the creation of educational materials.

What We Believe In

- **Developing partnerships** with individuals with ASD to promote occupation, advance inclusion and provide opportunities for participation.
- **Involving individuals** with ASD in developing materials about ASD.
- **Empowering individuals** with ASD with the opportunity to self-advocate.
- **Promoting decision-making** in the ASD community.

Scan here to see the authors discuss their work.



Video Presentation



Transcript

Acknowledgements

Appreciation is extended to the Texas Higher Education Board for the grant funding this project.

Utilizing Participatory Guidelines for Research

Many research guidelines for conducting research on or with autistic partners are available online or in the research literature. The two presented here emphasize the adaptability and flexible use of their guidelines.

Table 1. Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Guidelines adaptations to promote the successful inclusion of autistic adults

AASPIRE Guidelines		Developing Workshops and Training Materials with Partners with ASD
1	Have transparent partnership goals and choose an approach to match those goals.	<ul style="list-style-type: none"> - Determine type of partnership most appropriate for project (equal partnership vs. collaboration vs. consultation) - Communicate type of engagement expected based on selected partnership approach
2	Clearly define community partner roles, and consider who to include on the team	<ul style="list-style-type: none"> - Describe roles and expectations and select partners who can commit to them. - Identify people who are willing to share power with autistic partners.
3	Create processes for effective communication and power-sharing	<ul style="list-style-type: none"> - Agree on a structured process for making decisions. - Assess individual accommodation needs and provide materials in advance - Provide clear meeting agendas, time to process, and cues for transitioning.
4	Regularly focus on building and maintaining trust.	<ul style="list-style-type: none"> - Actively listen to community partners' views and demonstrate that you value the expertise that comes from lived experience. - Celebrate success and make space for humor and fun.
5	Collaboratively disseminate findings.	<ul style="list-style-type: none"> - Find ways to share the project to advance community priorities or goals.
6	Actively encourage community capacitation.	<ul style="list-style-type: none"> - Offer opportunities to pursue education and participate in other projects.
7	Fairly compensate community partners for their work.	<ul style="list-style-type: none"> - Be transparent about project funding.

Table 2. The Autism Cooperative Research Centre for Living (Autism CRC) Guides and Checklists most applicable for creating workshops and training materials

1	<i>Inclusive Research Practice Guide 1: Section on Providing Autism Friendly Environments</i> - provides tips for limiting distractions, reducing noise and strong smells, and adjusting lighting and temperature
2	<i>Inclusive Research Practice Guide 6: Section on Research Co-production</i> - defines principles of research co-production: equality, transparency, diversity, accessibility, reciprocity, mutuality
3	<i>Checklist 1: Practices that Support Participation in Research for Individuals on the Autism Spectrum</i> - checks for key aspects of how to increase involvement of individuals with ASD in research

Our Studies with Autistic Partners

- Autistic participants partnered with school and community participants in a formal interview series to determine barriers and supports to community participation for people with ASD
- Autistic participants with intellectual disabilities reported their opinions about essential items needed in a portable sensory self-regulation space via meetings and iPad polls.

What We Learned

- **Developing partnerships** with individuals with ASD is time and labor intensive.
- **Involving individuals** with ASD provides unique insights that may not be anticipated by others.
- **Empowering individuals** with ASD is a long process of changing perceptions of all involved, including the autistic individuals themselves.
- **Promoting decision-making** in the ASD community is also impacted by the roles and routines related to cognitive abilities, learned helplessness, and often low expectations.

References and Resources



Cooperative Research Center for Living with Autism. (2016). *Inclusive research practice guides and checklists for autism research* (Report Version 2).

Nicolaidis, C., Rammaker, D., Kapp, S., K., Baggs, A., Ashekenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A., (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007-2019. <https://doi.org/10.1177/1362361319830523>