SESSION III:
Equitable Inclusion of Autistic Adults as Co-Researchers

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June 29, 2018 // 4:00 pm ET

Course Materials

The purpose of these materials is to help provide an introduction to the Summer Institute session on equitable inclusion of autistic adults as co-researchers. The materials were designed to prepare trainees for the concepts and general background to this topic, in order to get the most educational benefit from Dr. Nicolaidis’ and Dr. Raymaker’s presentation. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) a glossary of terms and concepts; and (3) some broad review articles that are recommended reading. These materials could be considered “prerequisites” in preparing for Dr. Nicolaidis’ and Dr. Raymaker’s presentation.

In collaboration with Dr. Nicolaidis and Dr. Raymaker, these materials were developed by Dr. Laura G. Holmes (Postdoctoral Fellow, A. J. Drexel Autism Institute Life Course Outcomes Program), Dr. Alicia Montgomery (Pediatric Fellow at Sydney Children’s Hospital and Ph.D candidate, Sydney University), Dr. Brenna Maddox (Postdoctoral Fellow, University of Pennsylvania’s Center for Mental Health Policy and Services Research), and Dr. Anna Urbanowicz (Postdoctoral Research Fellow, Queensland Centre for Intellectual and Developmental Disability at the University of Queensland). Please do not hesitate to contact Laura at GRAHAMHOLL@email.chop.edu with any questions or comments.
Learning Objectives

The INSAR Summer Institute for Autism Research was established to provide early career researchers (graduate students, postdocs, etc.) with training opportunities in multidisciplinary topics. The Summer Institute team is now working to engage stakeholders as well. Summer Institute priorities are to provide a (1) freely available (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The Summer Institute covers broad topics and is meant for people who are not expert in the topic area. It is offered over a free web platform and allows researchers and stakeholders from around the world to connect with the presenter(s). The overarching goal of the Summer Institute is to expose junior scientists and community members to topics they are not currently engaged in, with the hope that basic scientists, clinical scientists, and the autistic community can learn from each other and advance the understanding of autism.

The current session, ‘Equitable Inclusion of Autistic Adults as Co-Researchers’, is led by Drs. Christina Nicolaidis and Dora Raymaker, and a team of trainees who helped to prepare these materials and the web presentation.

The learning objectives for attendees of this session include:

1. To gain an appreciation of the frustrations experienced by members of the autistic community in their encounters with research;
2. To gain an awareness of the ways in which autistic people may be disenfranchised by traditional research practices;
3. To gain an understanding of the principles of participatory research methods;
4. To explore approaches that avoid tokenism, and allow for meaningful inclusion of autistic people in all stages of the research process;
5. To introduce available infrastructures, resources and processes to facilitate researcher-stakeholder collaboration;
6. To highlight the potential impacts of participatory methods on research outcomes;
7. To outline factors to be taken into consideration when embarking on a participatory research project.

Glossary of Terms / Key Concepts

Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Project brings together the academic community and the autistic community to develop and carry out research projects relevant to the needs of adults on the autism spectrum. AASPIRE uses a Community Based Participatory Research approach where academics and community members serve as equal partners throughout the research process.

https://aaspire.org/

Community based participatory Research (CBPR) involves a full and equal partnership between, for example, autistic/autism community members and researchers, in which all partners are genuinely and meaningfully involved at all stages of the research (developing a research question, designing the study, conducting the study, analyzing and interpreting the findings, communicating the results to other researchers and the public).

See Nicolaidis and colleagues 2011 - https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3319698/
**Co-production** or co-design is a way of working whereby decision-makers and citizens (or service providers and users, or autism researchers and the autistic community) work together to create a decision, service, or research study which works for them all. The guiding principle is that those who are affected by a service or research study are best-placed to help design it.

**Neurotypical (or NT),** an abbreviation of ‘neurologically typical,’ is a word used for people with ‘typical brains’. It is sometimes used in the autistic community to refer to people who are not on the autism spectrum. Some feel that it excludes autistic cousins (people with ‘autism-like brains’). Because many non-autistic people have other neurological conditions (like ADHD or anxiety), the autistic community sometimes uses the term "allistic" to refer to non-autistic people (see below).

**Allistic** means not autistic. A less common word for 'not autistic' is typical. 'Allistic' includes people with other forms of neurodivergence or other brain-based conditions as well as people without any brain-based conditions.

**Neurodiversity** refers to how all human minds and brains are different. Being autistic is a form of neurodivergence. Neurodiversity advocates oppose the deficit model of autism, and argue against the goal of eradication of autism from the world. However, they are not opposed to efforts aimed at reducing the challenges associated with being autistic. They advocate for increased acceptance of autistic differences, and supports that help autistic people be part of their communities.

See Nicolaidis and colleagues (2012) -

The **autistic community** refers to autistic people, their family members and friends and the professionals who support them (e.g., educators, clinicians).

The **medical model of disability** views disability as a problem that is part of the disabled person. The focus is on ‘fixing’ or ‘curing’ the disabled person. The medical model focuses on what is ‘wrong’ with a person, rather than focusing on what they can do and/or how they can be better supported. Many in the autistic community oppose this way of viewing autism and advocate for the social model of disability (see below).

Rather than being centered in a person's differences from the norm, the **social model of disability** views disability as being caused by a society that does not take the needs of people with different abilities into account. Rather than "curing" a person's disability, how people behave toward other people and the environment itself should change to reduce barriers for disabled people: society should change, rather than the disabled person changing. An example of this is how elevators, ramps, and larger bathrooms are required in many places for people who use wheelchairs, rather than expecting people who use wheelchairs to be able to climb stairs or walk - or not granting them access at all. Many autistic advocates frame autism within a social model of disability, highlighting how society needs to be more accepting of autistic differences.

https://www.identityfirstautistic.org/social-model-of-disability
Recommended Background Reading


https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5023610/


http://journals.sagepub.com/doi/pdf/10.1177/1362361316661261
Additional Resources

The AASPIRE New Community Partner Packet. This includes some basic information on AASPIRE, our authorship guidelines, a description of roles and expectations for our community partners, decision-making processes, and so on. These resources may be helpful as examples that can be adapted for your own projects.

Additional resources can also be found on the AASPIRE website (www.aaspire.org) or healthcare toolkit website (www.autismandhealth.org).

The Autism in Adulthood journal, which includes autistic adults as editorial board members, peer-reviewers, and authors. This is a different approach to inclusion, but an important one. You can learn more about the journal at https://home.liebertpub.com/publications/autism-in-adulthood/646/

The journal has a helpful page on use of language in manuscripts and presentations: https://home.liebertpub.com/publications/autism-in-adulthood/646/for-authors#useoflanguage

Get Engaged

Continue the conversation and connect with peers currently working or interested in autism.

Contact the INSAR Student & Trainee Committee: studentcommittee@autism-insar.org