Nothing About Us Without Us:
The Importance of Community-Based Participatory Research to Improve the Validity, Translation, and Impact of Clinical Research

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Disclosures

- I receive a stipend from Mary Ann Liebert Publishers for serving as Editor in Chief of *Autism in Adulthood*. 
But We Don’t…
CBPR and Other Participatory Research Approaches

Ways to try to increase inclusion and equity and improve the impact of research
Participatory Research Approaches

Equal Power Sharing (e.g., CBPR / some PAR)

Authentic Inclusion (e.g., PCOR / Co-Production)

Consultation (e.g., Advisory Boards / Delphi Panels)

And no, just getting qualitative data from study participants does NOT count.
2006

Nicolaidis (2012) [link]
Co-Founded in 2006 by Christina Nicolaidis and Dora Raymaker

Autistic and non-autistic academic scientists

Community partners
  - Autistic adults with and without ID, speaking and non-speaking, with wide range of support needs, and other intersectional identities
  - Family members, disability services professionals

Community Based Participatory Research (CBPR)

Nicolaidis et al. (2019) [https://doi.org/10.1177/1362361319830523](https://doi.org/10.1177/1362361319830523)
AASPIRE Research Projects

Health Care

Outcomes

Mental Health

Employment

Pregnancy

Violence and Abuse

https://aaspire.org/projects/
Community Based Participatory Research (CBPR)

Disabled Scientists (or Scientists in Training)

- Extremely important to increase diversity - including neurodiversity and communication diversity - in academia!!!
- “Insider researchers” bring wonderful strengths and perspectives to research.
  - Outsider researchers are not any more objective or less biased just because we may not notice their identities and biases.
- However, just including an insider researcher does not make it CBPR. (And CBPR cannot replace the need for researchers with disabilities.)
  - Disabled scientists cannot represent full range of lived experiences.
- Need to pay attention to inherent power imbalances.
Not All Participatory Research is (or should be) CBPR

- Need to match to the context and goals of the research
- Be transparent about approach and expectations
- Don’t pretend to be doing something you are not!
- Be careful not to tokenize people
- Actively work to match theory and practice
What Does it Take to Be Equal Partners?

- True commitment to equal power sharing
  - In EVERY phase from start to finish
- Community representatives in leadership roles
- LOTS of work
  - Clearly define roles and expectations
  - Understand and meet accessibility needs
  - Build and maintain trust
- Shared Decision-Making
- Accessible Communication
  - E.g. structured email format
- Transparency
- Continuous evaluation and creative solutions!

5-Finger Consensus Process

1. I love it!
2. It’s fine.
3. I have more questions. (and what they are)
4. I don’t like it, but I won’t block it. (and why)
5. I dislike it so much I can’t live with it. (and why)

Keep / Change for Today’s Meeting

What do you want to keep doing?
What would you like to change?
Full Team Meetings

- Far, far more thought and work than typical team meetings.
- Preparation materials shared a week in advance
  - Multiple formats (detailed, easy read, and compact)
  - Optional pre-meeting to go over materials.
- Mix of slides, video, text chat, professional closed-captioning.
- Strong facilitation and clear etiquette to avoid feeling like it’s “two meetings.”
- Structured consensus process for all decisions.
- Survey Geek meeting (week before).
The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants

Christina Nicolaidis¹,², Dora Raymaker¹,³, Steven K Kapp¹,², Amelia Baggs¹, E Ashkenazy¹, Katherine McDonald², Michael Weiner⁶,⁷, Joelle Maslak³, Morrigan Hunter³ and Andrea Joyce³

Webinars and LOTS of Sample Materials at:
https://aaspire.org/inclusion-toolkit/
CBPR Greatly Affects the Research Itself

Inclusion on the research team → Inclusive research

Inclusive research ← Inclusion on the research team
A Common Fallacy

Equity * Neurodiversity * Social Justice * CBPR * Qualitative Methods * Lived Experience * Power Sharing

Scientific Rigor

Quantitative Methods * Sampling Frames
Validity * Reliability * Effectiveness *
Protection of Human Subjects

Inclusion
But I Would Say It’s the Opposite
Partnership Affects Every Part of the Project

- Choice of topic / research question
- Recruitment and consent materials
- Data collection
- Data Interpretation
- Intervention Development
- Dissemination
Choice of Topics / Research Question

- Team discussions about new ideas / opportunities.
- Focus on high priority topics (for example, healthcare, employment, violence).
- Autistic Burnout Study
  - Autistic adults talk about it all the time, but it was totally missing from research and practice.
  - Small study to define and describe autistic burnout.
  - Viral response from autistic community.
  - Now, lots of interest among researchers and clinicians.

Raymaker et al. (2020) [https://doi.org/10.1089/aut.2018.0020](https://doi.org/10.1089/aut.2018.0020)
Accessible Consent

- Co-create materials with community partners
- Clear, simplified consent materials
- Q&A format
- Visual aids / white space
- Reduce participant burden (e.g. online consent)
- Time to discuss with trusted person

See https://aaspire.org/inclusion-toolkit/accessible-research/ for sample consent forms.
And, YES, you can change IRB templates (even the parts that say you aren’t allowed to change) if you offer a good argument.

See [https://aaspire.org/inclusion-toolkit/accessible-research/](https://aaspire.org/inclusion-toolkit/accessible-research/) for sample consent forms.
Effective Recruitment

- Recruitment materials that “speak” to the population
- Recruitment via trusted community leaders
- Access to community forums / events / venues
- But be careful not to abuse trust!
Data Collection - Qualitative Interviews

- Challenges with “open-ended questions”
- Community partners help create effective interview guides
  - Instructions to help participants understand what we want
  - Make questions specific, even when they are open-ended
  - Make sure questions are concrete enough to be answered
- Partners helped us come up with good strategies
  - Show materials to participants before the interview
  - Offer lots of different ways to take part (telephone, video, IM chat, email, in person)
- Sometimes community partners collect data

See AASPIRE Inclusion Toolkit for sample interview guides
Example Qualitative Results

Nicolaidis et al. (2015) [https://doi.org/10.1177/1362361315576221](https://doi.org/10.1177/1362361315576221)
Data Collection - Surveys

Over 16 years, our community partners have reviewed LOTS of existing survey “instruments”.

Found most existing instruments to be inaccessible.

Felt they would experience significant confusion, frustration, anxiety, or anger

Stated they would offer unreliable answers, leave many items blank, or stop participating in the study

Bad Data ⊳ Wrong Conclusions ⊳ Ineffective Efforts
Common Concerns

- Difficult vocabulary, confusing terms, imprecise language, or figures of speech
- Complex sentence structure, confusing grammar, or convoluted phrases
- Response options with vague terms
- Not enough context
- Anxious if responses could vary in different situations
- They don’t fully capture the idea we want to measure
- Offensive and ableist language or concepts

Nicolaidis et al. (2020) - https://doi.org/10.1089/aut.2019.0074
### Common Adaptations to Survey Instruments

<table>
<thead>
<tr>
<th>Adaptation Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prefaces</td>
<td>Adding or changing prefaces to increase precision or explain context</td>
</tr>
<tr>
<td>Simplifying grammar</td>
<td>Simplifying sentence structure; removing passive voice</td>
</tr>
<tr>
<td>Vocabulary Substitutions</td>
<td>Substituting difficult vocabulary words, confusing terms, or figures of speech with more straightforward terms</td>
</tr>
<tr>
<td>Hotlinks</td>
<td>Adding hotlinks that define problematic terms or offer examples or clarifications</td>
</tr>
<tr>
<td>Graphics</td>
<td>Adding graphics to increase clarity of response options</td>
</tr>
<tr>
<td>Autism-specific items</td>
<td>Adding new items related to autism-specific aspects of the construct</td>
</tr>
</tbody>
</table>

Nicolaidis et al. (2020) - [https://doi.org/10.1089/aut.2019.0074](https://doi.org/10.1089/aut.2019.0074)
AASPIRE Outcomes Study

- Large NIH grant to create and test “AutPROM Toolbox”
  - Set of survey instruments to evaluate the effectiveness of services for autistic adults.
- Phase 1: Nested Delphi process with CBPR approach to choose high priority outcomes
- Phase 2: Co-created or adapted instruments for each of these 15 outcomes.
- Phase 3: Large prospective cohort study to
  - Rigorously test psychometric properties
  - Identify predictors of change in outcomes over time.

https://aaspire.org/projects/outcomes/

Much more at session 4519L, Thursday 5:30pm
AutPROM Toolbox Outcomes

- Quality of Life and Overall Health
- Mental Health (Depression, Anxiety, Emotional Wellbeing, Autistic Burnout)
- Self Determination / Freedom to Make Choices
- Barriers to Communication
- Community Participation
- Employment Satisfaction
- Social Support
- Quality and Satisfaction with Healthcare Services and Social Services

Survey also includes demographic, health, and disability characteristics, use of services, experiences of discrimination, and a module on gender identity and sexual orientation.
Data Interpretation

- Community partners help make sense of the findings.
- “Confidence in Managing Health and Health Care Scale” factor analysis.
  - Two factors, but not the ones we intended.
  - Partners helped explain difference in two groups of questions.
- Individual Healthcare Self-efficacy (i.e., only involves your own skills).
  - e.g. “How confident are you that you can bring what is needed to a healthcare visit?”
- Relationship-Dependent Healthcare Self-Efficacy (i.e., also depends on the provider and/or health system).
  - E.g. “How confident are you that you can answer your healthcare provider’s questions?”

Nicolaidis et al. (2021) [https://doi.org/10.1177/1362361320967178](https://doi.org/10.1177/1362361320967178)
Intervention Development

- Academic and community partners work together to:
  - Come up with ideas for what the intervention could be
  - Decide what it should include
  - Work out all the details / co-create intervention.

- Examples
  - AASPIRE Healthcare Toolkit (www.autismandhealth.org)
  - Pregnancy decision videos (www.pregnancyanddisability.org)
  - Pregnancy Decisions App (in progress)
  - Community Suicide Prevention Program (in progress)
AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This web site has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

The resources on this site are meant to improve the healthcare of autistic adults. They were made by the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) through a series of research studies funded by the National Institute of Mental Health. AASPIRE hopes that you will find these resources helpful.

PATIENTS & SUPPORTERS

click here

This section has information on:

- Healthcare
- Staying Healthy
- Your Rights in Healthcare
- Autism Information
- Medical Information
- Checklists and Worksheets

HEALTHCARE PROVIDERS

click here

This section has information on:

- How Autism Can Affect Healthcare
- Tips for Successful Office Visits
- Legal and Ethical Considerations
- Autism Information, Diagnosis, and Referrals
- Associated Conditions

Healthcare providers also might want share our Autism Healthcare Accommodations Tool, and other checklists and worksheets with their patients on the autism spectrum.

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[Links to related organizations and resources]
Resources, Forms, and Worksheets

- Practically address patients’ most pressing needs.
- Co-created by providers and autistic adults.
- Team members pilot-tested them in their own care.
- 1-month pre/post-test improvements in patient-provider communication, self-efficacy, and barriers to care.

Autism Healthcare Accommodations Tool (AHAT)

- Patient or supporter fills out a survey
- Computer uses answers to create a personalized and healthcare provider-friendly accommodations report

Mobile app coming soon!

www.autismandhealth.org
Dissemination

- Community partners included on all scientific papers
  - Strategies to ensure they truly meet authorship criteria
- Community Briefs, Newsletters, Blogs, Social Media
- Presentations at scientific and community events
- Written guidelines from start of project
Inclusion in the Literature

- Focuses on most pressing issues affecting autistic adults.
- Editor-in-Chief - Christina Nicolaidis
- Associate Editor - Dora Raymaker
- 12 autistic adults on editorial board (and many family members and clinicians)
- Anti-ableist Language Policy
- Each manuscript gets traditional scientific peer-reviews AND review by autistic adult
- Insights section for personal perspectives of autistic adults
- Approximately 1/3 of articles have included autistic authors so far

www.liebertpub.com/aut
Take Home Points

- Participatory research with people with communication disabilities is possible.
- It is very hard work, but it’s worth it!
- Don’t pretend to do it if you aren’t ready to do the work, and to mess up, and to try harder.
- It can help strengthen the rigor and impact of research.
- Let’s work to ensure all research is respectful, anti-ableist, rigorous, and impactful.
Thank you to the AASPIRE Team

- Co-Directors: Christina Nicolaidis\textsuperscript{f} and Dora Raymaker\textsuperscript{a}
- Steering Committee: Co-directors and Andee Joyce\textsuperscript{a}, Mirah Sharer, Ian Moura\textsuperscript{a}, Ericka Fox\textsuperscript{a}, Anne Kirby, and Whitney Lee\textsuperscript{a}
- Community Council: Andee Joyce\textsuperscript{a} (Chair), Reid Caplan\textsuperscript{a}, Emanuel Frowner\textsuperscript{a}, Finn Gardiner\textsuperscript{a}, Rachel Kripke-Ludwig\textsuperscript{a}, Julia Love, Joelle Maslak\textsuperscript{a}, Shannon des Roches Rocha\textsuperscript{f}, Ivanova Smith\textsuperscript{a}, Furra Wallington\textsuperscript{a}, and Zack Siddeek\textsuperscript{a}
- Academic Council: Christina Nicolaidis\textsuperscript{f}, Dora Raymaker\textsuperscript{a}, Katherine McDonald, Clarissa Kripke\textsuperscript{f}, Steven Kapp\textsuperscript{a}, Anna Urbanowicz, Anne Kirby
- Additional Outcomes Project Staff: Joseph Vera, Patrick Bowden, Madeline Proctor\textsuperscript{a}

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\textsuperscript{a} - autistic; \textsuperscript{f} - family member
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- The Centers for Disease Control (Partnering Project)

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References


