Community Based Participatory Research
Lisa Croen, PhD and Maria Massolo, PhD
Kaiser Permanente Northern California
Gender, Sexuality and Reproductive Health node co-leads
AIR-P is supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under award UT2MC39440, the Autism Intervention Research Network on Physical Health. The information, content, and/or conclusions are those of the author and should not be construed as the official position of, nor should any endorsements be inferred by HRSA, HHS, or the US Government.
Lisa Croen, PhD

Director, Autism Research Program,
Kaiser Permanente Northern California
Co-lead Gender, Sexuality and Reproductive Health node
Maria Massolo, PhD

Manager, Autism Research Program,
Kaiser Permanente Northern California

Co-lead Gender, Sexuality and Reproductive Health node
Plans for this presentation

• What is Community Based Participatory Research (CBPR)
  • Definition of CBPR
  • Benefits of CBPR

• Brief history of CBPR in health research
  • Establishment of Patient Centered Outcomes Research Institute (PCORI)

• CBPR in Autism Research
  • AASPIRE
  • AIR-P Gender, Sexuality, and Reproductive Health Node
Definition of CBPR

“Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.” (Viswanathan, 2004)
Key elements of CBPR

• Equitably involves all partners in the research process

• CBPR begins with a research topic of importance to the community

• Combines knowledge and action for social change to improve community health and eliminate health disparities
### Old Research Approach versus CBPR

<table>
<thead>
<tr>
<th>Old Research Approach</th>
<th>CBPR</th>
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<td>• Outside researcher determines questions, research tools, interventions</td>
<td>• Research begins with a research topic of importance to the community</td>
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<tr>
<td>• Researcher team implements the study, analyzes results, publishes manuscript</td>
<td>• Equitably involves all partners in the research process</td>
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<td>• Data is transferred from the participant to the researcher</td>
<td>• Commitment to change power relationship between researcher and researched</td>
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Benefits of CBPR

- Benefits community participants, health care practitioners, and researchers
- Creates bridges between scientists and communities
- Facilitates the development of culturally appropriate instruments
- Establishes mutual trust that enhances both the quantity and the quality of data collected
- Offers a deeper understanding of a community’s unique circumstances
Brief history of CBPR in health research

• **2001** Agency for Healthcare Research and Quality (AHRQ), several Federal agencies and the Kellogg Foundation, conference
  • to promote and support the use of CBPR
  • to develop strategies to advance CBPR
  • to explore the use of CBPR as a resource for policymakers to help guide their program development

CBPR was meant to:
• increase the value of studies for researchers and for the community being studied
• address the problems of health care disparities in a variety of populations
Establishment of Patient Centered Outcomes Research Institute (PCORI)

“We are committed to ensuring that patients and other healthcare stakeholders have a seat at the table throughout the research process—helping to prioritize research topics, design and conduct the studies, and share the results.” (https://www.pcori.org/about/about-pcori)
Why CBPR in Autism Research?

“The vast preponderance of autism research worldwide still focuses on the underlying genetic causes and biology of autism (see Pellicano et al., 2014). This focus is in sharp contrast to the stated research priorities of community members – autistic people, their family members, educators, clinicians and other professionals – who have consistently called for research in areas of more immediate, practical concern, including interventions, education, services and supports.” (E.Pellicano, 2020)
Implementing CBPR in Autism Research

The Academic Autistic Spectrum Partnership In Research and Education (AASPIRE)

• Academics, the autistic community, and people who provide support and services to autistics

• Conducts community-based participatory research focused on improving the lives of autistic adults
AASPIRE Inclusion Toolkit

Outcomes
What are the most important outcomes for autistic adults and how can we best measure them?

We are working with the autistic community to create and test the AASPIRE Toolkit – a set of accessible survey instruments to measure the outcomes that matter most to autistic adults.

Now recruiting participants!

Employment
What leads to success for autistic professionals, and how can we improve employment outcomes?

We have completed a qualitative study about successful skilled employment. We are currently conducting a study to adapt and test employment outcome measures.

Healthcare
How can we improve healthcare for autistic adults?

We have completed studies identifying healthcare disparities and experiences and have created and tested an online Healthcare Toolkit. We are now exploring how to integrate tools into health systems and understand emergency room experiences.

Mental Health

Reproductive Health
Participatory Research Approaches with Autistic Community

The following training provides a high-level summary on how to use a variety of participatory approaches, including Community-Based Participatory Research, to include autistic community members as collaborators on the research team.

It is meant to be used in conjunction with the training on Human Subjects Research with Autistic Participants.

- Presented by Christina Nicoliolis, MD, MPH
- August 2022
- Length: 21 minutes, 53 seconds
- Created for use by the AIR-P

Supplemental Materials

The following sections go into greater detail on each of the main topics discussed above. They also offer templates and sample collaboration materials created by the AIR-P team. We provide these materials in hope that they may help other teams collaborate effectively. Feel free to use and adapt them to your own needs, with appropriate attribution.
Implementing CBPR in Autism Research

AIR-P Gender, Sexuality, Reproductive Health node: working with a Stakeholder Advisory Group

• Creation of the Stakeholder Advisory Group
  • Diversity
  • Inclusion
  • Accommodations

• Bring lived experience and academic or advocacy expertise
Research Basics Training

• Co-production and pilot of 3-Unit online course
  ❖ Unit 1: What is Research?
  ❖ Unit 2: How is Research done the Right Way? (Ethics)
  ❖ Unit 3: Being a Community Research Partner
Focus Group: Gender, Sexuality, and Reproductive Health

• Led by an autistic person

“Sometimes, people with disabilities get left out of conversations about gender and sexuality. That makes our lives harder. It makes it more likely for us to have health problems. People who study gender, sexuality, and health need to listen to us!” (Focus Group invitation)

• Bridge informational session
  • Showed short videos, answered questions

• Focus group implementation
  • Virtual using Zoom
  • Used Jamboard, chat function
  • Included supporters
Focus Group: Example Theme

Sex education and consent

• How do autistic people learn about sexuality? From whom? Friends, school, doctor, parents?
• How can autistic people ask the right questions about their sexuality, and get the right answers?
• How do autistic people know who they can go to and safely ask questions about sexuality?
• How does sex ed line up (or not line up) with how autistic people experience sexuality?
• How do people who work with autistic individuals talk about consent?
• Does the way consent gets talked about make sense to autistic people?
“It’s really rewarding to do this kind of work because it was clear how much the participants want to be involved with research. There were so many things they were really passionate about, and researchers may never have asked what is important to them before. This training could provide them with tools to become researchers themselves.” (Morrigan Hunter, Research Basics Training facilitator)

“Nothing about us without us” (Disability Rights Advocates)
References


References, cont.


16. [https://www.pcori.org/about/about-pcori](https://www.pcori.org/about/about-pcori)
Thank you for attending!
A link to view the recording will be emailed to all registrants.
We hope to see you next month!

Tuesday 9/20/22
4-5pm EST

Presentation by Dr. Denise Nunez

Topic to be announced
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