



Autism Intervention Research  
Network on Physical Health

## Community Based Participatory Research

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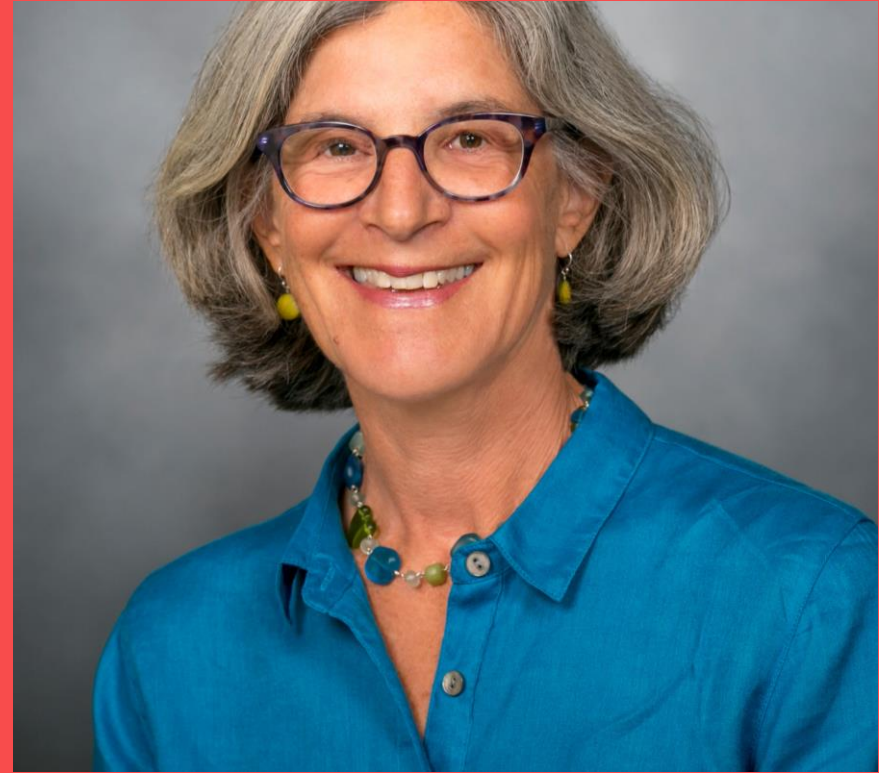
Gender, Sexuality and Reproductive Health node co-leads

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# Plans for this presentation

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

## Old Research Approach

- Outside researcher determines questions, research tools, interventions
- Researcher team implements the study, analyzes results, publishes manuscript
- Data is transferred from the participant to the researcher

## CBPR

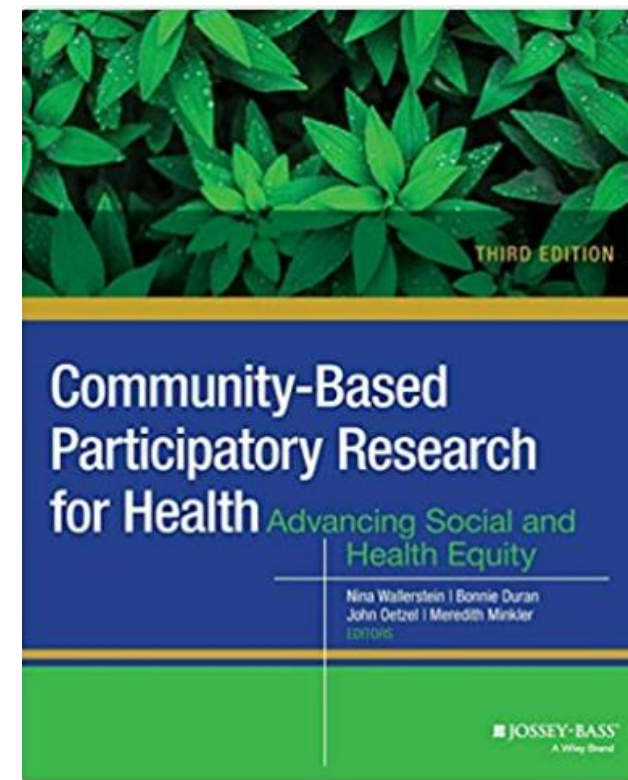
- Research begins with a research topic of importance to the community
- Equitably involves all partners in the research process
- Commitment to change power relationship between researcher and researched





# 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

The screenshot shows a web browser window displaying the AASPIRE website. The browser's address bar shows 'aaspire.org'. The website header features the AASPIRE logo and the text 'Academic Autism Spectrum Partnership in Research and Education'. A navigation menu includes 'Home', 'About', 'Inclusion Toolkit', 'Research', 'Publications', 'Audio/Visual', 'News', and 'Contact'. The 'Inclusion Toolkit' menu item is highlighted, and a dropdown menu is open, listing 'Participatory Research', 'Accessible Human Subjects Research', 'Neurodiversity and Disability Justice', and 'AASPIRE Guidelines'. The main content area is divided into several sections: 'Outcomes', 'Employment', 'Healthcare', 'AASPIRE Resources', 'Mental Health', and 'Reproductive Health'. The 'Participatory Research' section is currently visible, containing text about community-based participatory research and a link to 'AASPIRE Guidelines'. The 'AASPIRE Resources' section includes links to 'AASPIRE Healthcare Toolkit', 'AASPIRE Inclusion Tools', and 'Autism in Adulthood'. The browser's taskbar at the bottom shows various application icons and the system tray with the date '8/11/2022' and time '4:37 PM'.

Academic Autism Spectrum Partnership in Research and Education

Search ...

Home About Inclusion Toolkit Research Publications Audio/Visual News Contact

Participatory Research

Community-based participatory research

Founded in 2010, AASPIRE is a Community-Based Participatory Research (CBPR) approach where autistic and non-autistic scientists and community members work together to address research focused on improving the lives of autistic adults. We use a CBPR approach where autistic and non-autistic scientists and community members work together to address research process.

Accessible Human Subjects Research

Neurodiversity and Disability Justice

AASPIRE Guidelines

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 [AutPROM Toolbox](#) – 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](#).

AASPIRE Resources

[AASPIRE Healthcare Toolkit](#)

[AASPIRE Inclusion Tools](#)

[Autism in Adulthood](#)

Mental Health

Reproductive Health

https://aaspire.org/inclusion-toolkit/participatory-research/

82°F Sunny 4:37 PM 8/11/2022



# Participatory Research Approaches with Autistic Community

The screenshot shows a web browser window with the URL [aaspire.org/inclusion-toolkit/participatory-research/](https://aaspire.org/inclusion-toolkit/participatory-research/). The page title is "Participatory Research Approaches with the Autistic Community". The main content includes a paragraph explaining that the training provides a high-level summary on how to use various participatory approaches, including Community Based Participatory Research, to include autistic community members as collaborators. It also mentions that the training is meant to be used in conjunction with training on Human Subjects Research with Autistic Participants. A list of details for the training is provided:

- Presented by Christina Nicolaidis, MD, MPH
- August 2022
- Length: 21 minutes, 33 seconds
- Created for use by the AIR-P

A video player is embedded on the page, showing a thumbnail for the video "Participatory Research Approaches with Autistic Community" with a red play button. The video title is partially visible as "Participatory Research Approaches with Aut...". Below the video player, there is a section titled "Supplemental Materials" with a paragraph explaining that 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 AASPIRE Team. At the bottom of the page, there are two dropdown menus: "Participatory Approaches" and "Team Meetings". The browser's taskbar at the bottom shows the Windows logo, search icon, and various application icons. The system tray shows the date and time as 4:45 PM on 8/11/2022, and the weather as 82°F Sunny.



# 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)



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# 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**

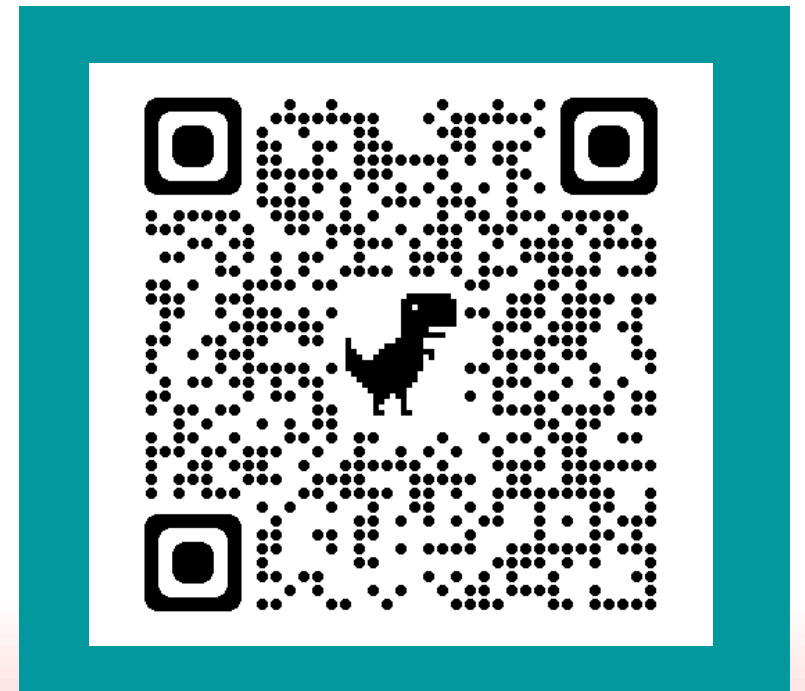
**4-5pm EST**

**Presentation by Dr. Denise Nunez**

Topic to be announced



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