Creating Sustained Co-Production Partnerships within Autism Research and Practice

ABCT ASDD SIG PRECON | 11I3I23

Autism Spectrum &
Developmental Disabilities
Special Interest Group

Moderator

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Definitions

- Participatory Research (PAR): Research that actively involves community members as partners, not merely as subjects (Israel et al., 2005).

- Community-Based Participatory Research (CBPR): An approach that equitably engages community members, organizational representatives, and researchers throughout the research process (Israel et al., 2019).

- Other Research Partnerships: Academic-community partnerships and patient-led research.

Literature on Participatory Research

- "participatory research" OR "community based participatory research" OR "community led research" [TITLES/ABSTRACTS] = 6,181 results

- Earliest in 1981 in *Canadian and International Education*

- Topics ranged (e.g., nursing, gender and culture, HIV/AIDS, breast and cervical cancer, learning disabilities)

- Earlier pubs consistent in terms

- "co production research" [TITLES/ABSTRACTS] = 16 results
  - + "autism" = 0 results

- PAR or CBPR and autism: *Autism Research* 2023 and only a handful of other pubs in recent years

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Historical Context

- Emerged in the mid-20th century as an alternative to traditional top-down research approaches

- Initially used in social sciences to *challenge traditional power dynamics* between researchers and subjects.

- Closely aligned with civil rights movements and social justice initiatives

- Evolved as a *democratic approach* to research, focused on including community members in the research process to ensure that the research is *equitable and socially just*

- Principles of social justice inherent in participatory research make it suitable for autism research, where there is a need to *challenge prevailing norms* and to include marginalized voices

Importance Today

- Initial focus on community concerns and social inequities

- Potential to produce effective, sustainable, and just solutions

Participatory Research (PAR) in Autism Communities

- Rooted in the principle that research *should involve people who are the focus* of the research

- Can be applied in various settings and *not confined solely to community contexts*

- Democratizing knowledge, recognizing diverse forms of expertise, and ensuring participants have a voice in decision-making throughout research process

- Goal is often *empowerment and transformation*

Community-Based Participatory Research (CBPR) in Autism Communities

- A type of participatory research
  - *Co-learning* and *reciprocal transfer* of expertise
- Co-production of knowledge
  - Define problems, design the study, interpret results, implement solutions
- Ethical considerations
  - Informed consent and assent
- *Sustainable* community change, *improved* health outcomes, and *elimination* of health disparities
- Challenges and opportunities

Academic Autism Spectrum Partnership in Research and Education (AASPIRE)
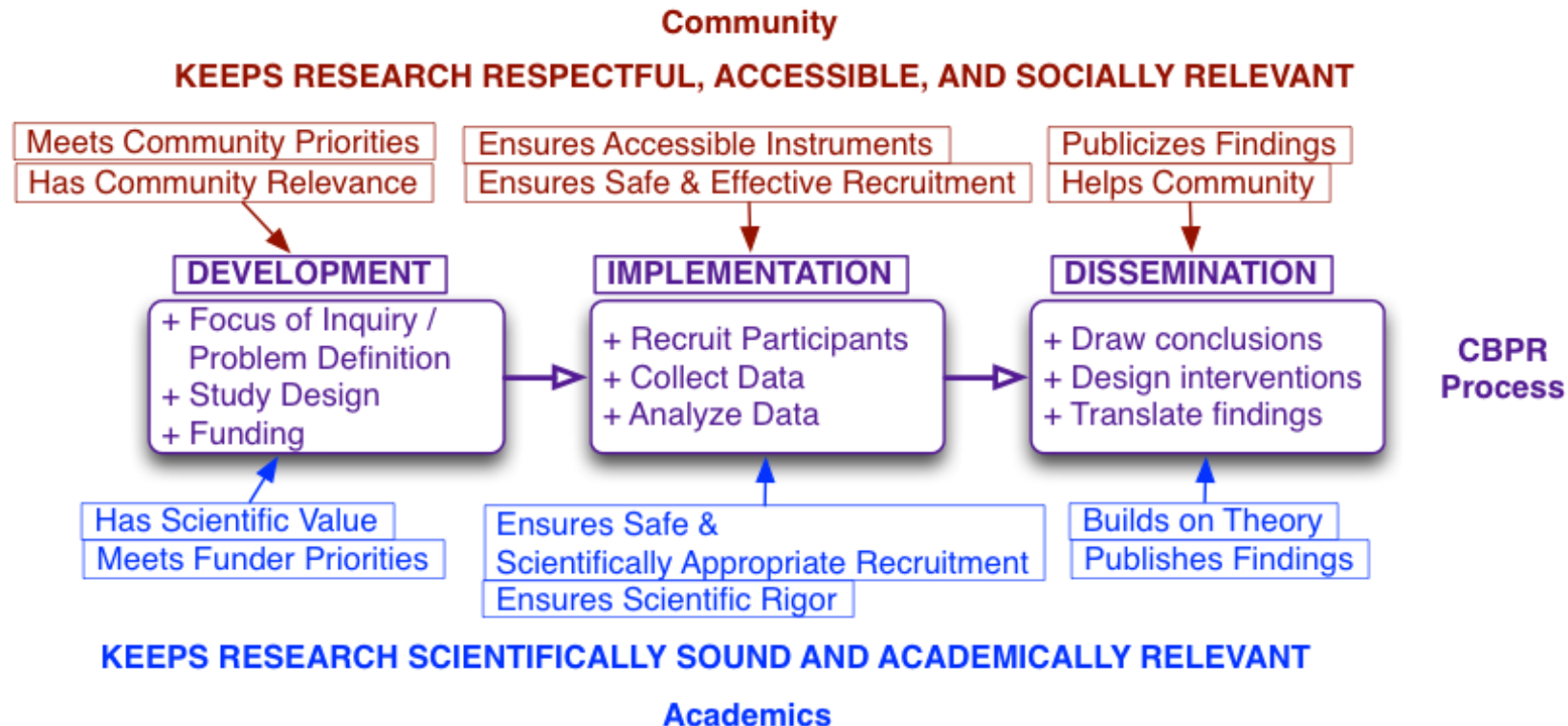

diagram from *Collaboration strategies in non-traditional CBPR partnerships: Lessons from an academic-community partnership with autistic self-advocates* [2].

aaspire.org

Other Models of PAR/CBPR

Autism Intervention Research Network on Physical Health (AIR-P)

- Create and disseminate evidence-based practices to *improve the physical health and well-being* of children and adolescents on the autism spectrum and other developmental disabilities

- *Vetted and co-developed* by the Autistic Researcher Review Board, caregivers and family members of autistic individuals, and other stakeholders

- Involves professionals from various disciplines such as pediatrics, psychiatry, and gastroenterology

- Community outreach, webinars, and training programs for both healthcare providers and families

Panel Guidelines

Listen Respectfully	Listen Actively	Critique Ideas, not Individuals
WAIT (why am I/ am I not talking?)	Avoid Assumptions & Assume good intent	"Oops/Ouch Rule"

Panelist Introductions

Sandy Magaña, PhD (she/her)

Steve Hicks School of Social Work at The University of Texas at Austin

Latina professor and researcher focused on identifying experiences and ethnic disparities of Latine families of autistic children.

Nelsinia Ramos, MS (she/her)

Wisconsin Family Assistance Center for Education, Training, and Support, Inc (WI FACETS).

Associate Director of WI FACETS, Co-Director of the Wisconsin Parent Training and Information Center, Mother of autistic daughter.

Laura Anthony, PhD, LCP (she/her)

University of Colorado School of Medicine

Professor, Director of Research, and Co-Developer of *Unstuck and On Target.*

Donnie TC Denome, MPH (they/them)

Autistic Self-Advocacy Network (ASAN)

Multiply disabled autistic self-advocate, AAC user, writer, and graphic designer. ASAN inclusive publications and research coordinator

Becca Lory Hector, BA (she/her)

Truly Inclusive Leadership, DEIB & Workplace Wellness

Autistic Professional on a mission to close the disability gap in leadership; Neurodiversity & Disability Advocate

Dena Gassner, MSW, PhD candidate (she/her)

Adelphi University Doctoral Candidate;

PhD candidate in Social Work; National board member for the Institute for Exceptional Care, AIR-P Gender, Sexuality and Healthcare Node; IACC Member

Take two minutes to introduce your partnership

What tips do you have to lay the foundation for a strong partnership?

What do you think are the most important benefits of partnerships and co-creation processes?

How do you manage power imbalances and ensure equitable recognition within your partnerships?

How can we do better reaching and including partners with more diverse identities and experiences?

Co-Production Resources

- AASPIRE healthcare toolkit: https://autismandhealth.org/

- AASPIRE Practice-Based Guidelines for the Inclusion of Autistic Adults in Research as Co-Researchers and Study Participants: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6776684/

- *Autistic Adults and other Stakeholders Engage Together: Engagement and Compensation Guide*.
(2018). https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf

- "Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project" (2020). *Autism*. Open access: https://journals.sagepub.com/doi/full/10.1177/1362361320908410

- INSAR Community Collaborator Request: https://www.autism-insar.org/page/ICCR

- PCORI modules: https://research-teams.pcori.org/