The Dynamics of Autistic-Academic Partnerships

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The Dynamics of Autistic-Academic Community Partnerships

Dora M Raymaker, MS
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Introduction

• Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)
  – Started 2006 by Christina (health services researcher, parent) & Dora (autistic, systems scientist)
  – Uses a CBPR/PAR approach

• Current research
  – Healthcare Study 1
  – Partnering with People with Developmental Disabilities to Address Violence
  – Internet, Community, and Well-Being Study
Systems and Feedback

• Systems are Dora’s favorite thing
• Systems science gives some tools to help understand the dynamics between scientists, majority society, and minorities
• System – a collection of parts related to each other relative to an environment
Properties of Complex Systems

- Long time spans
- Feedback
- Synergy, non-linearity, emergence
- Decentralization
- Generative structures
Minorities and Research

• Minorities have experienced
  – Direct harm
  – Stigmatization
  – Underrepresentation

• Researchers have experienced
  – Difficulty getting study participants
  – Inappropriate study design
  – Failed interventions
Vicious Cycles

- Reinforcing feedback makes change difficult

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Scientists

 Minorities Community

 Majority Society

 theory, scientific findings

 values, priorities, research funding, cultural context

 treatments/interventions

 raw data

 advocacy

 values, policy, public perception, services funding

Traditional Dynamics
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Participatory Approaches to Research

• Change the relationship between minority communities and researchers
• “Subjects” become part of the research team
• Equitable exchange of power and expertise
• For example, CBPR or PAR
• Research approach, not research method
The Principles of CBPR

- Acknowledges community as a unit of identity
- Builds on strengths and resources in the community
- Facilitates a collaborative, equitable partnership in all phases of research
- Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners
- Facilitates co-learning and capacity building among all partners.
Principles of CBPR, ctd.

- Involves systems development using a cyclical and iterative process
- Focuses on community relevance and on ecological perspectives that attend to the multiple determinants of health and wellbeing
- Disseminates results to all partners and involves them in the wider dissemination of results.
- Involves a long-term process and commitment to sustainability
Community and Identity

- Community is a **unit of identity**
- A "readily available, mutually supportive network of relationships on which one [can] depend."
- Includes shared values, symbols, history, and a sense of emotional safety and personal identification
Communities Defined by Disability

• CBPR typically done with communities defined by race, ethnicity, or geography
• Communities can also be defined by disability, or other traits
• Communities of autistic adults exist
• CBPR is being successfully conducted with communities defined by disability
Traditional Autism Research Dynamics

• “The daydreaming study...”
  – fMRI study about mental “resting states”
  – Autistics “failed” to go into them under the same conditions as non-autistic controls
  – Headlined in the press as autistics don’t “daydream”
“The Daydreaming Study”

• Community response
  – Huh? But, we do daydream!
  – Questions about methods
  – Concerns about stereotyping
Possible Issues with Lack of Inclusion

• How might lack of autistic involvement lead to
  – Issues with study design
  – Inaccurate conclusions
  – Stigmatization in publications
  – Reinforcement of stereotypes in mainstream society
  – Sabotaging of community priorities
Community Priorities

• CBPR focuses on **community relevance**...

• Community priorities can reach researchers though advocacy to majority society
  – But what if self-advocates are excluded from policy?
  – Or dismissed as not able to advocate or even self-advocate?

• Community Priorities can reach researchers directly through participatory research
Participatory Dynamics

- Scientists
  - values, policy, public perception, services funding, research funding
  - advocacy
  - values, priorities, research funding, cultural context
  - theory, scientific findings
  - access, raw data, cultural expertise, community resources, insights, values

- Minority Community
  - advocacy
  - values, policy, public perception, services funding, research funding
  - treatments/interventions, scientific findings, academic expertise, academic resources, capacitiation, credibility

- Majority Society
  - access, raw data, cultural expertise, community resources, insights, values
  - treatments/interventions, scientific findings, academic expertise, academic resources, capacitiation, credibility

Participatory Dynamics
CBPR with AASPIRE

Community

KEEPS RESEARCH ETHICALLY SOUND AND SOCIALLY RELEVANT

- Meets Community Priorities
  - Has Community Relevance
- Ensures Accessible Instruments
  - Ensures Safe & Effective Recruitment
- Publicizes Findings
  - Helps Community

DEVELOPMENT

+ Focus of Inquiry / Problem Definition
+ Study Design
+ Funding
- Has Scientific Value
- Meets Funder Priorities

IMPLEMENTATION

+ Recruit Participants
+ Collect Data
+ Analyze Data
- Ensures Safe & Scientifically Appropriate Recruitment
- Ensures Scientific Rigor

DISSEMINATION

+ Draw conclusions
+ Design interventions
+ Translate findings
- Builds on Theory
- Publishes Findings

KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT

Researchers

AASPIRE
Research Development

• Topic selection
  – Community importance
  – Researcher expertise

• Funding procurement

Focus of Inquiry / Problem Definition
Study Design
Funding

DEVELOPMENT
Meets Community Priorities
Has Community Relevance

Has Scientific Value
Meets Funder Priorities
Research Implementation

- Measurement adaptation
  - Construct selection
  - Wording
  - Instructions and comments
- Interview formats
- Recruitment
- Community and academic partners work together to interpret results
Research Dissemination

- Data and credibility to support policy change
- Web Tools project
- Conferences and workshops like this one
CBPR and Systems Change
Thank You

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