Effective Partnering with the Autistic Self-Advocacy Community to Advance Intervention and Services Research

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But We Don’t
Minority Communities’ Frustrations

• Misalignment of research priorities
• Lack of inclusion in the research process
• Inadequate informed consent
• Threats to study validity
• Dehumanizing, stigmatizing language
• Use of findings to advance agendas that oppose community values

→ Low participation rates, poor science, questionable impact, continued disparities
Autistic Self Advocates’ Frustrations

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Community-Based Participatory Research

- Response to problems of traditional research
- An APPROACH, not a method
- One of many forms of community-engaged or participatory research
- Equal partnership between academics and community members
- Can be used with quantitative or qualitative methods
- Not only for intervention or services research
Community-Based Participatory Research

Nicolaidis et al, PCHP, 2011
Unique Challenges in Autism

• Who is “the community”? 
  – Self-advocates, family members, professionals?
• What if the community is geographically dispersed?
• How does one implement CBPR with partners whose disability is defined by atypical social interactions and communication?
Who is the Community?

• Autistic self-advocacy community
  – Own culture, support systems, leaders, shared values, social spaces, events, organizations, terminology...

• Community of family members and professionals

• Similar pattern as LGBT and Deaf communities
Who is the Community?

• Values and priorities can at times be in opposition
  – Search for a “cure”, blaming vaccines, emphasis on “devastating” effect on families, potentially dehumanizing or harmful messages

• Desire for research to improve quality of life
  – improving healthcare, decreasing violence and bullying, increasing access to alternative communication, disproving false stereo-types, increasing employment opportunities
Mission:
• To encourage the inclusion of people on the autistic spectrum in matters which directly affect them.
• To include adults on the autistic spectrum as equal partners in research about autism.
• To answer research questions that are considered relevant by the autistic community.
• To use research findings to effect positive change for people on the spectrum.
AASPIRE’s Overlapping Communities
AASPIRE Projects

• Healthcare disparities study
• Internet, community, and wellbeing study
• Tools to improve primary care services
• Collaborations with other groups:
  – Registration system for online studies committed to inclusion, respect, accessibility, and community relevance (the Gateway Project)
  – Partnering to Address Violence in People with Developmental Disabilities
Ensuring Equal Partnership

• Academic and autistic Co-PIs
• Very wide range of skills and needs
• Preference for text-based communication
• “Translation” of science jargon / concepts
• Great attention to process
  – Strict agendas, structured email formats, process for reaching consensus, clear expectations
• Need for great flexibility
  – Multiple formats for providing input
  – Individualized supports and accommodations
Effects on Research Materials

- Informed consent materials
- Prefaces to add specificity
- Hotlinks for confusing or ambiguous terms
- Wording changes to increase clarity
- Consistent pronouns (1\textsuperscript{st} or 2\textsuperscript{nd} person)
- Graphics for response options
- Comment boxes
- ASL, read-out-loud options
- Cognitive interviewing, internal consistency
Conclusions

• It is possible and desirable to use a CBPR approach with autistic self-advocates
  – True community, capable of working as equal partners
• True inclusion requires significant attention to infrastructure and processes to equalize power and avoid tokenism
• Participatory approaches have the potential to address ethical challenges, enhance science, and improve outcomes
Future Challenges

• Inclusion of autistic self-advocates with minimal spoken and written communication
• Greater use of participatory approaches over entire range of autism research
• Adequate funding / alignment of research agendas
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