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

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But We Don't

UNEQUAL
TREATMENT
CONFRONTING RACIAL AND ETHNIC
DISPARITIES IN HEALTH CARE
INSTITUTE OF MEDICINE
THE FUTURE OF
DISABILITY
IN AMERICA
RESPONSIBLE
RESEARCH

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

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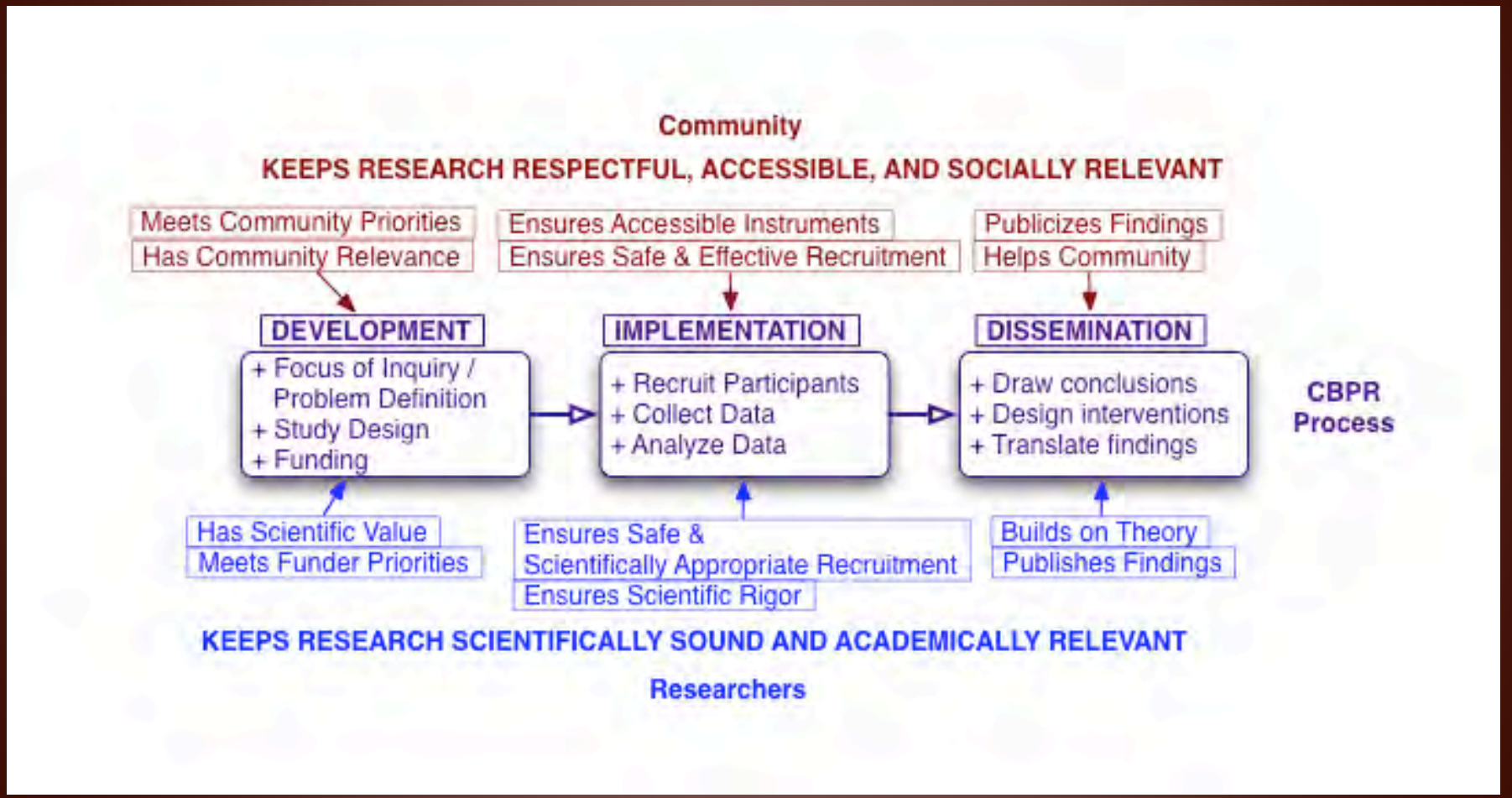
DITTO

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

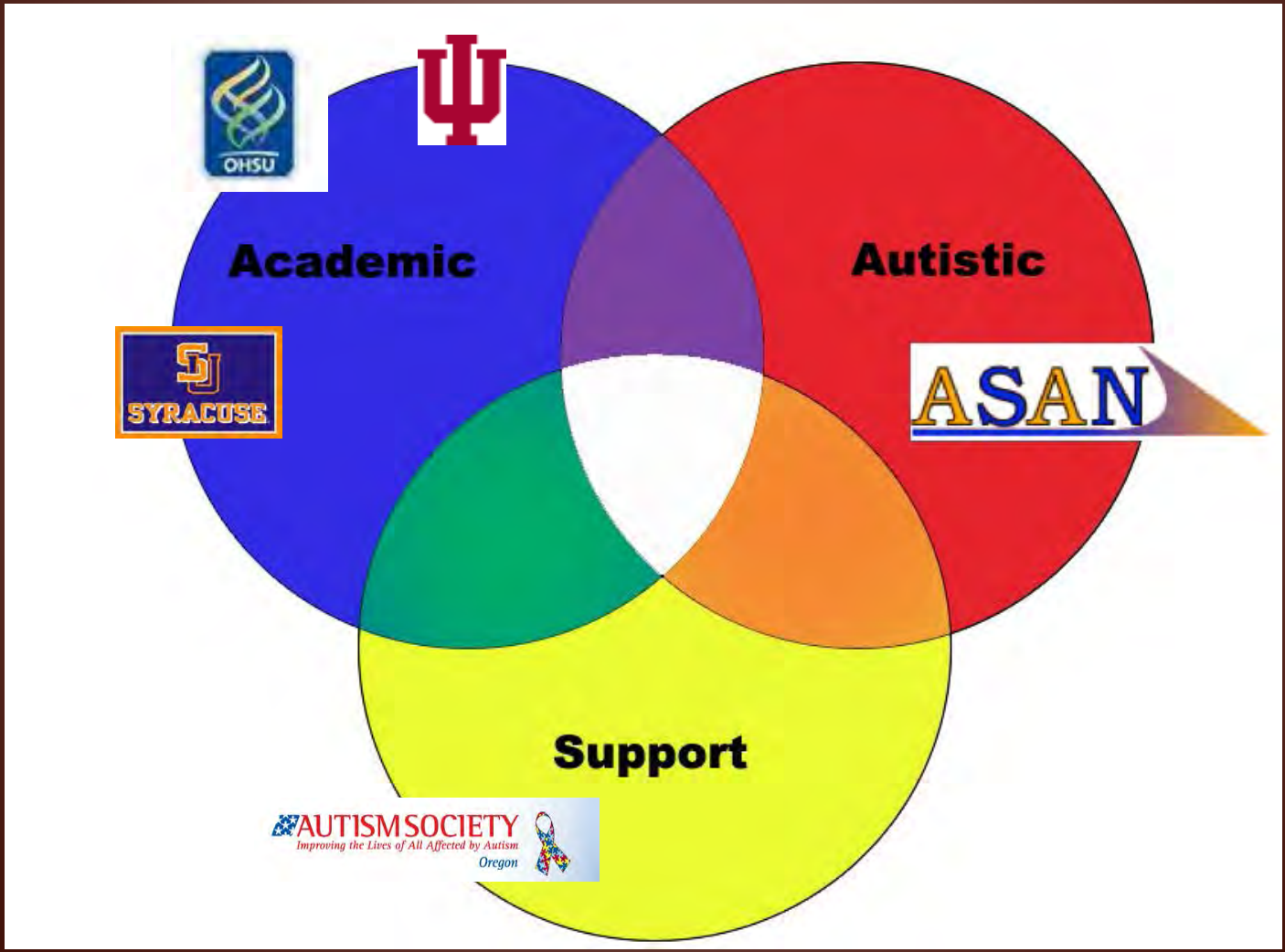
Who is the Community?

- 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 (1st or 2nd 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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For More Information

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