Partnering with Autistic Adults to Improve Healthcare

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Community Frustrations

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

→ Low participation rates, questionable impact, continued disparities
It’s Never That Easy

• Who is “the community”?  
  – Self-advocates, family, professionals? (LGBTQ analogy)
• 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 stereotypes, increasing employment opportunities
• Unique CBPR challenges related to disability defined by social communication
Academic Autism Spectrum Partnership In Research and Education
www.aaspire.org

• CBPR approach
• Primary focus is on including autistic adults as equal partners through all phases of research. Welcome allies/stakeholders.
• Great attention to accommodations, power sharing, and flexible collaboration processes.
• Funding from OCTRI, PSU, and NIMH

Nicolaidis et al, Progress in Community Health Partnerships, 2012
Academic Autism Spectrum Partnership in Research and Education Projects

• Healthcare Disparities Survey (Nicolaidis et al, JGIM 2013)
• Qualitative Study of Autistic Adults’ Healthcare Experiences
• Interactive Healthcare Toolkit for Autistic Adults and their Primary Care Providers
• Internet, Community, and Wellbeing Study
• Collaboration with Partnering with PWDD to Address Violence Consortium
• “Consult service” to other autism researchers
AASPIRE Healthcare Toolkit

Primary Care Resources for Adults on the Autism Spectrum and their Primary Care Providers

This website has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on primary healthcare, or healthcare with a regular doctor.

The resources on this site are meant to improve the healthcare of autistic adults. They were made by the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) through a series of research studies funded by the National Institute of Mental Health. AASPIRE hopes that you will find these resources helpful.

PATIENTS & SUPPORTERS

Make a Personalized Accommodations Report for your healthcare provider.

This section also has information on:

- Healthcare
- Staying Healthy
- Your Rights in Healthcare
- Autism Information
- Medical Information
- Checklists and Worksheets

HEALTHCARE PROVIDERS

This section has information on:

- Autism Information, Diagnosis, and Referrals
- Caring for Patients on the Autism Spectrum
- Legal and Ethical Considerations
- Associated Conditions
- Resources and Links

Healthcare providers also might want to share our Autism Healthcare Accommodations Tool, and other checklists and worksheets with their patients on the autism spectrum.