



Ethical Concerns in Autism Research

The Autistic Self-Advocacy Network

- **An International Nonprofit Organization Run By Autistic Self-Advocates**
- **Focuses:**
 - **Public Policy Advocacy**
 - **Community Research Partner**
 - **Social/Support Groups**
 - **Other Initiatives**

Major Ethical Concerns for Autism Research

- **Expanding Focus on the Whole Individual (Strengths Included)**
- **Inclusion of Autistic People on the IACC and IACC Workgroups**
- **Quality of Life issues**
- **Inclusion of Autistic People As Research Collaborators**
- **Funding considerations**

Expanding Focus on Whole Individual: Balanced view of Autism

- **Strengths and weaknesses in each individual**
- **Research on strengths can translate to meaningful outcomes**
- **Research into differences can look at positive aspects of differences**

Expanding Focus on Whole Individual: Lifespan Approach

- **Infants/Toddlers**
- **Children**
- **Teens**
- **Adults**
- **Older adults**

IACC: Including People on the Autism Spectrum

- **Current situation:**
 - **One autistic member on IACC, one on a single workgroup**
- **New situation:**
 - **Additional members from autistic self-advocacy community**

Quality of Life Issues

- **Domains measured by World Health Organization Quality of Life Instrument:**
 - **Social Relationships & Social Support**
 - **Physical Health**
 - **Mental Health/Psychological Health**
 - **Independence: Mobility, Activities of Daily Living, Communication & Work Capacity**
 - **Transportation Access**
 - **Vocation**
 - **Recreation & Leisure**

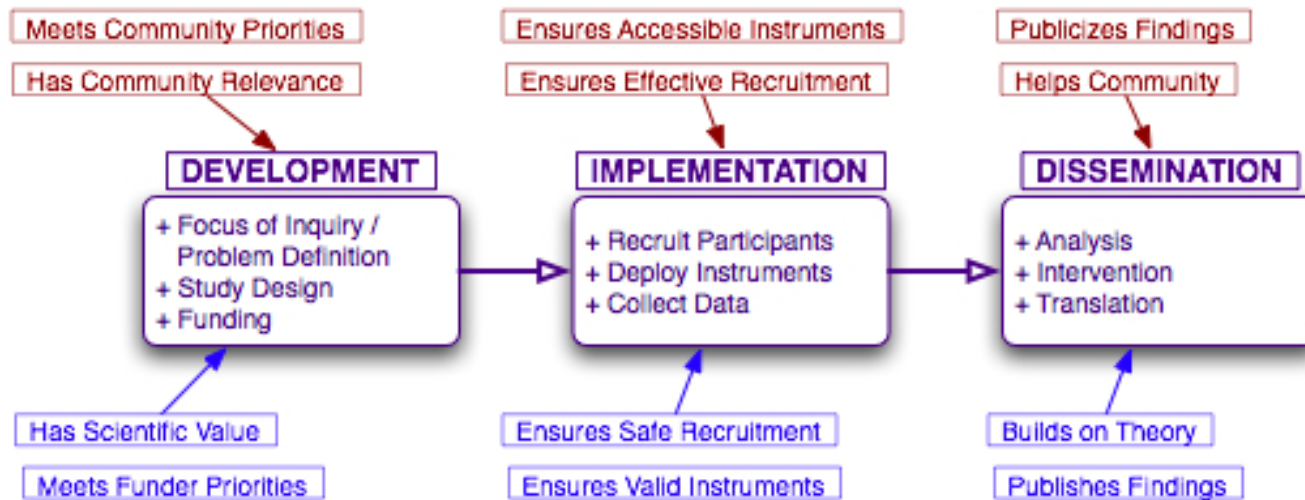
Inclusion of Autistic People As Research Collaborators

- **Inclusion of people on the autism spectrum not only as research subjects but as full participants in research that will impact on our lives.**

CBPR Process

Community

KEEPS RESEARCH ETHICALLY SOUND AND SOCIALLY RELEVANT



CBPR Process

KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT

Researchers



**Academic Autistic Spectrum Partnership
In Research and Education**

Funding considerations

- **Adequate funding for services and supports area**
- **Choice of topics studied**



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Ethical Concerns in Autism Research: Contributors

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