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# Participatory Action Research: Science and Social Change

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# Participatory Research: Science and Social Change

Dora Raymaker, MS

<http://aaspire.org>



# A Bit About Bridges...





# CBPR Projects I Work On

- \* Co-Director - Academic Autistic Spectrum Partnership in Research and Education (AASPIRE, <http://aaspire.org>)
- \* Community side - Partnering with People with Developmental Disabilities to Address Violence
- \* Academic side - Interconnections



# Participatory Approaches to Research

- \* Places “subjects” as part of the research team
- \* Often aims for a practical outcome--an “action”
- \* Is flexible in its implementation
- \* Is interdisciplinary and method-agnostic
- \* Is an approach, not a method



# Many Flavors of Participatory Research

- \* Action Science, organizational management (Chris Argyris)
- \* Participatory Action Research, psychology (Kurt Lewin)
- \* Community-Based Participatory Research, health sciences (Barbara Israel)
- \* others...

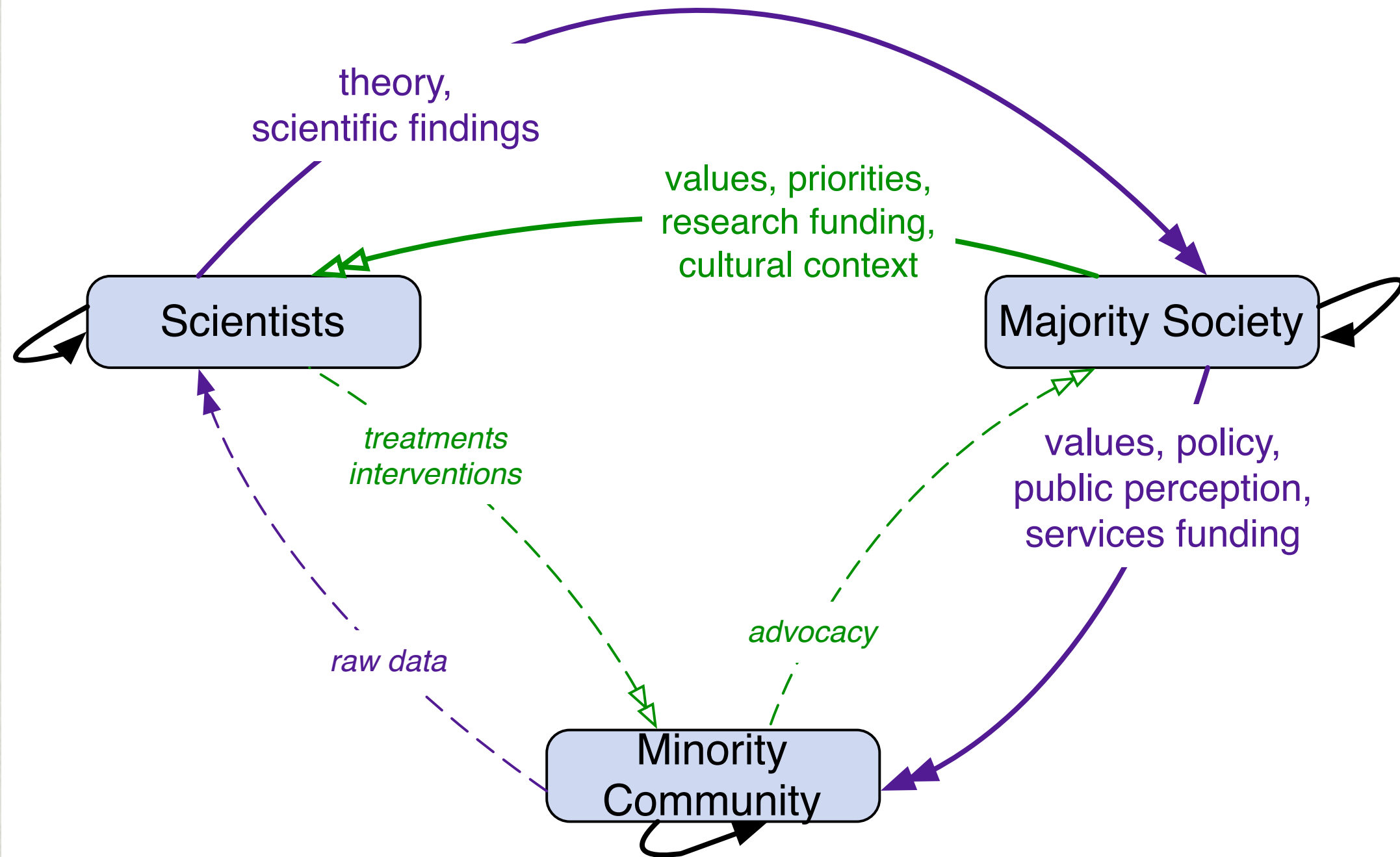


# Minority Issues in Research

- ✱ Minorities have experienced
  - ✱ Direct harm
  - ✱ Stigmatization
  - ✱ Disagreement with research agendas
  - ✱ Exclusion from participation in policy, distrust of research, and underrepresentation in general
- ✱ Researchers have experienced
  - ✱ Difficulty finding study participants
  - ✱ Inappropriate study design
  - ✱ Failed interventions



# Traditional Research





# Participatory Approaches to Research

- \* Places “subjects” as part of the research team
- \* Enables co-learning and the equitable exchange of expertise
- \* Changes the relationship between researcher & subject
- \* Changes the relationship between minority communities and researchers
- \* ***Change the structure, change the behavior***



# 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
- \* Facilitates co-learning and capacity building among all partners.
- \* Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners

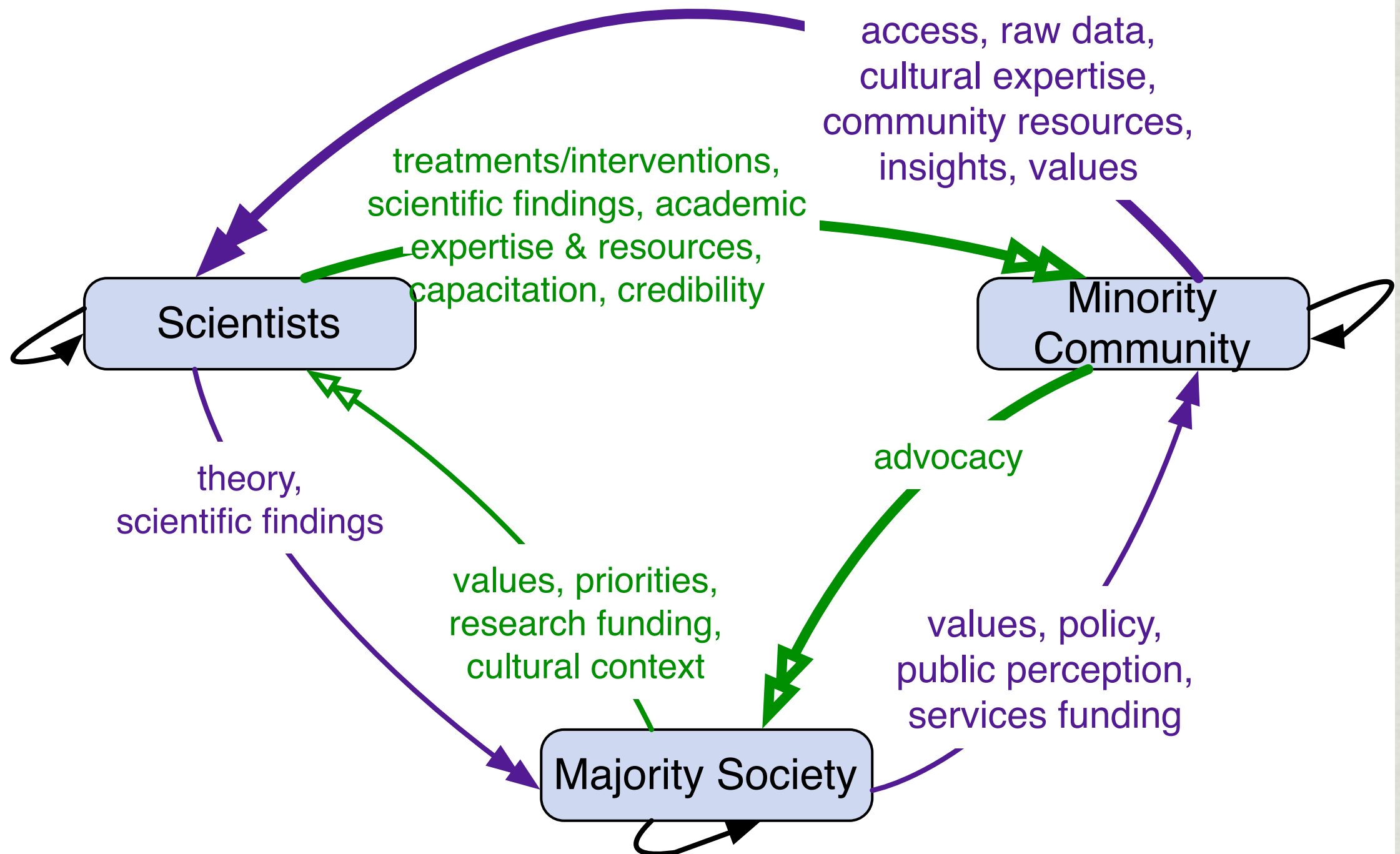


# Principles of CBPR, ctd.

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



# Participatory Research





# CBPR in Practice



# Model of CBPR Process

## Community

**KEEPS RESEARCH RESPECTFUL, ACCESSIBLE, 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

### IMPLEMENTATION

+ Recruit Participants  
+ Collect Data  
+ Analyze Data

### DISSEMINATION

+ Draw conclusions  
+ Design interventions  
+ Translate findings

**CBPR  
Process**

Has Scientific Value  
Meets Funder Priorities

Ensures Safe &  
Scientifically Appropriate Recruitment  
Ensures Scientific Rigor

Builds on Theory  
Publishes Findings

**KEEPS RESEARCH SCIENTIFICALLY SOUND AND ACADEMICALLY RELEVANT**

**Researchers**



# Academic Autistic Spectrum Partnership in Research & Education

- \* Developed organically
- \* Research studies selected to the intersection of academic expertise and community priorities
- \* Structured to support multiple simultaneous studies





## 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.



# Current AASPIRE Projects

- \* **Healthcare Study 1** mixed-methods study to assess healthcare disparities and to understand autistic adults' healthcare experiences and recommendations
- \* **Healthcare Toolkit** to develop and try out an interactive toolkit for helping to improve healthcare access and quality for autistic adults.
- \* **Internet Use, Community, and Well Being** study to examine the relationship between Internet use, sense of community, and well-being
- \* **The Gateway Project** secure online registration system for ongoing research





# AUCD Partnering Project

- \* Response to a general CDC grant proposal call
- \* Study topic was supported by the community
- \* CBPR Project in collaboration with U of Montana, OHSU, PSU, ASAN, SAAL, People First and SILC
- \* Include adults with DD/ID in violence research
- \* Develop study materials that can be safely and validly used with adults with DD;
- \* Identify the physical and mental health outcomes of intimate partner violence against people with DD;
- \* Assess the association between disability characteristics, secondary conditions, and IPV.



# CBPR with Partnering

- \* Steering Committee – researchers, self-advocates
  - \* Major decisions
  - \* Prepare initial materials
- \* Community Advisory Board – self-advocates, family members, direct support professionals
  - \* Adapt and refine materials
  - \* Offer advice and help solve problems
- \* Two-site – Portland and Montana





# Communication Matters

- \* Translation (cultural, linguistic, scientific, etc.)
- \* Accessible modes
- \* Power balance dependent on equalizing communication
- \* Requires constant creative adaptation



# Process Matters

- \* Complex dynamics in projects require process to manage
- \* Lay/Science differences require process to manage
- \* Social choice, voting dilemmas, and quieter partners need consideration



# Finger Count

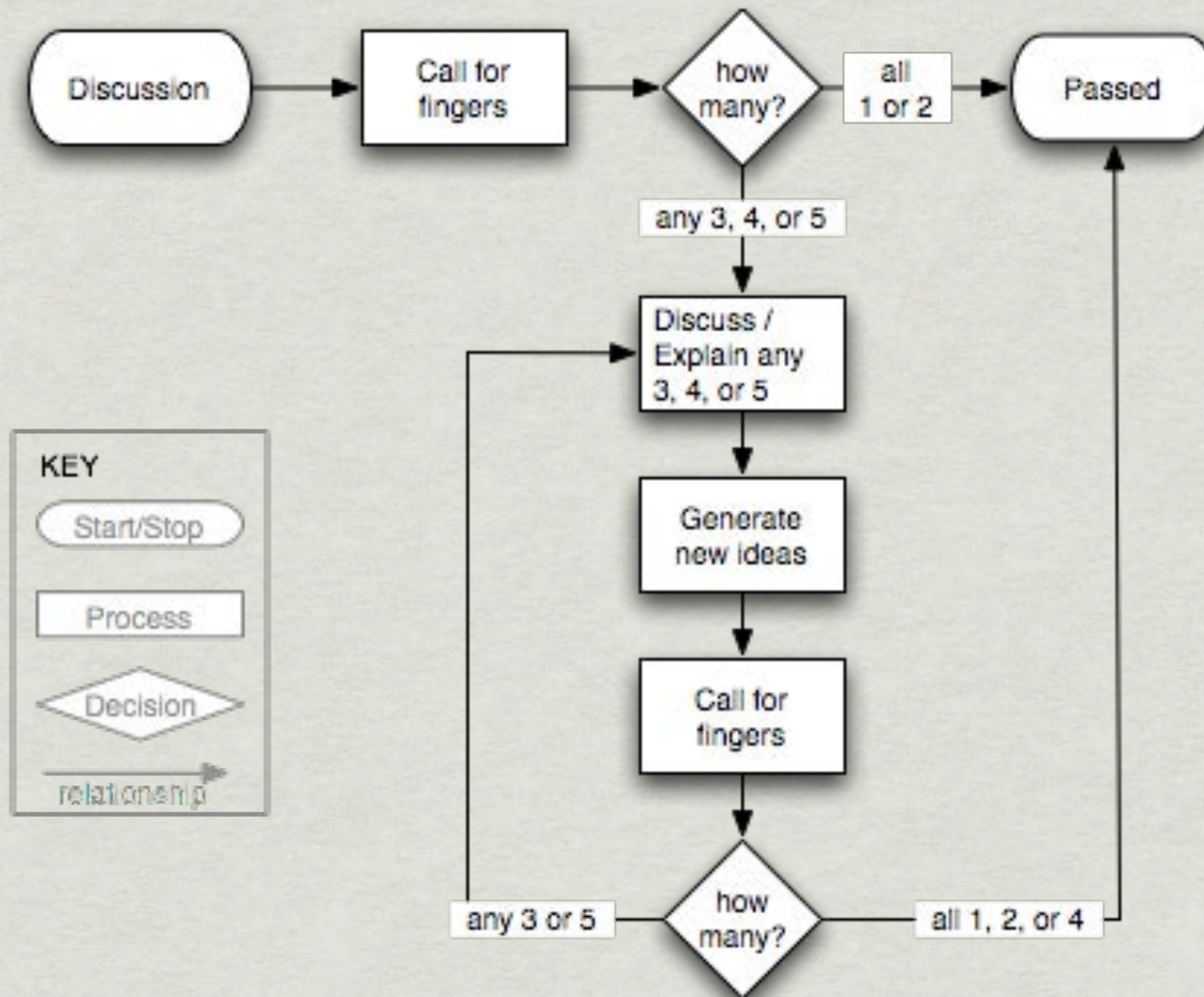
**ONE FINGER -- YAY, I LOVE IT!**

**TWO FINGERS -- IT'S OK.**

**THREE FINGERS -- I AM NOT SURE, I NEED MORE INFORMATION OR DISCUSSION.**

**FOUR FINGERS -- I DON'T LIKE IT, BUT I CAN LIVE WITH IT.**

**FIVE FINGERS -- I HATE THIS SO MUCH THAT I CAN'T LIVE WITH IT.**





# **Study Adaptation Examples**



# AASPIRE Study Adaptation Example

The image shows a screenshot of a web browser displaying a survey titled "Healthcare Study 1a". The survey question asks: "During the past 12 months, there was a time when I felt that I needed the following type of healthcare, but did not receive it. (Check all that apply)". The options are:  Medical care for a physical health problem,  preventive healthcare (including routine physical examinations),  Mental healthcare or counseling,  Dental care (including dental checkups),  Prescription medicines,  Eyeglasses or contact lenses,  Other [text box],  None of the above, and  Do not wish to say.

Below the question are radio buttons for "I last saw or talked to a doctor":  less than a year ago,  1 or more years ago, but less than 2 years ago,  2 or more years ago, but less than 5 years ago,  5 or more years ago, and  Do not wish to say.

A hotlink definition window is open, titled "Hotlink Definition", which defines "Preventive healthcare" as healthcare aimed at early detection and treatment or prevention of disease. Examples include screening tests (pap smears, mammograms, colonoscopies), blood draws for cholesterol, counseling on diet/exercise/tobacco/alcohol, and routine physical examinations.

At the bottom of the survey, there is a text box for comments with the instruction: "If you are not sure how to answer a particular question, please make your best guess and move on to the next question. If you would like to, you can write comments in the comment box below. (Note: information you choose to provide in the comment box will be read, but it will not be considered an answer to the survey questions.)".

Green arrows point from the "preventive healthcare" option in the survey to the hotlink definition window, and from the hotlink definition window to the comment box.





# Survey Validity

- \* Internal Consistency – all new scales had alpha's  $>.8$  for both autistic and non-autistic
- \* Expected correlations





# Partnering Study Adaptation Example

Original

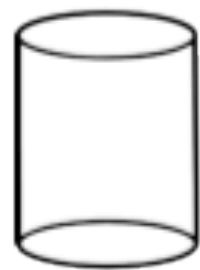
7. Someone to confide in or talk to about yourself or your problems.

1	2	3	4	5
None of the time	A little of the time	Some of the time	Most of the time	All of the time

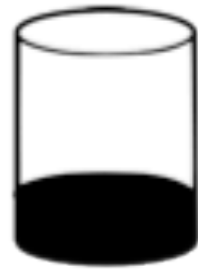
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New

7. How often do you have someone with whom you can share personal information about yourself or your problems?



None of  
the time



A little of  
the time



Some of  
the time



Most of  
the time



All of  
the time



# Partnering Cognitive Interviews

- \* 18 people with ID, ASD, or other DD
- \* Shown the most complex survey questions and asked to paraphrase
- \* Most questions were found easy to understand
- \* Many participants found hotlinks helpful
- \* Pictures were helpful to some
- \* We re-adapted the small number of questions that remained problematic





# Ongoing CBPR Questions and Challenges

- \* Time and effort (and cost)
- \* Ensuring power balance / use of power
- \* Criticisms concerning CBPR/participatory research and research validity
- \* Issues surrounding representation



# Thanks!

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