Systems Science Friday Noon Seminar Series   Systems Science

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Participatory Action Research: Science and Social Change

Dora Raymaker
Portland State University, draymake@pdx.edu

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)

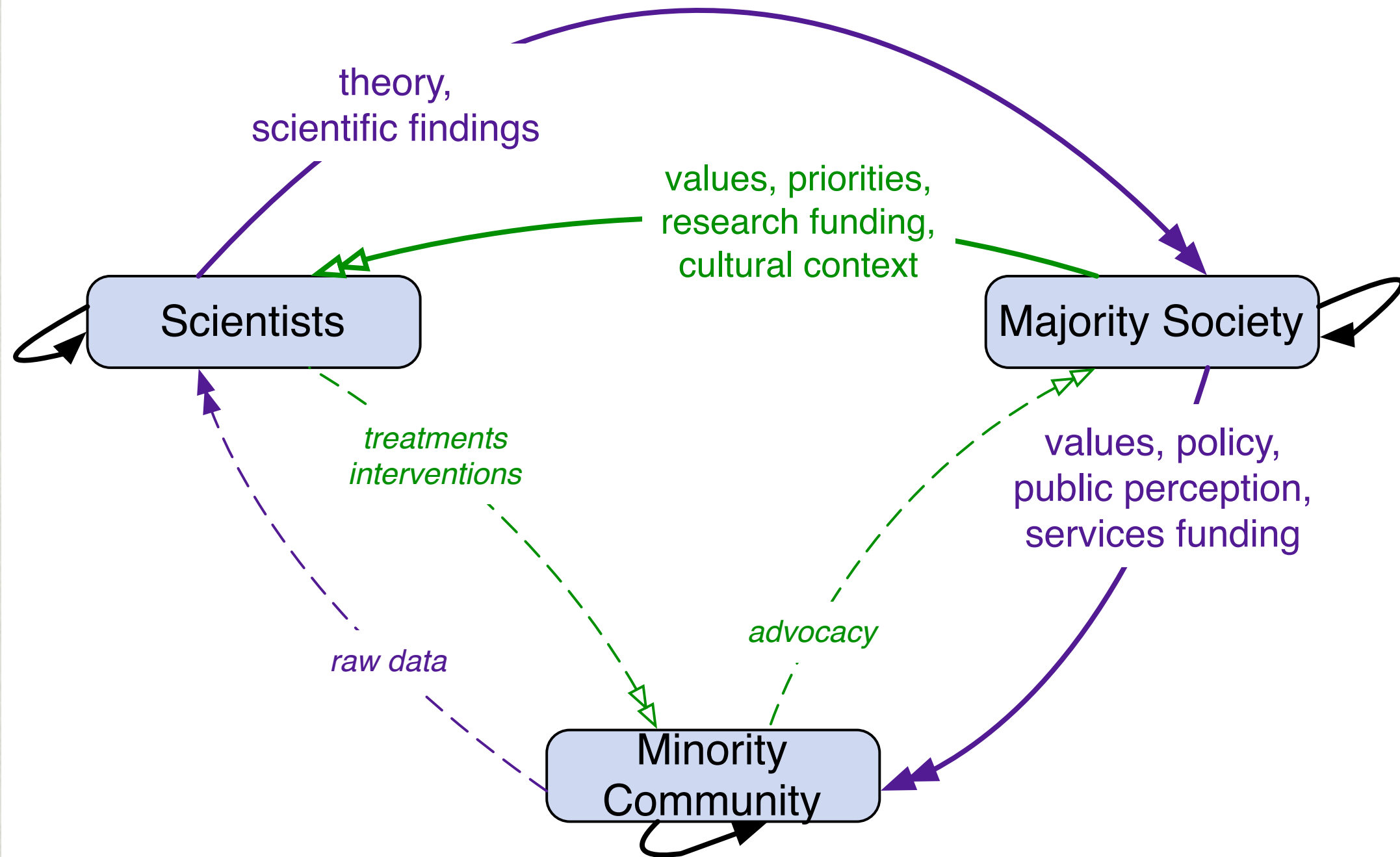* Community-Based Participatory Research, health sciences (Barbara Israel)

* 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
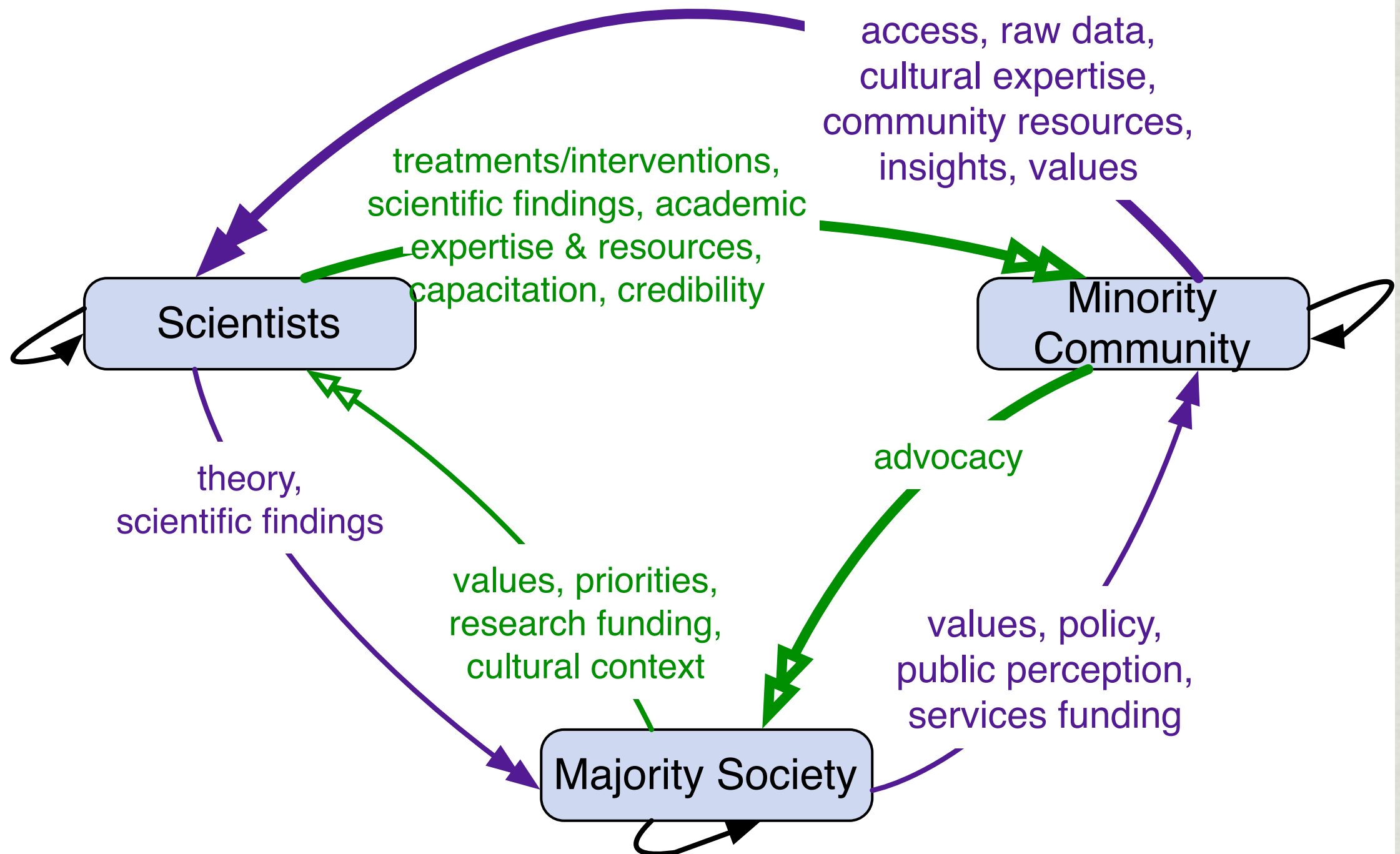
Principles of CBPR, ctd.

* 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

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

AASPIRE

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

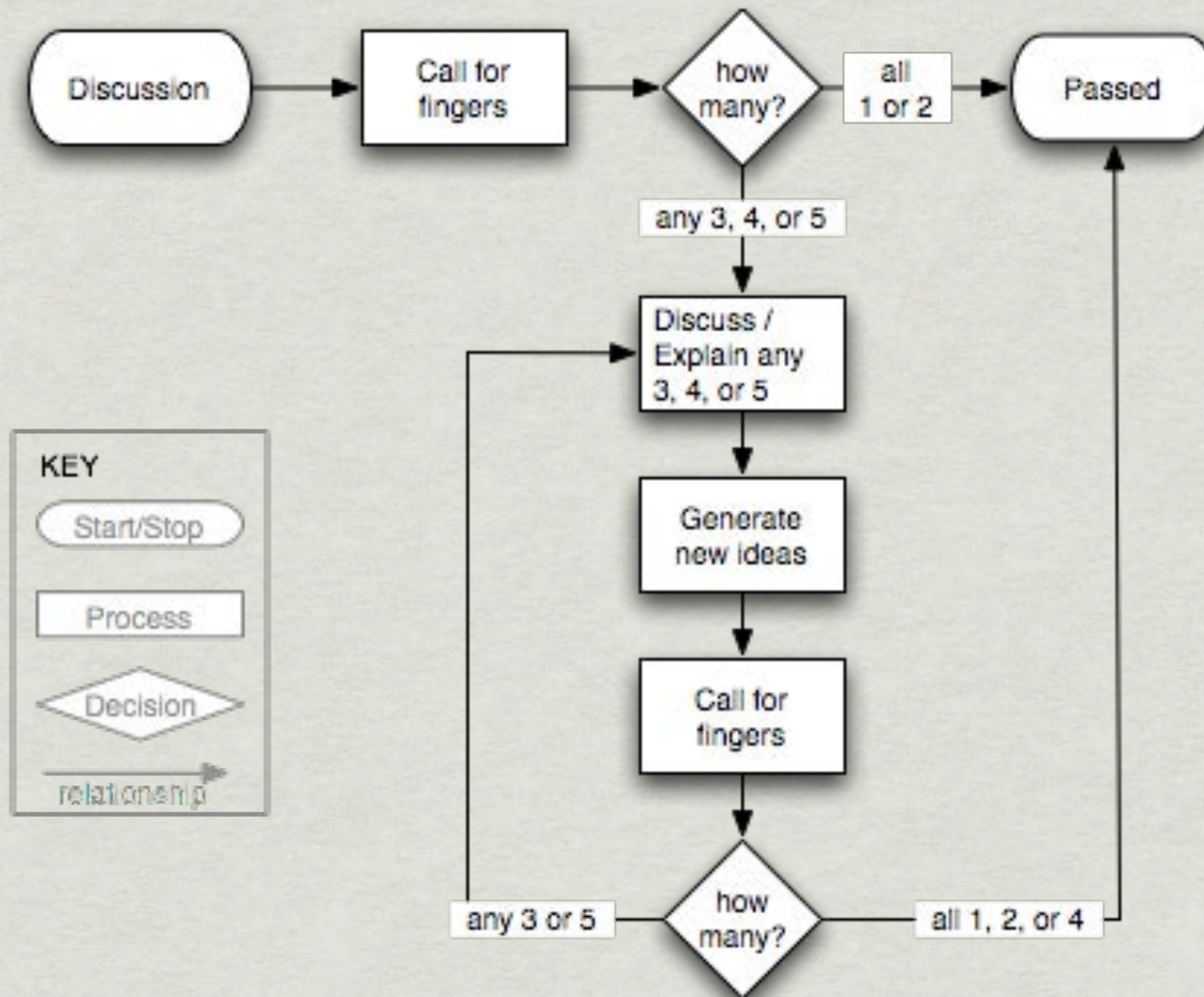* Social choice, voting dilemmas, and quieter partners need consideration

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

Survey Validity

✳ Internal Consistency – all new scales had alpha's >.8 for both autistic and non-autistic

✳ Expected correlations

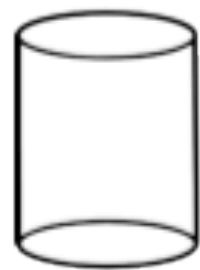AASPIRE

Partnering Study Adaptation Example

Original

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

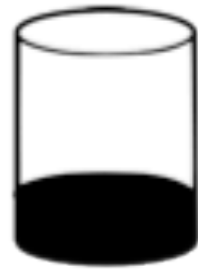| 1	2	3	4	5
None of the time	A little of the time	Some of the time	Most of the time	All of the time

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
With People with Developmental Disabilities on Health and Safety

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!

Dora Raymaker
dora@aaspire.org
http://aaspire.org