

# CBPR and Other Participatory Approaches: Effectively including communities in research and action

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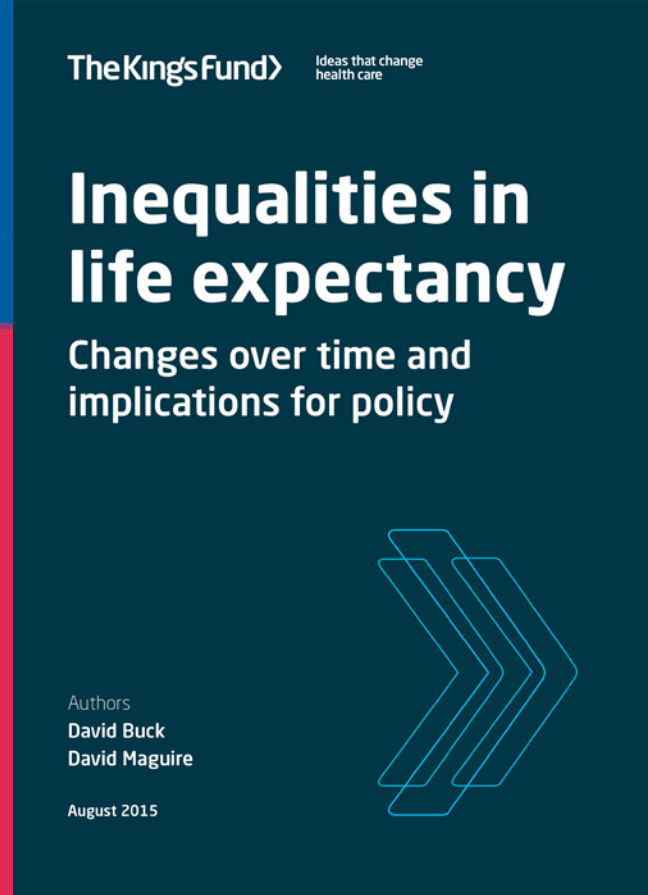
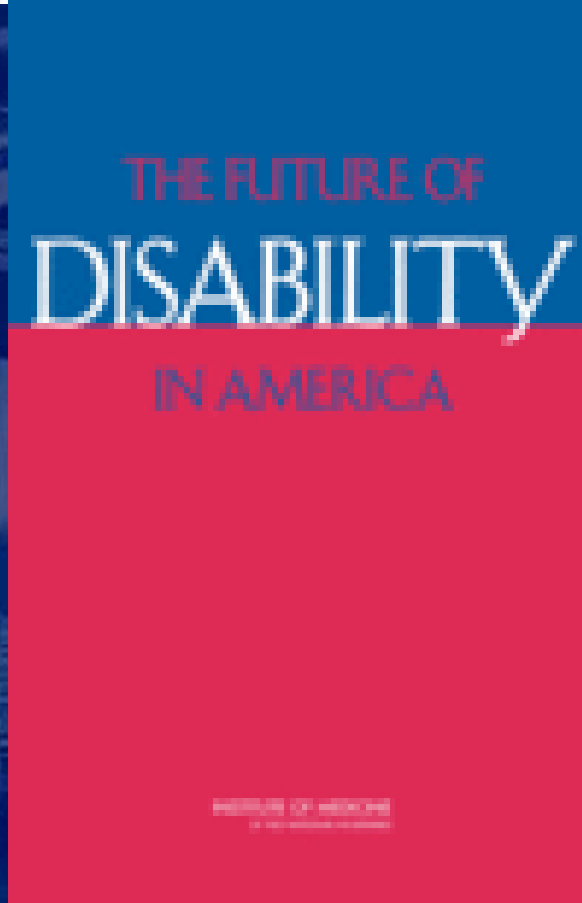
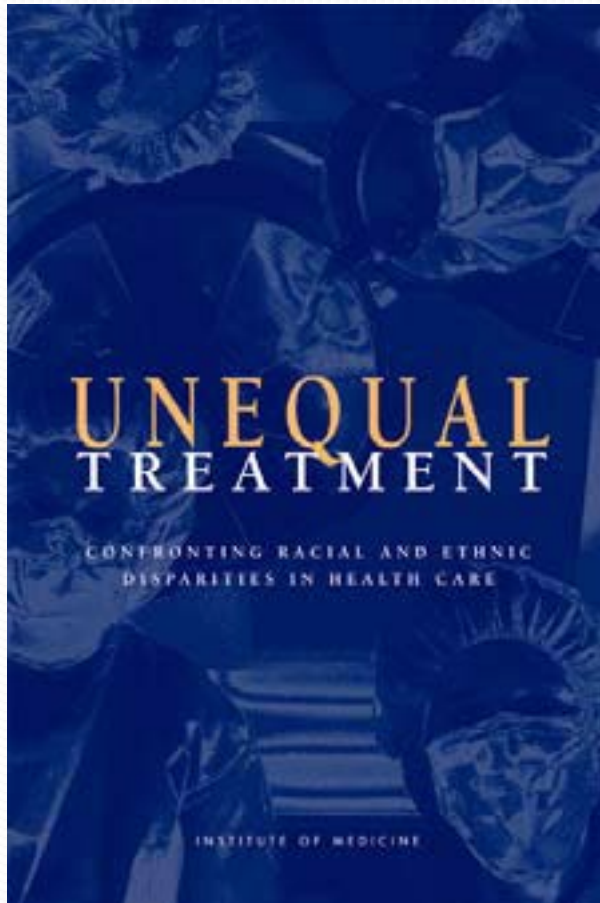
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# But We Don't





# Marginalized 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

# Participatory Approaches

- Representatives from the community or population being studied and other stakeholders become **part of the research team**.
- Response to problems of traditional research:
  - Ethics / power / trust
  - Inclusion of marginalized populations
  - Validity of methods / results
  - Interpretation of data
  - Implications / usefulness of findings
- Intended to strengthen quality and impact of research
- Traditionally used to address racial and ethnic disparities or improve outcomes in marginalized populations.



# Today's Talk

- Different Models of Participatory Research
- Examples from some of my own projects
- Infrastructures/processes for collaboration
- Impact of participatory approaches on research
- Discussion

# Models of Participatory Research



# Participatory Research (PR)

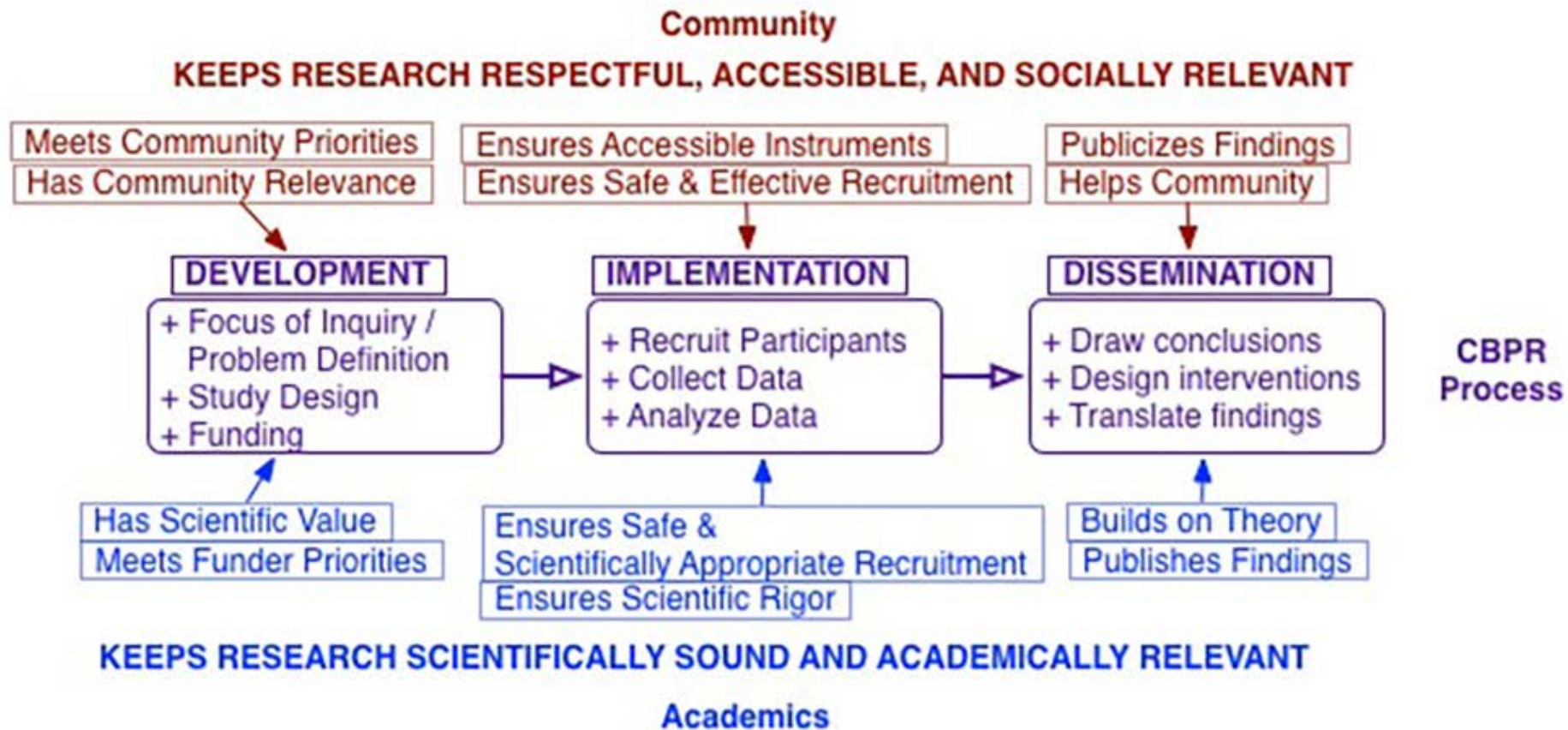
- Approaches that can be used with any methods.
- Many different flavors and levels of intensity
  - Participatory action research (PAR)
  - Community based participatory Research (CBPR)
  - Patient and Stakeholder Engagement (PCORI PSE model)
  - Community-initiated research
  - Other community partnered / community engaged research
  - (Contributions of “insider researchers”)
- No one best model – need to match to the context and goals of the research

# Different Models of PR

- Level of community participation?
  - Advisory role, “authentic participation”, equal partnership, community hiring researcher to perform specific tasks
- Timing of community participation?
  - Specific, limited tasks (e.g. review of materials); initiation and dissemination; every phase of the project
- Focus on action?
- Community as unit of identity vs. inclusion of specific patients/clients and stakeholders?
- Role of community agencies and stakeholder organizations

CBPR	Pt & Stk Engagement	Other CER/CPR; “PAR lite”
Equal Partnership	Authentic Engagement	Avoid Tokenism
“Community members”	“Patients and Stakeholders”	Either
Partner with community organizations	Include reps from pt and stk organizations	May or may not include organizations
All Phases of Research	All phases of Research	May be more limited?
9 Principles	Engagement Rubric	Various
Research to create action	Comparative effectiveness	Variable

# Community Based Participatory Research



# Principles of CBPR

- Acknowledge the community as a unit of identity;
- Build on the strengths and resources in the community;
- Facilitate a collaborative, equitable partnership in all phases of the research;
- Foster co-learning and capacity building among all partners;
- Balance knowledge generation and intervention for the mutual benefit of all partners;
- Attend to both local relevance and ecological perspectives;
- Develop systems using a cyclical and iterative process;
- Disseminate results to all partners, and involve all partners in dissemination;
- Commit to a long-term process and group sustainability.

# Some of My Examples



# Interconnections Project / Proyecto Interconexiones

- Partnership between OHSU, Bradley Angle House Healing Roots Center, and Familias en Accion
- Developed and tested a community-based depression care program for African-American and Latina intimate partner violence survivors
- NIMH and KPCF funding over 7 years
- Full CBPR approach



# Academic Autism Spectrum Partnership in Research and Education

- Partnership between academic investigators, autistic adults, family members, and disability/health professionals
- Full CBPR approach
- NIH funding
- Leadership: 2 Co-Directors with overlapping roles
- Academic and community members work as equal partners in all phases of the research projects
- Ongoing collaboration with multiple studies: healthcare survey, qualitative study of healthcare experiences, psychometric testing of AHAT, development and testing of Healthcare Toolkit, Internet and Wellbeing survey, starting employment study.



# Partnering Project



- Collaboration to conduct a CDC-funded observational study about the relationship between violence, health, and disability in people with developmental disabilities (DD)
- CBPR approach
- Leadership: Steering committee (SC) made up of 3 academic PIs; 4 community leaders with DD
- Community Advisory Boards (CAB) made up of people with DD, parents, disability professionals
- SC and CABs involved in all phases of the research project

# African American IDEA

(Improving Depression through Education and Action)

- Community-based intervention to address depression in African-Americans
- Community-initiated (African American Health Coalition)
- Group based program focused on racism and how it affects depression, stress, and healthy behaviors; psychoeducation and action planning.
- Two pilot studies found high acceptability and large improvements in depression score

# Other Examples

- Voices of Survivors (domestic violence education for MDs) – CBPR
- IMPACT (Coalition to address substance abuse in medically hospitalized patients) – Community-engaged research
- Autism diagnosis and intervention in Latino families – CBPR
- Pregnancy Decisions Project for women with developmental disabilities – “PAR lite”
- Buprenorphine vs opioid guidelines for chronic pain – Patient and Stakeholder Engagement model
- Various PhD student dissertations

# Infrastructures and Processes for Collaboration



# Infrastructures

- Can have significant impact on power sharing and project success
- Co-PIs (AASPIRE, AfAm IDEA)
- Steering Committees (Partnering, AASPIRE)
- Councils (AASPIRE, IMPACT)
- Advisory Boards (Partnering, Pregnancy, Latino Autism, some of the PhD dissertation projects)
- Teams (Interconnections)
- \*Research assistants, students, interns (almost all, but careful about power dynamics)

# Processes

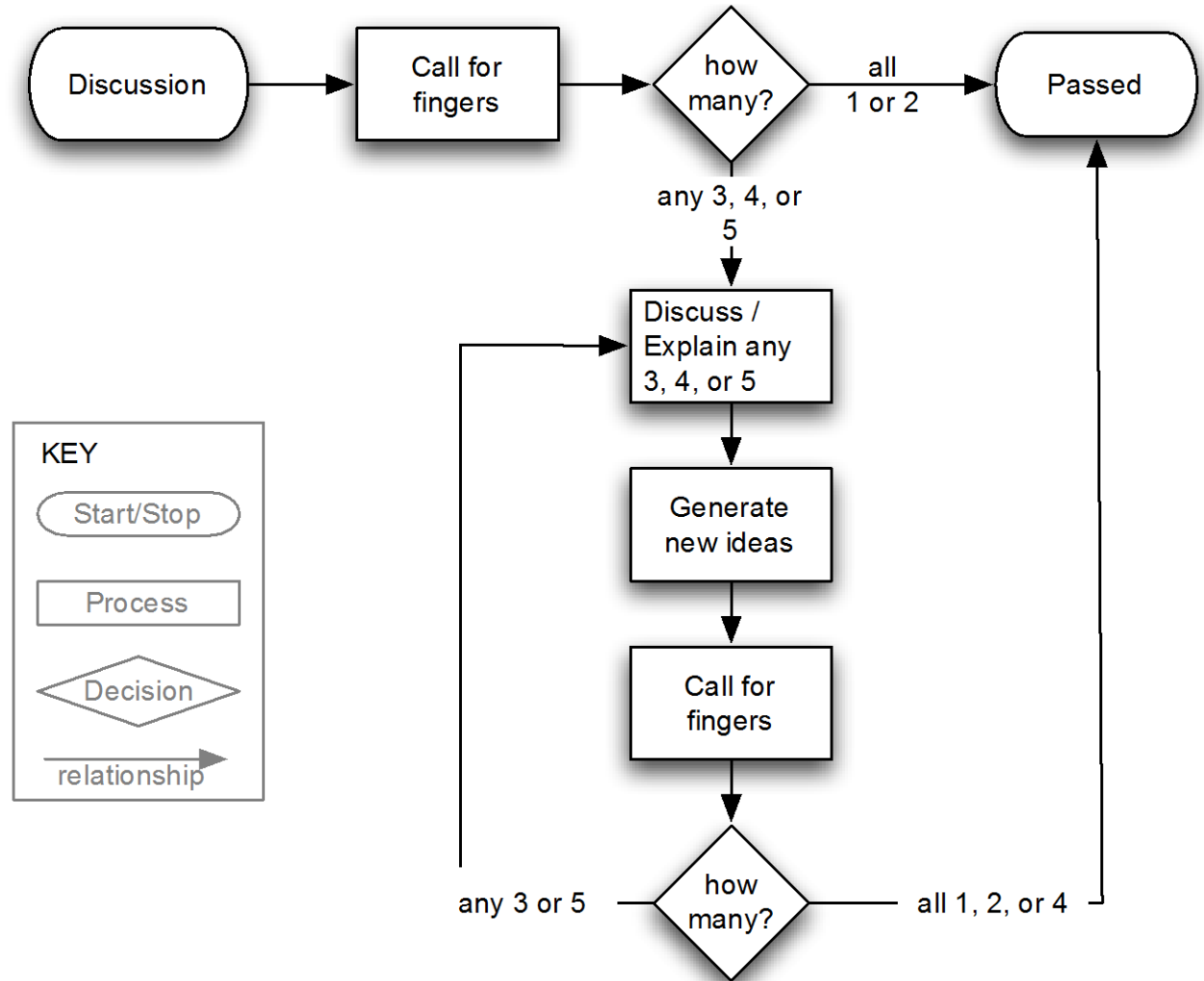
- Must match needs of research team
- Think about specific processes for communication, power-sharing, decision-making, accommodations, ongoing evaluation, authorship, data ownership, etc.
- Jointly created ground rules (usually made at first meeting and reviewed at least annually)
- Clear roles and responsibilities for all team members
- Shared vision / goals exercises
- Ice-breakers / “*dinamicas*”

# Communication Processes

- For AASPIRE
  - List serve
  - Text-based group chat (tables turned)
  - Structured communications (e.g. email format)
  - Flexible means of participation (IM, email, telephone)
- For Partnering and Pregnancy
  - In-person
  - Pre-meetings / materials in advance
  - “Process monitor” during meetings (shared role)

# Shared Decision- Making Process (used in all my projects)

- 1) I love it!
- 2) It's fine.
- 3) I have more questions.  
(and what they are)
- 4) I don't like it, but I  
won't block it. (and  
why)
- 5) I dislike it so much I  
can't live with it. (and  
why)



# Accommodations

- Provide what people need to work; a few examples from our projects:
  - ASL interpreter
  - One-on-one meetings
  - Personal assistance during meetings
  - Sensory accommodations (lights, sounds, providing fidgets, etc.)
  - Extra processing time
  - Alternate formats for materials or communication
  - Money for child care, transportation
- Ask your collaborators what they need and be willing to make changes based on feedback over time

# Authorship and Ownership

- Critical to jointly create written guidelines near the beginning of the project / partnership
- Useful for authorship, presentations, ownership of data, divvying of papers/products
- Strategies to allow community partners to meet authorship criteria
  - Lay translation table
  - Comments with explanations
  - Group and individual meetings



# Feedback Processes

- Keep / Change exercise at the end of meetings (Partnering, Pregnancy, others)
- Check-in discussion at the end of meetings, at project milestones, or when there's been a change (AASPIRE)
- Internal evaluation (Interconnections)
- External evaluation (Partnering)
- In all cases – most important thing is building a culture of trust, learning, forgiveness, and continuous adaptation.

# Compensation

- Make sure to fairly compensate community partners for their work
  - Might not be able to in planning stages – but make it clear you will when there is any funding
  - For small grants, can be fairly small stipends
  - For larger grants, make sure to include funding for community agencies and salary support
  - If you have money for participants/materials/staff, you have money for partners
  - Be creative

# Impact of Participatory Approaches on Research

# Interconnections Project Example

	Original Study	CBPR Studies
Research team	Academic co-investigators	Academic & community partners
Setting	Primary care clinics	Community-based agencies
Recruitment	Consecutive clinic patients	Flyers and word of mouth
Intervention	Created by PI and psych; administered by counselor	Created by team; administered by peer advocate
Interview guide / surveys	Created by PI	Created collaboratively by team
Facilitation & data collection	PI with RA's	Lay facilitators (PI with remote headset); RAs from community
Analysis	Academic co-investigators	Academic & community partners
Dissemination	Journal articles	Journal articles; depression awareness events

# Choice of Topics / Study Design

- Who's idea?
  - Sometimes initiated by community (AfAm IDEA)
  - Sometimes jointly decided (AASPIRE)
  - Sometimes initiated by funder (Partnering, Pregnancy)
- Always must be important to community and meet community priorities
- Sometimes design changes considerably based on community input (Interconnections)
- Help address ethical considerations; plan for how to handle difficult questions

# Accessible Consent Materials

- Community partners critical to ensuring consent process is actually informed
  - Clear, simplified consent materials (yes – you can change the boilerplate text on standard forms)
  - Q&A format
  - Visual aids
  - Time to discuss with trusted person
  - Need for / utility of comprehension assessment?



# Example Consent Form

## **What will happen if I do the study?**

If you decide to do the study, you will do an interview with Marcie, the Research Assistant. During the interview, you and Marcie will go through the questions together. If you choose, you can also have someone you know be there to help you.

Your answers will be recorded on a recording machine. After the interview, a research assistant will type everything you said onto a page.

You will be able to take a break at any time. You do not have to answer any questions that you don't want to. You will be able to stop the interview at any time. It may take one or two hours to complete the interview.



## **How will my information be kept private?**

- We will not use your name or other personal information in any public way, like when we write about the study.

# Effective Recruitment

- Recruitment materials that “speak” to the population
- Recruitment via trusted community leaders
- Access to community forums / events / venues
- Careful not to abuse trust... (e.g. from partner’s experience)

# Choice of Outcomes / Constructs

- Discussion to decide what key constructs should be
- “Patient-centered outcomes”
- Addition of variables/measures that may otherwise not have been included

# Example Effects on Survey Studies

- Measurement adaptation
- Accessible data collection
- Interpretation of data

# Measurement Adaptation

- Adaptation of existing survey measures
  - Prefaces (for greater context, precision, instructions, or disclaimers)
  - Hotlinks with definitions or examples
  - Simplifying sentence structure
  - Substituting simpler vocabulary (with caution)
  - Icons to help with Likert scale response options
  - One item per page; full sentences
- If possible, try to avoid changing meaning, # of items, scoring, response options
- Need to recheck psychometric properties, (but MUCH better than using an instrument that is inaccessible or not tested with your population).

# Example Instrument Adaptation

Original

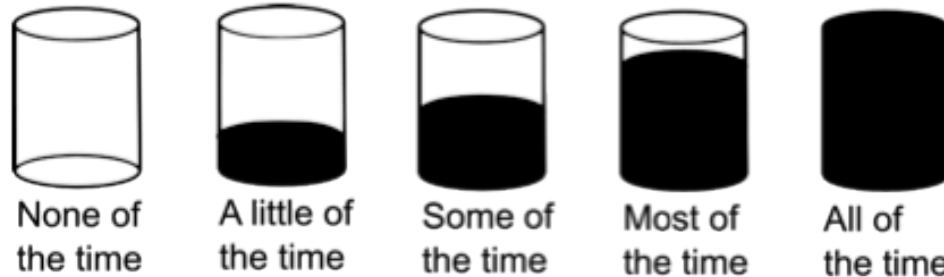
7. Someone to confide in or talk to about yourself or your problems.

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?



# Data Collection Methods

- Choice of participation mode (e.g. in-person, IM, email, telephone)
- Breaks
- Audio computer-assisted self-interview (ACASI)
- Participatory process or at least pilot-testing while creating or adapting materials and processes
- ? Consider using community members to collect data



# Example Accessible Data Collection

A A A A

UID: YPgN8Ab2ZJDhAGO

☐ Text Only ☒ American Sign Language ☐ Read Text Aloud

Introduction

Help Page

Disability

General Information

Physical Health

Health Problems

Depression

Stress

**Response to Stressful Experiences**

Alcohol and Drug

Social Support

Childhood Experiences

Adult Mistreatment

Impact and Help-Seeking

Abusers

Barriers to Getting Help for Abuse

Evaluation Questions

In the last month, how much have you been bothered or upset by repeated bad memories, thoughts, or pictures in your mind of a [stressful experience](#) from the past?

Not at all

A little bit


Moderately

Quite a bit

Extremely

Next

Replay



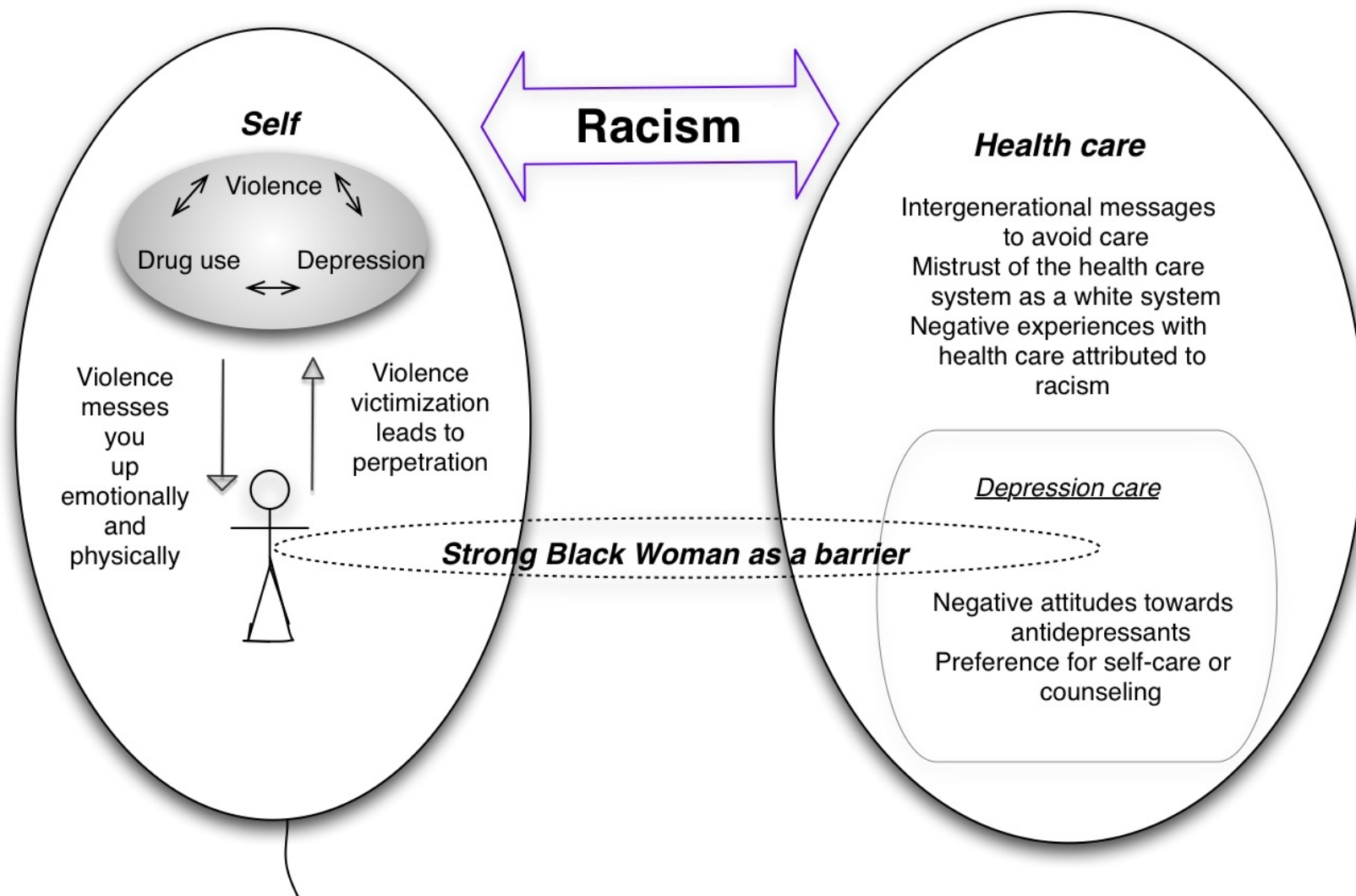
# Example Effect on Data Collection - Partnering Project

- Accessible, private process allowed for collection of abuse data without the need for mandatory abuse reporting (even with >60% disclosing abuse)
- Adapted instruments had high internal consistency reliability, construct validity, and congruent validity
- Participants said:
  - The computer was easy to use (83%)
  - The survey questions were easy to understand (75%)
  - Using a computer to answer IPV and health-related questions was preferred rather than talking to someone directly (69%)
  - Addressing health and safety are critical (90%)

# Effects on Qualitative Research

- Partner input to improve data collection
  - Advance look at materials
  - Prefaces to help participants understand what is wanted (“help make a mini-movie of your experience”)
  - Providing enough specificity, even with open-ended questions
  - Ensuring questions are concrete enough to be answered
- ? Consider using community members to collect data
- Collaborative process to finalize themes

# Example Qualitative Results





# Intervention Development

- Community key to ensuring that intervention is effective, respectful, useful, accessible, appropriate
- May inherently change intervention...

# E.g. Interconnections Intervention

Group Topics	Activities / Handouts
<i>Introduction to the group program</i>	Group mural describing group rules and goals
<i>What is domestic violence?</i>	Art/Craft: Jewelry box activity representing the inner self *
<i>Making a safety plan</i>	Review social services / local resources*; Create safety plans*
<i>Goal setting and planning for the future</i>	Art/Craft: Paper lantern representing the stages of change *
<i>What is depression?</i>	Create, personalize, and learn how to use a mood calendar*
<i>Maintaining a mood diary</i>	Depression booklets from NAMI and NIMH†
<i>Truths and myths about depression and other mental disorders</i>	Puzzle activity on depression myths and truths*; Mental health pamphlets from NIMH†
<i>Learning about automatic thoughts</i>	Socio-drama: Skits on alarming ideas*
<i>Defeating automatic thoughts</i>	Socio-drama: Skits on automatic thoughts*; Art/Craft: Personalized positive thinking cards
<i>Using core beliefs and fundamental truths</i>	Socio-drama: Skits on core beliefs*; Art/Craft: Decorate positive message stones*
<i>Self-care</i>	Introductory yoga moves and self-massage*
<i>Putting lessons into action</i>	Art/Craft: Placemat representing future hopes and dreams using collage*

# AASPIRE Healthcare Toolkit –

## www.autismandhealth.org



[HOME](#) • [ABOUT](#) • [SITE MAP](#) • [PARTNERS](#) • [CONTACT](#)

Theme:



## AASPIRE Healthcare Toolkit

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

This web site 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

[click here](#)



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

[click here](#)

This section has information on:

- [How Autism Can Affect Healthcare](#)
- [Tips for Successful Office Visits](#)
- [Legal and Ethical Considerations](#)
- [Autism Information, Diagnosis, and Referrals](#)
- [Associated Conditions](#)

Healthcare providers also might want share our [Autism Healthcare Accommodations Tool](#), and other [checklists and worksheets](#) with their patients on the autism spectrum.

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SYRACUSE UNIVERSITY



INDIANA UNIVERSITY



Portland State UNIVERSITY



# Dissemination

- Using respectful language in both academic and community communications about the research
- Creating plain language versions of findings
- Creating materials in accessible formats (audio, video, plain text, etc.)
- Creating policy briefs
- Letting people who might find the research useful know about it
- Working with people who need the data to put it into formats that they can use
- Community events
- Lasting tools and products

# Example Dissemination Event

## REDEFINING the **BLUES**

**Saturday**  
**Jan. 17, 2009**  
**2 - 3:30 p.m.**

 **Curious Comedy Productions**  
**5225 NE MLK Jr. Blvd**  
**( south of Killingsworth )**  
**Tel: 503-477-9477**

*Brought to you by:*  
**OHSU & Healing Roots Center**

Sistahs, this is a special invitation to  
**ALL STRONG BLACK WOMEN**  
in the Portland metro area

**GUMBO**

ENTERTAINMENT

WITH SPECIAL GUEST

*Sen. Avel Gordly*



*(Don't miss her heartfelt message!)*

**GIVEAWAYS**

**Spoken word performance by S. Renee Mitchell**

*What are you burying? Your feelings or THE MYTH?*

## Black Woman, What Are You Burying?

© 2009, S. Renee Mitchell

**CHORUS:** *Black woman, black woman*

*What are you burying?*

*Your feelings or the myth?*

*When you gon' deal with this?*

*My strong black woman, black woman*

*No wonder you're all depressed*

*You're carrying the weight of the world*

*Taking care of everyone but yourself*

Sometimes, I feel like my body is better off dead

Don't even want get up when I lay on my bed

Everybody gets on my nerves, can't find no peace

Can't laugh, can't dance, can't even sleep

The dishes, the clothes, the kids, I wash and rinse

So tired, I give out attitude like they was peppermints

Anybody get in my way, I fuss and I fight

Then I cry myself to sleep at night

### CHORUS

I hate my boss, I love my man but they both treat me bad

Can't provide for my children and it makes me so sad

I can't deal with the truth, about my childhood abuse

I bury shame, guilt and regret, but I still can't forget

I want to give up my breath, I get so low

How I sunk down in this pit, I sho don't know

But ask me how I'm doing: I'm fine, I'll speak

Don't want anyone to think that I'm weak

### CHORUS

Sistah, stop sacrificing joy to prove that you're strong

Admit you need help, that there's something's wrong

People are here to help, to advise and assist

All you go to do now is bury the myth!

We're strong. We're black. We're women. It's true.

But stringing those words together just creates the blues

We all got grief, secrets, pain, and deep inner stuff

So let's kill off the myth. Cause it's sho killing us

*Black woman, Black woman*

*What are you burying? Your feelings – or the myth*

*When you gon deal with this*

*My strong black woman, black woman*

*No wonder you're all depressed*

*You're carrying the weight of the world*

*It's time you take care of yourself!*

# REDEFINING the **BLUES**



A special event  
for  
**STRONG  
BLACK WOMEN**  
in the Portland  
metro area

**Saturday, Jan. 17, 2009**

.....  
*This event has been brought to you by:*



**Curious  
Comedy  
Productions**



**OREGON  
HEALTH & SCIENCE  
UNIVERSITY**

*Renee Mitchell Speaks*



**The Healing  
Roots Center**



**The Avel Gordly  
Center For Healing**



**Kaiser Permanente  
Community Fund**



**National Institute of Mental Health**  
Transforming the understanding and treatment of mental  
illness through research

WITH SPECIAL GUEST



*former*

*Sen. Avel Gordly*

*What are you burying? Your feelings or THE MYTH?*

# Can/Should You Use a Participatory Approach?

# Considerations

- I'd say it's worth it, no matter what type of research you do – but you need to decide for yourself
- It takes a LOT of thought and effort
- Are you willing to share power? Do you want to learn from the population you study?
- Think about how and where inclusion of autistic or other stakeholders will benefit your work
- Think about the level of involvement that is desirable and feasible now (and in the future)



# Considerations

- Who needs to be included?
- What organizations can you partner with? What are the benefits and/or downsides of working with a particular organization?
- How will you ensure that partners are authentically engaged?
- Think about how to avoid tokenism, breaking trust, pretending to do something you are not doing...
- Go for it!

# Discussion and Questions

- Thoughts?
- Thanks to all the AASPIRE, Partnering, Pregnancy, and Interconnections Partners and the AAHC
- Feel free to contact me:
  - [nicol22@pdx.edu](mailto:nicol22@pdx.edu)
- Useful Websites:
  - [www.aaspire.org](http://www.aaspire.org)
  - [www.autismandhealth.org](http://www.autismandhealth.org)
  - [www.pdx.edu/social-determinants-health](http://www.pdx.edu/social-determinants-health)
  - [www.ccph.info](http://www.ccph.info)