

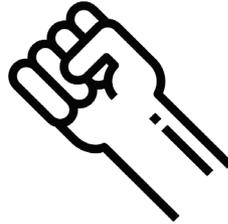
# 2018 Online KT Conference: Engaging Ways to Engage Stakeholders

Hosted by AIR's Center on KTDRR

November 5, 7, and 9, 2018

Center on  
**KNOWLEDGE TRANSLATION FOR  
DISABILITY & REHABILITATION RESEARCH**

at American Institutes for Research ■



# Disability Rights in Science:

Community-Engaged Research With People With Disabilities

Katherine (Katie) McDonald, PhD  
Professor, Public Health

# Overview



- Community-engaged research with people with (developmental) disabilities

Theory

*What is it and why use it?*

Evidence

*Does it Work?*

Actionable Strategies

*How can you do it?*



# Your Experience?

Poll time!

- 1. How familiar are you with the theory, evidence base, and effective strategies of/for approaches to community-engaged research?*
- 2. Have you ever used any of the following approaches to community-engaged research?*

# Projects and Funders



AASPIRE

Academic Autism Spectrum Partnership in Research and Education



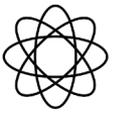
Project  
ETHICS





# Language

- People first
- Identify first



# Disability Rights in Science: Theory

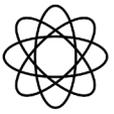
## (part 1)

- New knowledge is needed for equity
- Legal, ethical, and social dynamics contribute to people with disabilities:
  - being understudied,
  - being at risk for exclusion and inappropriate inclusion, and
  - a mismatch of values and priorities in science and scientific approaches
- Little influence over science

# Disability Rights in Science: Theory

## (part 2)

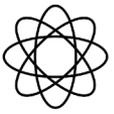
- Direct representation in research
  - Inclusion
  - Benefits
- Self-determination in research participation decisions, maybe with support
- Interpersonal dynamics impact perceptions of safety



# Disability Rights in Science: Theory

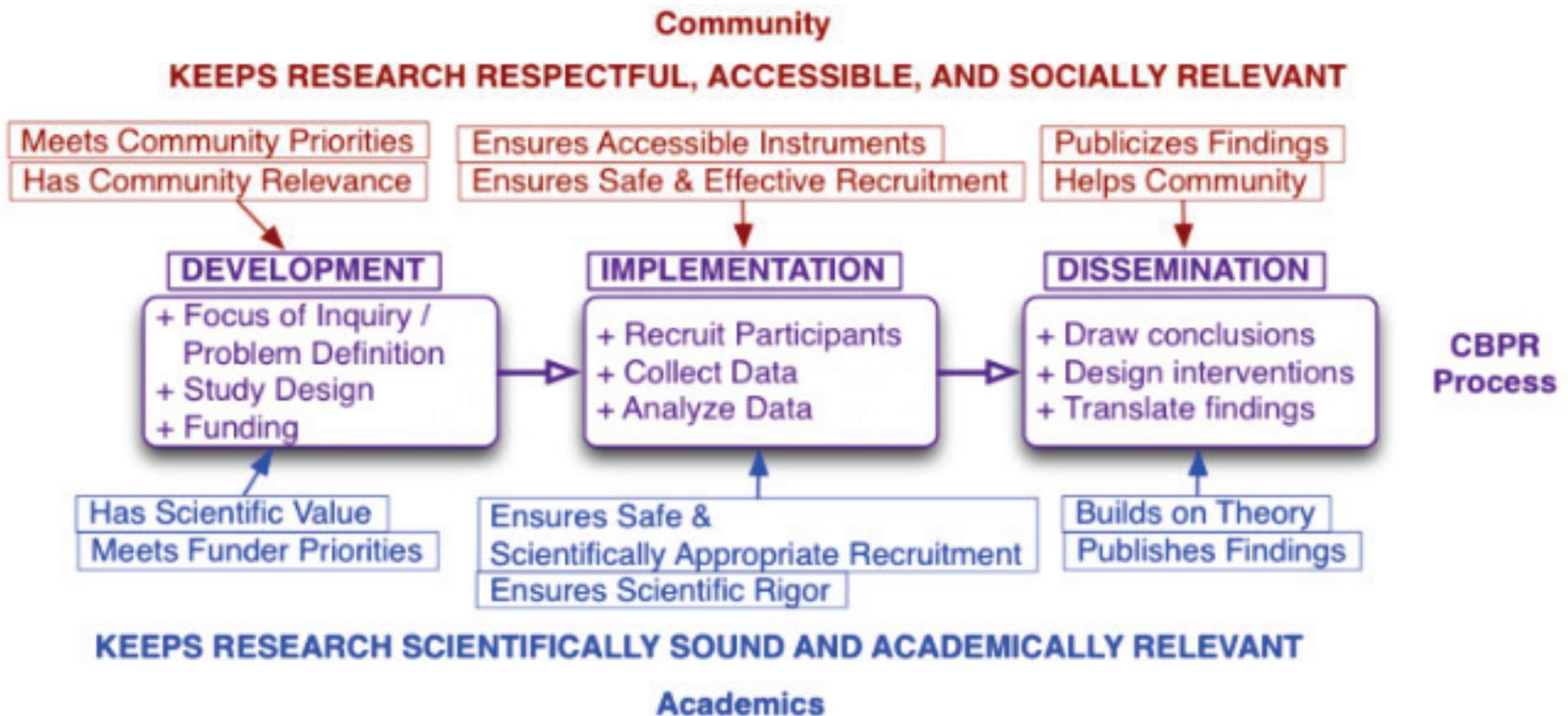
## (part 3)

- Community-Based Participatory Research
  - Response to issues faced by marginalized communities
  - Community representatives as full members of research team
  - Equitable exchange of power and expertise
    - Build insight and capacity
    - Knowledge and social action
  - Can be used with any research methodology
  - *Better science, community capacitation, empowerment, and knowledge translation?*

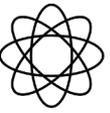


# Disability Rights in Science: Theory

## (part 4)



Source: AASPIRE website: <https://aaspire.org/about/cbpr/>



# Disability Rights in Science: Theory

## (part 5)

- Shared roots, many branches
  - Different levels of collaboration and power-sharing

Poll time!

- *In what aspects of research have you engaged with people with disabilities?*



# Disability Rights in Science: Evidence

- Researcher reported motivations consistent with theory
- Enhances appropriateness of research and quality of science, including translational science
- Identifying facilitators and challenges
- Equal partnerships are rare, but growing?
- Weak evidence base



# Community-Based Participation Research Diagram

## Challenges

- Innovative
- Identifying & adhering to accommodations
- Adhering full to CBPR
- Inadequate resources
- Power sharing & collaboration
- Clarity
- Inadequate communication
- Nature of the work
- Full representation

## Facilitators

- CBPR & disability rights values
- Values-based actions
- Member characteristics
- Structures
- Reflective practice

## Outcomes

- *Project Members*
  - Learning, growth, skill development, meet new people, contribute, earn money
- *Project*
  - Valid & accessible instruments, improved recruitment & KT, stronger partnerships
- *Society*
  - Demonstration of capacity, model of inclusion, information to spur action



# Quotes

*I find it real hard sometimes when like [group members] are talking and they have real hard words... That is really frustrating to me ... when you don't understand something, it is pretty hard... I feel like, 'Why am I here?'*

*Often we stop things and go back and make sure that ... one or more people who have expressed confusion about what we are talking about, we can address that.*

*Seeing my suggestions considered and implemented without giving me the ninth degree was also quite lovely.*

*I am learning more so I can help others to advocate for themselves.*

*It is empowering to be in charge of a topic like this rather than being on the receiving end of the application of this topic, or this study, or project.*

*It brings people together so there is not a big gap between the community and researchers. So things are more accurate.*

*Sometimes people don't realize people with disabilities are capable of doing things like this.*

# Consent and Assent Form

You are invited to be in a **research study about adults with an intellectual disability being in research.**

Katherine (Katie) McDonald, PhD, at Syracuse University is in charge of this study.



You are being asked to take the survey because **you have important experiences.** We hope to have 500 people take the survey.

This form has **information about being** in this study.



It is **up to you** to decide whether you want to be in this research study.

This project is funded by a grant from the National Institute of Child Health and Human Development, a part of the National Institutes of Health (NIH).

## What is the study for?



To learn what **you think** about topics such as:

- How important it is that different things happen when adults with an intellectual disability are in research studies.
- How safe adults with an intellectual disability are when people who do research do certain things.



We also want to learn about your experiences being in research studies and some of your personal information, like your gender and age.



We hope to learn about what different people think about these topics.

# Visual Communication Examples

Project ETHICS  
Informed Consent – Your Choices

**YES!**

*I don't know...*

**NO!**

Project ETHICS  
Your Options

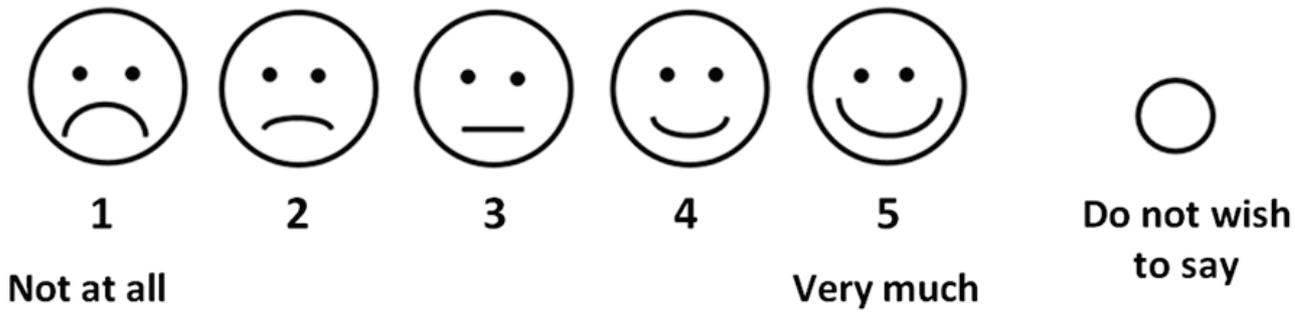
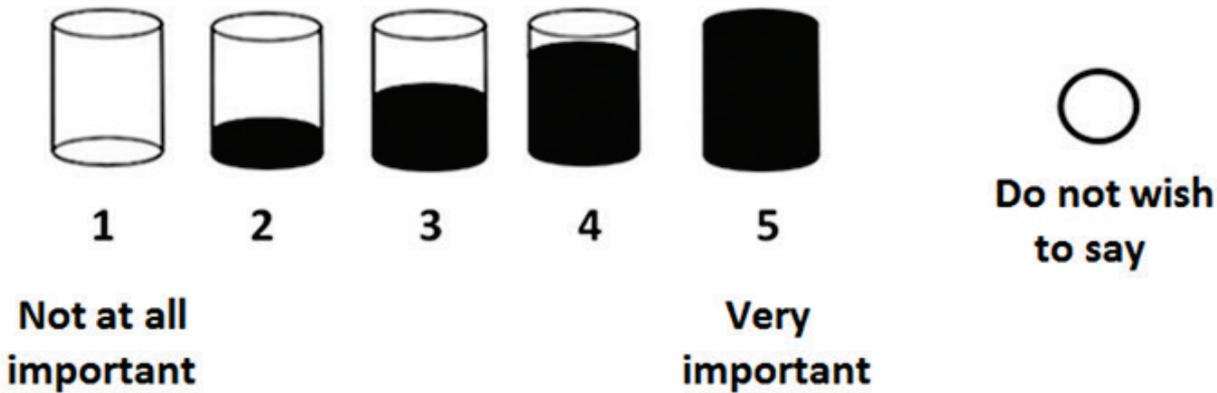
At any time,  
you may...

Stop for today

Take a break

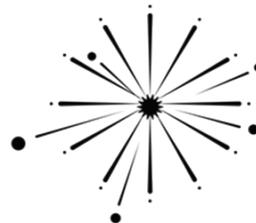
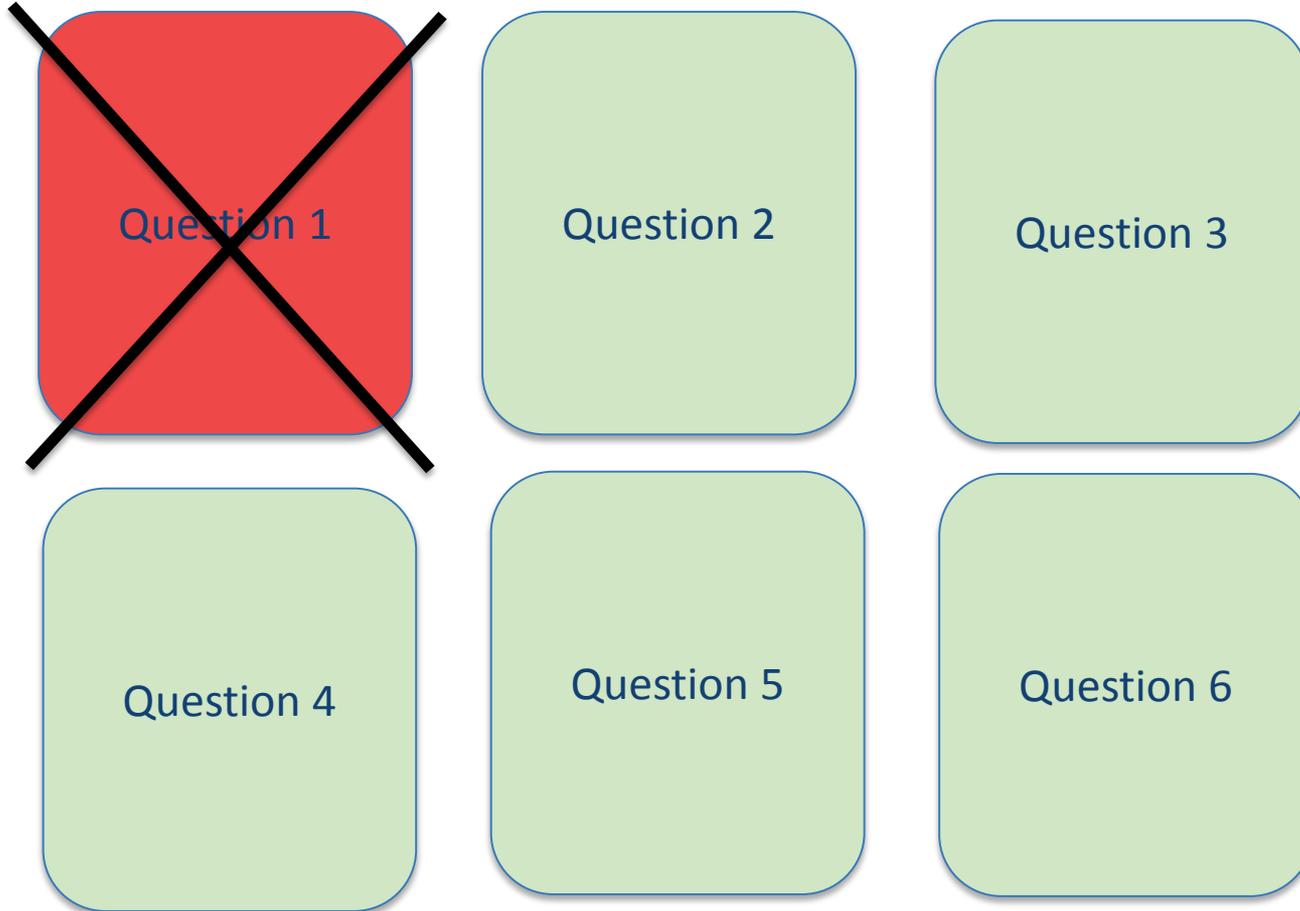
Keep going

# Response Scales



Source: McDonald.

# Interview Guide Progress



# Interview Guide Progress (cont.)



## 2. BAD things about ...?



# HotBox to Explain Constructs

In the past six months, the time I spent participating in any online community activity was spent with (check all that apply)

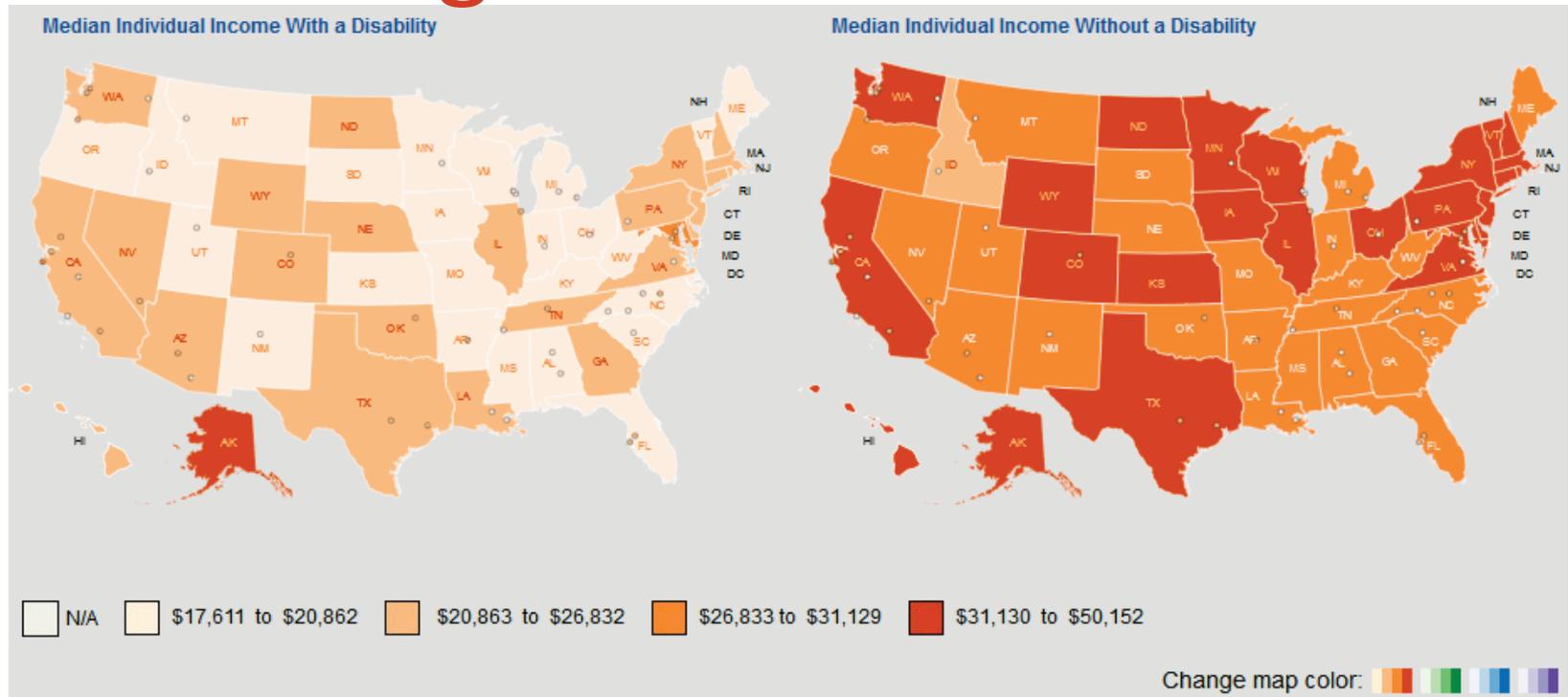
- forum, blog, wiki, or other community-edited web pages (for example: WrongPlanet, DailyKos, Wikipedia)
- social networking (for example: FaceBook, Twitter, Flickr, YouTube)
- list serves, newsgroups (for example: Yahoogroups, Usenet)
- live chat groups (for example: MSN, AIM, IRC)
- virtual environments (for example: SecondLife, World of Warcraft)
- other
- cannot or do not wish to say



**Participating in any online community** refers to using the Internet to socialize, interact, exchange information, coordinate events, or participate in any activity that involved interacting with **other people** over the internet.

Source: Author-developed survey item.

# Knowledge Translation



Region	With a disability	Without a disability
<u><a href="#">United States</a></u>	\$21,509	\$31,865
<u><a href="#">Alaska</a></u>	\$31,164	\$37,189
<u><a href="#">Alabama</a></u>	\$20,661	\$28,978
<u><a href="#">Arkansas</a></u>	\$19,722	\$27,469

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# Knowledge Translation (cont.)

**AASPIRE** HOME • ABOUT • SITE MAP • PARTNERS • CONTACT

Theme: Light (default) search Search

## 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:

- [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 share our Autism Healthcare Accommodations Tool, and other checklists and worksheets with their patients on the autism spectrum.

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Source: AASPIRE.



# Disability Rights in Science: Actionable Strategies (part 1)

- Relationships
- Accommodations and Power Sharing
  - Respect and Trust
- IRB approval



# Disability Rights in Science: Actionable Strategies (part 2)

- Relationships
  - Partnership goals and roles
  - Select community members based on needs
    - Partners without disabilities? Share values and commitments
  - Personal relationships
  - Evaluate



# Disability Rights in Science: Actionable Strategies (part 3)

- Accommodations and Power Sharing
  - Individualized accommodations
  - Transportation support
  - Group guidelines (including authorship), process monitor
  - Structured process for communication, discussions and decisions
  - Provide breaks
  - Offer inclusive food and beverages
  - Evaluate



# Disability Rights in Science: Actionable Strategies (part 4)

- IRB approval
  - Differentiate co-researchers from research participants
  - Identify roles
  - Accessible, project- and role-specific “research ethics 101” training

## Project ETHICS Expert Panel Member Roles and Responsibilities

### What will my role on the Expert Panel be?

As an Expert Panel member, you will:

1. Make sure that all Expert Panel **members are valued**.

2. Make sure that Expert Panel activities and discussion are **accessible** to all participants.



3. Make sure that the discussion respects and values both those in the room and the **disability community**.

4. Offer **advice and ideas** to all Expert Panel members.



5. Assist in **making decisions** throughout the Expert Panel.

6. Make sure materials are **accessible** for all people.

7. Help us **understand findings** from Project ETHICS focus groups and other research.

8. Play an active part in **developing a survey** that will that make sense to others.



9. Help **create, review, and edit** materials for recruitment and informed consent.

# What will I be responsible for?

When you are on the Expert Panel, you will be expected to:

1. **Share your expertise** as a person with an intellectual disability, family member of a person with an intellectual disability, researcher, IRB member, or disability services professional.
2. Attend **six (6) meetings**, which will each be about three hours long.
3. **Review** the information presented at the meeting.
4. Suggest ways to **make surveys** that are easy to understand.
5. Suggest ways to **explain the survey** to potential participants.
6. **Describe to others** what Project ETHICS is all about, and your role on the Expert Panel.

# As a member of the Expert Panel you will:

As a member of the Expert Panel you will:

1. **Receive \$50** at the end of each meeting that you attend.
2. Be reimbursed for **travel expenses** to and from meetings.
3. Be **fed!**
4. Have an opportunity to **contribute** to important research.

# Co-Create Group Guidelines

## Group Guidelines – ways we want to work together

1. Meetings will start and end on time.
2. Everyone's thoughts are welcomed, encouraged and valued. It is okay to say how you feel, and okay to respectfully disagree with someone else.
3. Everyone is included in the conversation.
4. Speak one at a time.
5. No private conversations during meetings.
6. Respect confidentiality – personal stories “stay in the room.”
7. Speak your name before talking.
8. When you are done talking, say “done” or “next.”
9. Respect everyone's time by staying on topic.
10. Be patient while learning everyone's accommodation needs.
11. Do frequent check-ins and do “round robins” to get everyone's feedback.
12. Finger counts will be taken when making decisions.

# Accessible Work Materials

## PURPOSE

The purpose of this email is to

- 1) show everyone the original Patient Activation Measure (PAM) in two different versions, one for people who have chronic health conditions, and one for people do not have chronic health conditions, and to
- 2) find out what you think of using the original PAM questions instead of what you previously saw in the survey.

The instrument is both attached (Original PAM.jpg, probably easier to read) and pasted in plain text into this email.

---

## ACTIONS

- 1) Look at the original instrument.
- 2) Answer: What do you think of using this instrument?
- 3) Answer: Are there any changes you feel would need to be made to the original instrument in order to make it more understandable or work better? Or should we keep looking for a different instrument?

Please answer by FRIDAY 16 OCTOBER.

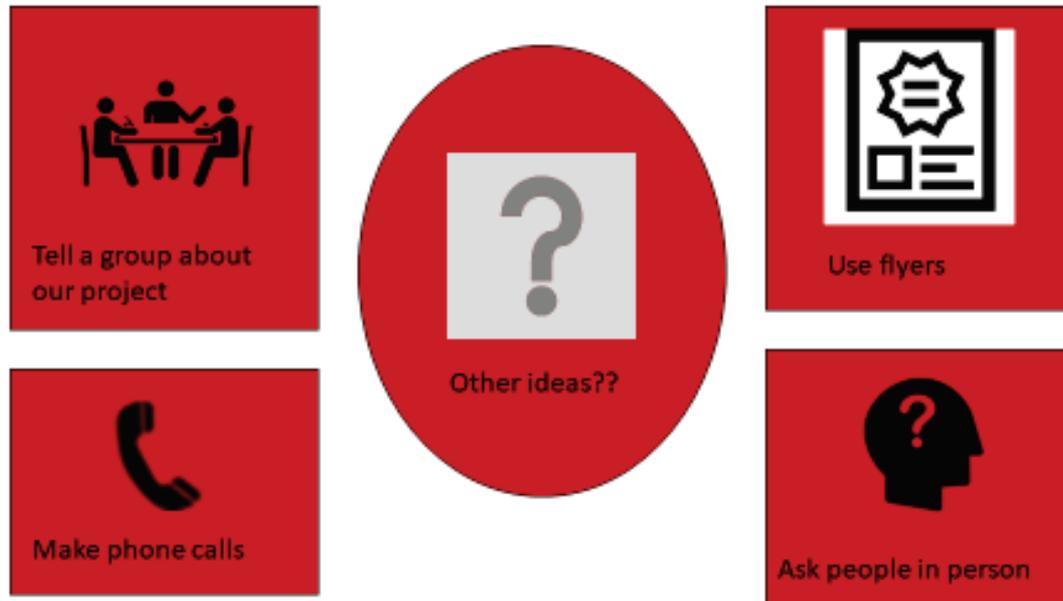
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## BACKGROUND

Dora originally modified the original Chronic Condition Version of the Patient Activation Instrument. Some of the questions she re-wrote because she couldn't understand the language. Others she re-wrote

# Accessible Work Materials

Recruitment: How do we recruit people for our study?



# Accessible Work Materials

## Five (5) Finger Decision Making



**Yay, I approve!**  
Do it!



Meh, I'm **not thrilled**, but I **approve**.



I'm **not sure**. I need more information or discussion.\*\*



I **don't like it**. I won't approve it.  
But I **can live with it**.\*\*



I **hate** this so much that I **can't live with having my name associated with it**.\*\*

\*\* **We will:** Explain. Discuss. Generate new ideas.

# Accessible Work Materials

## What did we learn?

### Views on Safety

- The 5 groups had different thoughts about safety for 8 of the 17 safeguards. Groups disagreed the most about the safety of different ways to recruit, and agree more on the safety of different decision-making and participation safeguards.
- All groups thought it is less safe when researchers talk to others before talking to adults with intellectual disability than all other decision-making and research participation safeguards.
- Adults with intellectual disability thought it was safer to:
  - be recruited by researchers (compared to other group)
  - have researchers give them time to think about the participation decision (compared to service providers, researchers and IRB members)

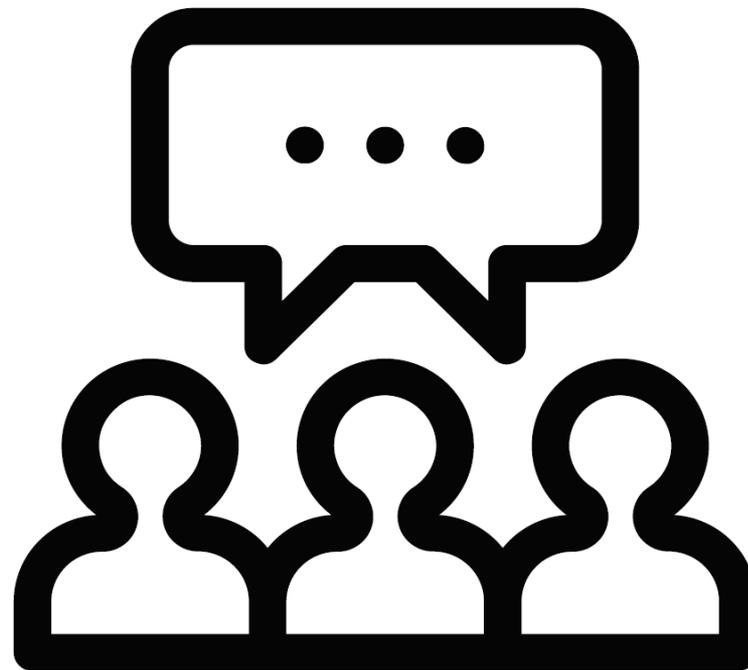
# How did it go today?



# Disability Rights in Science

- CBPR with people with (developmental) disabilities is possible and can address problems with traditional research, including enhancing KT
- CBPR can be used to effectively develop study materials and protocols for facilitating self-determination in consent and assent and collecting safe and valid self-report data
- CBPR requires resources, skills, and constant attention to inclusion and power
- We still have a lot to learn (ethical concerns, effective practices), but we have a growing toolkit and community of practitioners

# Discussion



# Acknowledgments – the Noun Project

- action by Vectors Market from the Noun Project
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- disability by BomSymbols from the Noun Project
- discussion by Gregor Cresnar from the Noun Project
- flyer by b farias from the Noun Project
- go by Dinosoft Labs from the Noun Project
- journey by Logan from the Noun Project
- language by Prasanta Kr Dutta from the Noun Project
- meeting by b farias from the Noun Project
- one, two, three, four, five by Laurent G n reux from the Noun Project
- relax by Adrien Coquet from the Noun Project
- rights by anbileru adaleru from the Noun Project
- science by Made by Made from the Noun Project
- stop by Delta from the Noun Project
- unsure by Adriane Harcourt from the Noun Project

# References

- Brett, J., Staniszewska, S., Mockford C., et al. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations*, 17, 637–650.
- Hughes, R., Robinson-Whelen, S., Goe, R., Schwartz, S., McDonald, K., Arnold, C., Cesal, L. & The Safety Project Consortium. (First published 2018, August 12, online). “I really want people to use our work to be safe” ... Using participatory research to develop a safety intervention for adults with intellectual disability. *Journal of Intellectual Disabilities*. doi:10.1177/1744629518793466
- Israel, B. A. (1998). Review of community based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19, 173–202.
- Isreal, B. A., Eng E., Schulz, A. J., & Parker, E. A. (2005). *Methods in community-based participatory research for health*. San Francisco, CA: John Wiley.
- Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (2001). Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Education for Health*, 14, 182–197.
- Kidney, C., & McDonald, K. (2014). A toolkit for accessible and respectful engagement in research. *Disability & Society*, 29, 1013–1030.
- Lewin, K. (1946). Action research and minority problems. *Journal of Social Issues*, 2, 34–46.
- McDonald, K., Conroy, N., Olick, R., & The Project ETHICS Expert Panel. (2016). Is it worth it? Benefits in research with adults with intellectual disability. *Intellectual and Developmental Disabilities*, 54, 440–453.

# References (Cont.)

- McDonald, K., Conroy, N., Olick, R., & The Project ETHICS Expert Panel. (2017). What's the harm? Harms in research with adults with intellectual disability. *American Journal on Intellectual and Developmental Disabilities, 122*, 78–92.
- McDonald, K., Conroy, N., Olick, R., & The Project ETHICS Expert Panel. (2018). A quantitative study of attitudes toward the research participation of adults with intellectual disability: Do stakeholders agree? *Disability and Health Journal, 11*, 345–350.
- McDonald, K., Conroy, N., Olick, R., Kim, C., LoBraico, E., Prather, E., & The Project ETHICS Expert Panel. (2016). Is safety in the eye of the beholder? Safeguards in research with adults with intellectual disability. *Journal of Empirical Research in Human Research Ethics, 11*, 424-438. doi:10.1177/1556264616651182
- McDonald, K., & Raymaker, D. (2013). Paradigm shifts in disability and health: Towards more ethical public health research. *American Journal of Public Health, 103*, 2165–2173.
- McDonald, K., & Stack, E. (2016). You say you want a revolution: An empirical study of community-based participatory research with people with developmental disabilities. *Disability and Health Journal, 9*, 201–207.
- McTaggart, R. (1991). Principles for participatory action research. *Adult Education Quarterly, 41*, 168–187.
- Minkler, M., & Wallerstein N. (2003). *Community-based participatory research for health*. San Francisco, CA: John Wiley.

# References (Cont.)

- Nicolaidis, C., Raymaker, D., McDonald, K., Robertson, S., Dern, S., & Ashkenzy, E. (2011). Collaboration strategies in non-traditional CBPR partnerships: Lessons from a geographically-dispersed partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, Education, and Action, 5*, 143–150.
- Patient-Centered Outcomes Research Institute. (2015). PCORI Evaluation Framework 2.0.
- Stack, E., & McDonald, K. (2014). Nothing about us without us: Does action research in developmental disabilities research measure up? *Journal of Policy and Practice in Intellectual Disabilities, 11*, 83–91.
- Stack, E., & McDonald, K. (2018). We are “both in charge, the academics and self-advocates”: Empowerment in community-based participatory research. *Journal of Practice and Policy in Intellectual Disabilities, 15*, 80–89.
- Wallerstein, N., & Duran, B. (2010). Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *American Journal of Public Health, 100*, S40–46.
- Whyte, W. F. (1990). *Participatory action research*. Newbury Park, CA: Sage.

# Disclaimer

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