

The Disability Experiences Expert Panel: Empowering Self-Advocates to Engage in Participatory Action Research



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Nisonger Center
Rehabilitation Research and Training Center**

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The Need for Inclusive Health Research

- We do not have accurate data on the health care needs of people with intellectual disabilities (ID)
- Mental health issues are hard to diagnose



The Need for Inclusive Health Research

- Health professionals often rely on the opinions and observations of someone close to the patient (proxy report) instead of getting answers directly from them



The Nisonger RRTC on Health and Function

The Nisonger Rehabilitation and Research Training Center (RRTC) is a five-year Participatory Action Research (PAR) project



What are we trying to do?

- Learn how adults with ID can speak up about their own health
- Make health surveys easier to understand for self-report



What are we trying to do?

- Find the prevalence rate of adults with ID and mental health issues
- Understand best practices in treating mental health issues for adults with ID



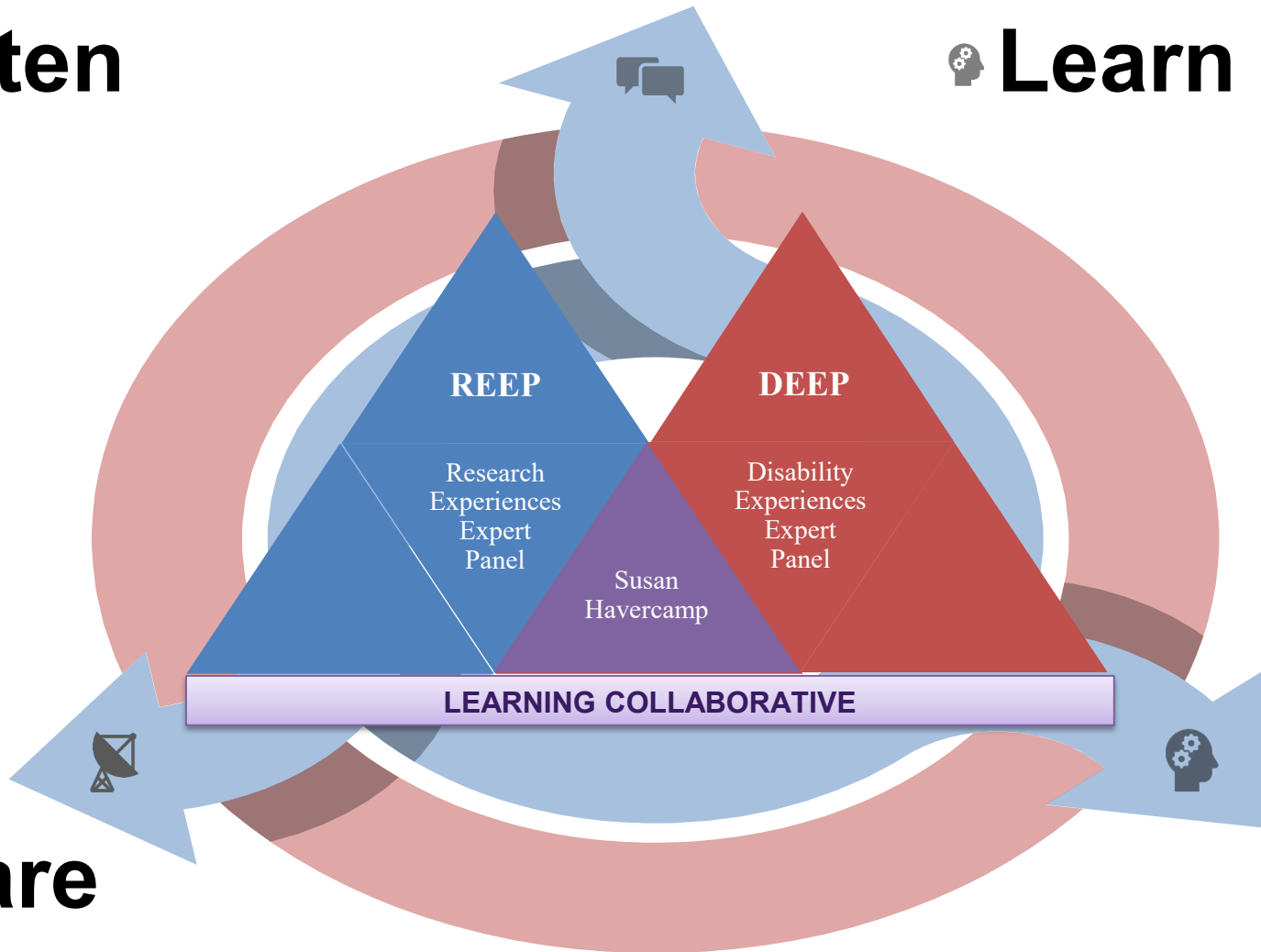
What are we trying to do?

- Construct and share guidelines for clinical care
- Conduct research that includes people with lived experience



 **Listen**

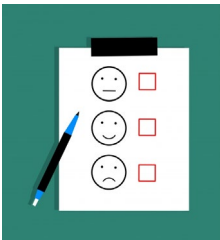
 **Learn**



 **Share**

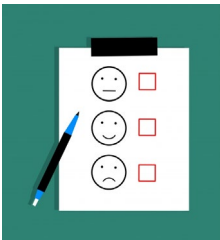
Study 1: Health Surveys

- Make health surveys more accessible
 - Reduce reading level
 - Simplify vocabulary
 - Add images and icons
 - Improve technology access



Study 1: Health Surveys

- Increase self-report in adults with ID (Intellectual Disabilities)
- [Survey 1 Draft](#)
- [Survey 2 Draft](#)



Study 2: Rate of ID and Mental Health Conditions

- Find the rate of mental health conditions & health outcomes among adults with ID
- National Core Indicators (NCI): Random sample from different states



Study 3: Best Practice Guidelines

- Make best practice guidelines for health professionals to support adults with ID
- Improve health care and mental health treatment for adults with ID





Our Goal

Improve health and quality of life outcomes
for people with ID (Intellectual Disabilities)



Our Commitment Statement

The RRTC at Nisonger Center is committed to including individuals with lived experience with intellectual disability in every aspect of our research.



Participatory Action Research (PAR) Overview

PAR is a way to study issues by including community members and stakeholders on the research team.



Participatory Action Research (PAR) Overview

PAR aims to make positive social change and empower stakeholders by including and valuing their voice.



Participatory Action Research (PAR) Overview

Nothing about us, without us.



PAR Principles

- Empowered Participation
- Commitment to Action and Social Change
- Collaborative and Equitable Research

[\(Coghlan & Brydon-Miller, 2014\)](#)



The Stages of PAR

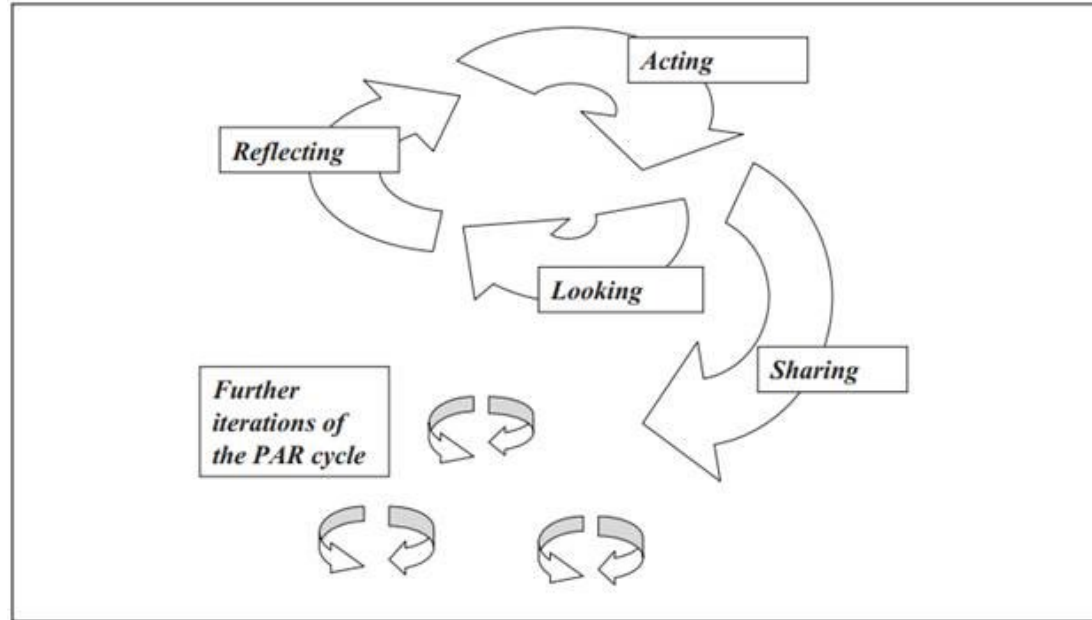


Figure 1. The continual process of the PAR cycle

[\(Bacon et al., 2005\)](#)



Stage 1: Looking



PAR begins by **“forming a group to participate in the process.”**

- Nisonger Center won a grant to adapt health surveys, study rates of comorbidity, and advance mental health treatments



[\(Bacon et al., 2005, p.2\)](#)

Stage 1: Looking



- We recruited researchers and community members to form a “**Learning Collaborative:**”
 - Research Experiences Expert Panel (REEP)
 - Disability Experiences Expert Panel (DEEP)



Learning Collaborative

1. REEP: Research Experiences Expert Panel

- OSU and National Researchers
- Design Research
- Collect Data
- Report Findings



Learning Collaborative

2. DEEP: Disability Experiences Expert Panel

- Community Members with ID
- Inform and Support Research Process
- Give Feedback, Ideas, and Perspective
- Share Project Information



Disability Experiences Expert Panel

2 DEEP Co-Chairs and 1 REEP Liaison

- Clinical Research Assistants at OSU
 - Christine Brown
 - Braden Gertz

- Ph.D. Candidate at UCF



Disability Experiences Expert Panel

12 Consultants

- Community members from Ohio
 - A few consultants bring a support staff
- Pickaway County Board of DD employee
- Goodwill Columbus employee
- Nisonger Center employee



Disability Experiences Expert Panel

Training

- Research Knowledge
- Self-Advocacy Skills



Disability Experiences Expert Panel

Meetings

- Adapting Health Surveys
- Reviewing Easy Read Papers
- Recruiting Study Participants



Stage 2: Reflecting

PAR helps collaborative learning by **“creating a forum for ongoing analysis and reflection.”**



[\(Bacon et al., 2005, p.2\)](#)

Stage 2: Reflecting

- REEP asked questions about how to make health surveys easier to understand



Stage 2: Reflecting

- DEEP responded in a focus group, asked their own questions, made suggestions, and offered valuable insights



Stage 2: Reflecting

- REEP reflected on the responses, asked more questions, and took actions



Stage 3: Acting



Participants “take a number of actions in accordance with what they have learned.”



[\(Bacon et al., 2005, p.2\)](#)

Stage 3: Acting



- The REEP reflected on DEEP feedback, adapted the surveys, and asked more questions



Stage 3: Acting



- The DEEP reviewed the adapted surveys and provided more feedback



Stage 3: Acting



- Together, the REEP and DEEP adapted survey language, item prompts, answer choices, images, icons, and technology options to improve accessibility for self-report



Reflection - Action - Reflection Cycle

New PAR cycles will “**refine the questions and findings [and make] continued improvements.**”



[\(Bacon et al., 2005, p.2\)](#)

Reflection - Action - Reflection Cycle

- How well do the adapted surveys work?
- How can we improve the adapted surveys to increase self-report for adults with ID?



Reflection - Action - Reflection Cycle

- How can we adapt the measures to support adults with significant or profound disabilities?

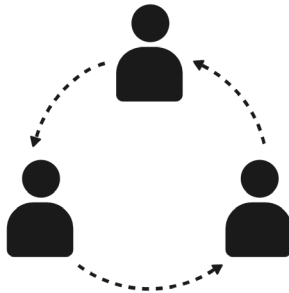


Reflection - Action - Reflection Cycle



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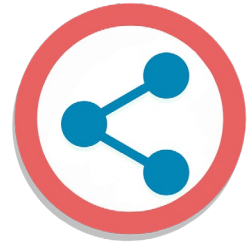


REEP

DEEP



Stage 4: Sharing

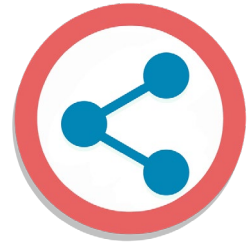


The participants “**reflect, assess, and summarize the research**” for distribution.



[\(Bacon et al., 2005, p.2\)](#)

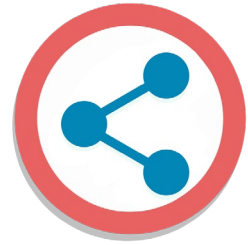
Stage 4: Sharing



- PAST:
 - Ohio Self-Determination Association
 - Learning Collaborative Summit
- PRESENT: AUCD Conference



Stage 4: Sharing



- FUTURE:
 - TASH Conference Presentation
 - Journal Articles
 - Easy Read Papers
 - Video Summaries



Year 2 PAR Cycle: New Looking Stage

We are now looking for more people to participate in the process:

- 25 community members with ID in Central Ohio to complete the adapted surveys



Year 2 PAR Cycle: New Looking Stage

- 56 community members with ID to conduct focus groups on accessible therapy
 - 32 (Central Ohio)
 - 24 (Nationally)



Year 2 PAR Cycle: New Looking Stage

- 56 mental health professionals to conduct focus groups on accessible therapy
 - 32 (Central Ohio)
 - 24 (Nationally)



HELP US HEAR YOUR VOICE!



YOUR VOICE MATTERS.

To Learn More:

- Visit our website: <http://go.osu.edu/RRTC>
- Send us an email: rrtcnisonger@osumc.edu
- Give us a call: **1-833-678-7782**



Thank You!

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