Inclusive Research in Community-Based Settings: Practical Approaches to Meaningful Engagement

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What We’re Talking About Today

Inclusive research is not one method, strategy, or approach. It is a way of conceptualizing the work.

Today we'll talk about:

- What meaningful engagement actually looks like
- How people with lived experience can contribute throughout research
- Practical strategies we've learned through applied research
- What gets in the way—and what helps
- Where IDD-MH research still needs to go

What Do We Mean by “Inclusive Research”?

Research WITH people—not only ABOUT people.

Meaningful engagement can include people with IDD, family members, clinicians, and other community partners as:

- Advisors
- Research partners
- Co-researchers
- Decision-makers
- Interpreters of findings
- Authors and presenters
- Partners in dissemination



Participation ≠ Partnership



AP1

Not every decision has to involve everyone.
We should be intentional and transparent about who has influence over what.

Why Does This Matter?

Inclusive research can help us ask better questions—and produce research that is more useful in the real world.

Community partners can help researchers understand:

- What questions actually matter
- Whether procedures are realistic
- What outcomes are meaningful
- What language makes sense
- What barriers researchers may be missing
- What findings mean in real life
- How results should be shared

Inclusion Across the Research Lifecycle

Where can people with lived experience have meaningful influence?



Partners can influence every stage — and the next question.

AP1

It Begins Before the Study Starts

Inclusive research begins with deciding what is worth studying.

- Instead of: Here’s the study we designed. What do you think?
- Start with:
  - What problems matter to you?
  - What do we still need to understand?
  - What would make a difference in your community?
  - What outcomes actually matter?

Accessibility is Part of the Research Methods

Accessibility isn't an add on

- Plain and understandable language
- Amount of information presented at once
- Visual supports
- Meeting length and pace
- Processing time
- Technology access
- Communication needs and preferences
- Different ways to participate
- Preparing people before meetings
- Checking understanding without being patronizing



If someone cannot access the process, they cannot meaningfully influence it.

Meaningful Engagement Requires Structure and Support

Ask what each person needs to participate successfully.

Examples:

- Information ahead of time
- Clear expectations
- Defined roles
- Orientation/training
- A trusted person to check in with
- Extra processing time
- Opportunities to ask questions
- Accessible materials
- Flexible ways of contributing
- Feedback about how their input was used

Sharing Decisions Means Sharing Power

- What decisions can partners influence?
- Who has final decision-making authority?
- How will disagreements be handled?
- How will we communicate decisions?
- How will people know what happened with their input?

If the decision has already been made, be honest about that.

Compensation Matters

Lived experience is expertise. Partners should not be expected to continually donate their time and expertise.

- Plan for:
  - Compensation from the beginning
  - Clear expectations about role and time
  - Timely payment
  - Transportation/technology/support needs
  - Potential impact on public benefits
  - Partner preferences regarding compensation

What Does This Look Like In Real Life?
Leading the Way to Our Own Health

The question/problem:

- People with Disabilities are designated as a health disparities population by the WHO (2023)

Who was involved:

- UNH researchers with backgrounds in MH, education, and social work
- 6 Self-Advocate Partners with lived experience and leadership training
- 12 Self-Advocate Participants from across the country, trained through our program

How partners contributed:

- Input into every step of the curriculum & content design
- Self advocate stories, videos, and resources
- Work team members served as co-pilot facilitators
- Provided input into project publications (Inclusion) and served as presenters on several webinars

What changed because of their involvement:

- Workgroup meetings-critical feedback, grounding questions
- Curriculum content-pace, activities, variety of formats led to optimal access and engagement
- Credibility and rapport-TRUST! Nothing About Us, Without Us

Real Talk with a Real Team

- What has made you feel valued as a research partner?
- What has made it easier for you to contribute?
- Have you ever suggested something that changed a project?
- What do researchers sometimes get wrong?
- What do you wish all researchers knew?

What We’ve Learned Along the Way

- Start engagement early.
- Relationships take time.
- Accessibility looks different for different people.
- Don't confuse attendance with engagement.
- Explain how people's input affected decisions.
- Build flexibility into the process.
- Don't underestimate people's ability to contribute.
- Don't underestimate the support needed to make contribution possible.
- Researchers need to change their practices too.

When “Inclusive” Isn’t Really Inclusive



Watch out for….

- Inviting partners after major decisions are made
- Asking for feedback but never explaining what happened with it
- One person expected to represent an entire community
- Materials that partners cannot reasonably access
- Meetings dominated by researchers and jargon
- Expecting lived-experience partners to volunteer indefinitely
- Including someone's name without giving them meaningful influence
- Assuming presence = participation

Good intentions do not result in inclusion….Structure matters.

Check In on the Partnership

We evaluate the research. Why wouldn't we evaluate the partnership?

Periodically ask partners directly:

- What's working?
- What's not?
- Do people understand their roles?
- Does everyone have opportunities to contribute?
- Are supports adequate?
- Are people's ideas influencing decisions?
- Does anything need to change?

Future Opportunities
Leading the Way to Our Own Health

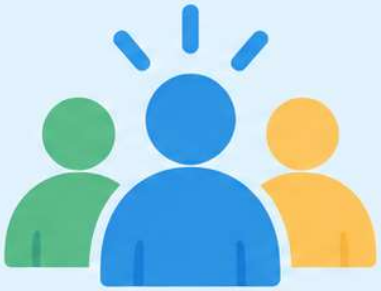
- Pilot Limitations
  - Small sample size
  - Virtual format
  - At least half of participants had some prior advocacy experience

- Can our results be replicated?
- How would participations experience this training in an in-person setting?
- How could the training complement existing trainings (PIP, for example)?
- What other methods can we use to evaluate our training effectiveness beyond self-report data?
- How do we assess outcomes in the long-term?

Future Opportunities

- Move beyond personal stories: Recognize people with IDD as research experts whose contributions extend beyond sharing lived experiences.
- Expand co-authorship and presentations: Create opportunities to write, interpret findings, present, and lead scholarly discussions.
- Invest in participation: Establish scholarships, grants, and dedicated funding for conferences, training, accessibility supports, and professional development.
- Build research leadership: Develop paid roles, mentorship, and opportunities for people with IDD to shape and lead research.
- Create lasting partnerships: Support relationships and research opportunities that extend beyond individual projects.

Where Does IDD-MH Research Need to Go?



Peer Support

How can peer-led approaches promote connection and emotional well-being?



Evidence-Based Care

How can we make effective mental health treatment more accessible to people with IDD?



Emotional Well-Being

How can we promote wellness, not just respond to crises?

What priorities would you add or change?

A Practical Checklist

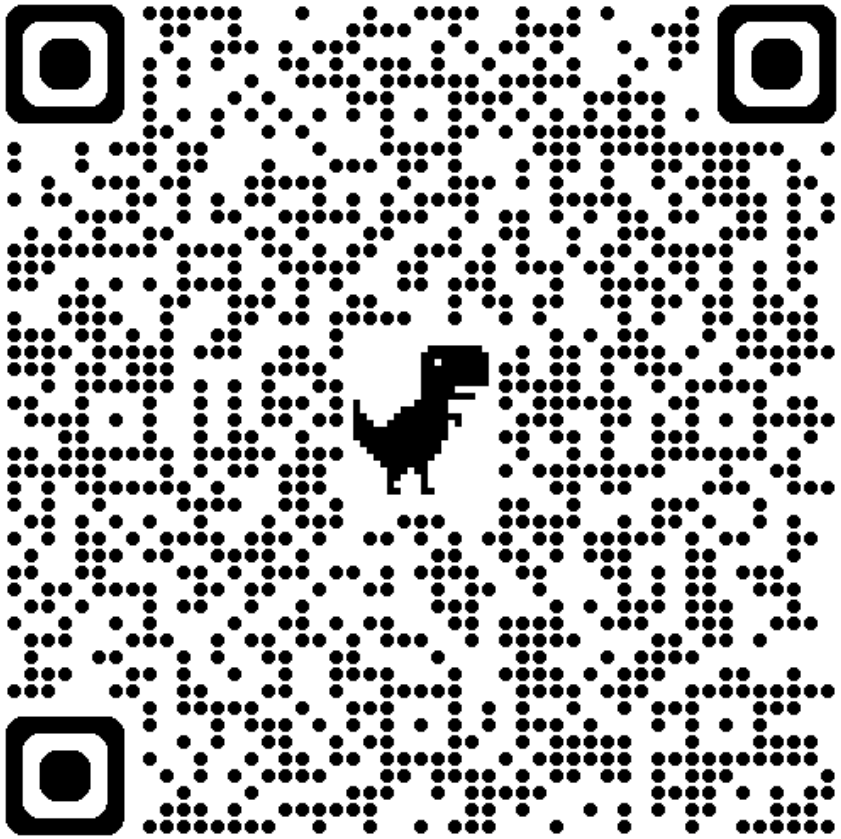
Before calling your research "inclusive," ask:

✓ Were partners involved early?
✓ Are the people affected by the research represented?
✓ Are roles clear?
✓ Are materials and meetings accessible?
✓ Do partners have meaningful influence over decisions?
✓ Are partners supported to participate?
✓ Are they compensated fairly?
✓ Do we explain how their input was used?
✓ Do we regularly ask whether the partnership is working?
✓ Are partners involved in interpreting and sharing what we learn?

Tools You Can Use

Category	Resource	What It Provides	Link
Planning Engagement	PCORI Foundational Expectations	Guidance for early engagement, meaningful involvement, and shared decision-making	PCORI Foundational Expectations
Building Research Teams	PCORI Engagement Tools & Resources	Tools for defining roles, supporting partners, and strengthening research teams	PCORI Engagement Resources
Self-Advocacy & Leadership	SARTAC – Self Advocacy Resource and Technical Assistance Center	Resources developed by self-advocates on leadership, accessibility, partnerships, group decision-making, and meaningful participation	SARTAC Resources
Compensation	PCORI Partner Compensation Framework	Guidance for fair compensation, payment planning, and partner preferences	PCORI Compensation Framework
Accessible Research Materials	AASPIRE Research Resources	Strategies for accessible communication and inclusive research practices	AASPIRE

Inclusive Approaches To Healthcare



Inclusive research is not just about who is at the table

It is about whose ideas shape the work, whose expertise is recognized, and who has opportunities to lead

What is one thing you could do differently in your current or future research projects?