

## Including Partners with Intellectual and Developmental Disabilities on Research Teams

A Study Guide on Community-Engaged Research

### What is community-engaged research?

Researchers partner with individuals from the community being studied to guide the research process.

**Example:** A study about adults with disabilities included partners with disabilities on the research team.



### Why is community-engaged research important?

- Because **the people we are studying** know a lot about themselves – they are experts.
- Community members help us ask questions that matter and can help their community.



Watch our video summary about community-engaged research: <https://go.osu.edu/CER>



**The teamwork builds respect and trust between researchers and communities.**

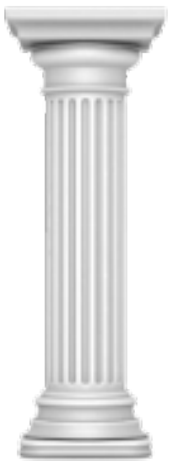


Listen to our video podcast on community-engaged research: <https://go.osu.edu/CERpod>

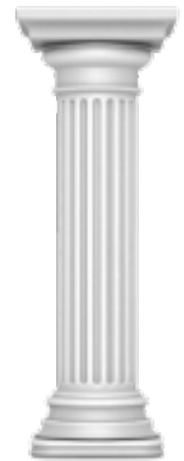
## How is community-engaged research done?

**Our Model** – Our research is studying the mental health of adults with intellectual disability. We partner closely with two teams of experts to guide the research from beginning to end:

1. **Disability Experience Expert Panel (DEEP):** Community members with intellectual and developmental disabilities, many of whom have experience with the mental health system
2. **Research Experience Expert Panel (REEP):** National leaders in disability research & policy, some of whom have disabilities



DEEP



REEP

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### Teamwork

- We listen to different opinions before making decisions.
- We ask questions and engage in respectful back-and-forth discussions.
- Together, we developed a health survey with clear questions, pictures, and technology supports.

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### Results

- Community engagement improved our research process and benefitted our team members.
  - DEEP members increased self-advocacy, communication, and professional skills.
  - REEP members learned to use community engagement in future projects.
- Together, we developed clear language summaries of research papers.



Read our project's clear language papers: [go.osu.edu/CLPs](https://go.osu.edu/CLPs)

# Community-Engaged Research Guidelines

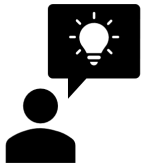
## Build Trust and a Shared Vision



- Co-create a safe, supportive, and respectful team culture
- Review the project's purpose and values regularly
- Our project values: [go.osu.edu/NisongerRRTCvalues](https://go.osu.edu/NisongerRRTCvalues)



## Set Specific Partnership Goals



- Is the goal for partners to provide guidance or leadership?
- How often and how long will team members meet?
- What will partners accomplish each meeting and year?



## Define Roles and Provide Training



- Describe responsibilities and expectations in a contract
- Provide training on research and communication skills
- Model and reinforce professional meeting practices



## Support Communication and Share Power



- Gather information on learning & communication needs
- Use clear language, photographs, and discussions
- Respect partner input when making key decisions



## Work Together to Share Research Findings



- Co-create academic articles and clear summaries
- Co-present findings



## Conclusion

- Community-engaged research values and learns from community members as part of the research team.
- When community members are part of the research team, we ask research questions that matter to the community and our research findings are stronger.
- Community-engaged research follows the disability rights motto, “*nothing about us, without us.*”

For more information about our research project: [go.osu.edu/rrtc](https://go.osu.edu/rrtc)