

Centering Disability in Research Ethics: Lessons from Research Ethics For All & CIL Partnerships

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Goals for the next 60 minutes

- Reflect on your experiences with disability research.
- Learn from historical research shortcomings and explore new, community-driven approaches.
- Hear from CIL staff members who have served as community research partners.
- Participate in a short research ethics training developed with disabled stakeholders.
- Discuss how research can support the disability community.

Introductions

- Cora Crecelius – Wyoming Independent Living, Wyoming
- Laurie L. Gonzalez, Ricardo Medina – VAIL, Texas
- Will Hoard, Krys Standley – Rural Institute for Inclusive Communities, Montana

Pair & Share

1. Turn to the person (or two) closest to you
2. Discuss the following questions:

If your CIL has participated in a research project, what was that experience like for you (positive or negative)?

If your CIL were to participate in a research project, what priorities would you want to bring to the collaboration?

History and Impact

- Historically, some research on people has involved exploitation and a lack of agency.
- Even well-intentioned research often fails due to a lack of meaningful inclusion.
- Research ethics rules exist to protect participants from harm.
- A strong ethical framework guides research toward more equitable outcomes.

A Collaborative Path Forward

- We can choose a more inclusive research model.
- This means working alongside the disability community as partners.
- We advocate for a partnership model that centers the role of CILs.
- CILs contribute indispensable lived expertise as essential co-researchers by:
 - Helping inform the research questions
 - Making sure research is relevant and respectful
 - Collecting and interpreting data

Current Project: Rural Health Pathways

Context:

- 5-year study in partnership with CILs
- CILs delivered health promotion curriculum (Living Well in the Community)
- 2 delivery models:
 - Peer Groups
 - One-on-One Health Coaching
- Data collection via surveys before, during, and after delivery

The Challenge: Rural Health Pathways

- The University **Institutional Review Board (IRB)** required ethics training for CIL staff.
 - *An IRB is a committee that reviews research to protect the rights and welfare of human subjects.*
- Traditional trainings (CITI) were:
 - Time-intensive (many hours)
 - Overly broad and not tailored to CIL roles
 - Used complex language and lacked disability perspectives
- **Turning Point:** Research Ethics for All (RE4All)

The Solution: Research Ethics for All (RE4All)

- Training co-created **by** and **for** people with disabilities.
- **Creators:**
 - Dr. Ariel Schwartz (University of New Hampshire)
 - Dr. Katie McDonald (Syracuse University)
- **Developed with:** People with developmental disabilities, disability service providers, researchers, and IRB members.
- Provides disability-accessible education in research ethics.



McDonald, K., & Schwartz, A. (2023). *Research Ethics for All*. [CC BY-SA 4.0.] <https://www.re4all.org>

Our Adaptation of RE4All

- **Format:** 90-minute online session + one-on-one certification
- **Key Adaptations:**
 - Focused on CIL staff roles and experiences
 - Used realistic scenarios (e.g., confidentiality, guardian consent)
 - Emphasized longitudinal research goals (pre/post/follow-up surveys)
- **Goal:** Empower staff to explain research ethics clearly to participants.

RE4All Example

- **Scenario:** A participant is concerned about who will see their survey answers.
- **Traditional Jargon:** "Your personal identifiable information will be kept confidential and stored securely."
- **RE4All Plain Language:** "Your answers are private. We will remove your name and keep the information safe on a password-protected computer. Your answers will not be shared with anyone outside our research team."

CIL Staff Perspectives

- Thinking back to taking the Research Ethics for All (RE4All) training, can you tell us about a specific moment or concept from the training that changed how you thought about your role in the research project?
 - This could be a moment that built your confidence, improved how you talk about the study, or where you felt your understanding of research ethics grew.
- In what way did the RE4All training change your confidence or your ability to talk about the research with participants?
 - We'd love to hear a short story about a conversation where you felt prepared specifically because of what you learned in the RE4All training.
- Looking back on the RE4All training, what stands out as the most memorable or significant part for you?
 - It could be a specific example used, the way the information was presented, or a moment where something just "clicked" for you.

Introduction



Research Ethics for All is an Accessible Research Ethics Education training for Community Research Partners.



You are being asked to take this training because you are a community research partner on a research study!



This training includes 5 units on important ways to keep people in research safe and respect their rights.

Unit 1: Community-Engaged Scientific Research

Unit 2: History of Scientific Research with People and Rules

Unit 3: Getting People Involved in Research

Unit 4: Keeping Research Participants Safe

Unit 5: Community Research Partner Rights



Unit 1: Community-Engaged Scientific Research

- In this unit you will learn about:
 - Research with people
 - Ways community research partners can make research better
- There are 2 topics in this unit:
 - Topic 1.1 What is scientific research?
 - Topic 1.2: What is community-engaged research?

What is Scientific Research?

- **Scientific research** is asking a question and using a step-by-step process to collect information to answer the question.
- **Scientific research** helps answer questions about how things work, including how to help people be healthy and live the lives they want.
- When doing research, it's important to follow a **research plan** or **protocol**.
- You can gather information in various ways, such as conducting surveys, interviewing people, or reviewing existing data like medical records (with proper permissions).
- Scientific research benefits communities and individuals by providing valuable insights that can lead to better healthcare, improved services, and enhanced quality of life.

What is Community-Engaged Research?

- **Community-engaged research** is when people who work at universities and people from the community do research together.
- Community members share their experiences and knowledge to make sure the research is helpful to people, accessible, and respectful.
- **Key Principle:** "Nothing About Us Without Us"

Community Research Partners

- **Community Research Partners** help with research studies by:
 - Helping identify research questions.
 - Sharing what it is like to be a person with a disability.
 - Making sure research participants are safe.
 - Sharing ideas and opinions.
 - Collecting and interpreting data.
 - Sharing findings.
 - Making sure research is respectful.

Learn more from the Mental Health For All team



Discussion Questions

- Why is it important for people with disabilities to help do research?
- How do you think Research Ethics for All fits with Independent Living Philosophy?
- What other questions or comments do you have?

Contact

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