

Unit 1: Written Training

Unit 1: Community-Engaged Scientific Research

In this unit, you will learn about scientific research and why we do research.

Topic 1.1: What is scientific research?

We all have questions.

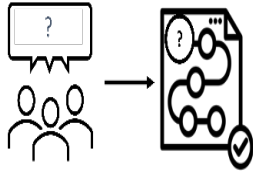


- What time will the bus come?
- Why do birds go south in the winter?
- How much does a new phone cost?
- Should I switch to self-directed services?

There are different ways to get answers to questions.

- You can look up information on the internet,
- Talk to an expert, a teacher, or religious leader, or
- Go to the library.

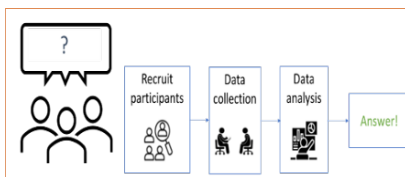
Sometimes you might want an answer to a question that someone else has *not* asked before like how to help people with developmental disabilities get good healthcare in their community.



You can answer new questions by doing **scientific research**.

Scientific research is when you look for an answer to a question by taking a step-by-step approach to gather information, or **data**. We do scientific research to find an answer that applies to a lot of people, not just a few.

When you do research, you make a plan to gather the information you need to answer your question. Then, you follow that plan step-by-step.



When you do research, it is important to follow your team's plan. Your team's plan is also called a **research protocol**.

You can find answers to your questions in different ways. You might gather information by asking people questions, or by getting information from their medical records.



We do research because good things, or **benefits**, can happen when we do it! Finding answers to important questions can make our communities better.

Research can also sometimes help the people who are in research. For example, research about what it is like to live with a disability can help doctors and therapists know what is most important to their patients.

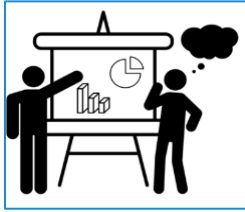
Research is important because it helps us answer questions about the way the world works and the things that help people be healthy and live the lives they want. There are many examples of how research has helped communities.

- Research to make vaccines helps people all over the world be safer from diseases, like COVID-19 or chicken pox.
- Research can also help people learn about the strengths of people with disabilities.
- For example, research has shown the ways that people with disabilities are really great at work.
- People who are in research may also benefit. For example, they may feel proud that they helped. Or, they might have fun doing the research study.

Sometimes, researchers test out a new medical treatment. This is called an experimental treatment. The treatment might not work, but it also might work. If it works, then the experimental treatment helped the people in the research study.

When you use the step-by-step scientific research process, you can be more confident that the answer to your question is the real way things work, and not just someone's opinion or based on something that only happened a few times. There are different ways to do research. Some research is done with materials like metals and liquids. Other research is done with animals, and some research is done with people. In this training, you will be learning about doing research with people.

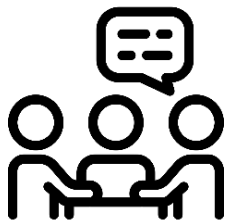
Unit 1.2 What is Community-Engaged Research



In this unit you will learn about when people from the community help do the research.

Community-engaged research is when people who work at universities or colleges and have training in research do research together with people from the community.

For example, people with cerebral palsy may work with researchers at universities to find treatments to reduce pain in people with cerebral palsy. Or, people with intellectual disability may work with people at universities to learn about accommodations that support people with intellectual disability to feel like they belong at work.



When people from the community help do research, they are called **community research partners**.

There are lots of different ways that community members with disabilities can work with people at universities to do research together. Talk with your project leader and team about the way your team is doing research together.



Mental Health for All Team Shares about Community-Engaged Research



Brendan: Hi! My name is Brendan and I am part of a team of community research partners and people who work at universities working together to do research. Our team is called Mental Health for All. Because we work together doing research, we are all researchers. We are teaching you because you are also a community research partner.



Micah: My name is Micah. I am a community research partner. I have a disability.

Brendan: And I have Down syndrome and worry sometimes.



Ariel: My name is Ariel. I am an academic research partner. I work at a university and want to find ways to help people with disabilities who also have mental health conditions like anxiety and depression feel better.



Katie: My name is Katie. I am also an academic research partner. Since we all have different experiences, we have different jobs on the research team. We all work together to make our research study the best it can be.

We have a great team!

Brendan: My job is to help make sure research asks questions that are important to people with disabilities. I help make sure that we stay focused on how to improve mental health services for people with disabilities and that the answers we find can help people with disabilities feel good and live the lives they want to live.

Micah: That's right! We use our experience with taking care of our mental health to make the research better. Our experiences can help make sure the way we do the research is respectful and accessible.

Katie: As academic research partners, Ariel and I use what we know about doing research to find ways to gather information that will answer our research question. We also do the paperwork at the university. I am a project leader or principal investigator which means I am responsible for the research project going well.

Brendan: Without us, Katie and Ariel might miss important information or not look at what is most important to people with disabilities. We know what it is like to have a disability and can use our experience and ideas to make the research stronger.

Micah: The first thing we did together was figure out our research question. A research question is what you want to learn about. A research question is the first step in a research project.

Brendan: Micah and I know how much people with disabilities need mental health support, but they often don't get them. We talked with Ariel and Katie about ways we could make sure everyone had mental health support.

Ariel: I knew that most people with disabilities who live in group homes don't have mental health services as part of their individual support plans.

Brendan: That idea got us excited because we knew people's support plans were really important and we thought adding mental health services to the plans might help them.

Micah: So, we worked together to write our research question: Does adding mental health services to an individual's support plan help adults with disabilities living in group homes get mental health support and feel better?