

Unit 2.3: Vulnerability

In this unit you will learn about supporting people who may have a hard time making decisions or need extra help understanding.

When you do research, you have to think about how different people may need to be included in research in different ways. Researchers think a lot about giving extra support to help people who are **vulnerable** or who may be more easily hurt in research or have a hard time making a decision.



Vulnerable is a big word. Vulnerable describes people who may have a hard time understanding information and making decisions.

Vulnerable can also mean people who may be more likely to be hurt in research.

Lots of people wonder whether adults with developmental disabilities are vulnerable, and people don't always agree. If it doesn't seem right to just say that all people with disabilities are vulnerable, there are many people who agree with you. We don't want to say that all people with a certain label like developmental disability are vulnerable in all situations.

Instead, researchers should think about what bad things might happen if someone agrees to be in a research study and whether the people asking the person to be in the study can influence their decision too much.

It is important to think about how you can help people understand the good and bad things about research and help them use their strengths to make their own decision.

It is also important to make sure everyone has the dignity of risk, or chances to make their own decisions even if they may not turn out well, and that how you set up your research isn't ableist, or discriminatory against people with disabilities. We will keep talking about how to balance keeping people safe, while also making sure people have the right to make their own choices.



Mental Health for All Team Talks About the Belmont Principles



Micah: Our team talked a lot about how we could do our research project in a way that followed the ideas in the Belmont Principles.



Katie: That's right, we thought about how we would find people to be in our study, help them make their own decision about being in our study, and take care of people who agreed to be in our study. We knew it would be hard to balance taking care of everyone and giving everyone a chance to make their own decisions.

Micah: Brendan and I helped a lot because we know thinking about disability rights means balancing our worries about people getting hurt with their rights to make their own choices.



Brendan: First, we talked about how we could make sure people were making their own decision. This is the principle of Respect for Persons.

We agreed we would make sure that all the information was easy to understand or accessible. We talked about what words and pictures would be easy to understand. We also talked about how to help people feel comfortable asking questions. We also talked about how to make sure they felt ok saying no.

Micah: We decided to give people lots of time to think about their decision and a chance to talk to someone they trust. We also let them know we wouldn't be upset if they didn't want to be in our study.

Brendan: We agreed we would remind the people who work in the group homes that it is the person's choice about whether to agree to be in our study.



Ariel: We also knew some people might have a guardian appointed by a judge or court. We knew we would need to work with their guardian and with the person to follow the rules and respect everyone. We will talk more about this later.

Micah: We also talked about how to make sure our study would help make communities better and not hurt the people who agreed to be in the study. This is the principle of Beneficence—that's a big word but see how it looks a lot like benefit?

Ariel: We also tried to imagine what bad things might happen in the study. We thought the worst thing that would happen is that some people might get upset answering our questions about their experiences with mental health services. So, we made a plan for what to do if that happened.

Katie: The last principle or big idea we talked about was Justice or how we work to give everyone a chance to be in research. We wanted to make sure we recruited people from all different kinds of backgrounds. We wanted people from a lot of different backgrounds and experiences so that our findings can apply to a lot of people.

Micah: We thought about only including our friends in the study because that would make doing the research a lot easier. But, we decided not to do this because we wouldn't be able to learn about all types of people with disabilities if we only included our friends.

Brendan: We'll talk more about how these 3 big ideas can help you make decisions about how to set up your research project. Remember, anytime you aren't sure about something, talk to your project leader.