## Topic 3.4: Consent Capacity

In this unit you will learn about people’s abilities to make their own decisions and how sometimes people need help to make research decisions.

Having the ability to make your own research decision is called **consent capacity.** Often, we assume people can make their own choice—and have consent capacity.

Sometimes researchers check to see if the person understands the important information about a research study like the good and bad things that might happen, what they will be asked to do, and their right to say no to being in the study.

Researchers may check for someone's ability to make a decision when a research study has a higher chance of hurting someone or includes people or groups who may be more likely to be hurt in research. How much researchers need a person to understand about the study may depend on what kind of good and bad things might happen if they are in the study. It is important to have a good reason to check consent capacity. Remember what we said before that a label alone may not be a good reason!

For example, we know that people with developmental disabilities are able to say no to being in a research study, especially when it involves things that might hurt them or feels too personal.

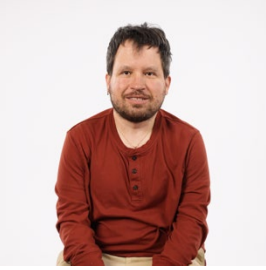
We also know they can understand information about a research study and that they may be harmed if they are excluded or if someone else makes a decision for them.

And we know we can improve consent capacity by helping people understand information and removing pressure. Consent capacity can change depending on how someone feels, where someone is, or who is around.

For example, if someone is not feeling well, they may have a hard time understanding all of the information researchers share. They might want to make a quick decision, because they are so overwhelmed with the information. On another day, they might be able to make a better decision for themselves.

Another example is if there are people around who make the person feel pressured. For example, it might be easier for some people to make their own decisions if they aren’t worried about disappointing the people who are there.

## Mental Health for All Team Talks About Consent Capacity

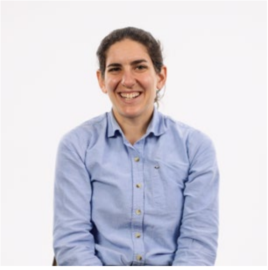


**Micah:** There is a lot to keep in mind when working with people to make a decision about being in research! Katie and Ariel helped us understand the important things to pay attention to with consent and consent capacity.

**Brendan:** Ariel and Katie also said sometimes the decision about whether someone has consent capacity needs to be made by the project leader. Katie and Ariel also taught us that if a person doesn't have consent capacity we might not be able to include them in our study or might need to work with someone else to make the decision with them.

**Katie:** We talked about how we could look for signs that someone understood the decision they were making and that it was their own decision. Some signs were if the person asked questions, said no, or chose to not answer some questions when we interviewed them. We also knew to offer a break or stop if the person looked uncomfortable.

**Micah:** We agreed that any time we were worried that a person was not making their own decision, we would talk to Ariel or Katie.



**Ariel:** We also know that a lot of people like to talk with people who support them when they make important decisions. We decided to ask each person if they wanted support in making their decision. If they did, we worked with them so they could talk to someone they trusted to get help with the decision.

**Micah:** We also knew we needed to remind the person helping that it was the person with a disability's decision. We decided we would ask to talk to the person alone if we were worried they were feeling pressured.