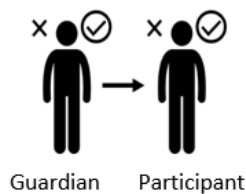


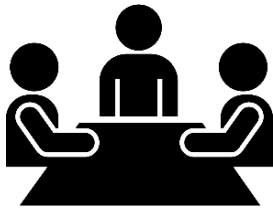
Topic 3.5: Assent: Working with Guardians and Parents of Children

As you may know, some people do not have legal capacity to make a decision--this includes children and adults who have a guardian appointed by a court or judge that makes decisions for them. In this unit, we'll talk about what to do when we invite children and people with guardians to be in research.

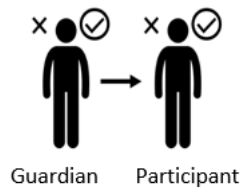


Some people with disabilities have legally appointed guardians. In research, we call this person a **legally authorized representative** or LAR. Guardians are people assigned by a state court to make decisions for the person. Each state has their own laws about guardianship, so be sure to talk to your project leader about what you need to know in your state.

It is important to know if someone has a guardian. However, that can be confusing for some people. You can also ask your project leader about how you'll find out.



When someone does have a guardian, you will need to involve the guardian in the research decision. The person with a disability may have a good relationship with their guardian, or they may not know them very well.

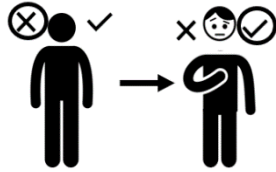


It is important to always involve the person with a disability in the decision and get their **assent**, or decision of the person with disability. Assent, or the decision of the person participating, is the final decision about whether the person is in the research or not.

If the study has already started, and the person with a disability shows signs of dissent, you should stop the study, even if the guardian wants to continue.

You should look to make sure that the person with the disability is not being pressured by their guardian. It can be hard if the guardian and person with a disability disagree about research participation.

Remember, no, is no from the person with a disability.



Guardian Participant

Sometimes the person with a disability might want to participate, but their guardian says no. Legally, you have to go with what the guardian says in this situation.

In these cases, you can try to find other ways for the person with a disability to participate. For example, maybe they do some of the activities, but you do not include what they share as research data. In these situations, you will have to work with your research team, the guardian, and the person with a disability to come up with a solution that works and follows the law. Your team will talk more about how you will handle these types of situations in your project.

Everything you learned about guardians is the same for people under 18 years old. If someone is under 18 years old, their parent or guardian has to give permission for them to be in research. But, you should always make sure to ask the person to make their own choice or give assent to be in the research study.



Mental Health for All Team Talks About Assent



Micah: We told Katie and Ariel that we might find people with guardians in the group homes. We all agreed that it was important to include them.



Brendan: We agreed that when we talked with a guardian, we also made sure that if the person with a disability was there, we talked directly to the person with a disability. We reminded the guardian that they should think about two things:

1. What does the person want? What do they think they want?
2. Will the study help them or hurt them?

Micah: We also agreed we would watch for signs that the guardian was pressuring the person with a disability to participate.

Brendan: Sometimes we made sure to talk privately with the person with a disability to make sure they were making their own choice. We had guardians and the person with a disability sign the same form saying they agreed to be in the study.

Ariel and Katie also taught us that there are no laws that say a guardian has a right to learn what the person shares when they are in a study. Even if a guardian asked about what the person with a disability shared, we could not share the information or research data.

Brendan: We felt prepared, but we still had some hard situations. One time I could tell the person with a disability wanted to stop, but their guardian kept encouraging them to keep going. The person with a disability seemed upset about the questions and stopped looking at me. I took a break and called Ariel to help me. We decided to stop the study, because the person seemed to be trying to tell us that they didn't want to give assent anymore.

Micah: Another time a guardian seemed confused—they seemed to believe our experimental mental health study would help the person with a disability.

Brendan: When we talked with Katie and Ariel about these kinds of situations, they taught us that sometimes we work to help people make their own decisions, and sometimes it is best to not let the person be in the study.