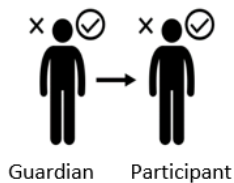


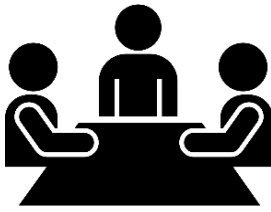
Topic 3.5: Assent: Working with Guardians and Parents of Children

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.

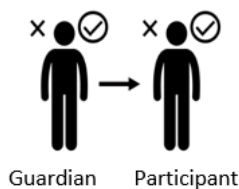


Some people with disabilities have legally appointed guardians. In research, we call this person a **legally authorized representative** or LAR. Guardians are people assigned by a state court to make decisions for the person. Each state has their own laws about guardianship, so be sure to talk to your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

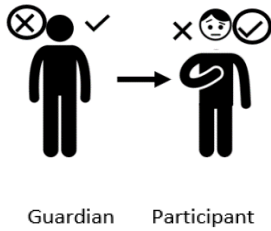


It is important to always involve the person with a disability in the decision and get their **assent**, or decision of the person with disability. Assent, or the decision of the person participating, is the final decision about whether the person is in the research or not.

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.



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.