



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.