Topic 4.1.3: Social risks and safeguards

In the last unit we talked about physical and psychological risks. In this unit, we will talk about a few other types of risks-- social, economic, and legal risks.



Social risks are bad things that can happen related to other people.



For example, if other people find out personal information related to the research, they might treat the person differently. To reduce this risk, we don't tell other people if someone is in our research study or what they shared with us.

Another social risk is if the research makes other people think badly about people with disabilities. To reduce this risk, researchers should be careful about how they share what they learned and make sure they talk about disability respectfully—we'll talk more about this later.

It is also important to think about the relationship between researchers and research participants.



You usually meet new people when you do research. Sometimes this is a part of research that makes people nervous. Other times it is a part of research that makes people excited. In some types of research, you will get to know the participants well and they get to know you.

For some people, it can be hard when research ends, because they won't get to spend time with the new people they met anymore. They might feel sad about the relationship ending, or feel like it is another person who came into their life and then left, just like having lots of different support staff come and go.

We can do things to help people feel better when research ends. For example, you can talk about the research relationship at the beginning and at the end. This means you can explain how long the relationship will last and what it will be like. It is important to make sure participants know what will happen when they are done being in the study.

If you have been spending lots of time with people in research, near the end you might add more time in between research visits to help people prepare for the study ending. You might have more ideas about how to handle research relationships ending—be sure to talk to your team and share your ideas!

It can also be hard to do research when you already know the person who wants to be in the research study. Maybe they are in your self-advocacy group or are someone you know from your Synagogue or Temple. When you have a research relationship and another type of relationship with participants, it is important to make sure everyone understands the different relationships. You can talk about the different responsibilities you have in each of these relationships.

Micah and Brendan will share more about this! It might also be hard for you to keep information private when you know someone from another part of your life. Be sure to talk with your research team about how to handle this—having someone else on the research team gather the information from the person might be a good idea.