Unit 5: Community Research Partner Rights

Topic 5.1: Keeping Community Researchers Safe

Main Ideas

- **Your safety** as a community research partner is **important**.

- Your team can **plan for what you will do** if a **community research partner is hurt doing research**.

- Your **project leader can help** you if you are hurt as a community research partner.

Discussion Questions

1. **What** do you think **could happen during** the **research** that might make the Mental Health for All **community research partners feel unsafe or uncomfortable**?

- **What can they do** if that happens?

Topic 5.2: Being an Author and Sharing Findings

Main Ideas

	• **Authors** are people who **share about** a **research** study and are **responsible** for the research.
	• **Authors get credit** for doing the research. • When someone is an **author** on a research paper, video, brochure, poster, or presentation, it means they **had an important role** in the research.
	• If you are part of a research team, you **might have the right to be an author**.
	• It's important to **talk** with your project leader about **who will be an author**. • You can **talk** about who will be an author **at the beginning, middle, and end of working together on a research team**.

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	• When we share about research it's important to **use words and ideas that are respectful**. • This can **help other people learn** about how to **respect people with disabilities**.
	• It is important to **reflect**, or **think about** what **you do** as a researcher. • If we think about how things went, we can make them **better for next time**.

Putting it into action: I Can Figure Out Who They Are

Read **quotes** from research **participants** in Mental Health for All team's research study.
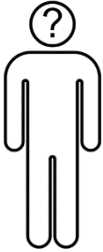
- Underline or <mark>highlight</mark> the **parts** of the quotes that could **give away** who the **participants are**.

- **How** can you **change** the **quotes** so **no one can figure out who** the **participants** are?

Participant quotes

- "I don't have anyone to talk to about my mental health at my group home, Crystal Springs. It is really hard to keep these things in my head."

- "When I used to talk to a therapist, I felt a lot less sad, but I don't get to talk to them anymore."

- "When I was a student in Ms. Bailey's class in 2015 and turning 22—my birthday is June 5!--I talked to Jamal at The Arc, they told me about getting therapy. I wish I had someone to talk to about my mental health."

- "I am really happy my friends Melissa and Paul from my job at the CVS on Main Street told me about getting a therapist. Talking to a professional helps me work through my tough emotions and makes me happier each day."

- "I am too busy at New Horizons and being the secretary of People First Chapel Hill to add another thing to my week."

- "I already see so many therapists every day, why do I need another?"

Topic 5.3: Wrap Up

Main Ideas
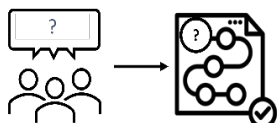
- **Scientific research** is **asking** a **question** and using a **step-by-step process** to **collect information** to answer the question.

- In **community-engaged research,** community research partners **share** their **experiences** and **knowledge** to help make research questions that **matter** to **people with disabilities,** and do research that is **accessible** and **respectful**.

- **Research ethics** are about **making sure people** are **treated well** and that their **rights are respected** when they are in research.

- Research ethics can **help** make sure **bad things** don't happen when people are in research.
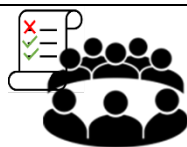
- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights** and **well-being**.

- **Eligibility criteria** are the **characteristics** and **experiences** that people **need** to **be in a** research **study**.

- **Only people** who have **all the characteristics** on the list **can be in the** research **study**. This list is different for every study.

- Consent must be:
    - **Informed:** people have all the information they need about the study.
    - **Voluntary:** people making their own choice without anyone pressuring them.
   - **Ongoing:** people can say no at any time during the study.
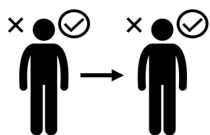
- We often get **assent** from people when they have a **legally authorized representative (LAR). Assent** is when someone with a LAR **says** or **shows** with their body that they **want to be in** the research study

Main ideas

- We work together with our team to have **safeguards**. **Safeguards** are the things we do or use to **keep people safe** in research.
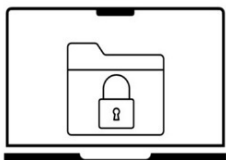
- Keeping **information private** and **confidential** is really important in research.

- We keep **information private** and **confidential** **before**, **during**, and **after** the **research** study.

- **Mandatory reporting** means if researchers learn that a research participant is being hurt or abused, they have to share the information with authorities (people who can stop other people from being hurt). Researchers also have to share information if they find out a research participant is hurting or abusing someone else.

Main ideas

- **Your safety** as a community researcher is **important**.

- Your team can **plan for what you will do** if a **community research partner is hurt doing research.**

- **Authors** are the people who **share about** a **research** study.

- If you are part of a research team, you m$_{ay}$ **have the right to be an author**.

- It is important to **reflect**, or **think about** what **you do** as a researcher. If we think together about what we do we can help keep participants **safe** and **respect** their **rights**.