Research Ethics for All Workbook

RE4ALL

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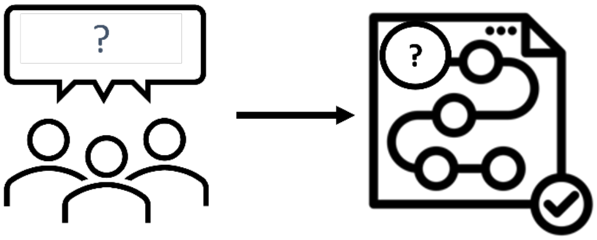
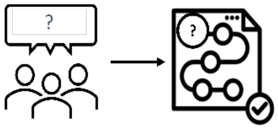
Unit 1: Community-Engaged Scientific Research

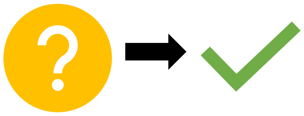


Topic 1.1: What is Scientific Research?

Main Ideas



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



- Scientific **research** helps **answer questions** about how things work. This includes understanding how to help people be healthy and live the lives they want to live.

Discussion Question

1. What are some **examples** of **scientific research helping** people?

Putting it into Action: What’s the Point?

Using the Mental Health for All team’s flyer, work together to find:

- The **research question** the Mental Health for All team wants to answer.

- The **good things** the Mental Health for All team thinks **could happen** from answering their research question.

The next page is the Mental Health for All team’s flyer

Flyer on next page

Do you have a developmental disability?
Do you also have a mental health condition?

WE WANT TO LEARN FROM YOU!

What we are doing?

- A research study about whether adding mental health services to support plans helps people get better mental health supports.
- You had mental health support added to your service plan. We want to learn about your new mental health supports.

To be in the study:

- Have a developmental disability.
- Have a mental health condition.
- Be 18 years or older.
- Live in a group home.

Mental Health for All

Mental Health for All is a team of adults with developmental disabilities lead by Ariel and Katie. To learn more

Email:

Call:

What will I be asked to do?

- Participate in a one-hour focus group and a 8 30-minute surveys.
- You can take a break, skip a question, or stop at any time.
- Everything you say is private and confidential (kept secret).
- You can receive up to $250 for participating in the surveys and focus group.

Note: Materials are for educational purposes only and may not include all required elements.

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Topic 1.2: What is Community-Engaged Research?

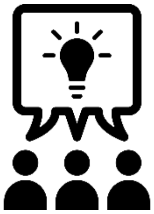
Main Ideas

- **Community-engaged research** is when people who work at universities and people from the community do research together.

- **Community research partners** who do research have an **important role**.
- Community members **share** their **experiences** and **knowledge** to make sure the research is **helpful** to people**, accessible,** and **respectful**.

Discussion Questions

1. Why is it **important** for **people with disabilities** to help **do research**?



2. Why **do you want** to **be part** of a **research team** or **learn** more about **research**?

Putting it into Action: Research Team Member Responsibilities

Think about the **responsibilities** of **each team member**. Read each responsibility and **decide** who **has the most responsibility** for a part of the research.

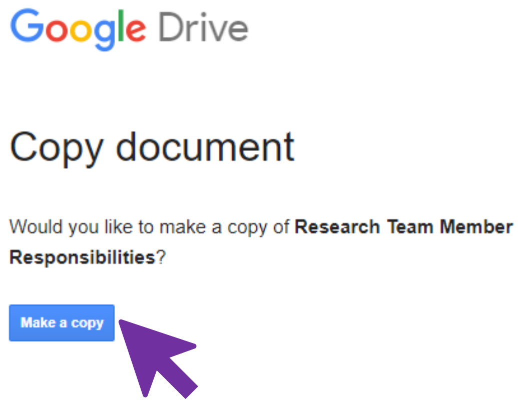
Circle or check ☑ community research partner for community researcher's responsibilities.

Circle or check ☑ academic research partner for academic researcher's responsibilities.

Sometimes both community and academic research partners are responsible for the same things. On the next page, circle both community research partner and academic research partner if they both have the responsibility.

You can also do this activity online.

Click "make a copy"



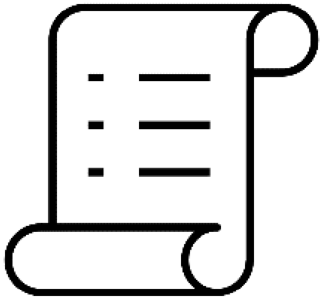
Google Drive

Copy document

Would you like to make a copy of **Research Team Member Responsibilities**?

Responsibility	**Who's job is it?**
Make sure research questions are **important** and **relevant** to **people** with **developmental disabilities**	Community research partner Academic research partner
Research **paperwork**	Community research partner Academic research partner
Use experiences to make sure the way the team finds people is **accessible** and **respectful**	Community research partner Academic research partner
Make sure the **project goes well** and everyone **follows** the **rules**	Community research partner Academic research partner

Unit 2: History of Scientific Research with People and Rules



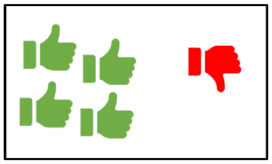
Topic 2.1: History of Research with People

Main Ideas

- **Good** things **can happen** when we do research. The good things that can happen are called **benefits**.
- Research benefits can be for the person in the research study or for other people in the future.

- **Bad** things **can happen** to **people in research**. The bad things that can happen are called **harms** or **risks**.
- Examples include hurting someone's body or feeling sad.

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



- **Research ethics** are also about making sure **more good** things happen **than bad** things when we do research.

Discussion Questions

1. When you **think about research**, what **pictures** or **words** do you think about? What **feelings** do you have?

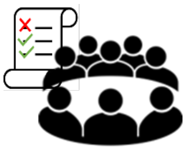
2. **How** do you think **other people** with developmental disabilities **might feel about research**?

Discussion Questions

3. How do you think **different experiences** with **research studies** in the past might **make people feel about** being in **research** studies now?

Topic 2.2: Rules for Scientific Research with People

Main Ideas

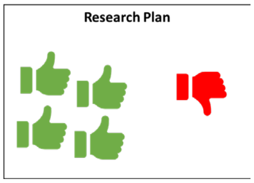


- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights** and **well-being**.

- The **Belmont principles** are the **values** that help us think about **how** to **treat people** when they are in research. They are:

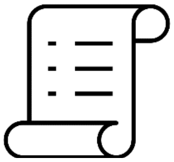
- **Respect for persons** is about **believing** that **everyone can make decisions** with or without support. Respect for persons also means **taking extra care of people** who have a hard time making decisions.

- **Justice** is making sure **all types of people can be in research** and that everyone shares the good and bad things that can happen in research.



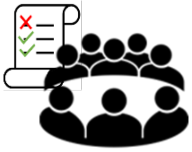
- **Beneficence** is about making research have **as many good outcomes** as possible and **keeping people** as **safe** as possible.

Discussion Questions



1. **Why** is it **important** to have **rules** for **research** with people?

2. **What** does the **IRB do**?



3. **Why** is what **the IRB** does **important**?

Putting it into Action: Disability Rights and Research Rules

Talk with your team about how some of the **main values** in **research** and **disability rights are similar** and **different**.

You may think of other disability rights—you can talk about those too.

Disability Rights	**Research Rules (Belmont Principles)**
• **Assuming people can do** things and **make choices** ○ This includes making choices that might not always work out or might be risky. This is sometimes called dignity of risk**.** • Having the **same opportunities** as everyone else to do things	• **Respect for persons** • **Justice** • **Beneficence**

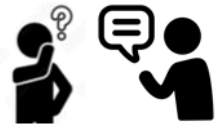
Topic 2.3: Vulnerability

Main Ideas

- It is important to be **extra careful with people** who are **vulnerable.** People who are **vulnerable** may **have a hard time making a decision** or **need help understanding** and **making decisions**. People who are vulnerable **may** get **hurt** by research more easily than other people.

Discussion Questions

1. What **helps** you **understand** and **make decisions**?



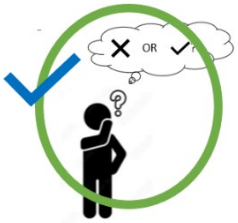
2. **How** can **you help someone else** with a developmental disability **understand** a **research** study better?

Discussion Questions

3. **How** can **you help people** who **have a hard time making** their own **decisions make a choice** about being in research?
    - How can we help people not feel pressured to make a decision?

4. Can you think of **a reason** we should **not include** someone in a research study because they are vulnerable?

Discussion Questions

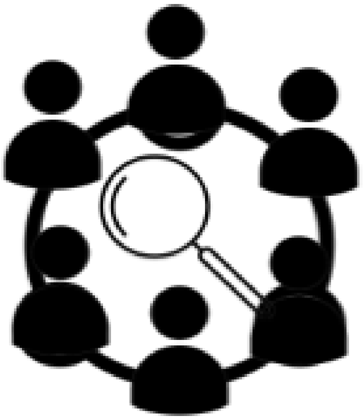


5. **Why** might we want to **include people** who are **vulnerable** in research studies?

    - When we do include people who may be vulnerable, **what** can **we do** to **include them safely**?

    - **How** can we **make sure** that **the rights** of people who are vulnerable are **respected**?

Unit 3: Getting People Involved in Research



Topic 3.1: Recruitment: Finding People to be in a Research Study

Main Ideas

- **Recruitment** is the things you do to **find people** to **be in** a research study.

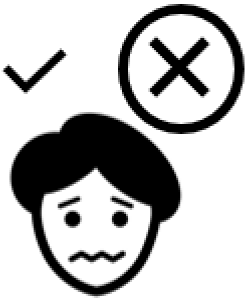
- To **recruit** people, you might **talk to people** at events, send emails, post on social media, or talk to self-advocacy groups.

Discussion Questions

Finding people to be in a research study

1. **How** did the Mental Health for All team **help people understand** what their **study is about** and what they would be asked to do?

2. What may **be hard** about **saying no** to:



   - A researcher you don’t know?
   - Your healthcare provider?
   - A teacher or service provider?
   - A friend?

Discussion Questions

3. What **helped** the Mental Health for All team **make sure** people **knew they could say no** to being in their study?

   - **How** can you **help make sure people know** they **can say no**?

4. What **helped** the Mental Health for All team **develop trust** and **show respect**?

   - What can **you do** to help people feel they **can trust** you when you are asking them to be in your research study?

Discussion Questions

5. **How** do you **think** it will **feel** when you ask someone to be in your research study and **they don't want to be in your study**?

- What can you do when that happens?

Putting it into Action: Practice Responding to "No"

- **Practice what you will say** when **someone says they do not want to be** in **your** research **study**.
  - Write a script to help you know what to say.
  - Act it out.

Eligibility Criteria

Main Ideas

- **Eligibility criteria** are the **characteristics** and **experiences** that people **need** to **be in a** research **study**.
- This includes the characteristics and experiences that people must **have** (inclusion criteria) and must **not have** (exclusion criteria) to be in a research study.
- **Only people** who have **all the characteristics** and **experiences** on the list **can be in the** research **study**. This list is different for every study.

Putting it into action: Recruitment Flyer Search

Review Mental Health for All team's recruitment flyer on the next page.

- Circle the part that says what the **study is about**
- Underline the part that says **what participants will** be asked to **do**
- Highlight the parts that you think **show respect** to people with disabilities. Put a box around the parts that **explain who is eligible** to be in the study

Mental Health for All Research team's flyer is on the next page

Flyer on next page

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Do you also have a mental health condition?

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What we are doing?

- A research study about whether adding mental health services to support plans helps people get better mental health supports.
- You had mental health support added to your service plan. We want to learn about your new mental health supports.

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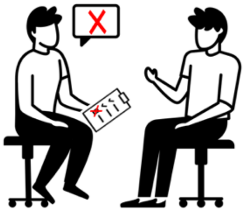
Putting it into Action: Practice Saying No

Practice **telling someone** they are **not eligible** for the Mental Health for All team's research study because they are **too young**.



Write out what you can say about:

- Them **not** being **able to be in** the study
- The **reasons** they **cannot be in** the study
- Anything else you might say

Topic 3.2: Finding Research Participants through Other People

Main Ideas

- Sometimes you need to **ask people** like service providers and family members to **help** you **find people with disabilities** to be in a research study.
- You can work with these people to help them understand **why people with disabilities** might **want** to **be in a research** study and **have the right** to make their **own choices** about being in a research study.

Discussion Questions

1. **How** did the Mental Health for All team **find people** who might want to be in their research study through **other people**?

    - What **made** it **hard** for them?

    - What **helped** them?

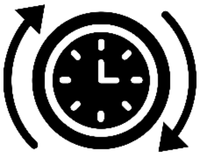
Topic 3.3: Consent: Working with People as they Make Decisions about Being in Research

Main Ideas

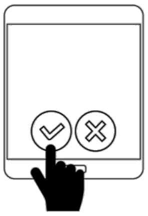
- **A consent meeting** is when someone **learns about** a research **study** and **decides** whether to be in the study or not.

- Consent must be:
    - **Informed:** people have all the information about the study they need.

    - **Voluntary:** people making their own choice anyone pressuring them.



    - **Ongoing:** people can say no at any time during the study.



- **Giving consent** is when someone **says yes** to being in a study.

- **Dissent** is when someone decides they **do not want** to be in a research **study**.

Discussion Questions

1. What does it mean to be **informed**?

- **What information would you want** to know about a research study before deciding to be in it?

2. What does it mean to make a **voluntary choice**?

Discussion Questions

3. What does it mean that being in a research study is an **ongoing decision**?

4. What are some **signs** that **someone changed their mind** and **does not want to be** in a research study **anymore**?

Putting it into Action: Consent Document Search

Consent Document Search

Look at the Mental Health for All team's consent document on the next page.

- Underline where the document explains people's **choices** to say yes (**consent**) or no (**dissent**).
- Circle information about **who is doing the study** and how to **contact** the research team.
- Highlight information about **why** the research study is being done
- Put a box around the parts of the form that tells people **what they will do** if they are in the study.
- Highlight information about **risks** and **benefits** of the research study.

Consent form on next page

Mental Health for All: Including Mental Health Services in Support Plans

Consent and Assent Form

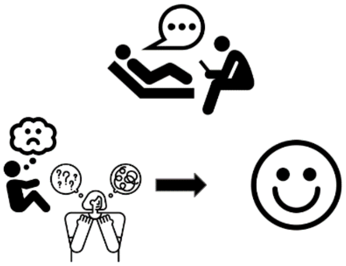
Note: This form is to help people learn about research ethics and not for a real study.

If you are the legally authorized representative for a person who may take part in this study, permission from you is required and the assent (agreement) of your relative or ward is required. When the word "you" appears in the consent form, it refers to the person for whom you are the legally authorized representative.

Principal Investigator: Ariel and Katie

Email ✉: (email address)

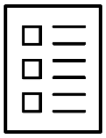
Phone ☎: (phone number)



You are invited to be in a research study. Many adults with developmental disabilities who live in group homes experience anxiety and depression, but don't get the support they feel they need. We want to learn if adding mental health services to support plans helps people get better support for their mental health.

Mental Health for All is a team of adults with developmental disabilities lead by Ariel and Katie

We are asking you to be in this study because you have important experiences that can help us to understand how adding mental health services to support plans might affect mental health.



This form has **information about being** in this study. If you want to be in the research study, you will sign this form. We will give you a copy of the form to keep.

It is **your choice** whether you want to be in this research study.

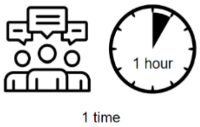
What will happen if you decide to participate?

Your service provider is adding mental health services as part of your support plan. This is something that is happening to everyone who has your service provider—even people who are not in the study. We want to know what that change is like for you.

This study has 2 parts:

1. **Surveys**: In an online form, you will answer questions about your experiences with mental health services and your mental health.

   We will ask you to complete 8 **surveys at different times.** You will do **1 survey every 3 months**. Each survey will take about **30 minutes**. You will share your experiences with mental health so we can learn more about how mental services may help you feel better.



2. **Focus group**: As an in person group interview with other people who have similar experiences to you, we will ask you questions about your experiences with mental health services.

   We will also ask you to be in a **focus group 1 time** at the end of the 2 years. You will be in a focus group with other adults with developmental disabilities who also have depression and anxiety and live in group homes. The focus group will take up to **1 hour**.

There are **no right or wrong answers** or **experiences.** You are the expert on your experiences and feelings and we want to learn from you.

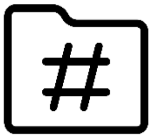
You can **skip questions** or **stop** whenever you want.

How will we protect your privacy and confidentiality?

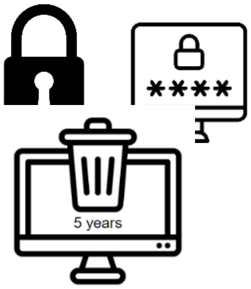
We will do the focus group in a place where no one not in the focus group can see or hear what you say.

We will keep what you say confidential (private or secret)

To keep what you say confidential, we will:



- Put a **number** on the information instead of your name.
- **Lock the office** where we keep your information and put **passwords** on all computer files.
- **Not share** your information:
    - with people who are not part of this research study
    - in ways that let other people figure out what you said
    - For other research studies

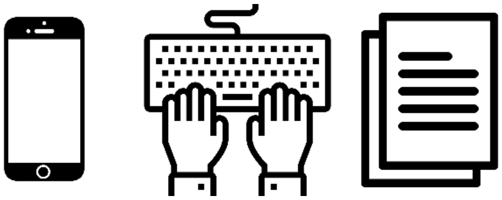


- **Only share** your information with people who are responsible to make sure that this research study is done correctly.
- **Erase** the file with your name and contact information after 5 years.

If during the research you tell us that **someone is hurting you** or **you are hurting someone**, then we **have to tell someone who can help.** We have to do this to help make sure **you are safe.**

Will you audio-record me?

If you agree, we will **audio-record** the focus group. The recording will only be used so we can make sure we have good notes about what you said. Only the research team will have the recording. If you do not want to be recorded, we will take notes.



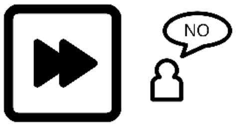
After the focus group, we will **type everything you said** onto a page. We will destroy the recording after we check our notes (no longer than 2 months).

Can anything bad happen to me?

We do not expect anything bad to happen to you from doing the survey and being in the focus group. However, it is possible that you might feel **uncomfortable** thinking about difficult experiences. Or, you might feel **frustrated** if you are not sure how to answer a question.

Sometimes when information is shared or stored online, it can get stolen by people who shouldn’t have the information. We will keep information safe by using encryption and passwords, but we cannot promise that someone will not find a way to get to the information.

Other participants may share what you said in the focus group with others. Although we will ask everyone to keep what is said in the room, in the room, we cannot promise that other participants will not share what you said outside of the room.



If you don’t want to talk about a topic, you can **skip** the question.

You can always say no to anything in the research.

What will I get from participating?

You might **like** sharing your ideas. You may **feel good about helping us learn** about how mental health services can help make people feel better.

Will I be paid for being in the study?

You will receive **a gift card** to thank you for being in the study. You can earn up to $250 for doing the surveys and the focus group for the study.

What should you do now?

Ask questions.

Think about it.

Talk to a friend or family member.

Decide if you want to share your experiences with mental health services in the survey and focus group

If you don’t want to be in this study, no one will be upset, and it will not impact your relationship with the university.

Who can I contact if I have questions?

Ariel and Katie are in charge of this study. You can contact them if you have any questions.

Email ✉: (email address)

If you have questions about your rights when you are doing the focus group or if want to speak with someone who does not work with Ariel and Katie, you can contact the IRB at the University. The IRB is in charge of keeping people safe when they do research.

Phone ☎: (phone number)

Email ✉: (email address)

If you would like to participate

Do you understand everything on this form? What questions do you have?

Remember:

- It is your decision whether or not to participate in this study. Your participation is voluntary.
- You may skip and/or refuse to answer any question for any reason.
- You may stop your participation in this study at any time, without anything bad happening.

Saying, “yes, I want to be in the study,” means you would like to volunteer to do this study.

Before you say “yes,” you will be asked to talk about all the things you might do in this study. Saying “yes” means you asked me all the questions you have about this study, and I was able to answer all your questions.

1. Do you agree to let audio-record the study?		**Yes** ✓ ☐	**No** X ☐
2. Do you want us to contact you in the future about other studies?		**Yes** ✓ ☐	**No** X ☐

All of my questions have been answered, I am 18 years of age or older, and by signing this consent form, I agree to participate in this research study. I have received a copy of this form for my personal records.

____

Participant Name Participant Signature Date

____

Guardian/Legal Representative Name Guardian/Legal Representative Signature Date

____

Researcher Name Researcher Signature Date

Topic 3.4: Consent Capacity

Main Ideas

- **Consent capacity** is someone's **ability** to **make** their **own decision about** being in **research**.
- Consent capacity can **change**.
- **How much consent capacity someone needs** to make their own decision will **depend** on the **bad things** that can happen in the study.

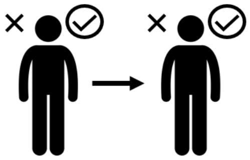
- We can make **information** about our research more **understandable** so more **people** can **understand** the **good** and **bad** things for themselves about being in a research study.

Discussion Question

1. **What** can **you do** if **you're not sure** if **someone can make their own decision** to be in a research study?

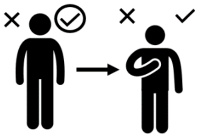
Topic 3.5: Assent:
Working with Guardians and Parents of Children

Main ideas

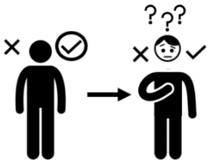


- If someone **does not** have **consent capacity**, they need a **legally authorized representative**, or LAR, to **decide** if they can be in a research study.
- **Assent** is someone with a legally authorized presentative (LAR) **saying** or **showing** with their body that they **want to be in** a **research** study.

Discussion Questions



1. **How** can **you help** someone with an LAR **make their own decision**?



2. **What** signs **might tell you** that **someone** might **not** be **able** to **make their own decision** about being in a research study?

Putting it into Action: Working with Guardians

Practice what you would do.

A participant has a guardian and uses pictures and body movements to communicate. **They gave assent** to do the study by picking the “yes” picture. **Their guardian wants them to do the study**. After about 30 minutes of an interview, **you notice** that **they are turning away from you** and **walking around** a lot.

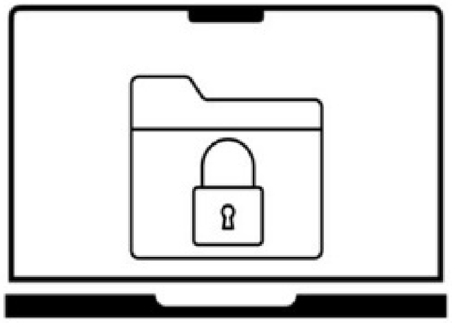
Putting it into Action: Working with Guardians

What would you do?

- **What could you say** to the participant to **find out** what **they want** and **need**?

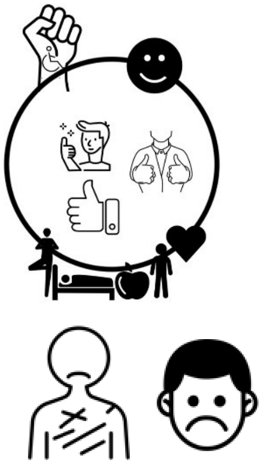
- **What** could you **say to** the **guardian** to **make sure** they **understand your job** to make sure the **participant feels respected** and **heard**?

Unit 4: Keeping Research Participants Safe



Topic 4.1: Risks and Safeguards

Main ideas



- It is **important** to **keep people safe** in research.
- Researchers have to **balance** the **good** (**benefits**) and **bad** (**harms or risks**) things that can happen to people when they are in research.

- Every research study has **different good** and **bad things** that can happen.
- The **good** and **bad things might** also **be different** for **different people** in a research study

- **Safeguards** are the things researchers do or use to **keep people safe** when they are in research.

Putting it into Action: Being Clear

You are doing a research study that will ask people to do **4 interviews over 4 months**. You **worry** some **people will be sad** about the **study ending** and not getting to talk to you anymore. **Practice explaining how many times you will see participants** during the study and **what will happen when** the **study ends**.

Write a script to help you talk to the participant. Explain:

- **How many times** you will **see each** other while you are doing the interviews
- **What will happen when** you are **done** doing the interviews:
    - You will **probably not see each** other after the interviews end.
    - What will you do with the information they shared with you?
- Think about **how** you will **say goodbye** in a way that makes them feel like you will not forget about them.
- Explain what will happen if you see each other in the community. Remember everything you learned about keeping people's information private and confidential.

Putting it into Action: Being Clear

Write your script to talk to the participant about the study ending.

Discussion Questions

1. **Who** may **have a hard time talking** about **mental health** with the Mental Health for All team?

- What **experiences** or **feelings** might be **hard** to **talk about**?

- **How** can you **help** someone who has a **hard time talking about** their **feelings** or **experiences**?

Discussion questions

Risks and Safeguards for the Mental Health for All team's study

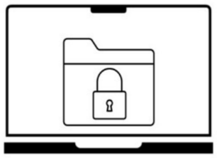
1. What are some possible **risks** or **harms** in the Mental Health for All team's study?

   - What can they do to **make sure people stay safe** in research?

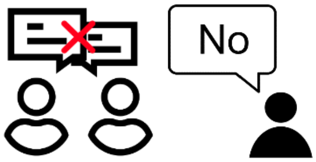
Topic 4.2.1: Privacy and Confidentiality

Main Ideas

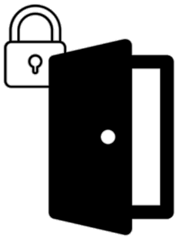
Privacy and confidentiality is about keeping research participants’ information (data) safe so other people don’t have research participants’ information.



- Keeping people’s **information private** and **confidential** is important in research.
- Researchers keep people’s **information private** and **confidential before**, **during**, and **after** people are in a **research** study.



- You cannot **share information** you learn about research participants **with anyone who isn’t on the research team**.



- We usually **do research in private places** to make sure information stays private and confidential.

Putting it into Action: “That’s confidential!”

Practice **explaining** to a family member or a friend **what** you **can** and **can not share about** the **research** study and the people in it.

You can write a script to help you **explain what** you **can** and **can not** share about the study. Then, act it out.

Topic 4.2.2: Privacy and Confidentiality when Other People are Present

Main Ideas

- Researchers also need to **think about privacy and confidentiality** when **participants bring someone** with them.
- Other people do not have a right to know research participants' information.

- You can **ask your project leader for help** when you are **not sure what to do** about something the person the research participant brought with them says or does.

Discussion Questions

1. What are some **concerns** or **challenges** the Mental Health for All team might have about **how** they will **keep** research participants' **information private** and **confidential**?

- **How** can they **keep** research participants' **information private** and **confidential**?

Putting it into Action: What does Privacy and Confidentiality Look Like?

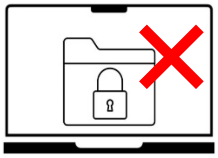
Describe, write, draw, or act out what **privacy** and **confidentiality looks like** when you are collecting information from participants in a research study.

- **What** would the **room look** like where you are collecting data?
- **Who** would be there?
- **What** could **you do** or **use** to keep research participants' information private and confidential?

Topic 4.3: Breaking Confidentiality and Mandatory Reporting

Main Ideas

- **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 found out a research participant is hurting or abusing someone else.



- Mandatory reporting means you **cannot keep information private** and **confidential** if you find out **someone is being hurt or hurting someone else**.

- Mandatory reporting **helps people be safe**.

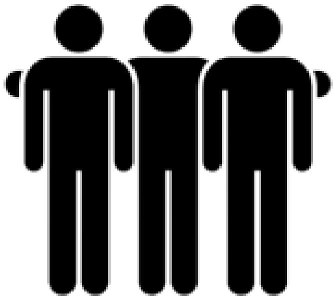
- **Mandatory reporting** can be **hard**. Your **project leader can help** you learn more about mandatory reporting.

Putting it into Action: Consent Document Search

Underline or highlight information about **mandatory reporting** in the Mental Health for All team's consent document.

Go to page 40 for the consent document.

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

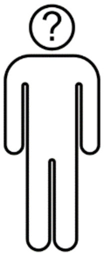
Main Ideas

	• **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**.

	• When we share about research it's important to **use works 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 highlight 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."

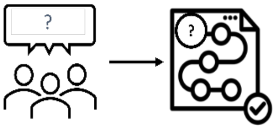
- "I am really happy my friends Melissa and Paul from my job at the CVS on Main Street told me about getting a therapist. Talking to a professional helps me work through my tough emotions and makes me happier each day."

- "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

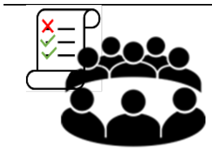


- **Scientific research** is **asking** a **question** and using a **step-by-step process** to **collect information** to answer the question.

- 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.

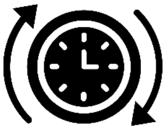
- Research ethics can **help** make sure **bad things** don't happen when people are in research.



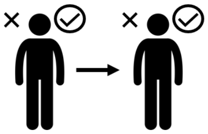
- **Institutional Review Boards (IRB)** are groups of people who **make sure** researchers **protect people's rights** and **well-being**.

Main ideas

- **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 privat**e 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 **may 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**.

Unit 6: Certification

Certificate of Completion

RE4ALL

This certificate certifies that

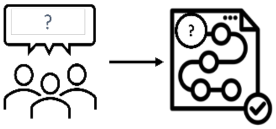
has completed *Research Ethics for All: Accessible Research Ethics Education for Community Research Partners*

Name and signature of trainer

Date

Individual Certification

To receive a certificate that says you have completed the training, do these certification with the person who helped you do the Research Ethics for All training. It is ok to re-watch a video, ask for help, and use your workbook to help you do some of the activities.



☐ Describe, write, draw, or act out a **definition** of **scientific research**.

☐ Describe, draw, write, or act out **3 ways community research partners** can **help** with **research** studies.

☐ Describe, write, draw, or act out 1 or 2 reasons **why** we have **rules for research**.

☐ Describe 1 way you can **respect people's rights** in research.

☐ Describe 2 ways you can **keep people safe** in research**.**

☐ If someone is considered **vulnerable,** we need to pay extra attention to how we do research with them. What are **2 things you can do** to help **respect** someone who is vulnerable is research and keep them **safe**?

Review the Mental Health for All team’s **eligibility criteria** on the next page.

Decide if each **person can be in** their **study**.

Circle or highlight the parts that match the eligibility criteria.

~~Cross out~~ the parts that do **not match** the eligibility criteria.

- Sally is 19 years old. She has Down syndrome. She just moved to a new group home 2 months ago. She calls you on the phone to say she saw your flyer. She is really interested in learning more about your study.

- John is 30 years old. He is autistic and has lived in a group home for 3 years. He loves it there and hopes to live there for a long time. John uses pictures and short phrases to communicate. You meet him at a self-advocacy conference and he says he is interested in knowing more about the study.

- Taylor is 42 years old. She has an intellectual disability. She has lived in a group home 5 years and speaks only Spanish.

Including Mental Health Services in Support Plans

Mental Health 4 All

Eligibility criteria:

Inclusion criteria-the experiences and characteristics people need to be in our study

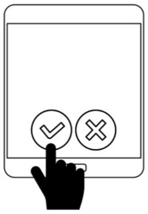
✓

- ☐ 18 years or older
- ☐ Have a developmental disability
- ☐ Live in a group home
- ☐ Can share their thoughts and feelings using words, pictures, or signs

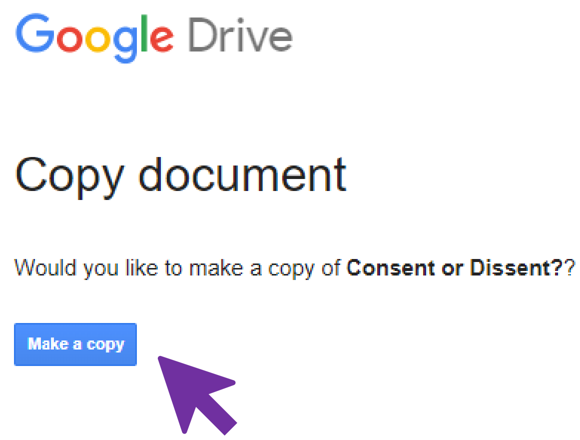
Exclusion criteria-the experiences and characteristics of people who can **not** be in our study

✗

- ☐ Have lived in a group home for less than 1 year
- ☐ Plan to move to a new place in the next 6 months
- ☐ Does not understand English



☐ Sort the pictures into “it looks like they consent” and “it looks like they do not consent (dissent).”
[Card sort link]



Google Drive

Copy document

Would you like to make a copy of **Consent or Dissent?**?

☐ Describe **3 ways** you can **keep** participants’ **information** (data) **private** and **confidential**

1.

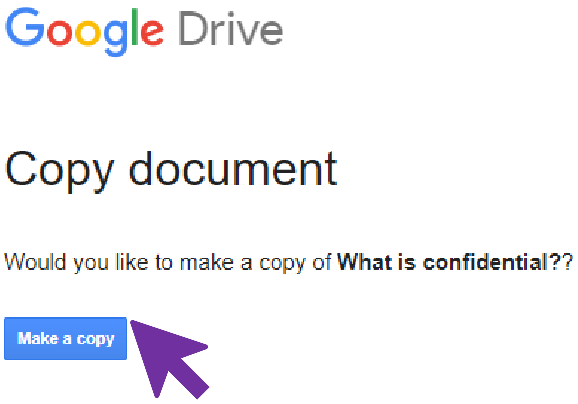
2.

3.

☐ Sort the information about participants into the categories: “confidential” and “not confidential.”

[Card sort link]()

Click “make a copy”



Copy document

Would you like to make a copy of **What is confidential?**?

☐ Sometimes we have to **break confidentiality** to keep research participants safe. This is called **mandatory reporting**. What is 1 **thing** that participants might talk about that **you would have to share** with someone else?

Congratulations on completing Research Ethics for All!

As you keep doing research you will learn more about research ethics.

Talk with your team members or project leader about the things you still want to know about being a community research partner.