

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.
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Discussion Questions

Finding people to be in a research study



1. How can you **help people understand** what a **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. How can you **help make sure people know** they can say **no**?



Discussion Questions



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



Putting it into Action: Practice Responding to “No”

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



Topic 3.1.2 Eligibility Criteria



Main Ideas



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- **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.
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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

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.

Citation: McDonald, K. & Schwartz, A. (2023). Research Ethics for All: Accessible Research Ethics Education for Community Research Partners. Syracuse University and Massachusetts General Hospital Institute of Health Professions. www.re4all.org



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

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- 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.
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- 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.
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Topic 3.3: Consent

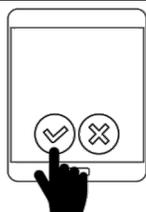
Topic 3.3.1: Consent: Working with People as they Make Decisions about Being in Research



Main Ideas



- **A consent meeting** is when someone **learns about** a research **study** and **decides** whether to be in the study or not.
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- **Giving consent** is when someone **says yes** to being in a study.
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- **Dissent** is when someone decides they **do not want** to be in a research **study**.
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Topic 3.3.2: Main ideas of consent: Informed, voluntary, and ongoing



Main Ideas

- 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.
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Discussion Questions



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

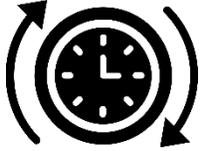
- **What information would you want to know** about a research study before deciding to be in it?



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**?

Topic 3.4: Consent Capacity



Main Ideas

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- **Consent capacity** is someone's **ability to make their own decision about** being in **research**.



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- 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.



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- 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.
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Discussion Question

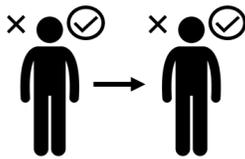


1. **What can you do if you're not sure if someone can make their own decision to be in a research study?**

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



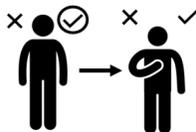
Main ideas



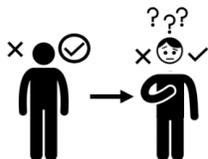
- If someone **does not** have **consent capacity**, they need a **legally authorized representative**, or LAR, to **decide** if they can be in a research study.
 - **Assent** is someone with a legally authorized representative (LAR) **saying** or **showing** with their body that they **want to be in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