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Making A Choice About Participating in this Study

What is a research study?



A research study is when people want to find the answer to a question.

Sometimes this is called a ‘study’ for short.

The name of this study is “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities.”

What is our research question?



We want to know if START services over the phone or internet are better, worse, or the same as in-person services.

Services provided over the phone or internet are called “telehealth.”



We are asking this question to learn if START service recipients are getting the help they need.

We will use what we learn in this study to make START services more flexible, so START service recipients can get help that meets their needs.



We will also use what we learn to teach providers better ways to work with people when they need mental health support.



Some people feel that getting their services in-person works best for them and their family.

Other people and their families may wish they could get services on telehealth instead.

We believe everyone should be able to choose what works best for themselves and their family.

What we learn from this study can help us make sure START service recipients have more choices about their services.

Who is doing the research study?



Dr. Joan B. Beasley from the National Center for START Services™ at the University of New Hampshire is leading a team of researchers.

There are self-advocates, professionals, and parents on the research team.

START stands for **S**ystemic-**T**herapeutic-**A**ssessment-**R**esources-**T**reatment.



START helps people with intellectual and developmental disabilities and mental health needs (**IDD-MH**), their families, and their support team.

You (or your family member) receive START services through a local agency.

You can join our study if....

3 months



You have been in START for 4 months or less.

12 – 45



You are 12 through 45 years old.



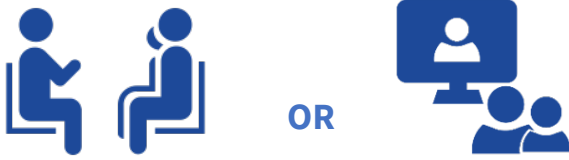
You live at home with your family/another caregiver **or** you live by yourself and are your own guardian.



You will have accommodations like captions or Sign Language if you need them.

If you need other accommodations to be in the study, please tell us.

What will I do in this study?



There are two groups in our study.

1. START services in-person
2. START services over telehealth

The group you will be in is random.

Random means you will be put into one of the two groups: in-person or telehealth.



Random means you don't get to choose which group you are in. You have an equal chance of being put into either group.



Random groups are the best way to learn if START telehealth is better, worse or the same as in-person services.

People get 4 different kinds of services at START.



Everyone in both groups will get all of these services. They are:

1. Intake and assessment
2. Crisis response
3. Therapeutic coaching
4. Outreach



In-Person Group
4 START services will be in person:
1. Intake/Assessment
2. Crisis Response
3. Therapeutic Coaching
4. Outreach

Telehealth Group
2 START services will be in person:
1. Intake/Assessment
2. Crisis Response
2 START services will be over telehealth:
3. Therapeutic Coaching
4. Outreach

Everyone in both groups gets intake and assessments (#1) and crisis response (#2) in person, even if you are in the telehealth group.

If you are in the in-person group, you will get all of your START services in person.



In-person means that someone from your START team will come meet you at your home or somewhere in your community to do therapeutic coaching (#3) and outreach (#4).

Everyone will get intake and assessments (#1) and crisis response (#2) in-person.

If you are in the telehealth group, you will meet with your START team over the phone or computer for therapeutic coaching (#3) and outreach (#4).



Everyone will get intake and assessments (#1) and crisis response (#2) in-person.

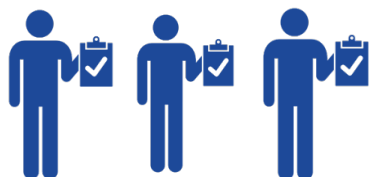
How will the research team learn about START telehealth and in-person services?



The researchers will get information in 2 ways.

1. Members of our research team will talk to you and your family (or supporter) 3 times.

We will talk to you at the beginning of the study to get to know more about you.



A member of our team will call you 6 months later to check in and answer some questions about how your services are going.

They will check in with you at the end of the study to make sure you get your gift cards.

This is not a part of your regular START services.

We will not tell your START team anything you share with us.

2. The research team will use information that START normally gathers on all people who use START services.



START puts information related to your mental health experiences into a password-protected system. This information might include:

- Assessments
- Crisis response



- Times you had to visit the emergency room
- Times someone called the police or an ambulance to help you
- Times you had to go to the hospital

If you decide to participate in this study, the research team will also use this information.

How long will I be in the research study?

About 12 months



You will be in this study for about 1 year long.



Even if you are done with the study, you might still get START services.

What are the risks and benefits?



A **risk** is something that might happen that feels uncomfortable or bad to you.

Risks can have a small chance or a large chance of happening.



There are only 3 risks in our study.



1. There is a small risk you may lose your privacy.

2. If you are in the telehealth group, you may have less privacy at home when you are using START telehealth.



Other people in your house might hear you talking to your START team.



3. There is a small risk that there will be a “breach of confidentiality.”

A “breach of confidentiality” is when someone sees or shares information about you without your permission.



The research team takes steps to protect you from these risks.



We will also check in with your START team to make sure you are safe if you experience any risk.



A **benefit** is something that might happen that helps you or other people.



A **direct benefit** is something that helps you.

There are no direct benefits in this study.



An **indirect benefit** is something that helps other people.

There are indirect benefits in this study.

They are listed below.



What we learn in this study will help us improve START telehealth services.

It will help other START service users get better mental health services.

It might feel good to know you are helping other people get better care in the future.

How will the study protect my privacy?



We will not share your name or where you live with anyone who is not on our study team.



The researchers store all the information they gather for the study in a password-protected system to protect your privacy.

How will I be compensated?



You will be paid with gift cards for your participation.

You will choose which store(s) you want gift cards for on a website called TangoCard.



You will get a \$50 gift card 4 times during the year you are in study. That is a total of \$200 in gift cards.

1. \$50 after the 3-month START assessment
2. \$50 after the 6-month START assessment and check-in with a member of the research team
3. \$50 after the 9-month START assessment
4. \$50 after completing the 1 year of the study



You can stop being in this study at any time.

You will stop getting gift cards if you are no longer in the study.

What is my choice?

Being in a research study is always voluntary.



Voluntary means it is your choice- you don't have to say yes. You can say no at any time, and no one will be mad at you.

If you have a guardian, they also have to give permission for you to be in this study. If your guardian says 'yes', you can still say 'no.'



If you agree to participate, you can still choose what questions you want to answer.

You can stop being in this study at any time.

If you want to stop being in the study, contact the research team as soon as possible.

If you stop being in the study, you will not get in trouble or lose your START services.



You can still use any START services available for you without being in this research study.

Call or email the study team if you have questions:



You can contact the research team at any time during the study.

Phone: (866) 807-0987

Email: start.telehealthstudy@unh.edu