

Improving telehealth experiences to help people with intellectual and developmental disabilities and mental health needs

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**EVALUATION OF TELEHEALTH SERVICES ON
MENTAL HEALTH OUTCOMES**
for People with Intellectual and Developmental
Disabilities

Improving telehealth experiences to help people with intellectual and developmental disabilities and mental health needs

Study Background

In the United States (US), many people with intellectual and developmental disabilities (IDD) get mental health supports from a program called **START**.

START helps people with IDD when they have a crisis.

Many people had to stay at home during the COVID-19 pandemic. People had to find new ways to get the services they needed while staying at home. Some providers, like START, used **telehealth** to solve this problem. Telehealth is when you use the phone or Internet to meet with your provider.

We wanted to learn more about how telehealth could be helpful. Our research question is: What supports help People with Intellectual and Developmental Disabilities (IDD) get good mental health care on Telehealth?

Our research team held focus groups to answer this question. A **focus group** is a small group of people who share their thoughts about a topic with researchers.

We held focus groups with three different groups of people:

1. People with IDD in START
2. Family Members
3. START Providers

Different people from our research team led the focus groups. We asked people to talk about their experiences on Telehealth. People from across the US came to the focus groups. They shared their ideas about how to make Telehealth better for People with IDD.

A team of researchers reviewed what people said in the focus groups to pick out the main ideas. The researchers found that people shared some of the same ideas. These main ideas are what we learned in the study.

This report includes examples of what people said in the focus groups. We made small edits to the quotes so they would be easy to read.

We learned providers can take three steps to make Telehealth better for people with IDD. The steps are:

1. Prepare
2. Engage
3. Assess

1: Prepare

The first step, **Prepare**, is all about getting ready for Telehealth.

Providers should schedule meetings at a time that works for People with IDD. That way, people can be in a comfortable, private place for Telehealth.

Telehealth can work on the computer, a tablet, or phone. Your provider can help you choose what you would like to use. They can help you learn how to use telehealth technology. They can help you get accessible technology to use, like a headset, an interpreter, or closed captioning for telehealth.

Some People with IDD may want a support person to sit with them during their telehealth meeting. One young adult described feeling more comfortable with their mom there for support:

“It helped because my mom knew that I felt some type of way. So she had a conversation with my provider and then I ended up talking to them for myself. They understood how I felt.”

A support person may help some feel more comfortable on telehealth, but others may prefer talking to their provider privately.

2: Engage

The second step, **Engage**, is about working together on Telehealth.

People with IDD might need **accommodations** to join in on activities on Telehealth. Accommodations are changes to remove barriers for People with Disabilities. They support the different ways people might think, move, or interact. Having the right accommodations makes it easier for People with IDD to join in on Telehealth meetings and have a good experience. All People with Disabilities have a right to get the accommodations they need. Your provider can help you decide what accommodations will help you use Telehealth.

There are a few ways that mental health providers can help People with IDD get more involved in Telehealth meetings.

START Providers can talk with People with IDD and their family caregivers during telehealth meetings to learn what activities and hobbies they enjoy. One family member said these chats were like *“a telehealth version of a cup of coffee”* which helped everyone get to know each other and build a good relationship.

The Providers also included people's interests in telehealth activities. One provider shared some examples:

"I'm thinking of one person, he loved to travel and go different places and kind of do a lot of visualization so, we'll do a museum tour online.

Another person I worked with loved Disney movies. So, we will watch a little clip of Disney movie on the screen and kind of talk about what was the lesson there? What can she apply to her own life?"

Using interests and hobbies in telehealth meetings helped people engage with providers.

People feel more included when they know their provider is listening to them.

Providers can show they are listening by asking follow-up questions. It also helps to check in about what has happened since the last meeting.

3: Assess

The third step, **Assess**, means reviewing how things are going. Assessing Telehealth helps Providers meet your needs.

Mental health providers should check in often to see how People with IDD are doing. There are a few ways for a provider to check on someone on telehealth:

- Providers can ask people questions about how they are feeling.
- Providers can notice clues in the person's camera background.
- Providers can talk to family, caregivers, or other people in the home.

Sometimes these other people can help the provider understand what's going on.

Sometimes a provider might visit in person to learn more about how a person is doing. The provider might visit in person to practice skills from telehealth meetings. One parent described how in-person visits can be helpful with telehealth meetings:

"The provider did some strategies during an in-person visit. But then during coaching, on Telehealth video, she would re-emphasize and reference back to when she was here in person."

Conclusion

We'll use these tips in the next part of our study. We'll teach providers how to run great online meetings with People with IDD. Then we'll compare START services in person to START Telehealth to answer our research question.