

Can You Hear Us Now?

Engaging Adults with IDD in Health Research



Q&A with Dr. Susan Haverkamp:

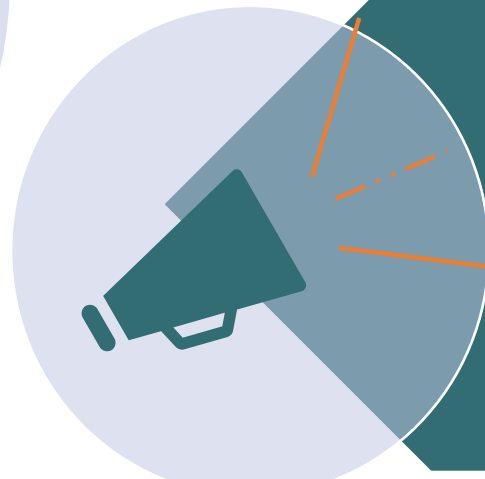
“I noticed that the title of this has changed from “Can You Hear Me...” to “Can You Hear Us...””

Could you talk about that evolution and what it means in the context of your research?”



“In Can You Hear Me Now?”

We made health surveys more usable so that adults with intellectual disability (ID) can speak for themselves. Too often in health research, people speak for the person with lived disability experience. We want to hear the voice of the person with ID.”



“In Can You Hear Us Now?”

We will focus on adults with ID *who are also people of color*. To meet people’s needs from different walks of life, we must first understand what those needs are. We want to hear the voices of diverse groups that often go unheard.”

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Q&A with Dr. Susan Haverkamp:

What are some of the pros and cons of this type of format and why is it applicable to this research?



For us, the DEEP is at the core of what we do. They make sure that our research represents the needs of the larger disability community. This community is made up of people from many different backgrounds. We will do our best to make sure their voices are heard. We want to do research, *not on the people we serve, but with the people we serve.*



This way, by listening to their health needs, we become better able to meet those needs. We can then provide health programs and services that are more likely to benefit people with ID across local communities. This is why community-based research is so important.

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Q&A with Principal Investigator, Dr. Susan Haverkamp:

“What is the next phase in this research that may have been informed by the previous 5 years?”

In the new project, we will build upon what we learned with four new studies.

Study 1



Measures

In the first study, we will test one of our adapted health surveys in a clinic. We will see if that survey helps patients talk about their mental health needs with their doctors.

We will also test different versions of this same survey to see how they compare. We want to make sure that this survey will be a good tool for doctors, patients, and researchers.

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Need for Study 1

Study 1



Measures

What patients have to say about their own healthcare needs is becoming more important.

Health researchers and service providers often use surveys to ask patients about the quality of care they receive. They also use surveys to track health outcomes of patients.

However, these surveys are not accessible for people with ID.

Health fields need usable and worthwhile surveys that allow people with ID to report on their own health.

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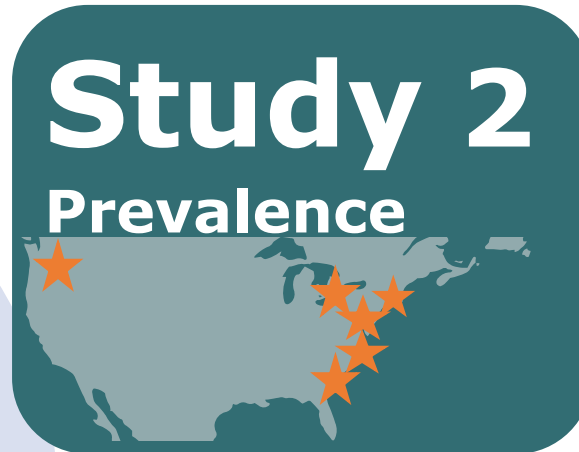
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“What is the next phase in this research that may have been informed by the previous 5 years?”

In the new project, we will build upon what we learned in the past project



In the past project, the main goal of Study 2 was to count how many adults with ID have mental illness nationwide.

Research shows that people with ID are at high risk for mental illness. Research also shows that there are no clear counts of adults with ID who have mental illness in the U.S. Estimates range from 10% to 60%.

Without clear counts, we do not know who needs services the most.

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Study 2

Prevalence



We will continue to test our surveys with people with ID across the country.

We will focus on learning about the mental health needs of adults with ID of color.

Black and Hispanic people are often left out of research.

When they are included, their health outcomes may not be reported due to small sample sizes. Less is known about the mental health needs of people of color.

The lack of health data for people of color with ID and mental illness is a challenge to planning programs and treatments.

When people of color are included in research, research is often done to them rather than with them. As with people with ID, health researchers should include people of color as partners in research planning.

That way, the research will reflect their voices, values, and be more likely to succeed

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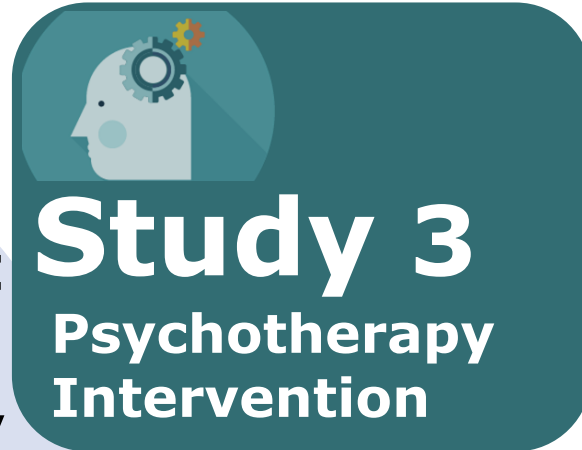
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In the new project, we will build upon what we learned in the past project

“What is the next phase in this research that may have been informed by the previous 5 years?”



First, we determined gaps in providing mental health therapy to adults with ID.

Then we wrote up guidelines for therapists to provide better therapy to adults with ID.

Now, we will build a new group therapy program to help people with ID cope with anxiety.

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Study 3

Psychotherapy Intervention

We will test this new program against a comparison group. By comparing, we will see how well the new therapy program works.

Research shows that there is a need for therapy programs that treat people with ID and mental illness. We need to know which therapies work for adults with ID.

Anxiety is a common problem for many people with ID.

We are focusing on making a therapy program using combined approaches from research to treat anxiety.

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Q&A with Principal Investigator, Dr. Susan Havercamp:

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Study 4 **Longitudinal Study**



We will work with grant partners to figure out how to track health information of people with ID over time.

We plan to build upon the work and systems of grant partners to improve what type, and how often, data is collected.

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Study 4

Longitudinal Study



Though different groups and agencies may collect data, it is often not complete. Also, data may be collected at just one moment in time. As such, we do not know about health changes for people with ID over time.

Information collected at different points in time helps us to know how health needs change.

This will help us plan programs and services to better meet needs of people with ID throughout their lives.