Can You Hear Us Now?

The Ohio State University Nisonger Center
Prevalence Study Frequently Asked Questions

Frequently Asked Questions for Communities

What are the goals of the study?

- Our goal is to learn about the health, mental health, and well-being of adults with intellectual disability (ID) across the country.
- We interview adults with ID about their health because we believe their ideas are important and too often overlooked.
- We want to learn from different communities, especially those that are often left out of research. These include communities of color, such as Black/African American and Hispanic/Latino communities, that may not receive the services they need.

Why is this research important?

- Understanding the needs of communities is essential to advocate for, plan, and deliver better services.
- People with ID, especially those who are Black/African American or Hispanic/Latino, deserve to have a voice in health research and services.

Who can participate in the study?

- Adults with ID (18+ years of age) and a study partner of their choosing.
- This study partner (18+ years of age) should be someone who knows the adult well, such as a family member, friend, or a paid caregiver. This person should know the moods, habits, and activities of the adult with ID.
- We welcome study participants from all racial and ethnic backgrounds and especially encourage Black/African American and Hispanic/Latino adults with ID to participate. These groups are often left out of health research.

What if the adult with ID has other disabilities?

- Adults who have ID and other disabilities, including autism, are welcome to participate.

Do participants need to speak English?

- Unfortunately, we can only conduct interviews in English at this time. We hope to translate our measures into Spanish and other languages in the future. For now, study participants must be able to understand and speak English.

What will you do with study findings?

- We hope our findings will be used to advocate for better healthcare for adults with ID. To make that possible, we will share what we learn with policy makers, the IDD community, researchers, communities of color, and study participants.

- We respect the privacy of everyone who participates. We will do our best to keep their information secure. When sharing study findings, we will never release the names or identifying information about research participants.

What is the study timeline?

- This study will run from September 2024 to August 2028.

- Recruitment of study participants will start in September 2024. We will work with communities throughout the duration of the study.

What do you ask of communities?

1) Work with our research team to build relationships that are mutually supportive.

2) Share important knowledge.

    a) Teach us about the culture, resources, and needs in your community.
    b) Help us understand how best to communicate.
    c) Work with us so that voices from your community are heard through our research and products.

3) Help us build a resource network for your community.

    a) Identify health resources to respond quickly to adults with ID or their families who may be in crisis.
    b) Identify services and providers who are culturally responsive.

How will you give back to the community partners?

- We want this study to benefit communities. We will seek suggestions from leaders and members on how best to do that. We can offer data or reports to help communities advocate for what they need.

- We will also offer resources and products based on what the community needs. Again, we will seek suggestions on how best to do that.

Who are the people conducting this study?

- The Ohio State University Nisonger Center is conducting this research through a federal grant. Please see Funding Statement below.

- The OSU Nisonger Center is one of 67 University Centers for Excellence in Developmental Disabilities nationwide.

- We partner with adults with ID, researchers, and policymakers from across the country to guide this study.

- **Study Lead: Marc J. Tassé, Ph.D., (614) 685-3193, marc.tasse@osumc.edu**

- *This research has been approved by The Ohio State University Institutional Review Board (IRB Protocol 2019H0312).*

Funding Statement:

The contents of this handout were developed as part of a Rehabilitation Research and Training Center on Health and Function awarded to The Ohio State University Nisonger Center through a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RTHF0006). NIDILRR is a Center within the Administration for Community Living, Department of Health and Human Services. The contents of this handout do not necessarily represent the policy of NIDILRR, the Administration on Community Living of the Department of Health and Human Services, and you should not assume endorsement by the Federal Government.

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Frequently Asked Questions from Potential Participants

What happens when I call the phone number or scan the QR code on the flier?

1. When you call the phone number, an OSU team member will answer the phone. If you get an answering machine, please leave a message with your phone number. We will call you back as soon as possible.

2. When you scan the QR code, you will see a few questions that will help us call you about the study. Please tell us how to reach you and the best times for us to talk. After you submit this form, we will call you as soon as possible.

3. Then, someone from the OSU team will talk with you on the phone for 10-15 minutes to answer your questions and see if the study is a good fit for you. You will choose someone who knows you well to be your study partner.

4. Lastly, you and your study partner will complete some forms, including an agreement to participate in the study, and participate in a Zoom interview.

How long will the Zoom interview take?

- The interview will take about three hours for you and three hours for your study partner. If you like, you can take a break or complete the interview over two days.

What kinds of questions will I be asked?

- You will be asked questions about your thoughts, moods, feelings, and actions.

- For instance, we will ask how often you felt happy in a given time period. We will also ask about your daily routines.

- We ask these questions so we can learn about your health and wellness. If you would like more information, please contact **marc.tasse@osumc.edu**.

Will my personal health information stay private?

- Yes. We respect your privacy. We will do our best to keep everything you tell us safe and secure. We will not share your name with anyone outside of research staff.

Will being in this study help my health or improve my healthcare?

- No, being in this study will probably not help you directly. We hope to use what we learn from you and from other participants to help adults with ID in the future.

Will I get paid for being in the study?

- To thank you for being in the study, you will get a $100 gift card. Your study partner will also get a $100 gift card.

Should I be in this study?

- It is your choice to be in this study or not. Even if you agree to be in the study, you can change your mind and stop at any time. Nobody will be upset or mad at you if you don't want to do the study.

Who is in charge of this study?

- Marc Tassé and Susan Havercamp are leading this study with a group of co-researchers who have intellectual and developmental disabilities.

- This research is based at The Ohio State University Nisonger Center, which is a University Center for Excellence in Developmental Disabilities.

- If you have questions about this study, you can ask **Marc Tassé, Ph.D., (614) 685-3193, marc.tasse@osumc.edu**

The Research Ethics Board at the Ohio State University reviewed and approved this study *(Protocol 2019H0312).*

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