



# Can You Hear Me Now? Listening to Adults with Intellectual Disability in Mental Health Research

Rehabilitation Research and Training Center on Health and Function

**Susan M. Havercamp, PhD, FAAIDD, NADD-CC**



## Project Goal

The goal of the center is to conduct systematic research that contributes to improving the mental health and quality of life of adults with intellectual disability (ID)



# Mental health in ID: What we know

1. People with ID are vulnerable to mental health conditions
2. Patient-reported outcome measures are critical for understanding health, particularly internal states such as loneliness, anxiety, distress, and pain
3. Self-report mental health instruments are not cognitively accessible for people with ID
4. Use of informant or proxy reports leads to **under-reporting** of health and mental health symptoms
5. Adults with ID can provide reliable and valid mental health reports when measures are cognitively accessible
6. Cognitively accessible measures are needed





## Mental health in ID: What we *don't* know

- In the US, we do not know the prevalence of mental health disorders in adults with ID
  - Lack comprehensive diagnostic instruments
  - Lack rigorous research with large representative samples
- Lack of credible prevalence estimates means that Federal and state agencies cannot budget or plan to meet the needs





# Mental health in ID: What about treatment?

- Clinicians struggle to get self-reported experiences
- Accurate diagnosis is essential to effective treatment
- Individuals with ID can benefit from psychotherapy
- However, high quality mental health treatment is lacking because
  - Clinicians lack training and confidence to care for this population
  - clinicians lack treatment guidelines



# RRTC Research Studies

1

## STUDY 1: MEASURES

Adapt diagnostic, health, and health related quality of life measures to increase self-report in adults with ID

2

## STUDY 2: PREVALENCE

Determine the prevalence of mental health concerns among adults with ID

3

## STUDY 3: GUIDELINES

Develop best practice guidelines for psychotherapy with adults with ID



# Our Approach

- Focus on Mental Health of adults with ID
- Use a Participatory Action Research (PAR) approach
- Learning Collaborative





# PROJECT PERSONNEL

- > Susan M. Havercamp, PhD (PI) – Ohio State Nisonger Center
- > Gloria L. Krahn, PhD, MPH (Co-PI) – Oregon State University
- > Marc J. Tassé, PhD (Co-PI) – Ohio State Nisonger Center

## Co-Investigators:

- > Rebecca Andridge, PhD
- > L. Eugene Arnold, MD
- > Richard A. Chapman, PhD
- > Jill A. Hollway, PhD
- > Margo V. Izzo, PhD
- > Luc Lecavalier, PhD
- > Paula Rabidoux, PhD, CCC-SLP
- > Lara Sucheston-Campbell, PhD
- > Chris Taylor, PhD
- > Katherine Walton, PhD
- > Craig E. Williams, MD
- > Andrea N. Witwer, PhD

## Research Team

- Alexa Murray, MGS, MA – Project Manager
- Chelsea Cobranchi, BA- Clinical Research Coordinator
- Andrew Buck, PhD – Learning & Development
- Bob Rice, PhD – Senior Data Manager
- Kristin Page, BS – Data Manager







# LEARNING COLLABORATIVE

## REEP: Research Experiences Expert Panel

OSU and National Researchers with expertise in ID and co-occurring mental health

- **Conceptual brain trust**
- **Consultants on research logistics**
- **Dissemination**



### REEP

Alixé Bonardi (HSRI)  
Mary Sowers (NASDDDS)  
John Seeley (Univ. of Oregon)  
Chris Sanford (SRI International)  
Robert Fletcher (Consultant)  
Jarrett Barnhill (UNC-CH)  
Karrie Shogren (KU)  
Dan Davies (AbleLink Tech.)

### External Evaluator:

Michael L. Wehmeyer, PhD (KU)



DEEP

Christine Brown (Co-Chair)  
Braden Gertz (Co-Chair)  
Travis Dresbach  
Marci Straughter  
Samantha Perry  
Christopher Cole  
Ethan Boerner  
Colin Schaeffer  
Rosie Lawrence-Slater  
Kristy Stepp  
Shawn Bodle  
Sarah Burkett  
Ashley Poling  
Megan Ryan



# LEARNING COLLABORATIVE

## DEEP: Disability Experiences Expert Panel

- Research partners
- Develop cognitively accessible measures
- Consult on focus group questions
- Recruit participants
- Translate findings into clear language
- Disseminate findings

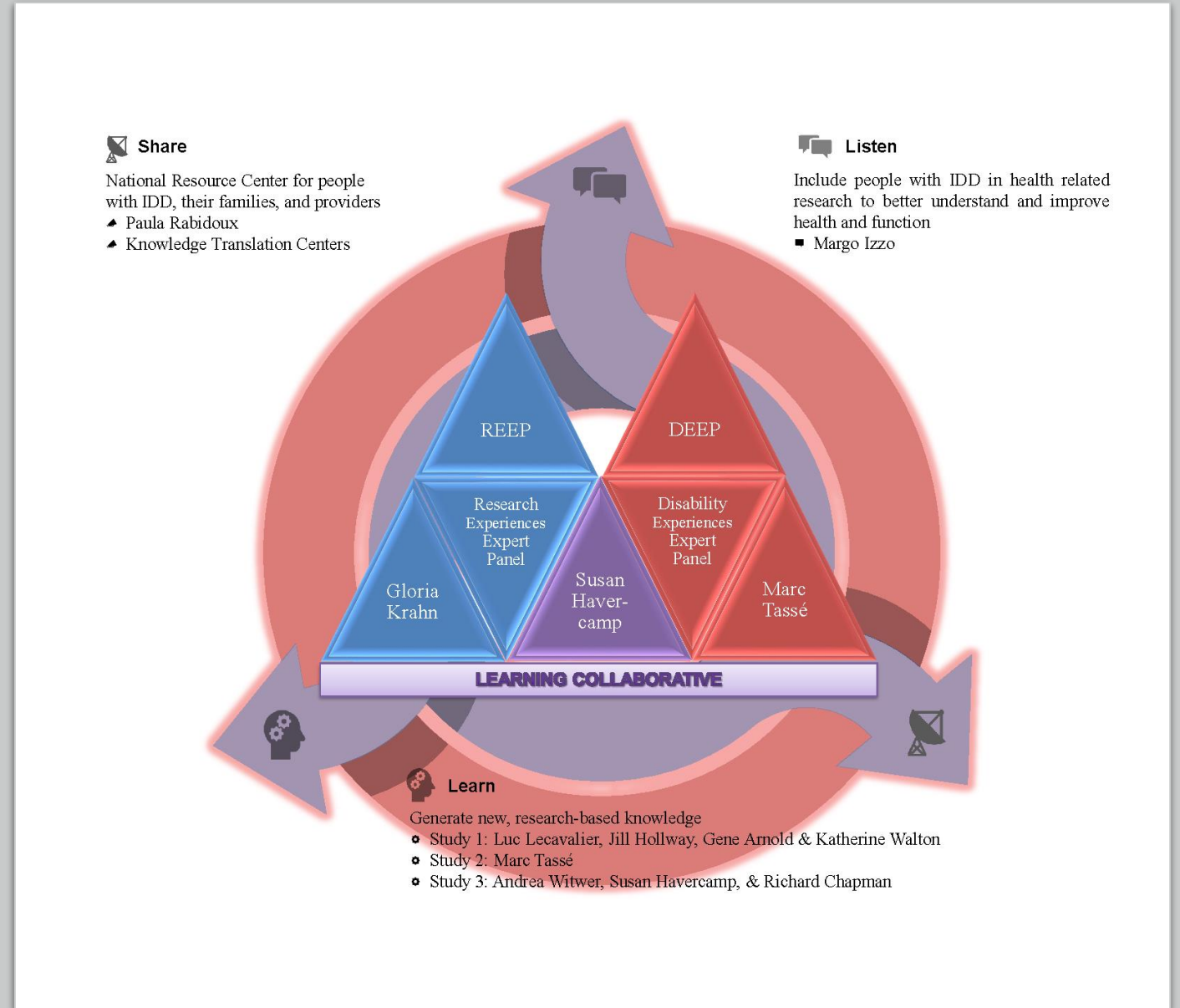






# RRTC Learning Collaborative

The Nisonger RRTC on Health and Function is committed to including adults with lived disability experiences in every aspect of our research



## Study 1: Measurement

- 1) Adapt established Diagnostic Interview for Adolescents with Intellectual Disabilities for adults (ages 25+) with ID (DIAAID)
  - a. Partnered with Seeley et al. to leverage ongoing study
  - b. Seeley et al adapted *Diagnostic Interview Schedule for Children* (DISC) for youth with ID (14 – 24 years) self-report & caregiver proxy report
  - c. We extended age range to adults (18+)



# Study 1: Measurement

- 2) Adapt Function Neutral Health-Related Quality of Life (FuNHRQoL) for adults with ID
- 3) Adapt Patient Reported Outcomes Measurement Information System (PROMIS) for adults with ID
- 4) Evaluate validity and reliability



# Improving self-report

- Teach adults with ID to respond to survey questions
- Get familiar with multiple choice response options and images
- Offer corrective feedback and practice





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# Learning Module

*Today we are going to be talking about how OFTEN things happen to you or how OFTEN you feel a certain way. Later, I will be asking you to answer questions by pointing to pictures or words to tell me about how often these things happen. I'm going to show you a few now to make sure you know what the different answer choices mean.*

*[Turn to flipbook page 1]*





# Pre-interview learning

A.

Sun	Mon	Tue	Wed	Thu	Fri	Sat
X	X	X	X	X	X	
	X	X	X	X	X	X
X	X		X	X	X	X
X		X	X	X	X	X

B.

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	X					
			X			
X						

Take a look at these pictures. The pictures are supposed to look like a little calendar. Someone placed X's on the calendar to show how often something happened. When there are a lot of exes, it means it happened a lot [point to calendar A]. When there are only a few X's, it means it happened a little or only once in a while [point to calendar B].

Point to which calendar shows something that happened on a lot of days.





# My Health and Well-Being Survey

In the last 2 weeks, did you feel healthy?



S	M	T	W	T	F	S
	✓					
				✓		

Almost Never

S	M	T	W	T	F	S
	✓		✓		✓	✓
✓			✓	✓		

Sometimes

S	M	T	W	T	F	S
✓	✓	✓		✓	✓	✓
✓	✓		✓	✓	✓	✓

Almost Always

◀ **Back**

I Don't Know

**Next** ▶





# Sampling Strategy: National Core Indicators

- Partnership of Human Services Research Institute and NASDDDS
- Quality Improvement protocol for ID/DD service delivery
- 38 participating states
- In Person Interview
  - At least 400 adults with DD selected randomly every year
  - Data drawn from case records, proxy informants, and in person interviews with adults with ID/DD



## NATIONAL CORE INDICATORS



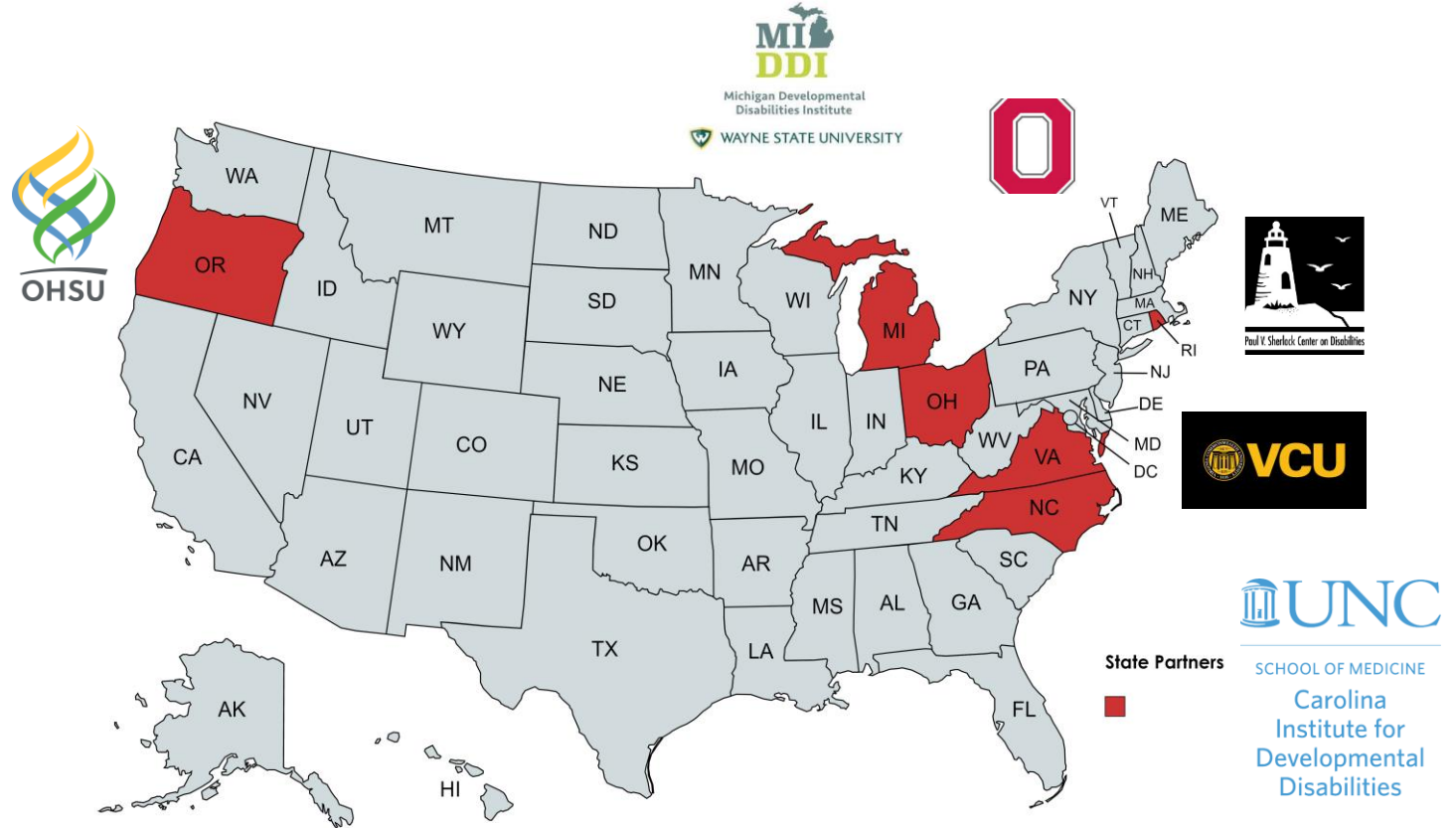
# National Core Indicators

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- 38 participating states
- In Person Interview
  - At least 400 adults with DD selected **randomly every year**
  - Data drawn from case records, proxy informants, and in person interviews with adults with ID/DD



# Prevalence Study: Partners

- Recruit from the NCI sample of adults with ID across six states: MI, NC, OH, OR, RI, VA



# Partnering with North Carolina

- University of North Carolina, Carolina Institute for Developmental Disabilities
  - Laura Hiruma, PhD (PI)
  - Anne Harris, PhD (site coordinator)
  - Becky Pretzel, PhD (NCI coordinator)
- North Carolina Department of Health and Human Services



# Prevalence Study: Sampling

- Interviewers from all six partner sites will conduct DIAAID interviews 2021-2023 to obtain a nationally representative sample



	2021-2022	2022-2023	Subtotals
MI	125	125	250
NC	125	125	250
OH	125	125	250
OR	125	125	250
RI	60	60	120
VA	125	125	250
TOTAL	685	685	1370





# Prevalence Study: Recruitment

- Warm handoff from NCI interview
- Mail and email to NCI sample



WE NEED YOUR HELP TO BETTER UNDERSTAND THE  
HEALTH OF PEOPLE WITH INTELLECTUAL DISABILITY



### What will you do?

We will meet you and your support person\* online through video chat or in-person. You will answer questions about your health.

### How long will this take?

About 3 hours.

### \*Who is a support person?

A family member, friend, or caregiver that knows you well.

### Want to sign up?

Call us Monday to Friday  
between 9:00am-5:00pm

**833-678-7782**

Scan here



OR go to  
[go.osu.edu/rrtcstudy](http://go.osu.edu/rrtcstudy)

You will earn a \$50 gift card.

+

Your support person will  
earn a \$50 gift card.

For more information, visit our website: [www.rrtcnisonger.org](http://www.rrtcnisonger.org)

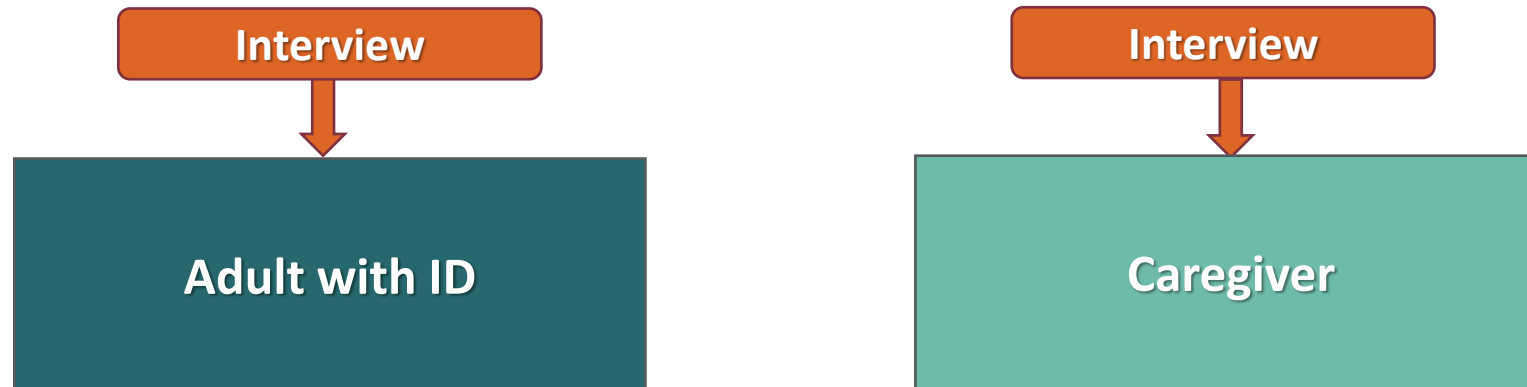


The Ohio State University Nisonger Center has created a Rehabilitation Research and Training Center (RRTC) on Health and Function for People with IDD. This research is funded through the Administration for Community Living (ACL) (NIDILRR grant number 90RTHF0002).



# Prevalence Study: Interview

- Administer the Diagnostic Interview for Adolescents and Adults with Intellectual Disability (N=1,370): individual with ID + caregiver
  - Self-report interview: 17 diagnostic categories
  - Proxy-report interview: 29 diagnostic categories
- Other measures



# Assessment Protocol

- Adaptive behavior (ABAS-3)
- Life Events for Persons with Intellectual Disability
- Behavior Problems Inventory for Individuals with ID – Short Form
- Structured mental health interview (DIAAID)

Caregiver



# Assessment Protocol

**Adult with  
ID**

- IQ (WASI-II)
- Social Desirability Short Scale for Intellectual Disability
- Health measure (PROMIS)
- Health-related QoL (FuNHRQOL)
- Structured mental health interview (DIAAID)



# Prevalence Study Research Questions

1. Prevalence of co-occurring ID + mental health conditions?
2. Relationship between self-report and caregiver reported symptoms?
3. Participation of adults with ID on self-reported mental health (DIAAID)?
4. What is the sensitivity/specificity of the DIAAID compared to clinician evaluation?
5. Health and health-related QoL for adults with and without co-occurring MH?



## Study 3: Psychotherapy Guidelines

- 1) Scoping literature reviews to identify evidence-based practices
- 2) Focus groups with adults with ID/MH and with clinicians to learn about effective accommodations and barriers
- 3) Develop best practice guidelines for clinicians





# This research will help to

- Improve measures to elicit self-report from adults with ID
- Establish the point prevalence of people with ID and co-occurring mental health issues;
- Develop a better understanding of health status of adults with ID
- Establish best practice guidelines for psychotherapy to advance mental health treatment for adults with ID



## Can you hear me *now*?



<http://go.osu.edu/RRTC>

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