RRTC Study 4:
Collecting IDD Data Across Time

RRTC Summit 2026

Purpose:

Work together to create a clear plan for how to collect **health**, **employment**, and **community living** outcomes for people with IDD as they grow and change over their life.

In the past year, we have:

1. Received funding to start this project
2. Built a team of research and lived experience experts
3. Completed listening sessions to understand what makes a good life for people with IDD

3 Rehabilitation Research and Training Centers on IDD

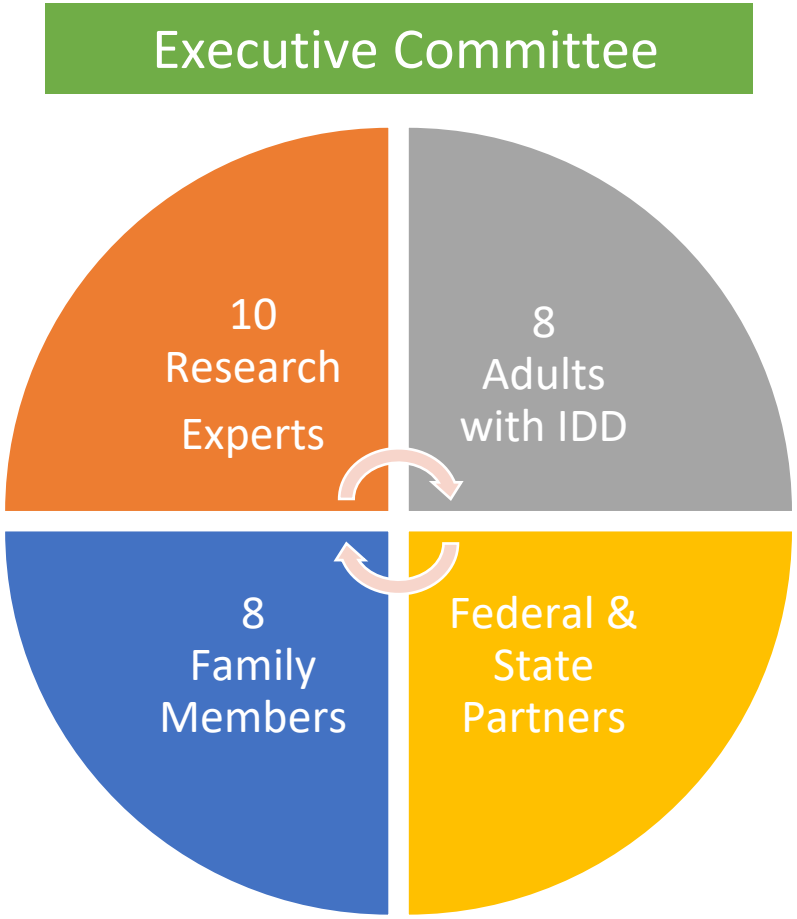
Health and Function

Community Living

Transition and Employment

Leadership and funding from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) of the Administration for Community Living (ACL)

Bringing together lived experience, scientific expertise, and federal leadership to create a plan for future action



Listening Sessions

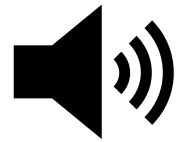
1. What should other people who are researchers, agencies, and others know about a **good life** for people with IDD?

2. What is important about:

- **Health**
- **School**
- **Working or Volunteering**
- **Where and With Whom You Live**

Listening Sessions

Lived experience is central voice to this project



What's Next?

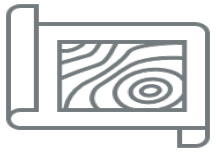
Subject Matter Experts

- Meet Monthly
- Develop 5 deliverables

Lived Experience Experts

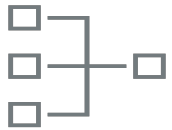
- Meet Quarterly
- Provide insight on deliverables and produce clear language summaries

5 Key Steps



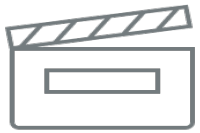
Landscape Analysis

Methodological Strategies



Recommended Data Infrastructure

Compendium of Requirements



Action Steps to Build the System

Step 1

Landscape Analysis

- Identify data from listening sessions
- Researchers provide input
- Review literature and existing datasets
- Lived Experience prioritized outcomes

We will be able to answer:

What data exists and what is missing?

Step 2

Methodological Strategies

- Outcomes to include
- Questions to Ask
- Connect current data
- How to collect new data

We will be able to answer:

What research methods will work to track across lifespan?

Step 3

Recommended Data Infrastructure

Review successful data systems

- Resources
- How often to collect data
- How to start data collection
- How to keep data collection going
- Strengths and Challenges

We will be able to answer:

What should the data system/s look like?

Step 4

Compendium of Requirements

Guide for longitudinal data

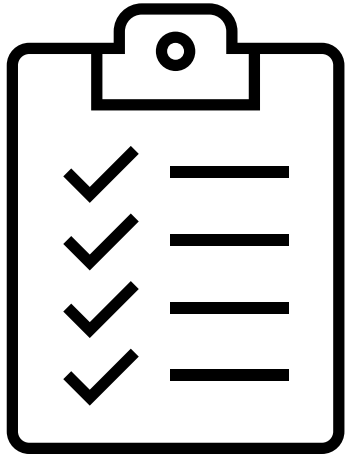
- Who is answering the questions?
- Who is the data for?
- What tool should be used?
- How to make measures accessible?

We will be able to answer:

How should data be collected over time in a way that works for people with IDD?

Step 5

Action Steps to Build the System



We will be able to provide:

Steps to take for create a longitudinal data system/s

Glance at the Next Year

1. Landscape Analysis	July 2026
2. Methodological Strategies	November 2026
3. Data Infrastructure	February 2027
4. Requirements	February 2027
5. Action Steps	August 2027

Our recommendations will help leaders **collect and link data** to **understand** and **improve the lives of people with IDD** from childhood to old age through better policies and programs

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NISONGER CENTER

The contents of this presentation 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 numbers 90RTHF0002-01-00 and 90RTHF0006-01-00). NIDILRR is a Center within the Administration for Community Living, Department of Health and Human Services. The contents of this presentation 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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