I/DD COUNTS Newsletter

Date: April 2025

Administration on Disabilities

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This newsletter is written in plain language to make the information accessible to as many people as possible.

Background

I/DD Counts started in 2015. The Administration for Community Living (ACL) leads the project. The goals of the project are to:

1. Collect information on **how many people have intellectual and developmental disabilities (IDD)** in the US. Another way of saying this is the **prevalence** of IDD.
2. Understand the **health of people** with IDD.

In 2020, I/DD Counts developed a 10-year plan to achieve these two goals. This plan is called the **I/DD Counts Roadmap ("the roadmap")**. Researchers, federal government agencies, and people with lived experience helped develop it. The roadmap organizes activities that need to happen to get better data on the health of people with IDD.

This newsletter has information on **three key areas**:

1. The I/DD Counts Planning Study
2. Panel presentation at a past conference
3. Related publications

I/DD Counts Planning Study

One activity in the roadmap is to consider creating a Center of Excellence in I/DD Health Data. This is also known as **"the Center."** In 2023, Human Services Research Institute (HSRI) received funding from the Administration for Community Living (ACL) and the Centers for Disease Control and Prevention (CDC) to do a planning study. The goal of the planning study was to learn more about what a Center could do. As part of the planning study, HSRI did an environmental scan of existing IDD data efforts, held listening sessions, and interviews with subject matter experts.

The planning study recommended:

- A **structure for a Center** of Excellence to better coordinate and organize IDD Health Data
- Examples of **how to fund the Center**
- **Important partnerships**, including with people with disabilities and their families

All activities happened between January and September 2024. HSRI submitted a final report to ACL in late 2024. A plain language summary was also created in early 2025. The plain language summary will be shared on the I/DD Counts website. The I/DD Counts team will work with federal partners on the next steps.

International Association of the Scientific Study of Intellectual Disability (IASSIDD) Congress

In August 2024, the I/DD Counts team presented a session at the IASSIDD Congress held in Chicago, Illinois. The session was called *Improving Data for Health Equity for People with IDD: Multiple Country Approaches.* Panel members included researchers from Australia, Canada, Ireland and the US. **Presenters shared ways different countries get and use data** to learn about the health of people with IDD:

- National data collection from the census in Scotland asks people if they have IDD. People can get help filling out forms if they need help.
- Ireland uses disability specific questions in national surveys to know who has IDD. There is also a study that looks at aging and intellectual disabilities (ID) over time. It allows for comparisons between people with ID and the general population.
- Australia and Canada link different types of federal government data, like health care data and education data. They can learn more about who has IDD and what supports they use.

During the conversation, many of the countries said similar things. These are also called themes. **Some of the themes include**:

- Using current opportunities or projects for **better data collection**.
- Needing to **include people with IDD** in respectful and meaningful ways. Having ongoing communication is important.
- The importance of **building networks and trusted relationships**.
- Communicating in ways that most can understand. Having **different ways of sharing information** can help reach more people.
- Recognizing that **we are always missing people in data**. We need to learn who they are and how to include them.

Publications

Researchers continue working on ways to get better data about the health of people with IDD. Below are four papers or articles written by researchers about what they have learned. We provided summaries for each article or paper.

1. *Using Medicaid Data to Characterize Persons with Intellectual and Developmental Disabilities in Five U.S. States*

Summary:

In December 2024, CDC created a summary of a 2018 article about how many people have IDD in 5 states (Delaware, Iowa, Massachusetts, New York, and South Carolina). The information comes from Medicaid data. Between 2008 - 2013, an average of 1 in 35 people insured by Medicaid had an intellectual or developmental disability.

2. *Using National Survey Data to Estimate Healthcare Communication Disparities for Adults with Intellectual and Developmental Disabilities*

Summary:

Data from this study was from the National Health Interview Survey (NHIS). The study looked at differences in healthcare communication and satisfaction between three different groups of people:

- Adults with IDD
- Adults with other disabilities
- Adults with no disabilities

Adults with IDD **were less likely to**:

- Understand information they received from their medical provider
- Be satisfied with the healthcare they receive
- Have their opinion asked
- Feel respected

The authors recommend more research to understand the differences among the different groups. Researchers also suggest better training for healthcare providers and longer appointments for people with IDD.

3. *About Whom Are We Talking When We Use Intellectual and Developmental Disabilities?*

Summary:

Researchers use different definitions and abbreviations for people with intellectual disability (ID) and developmental disability (DD). This causes confusion in research, prevalence, and policies. It creates a wide range of prevalence. Some definitions find that 3% of people have DD; other definitions find that 17% of people have DD. There is also inconsistent use of acronyms such as ID/DD, IDD, and I/DD. It is not always clear. This article recommends ways to help people to understand the data better. Authors should give clear definitions of who they are describing. They should also describe what acronyms they are using and why.

4. *Through the Looking Glass: A Data Lens on Health of People with Intellectual and Developmental Disabilities*

Summary:

This paper talks about how we need a common definition of IDD to identify people who have IDD in national surveys (e.g., the Census). The authors reviewed and summarized the work that federal agencies have done to improve disability and health data for people with IDD.

What have we learned from these new articles?

These articles show that there is still a problem with including people with IDD in health data. Some things that they highlight are:

- There are different definitions and ways of asking questions about disability which makes it hard to have accurate data.
- Some surveys use yes/no questions. Other surveys ask about how much help a person needs.
- Adults with IDD don't always feel respected by their doctor or asked their opinions.
- Doctors often use words or terms that people do not understand.

The articles summarize why surveys should ask more questions about disability to know if a person has IDD. They share that disability status should always be asked when people are being asked for information about themselves, like their age. People with IDD deserve to be counted.