I/DD COUNTS Newsletter

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Administration on Disabilities

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This newsletter is written in plain language to make it accessible to as many people as possible. It provides updates on recent presentations, publications, and activities related to IDD data since the last newsletter was released. To request any of the information shared, please email IDDCounts@acl.hhs.gov.

Background

The goals of I/DD Counts 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.

I/DD Counts started in 2015. The Administration for Community Living (ACL) leads the project.

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")**. People with lived experience, researchers and federal government agencies 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:

1. **Improving national survey data**
2. **Strengthening administrative data**
3. **Partnerships with people and organizations**
4. **Recent Publications**
5. **Upcoming Conferences**

Improving National Survey Data

There are different types of national surveys in the United States (U.S.). One of the surveys is called the National Health Interview Survey. This survey has questions that ask about people's health. The federal agencies, ACL and the Center for Disease Control and Prevention (CDC) have been working together to add new questions to that survey to make it easier to get a picture of the health of people with IDD.

The survey asks many questions about health. The new questions are being added to help understand who in the survey has IDD. The questions will help identify the health of this group. This is important because it is the first national survey effort since 1994-1995 to improve the collection of IDD data.

Organizations and agencies are working to improve national survey data in other ways. CDC and Special Olympics International have worked together to learn how people with IDD would describe things they need help with, in their own words. By hearing how people with IDD identify their disability, they can compare this to how surveys define IDD.

Strengthening Administrative Data

Administrative data is information collected after somebody has received some type of service. For example: when someone goes to the doctor or sees a specialist, the doctor submits the bill to the health insurance company. This bill includes certain codes for what health services the doctor provided. The bill also includes other codes for any diagnosis a person has. Federal partners are working towards having consistent codes to identify IDD. This paper describes a summary of commonly used definitions of IDD and how they are used. Operationalizing the

Definition of Intellectual and Developmental Disabilities in Administrative Claims Data for Research | ASPE. Beyond administrative data, recent efforts have also looked at using more consistent definitions of IDD from electronic health records of people visiting an emergency department.

Partnerships with Different People and Agencies

The I/DD Counts Roadmap identifies what needs to change to improve IDD prevalence and health data. It also identifies the activities to make the changes. Many of the activities are related to partnerships with different people and groups.

These partnerships help connect people and groups to learn from each other. This happens in different ways including the:

- **Federal Interagency Workgroup on IDD Data.** This is a meeting with federal agencies to learn what each agency is doing to improve IDD data.
- **I/DD Counts Partners Work Group.** This group includes people with lived experience, researchers and others that work at different organizations related to IDD. Federal agency staff benefit from the opportunities to connect and learn from this broader workgroup. The group has two different committees. One committee focuses on definitions of IDD and improving different IDD data sources. The other committee focuses on communication. The communication committee is working to create a video to explain more about I/DD Counts.
- **I/DD Counts Data Summits**, or meetings. There have been three summits that happened in 2017, 2019 and 2022. The I/DD Counts team is planning for Summit #4. This summit is by invitation-only and is specific to people working with IDD health data.

- **2017 Summit #1:** This was the first I/DD Counts Summit. There were two workgroups formed. They focused on national surveys and state data. An outcome from this summit was a special publication called "On Counting What Matters: Findings Adults with IDD in Population Health Data." There were also 9 articles released that looked at different types of data.
- **2019 Summit #2:** This summit included 26 participants. It led to 3 focus groups that published two papers. One paper looked at what people with IDD said the priorities are for health data, surveys, and information shared by US agencies. The second paper looked across the groups for similarities and differences in priorities depending on who you ask. Following this summit, the I/DD Counts Roadmap was developed.
- **2022 Summit #3:** This summit included more than 70 people. Options to attend were in person or virtual. There were six panel discussions. The summit expanded engagement of people with IDD and federal agencies. There is a full report and an executive summary available for this summit.
- **2026 Summit #4:** This summit will include more people with lived experience. There is a planning committee that is made up of people with lived experience and the I/DD Counts team to help plan an inclusive summit. The summit will be in September 2026.

Recent Publications

1. **Critical Issues in Health for People with Intellectual and Developmental Disabilities**

   Summary:

   AAIDD held a National Goals on Health Equity meeting in June 2024. This meeting focused on what we know about the health of people with IDD. One goal was to set national priorities in key areas.

There were 9 groups that focused on different topics. Some of the topics included:

- Mental health and IDD
- Challenges with funding supports and services
- Choices and making decisions

AAIDD published a book in 2025 that had chapters for all 9 topic areas. Several I/DD Counts team members and people who work with I/DD Counts helped to write the chapters in the book.

Upcoming Conferences

The I/DD Counts team will be presenting and/or having discussions with people at these upcoming conferences. Come find us!

- Charting the LifeCourse Showcase (May 5-7, 2026, Kansas City, MO)
- AAIDD (June 22-24 2026, Chicago, IL)
- Reinventing Quality (October 4-6, 2026, Baltimore, MD)