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

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 **two key areas**:

1. Highlights from Presentations & Resources
2. Recent Publications

Highlights from Presentations & Resources

I/DD Counts Presentation at the American Association of Intellectual and Developmental Disabilities (AAIDD) Annual Conference

In June, members of the I/DD Counts team went to the AAIDD annual conference in Washington, DC. They presented **"Data with a Purpose: Elevating Your Advocacy Efforts."** In addition to the I/DD Counts team, the session had three presenters who talked about their Projects of National Significance. Three projects have been collecting important data about IDD services for decades. They collect data on where people with IDD live, work, and how much states spend for these services.

The presenters talked about the importance of continuing to collect this data. They shared information about their projects and how to use their data for advocacy. States can also compare themselves to other states. For example, all three projects create state profiles.

- State of the States in IDD creates a state profile showing how much government money a state has spent on IDD services.
- Residential Information Systems Project (RISP) creates a state profile with information on the type of places people with IDD live.
- ThinkWork creates a state profile showing how many people with IDD have jobs and how many hours they work.

Some states may want to learn from other states about how to make services better. Advocates can use the data to ask for changes in waiver programs. This data helps support advocacy at both the state and national levels.

If you would like a copy of the presentation, you can contact Heather Young (hyoung@hsri.org).

Partner Resources

The American Association on Health & Disability (AAHD) shared a blog post in June of 2025 called Importance of Disability Data. This talks about why it is important to collect disability data. AAHD shares a list of data resources on their website.

The National Institutes of Health's All of Us Research Program hosted a webinar titled Disability Data in the All of Us Research Program. They explained how disability data is not always documented in electronic health records (EHR). The program collected disability status from people directly. They looked at this number and compared to numbers from current surveys in the U.S.

They found that if we only use EHR to count the number of people with disabilities, many people will not be counted. More people said they had a disability than those with a disability label in their EHR.

Electronic Health Records (EHR): EHR are an electronic version of someone's medical chart. It has health information about a person. Some examples of information in EHR include medical history, medications and lab results. EHR are important because it helps people to be able to access their records easier. It also can be helpful for health care providers to see the history. A person can share EHR with providers and other people you want to have it. The information is protected in EHR.

The Lurie Institute for Disability Policy hosted a webinar in July. They introduced their new Disability Data Dashboard. The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) funds this project. The dashboard uses information from the American Community Survey. The data tells us about the need for and use of long-term supports and services. We can also learn about how different demographics, or characteristics, affect services.

Recent Publications

1. **National Goals Briefs Available**

   Summary:

   In June 2024, AAIDD held the National Goals on Health Equity meeting. One goal was to look at what we know about the health of people with disabilities. Another 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

   In May 2025, AAIDD published Issue Briefs in the nine different topic areas. Their briefs include a plain language summary for each topic. They will be releasing ten more resources in fall of 2025 from this meeting. This includes nine journal articles and different chapters in a book.

2. **Identifying People with Disabilities in Surveys**

   Summary:

   Health Affairs is a journal that shares information about health and health policy. They published this article in July 2025. It talks about how U.S. surveys do not always identify people with a disability. Researchers tested a new question with over 2,000 people. They used information from current surveys and compared it with the new information. This question seems to do better than previous questions at identifying disability.

3. **Including IDD in Health Research**

   Summary:

   I/DD Counts team members helped to write this article. It explains how people with disabilities get left out of health research and policy. This makes it hard to understand the health of people with disabilities. The article describes four ways to help improve health equity for people:

   - Include more people with disabilities in research.
   - Collect better data on the health of people with disabilities.
   - Consider different individual characteristics.
   - Use data that is available when people access health care. This includes records from the doctors, pharmacies or hospitals.

4. **Identifying IDD in Public Health Data**

   Summary:

   The Association of State and Territorial Health Officials (ASTHO) wrote a blog post in July 2025 about a project that they did with the Council of State and Territorial Epidemiologists. The focus of the project is to help people at state agencies know where to look for data about the health of people with IDD. They read reports and articles that use data to describe the health of people who have IDD in the United States. They also met with people that are experts in health data. This group shared advice about good data sources. This was the first step, and there is more work to do.

5. **An Introduction to IDD for Public Health Workers**

   Summary:

   The American Public Health Association (APHA) provided this resource for Public Health Workers. This document helps public health workers learn how to get people with IDD what they need to be healthy. It also talks about how social causes of health problems affect people with IDD. It provides strategies and resources to support people with IDD.