



I/DD COUNTS

Quarterly Newsletter

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This newsletter is written in plain language to make the information accessible to as many people as possible. It provides updates since the last newsletter that was released in March 2024.

July is Disability Pride Month! The 2024 theme is “We Want a Life Like Yours.” Disability Pride Month gets celebrated every July. This is the month that the Americans with Disabilities Act (ADA) was signed into law. This law prohibits discrimination against people with disabilities.

The Administration for Community Living (ACL) is leading the **I/DD Counts** initiative. They are working together with:

- Federal government agencies,
- Researchers,
- Self-advocates and advocacy organizations.

ACL and the people working on the I/DD counts project have these goals:

1. Collect information on the number of people who have I/DD in the United States and its territories. A term used to describe how many people have a certain condition (like I/DD) is the “**prevalence.**”
2. Gather **better information about the health of people with I/DD.** This includes data about **how healthy people are and what services they use.** It is important to have this information to make services better for everyone.

Achieving these two goals will take changes in many areas. A national “road map” document lists the needed changes and steps to get them done.

I/DD Planning Study for a Center of Excellence or Coordinating Center on I/DD Health Data

Background

One of the steps in the road map to improve data about people with I/DD is to set up an I/DD Health Data Center. This Center would be a national Center that coordinates I/DD health data. The Center will help to:

- Focus on I/DD health data
- Coordinate current I/DD health data activities
- Help to build skills in using I/DD health data
- Share information about how many people have I/DD
- Help us learn new things about people with I/DD

There are lots of different projects and researchers looking at I/DD health data. This year, our contractor, Human Services Research Institute (HSRI), is doing a planning study to get information on

different models for the structure and activities of a center, and ideas for how to coordinate current I/DD health research. HSRI is a nonprofit organization that works to improve systems to make life better for people that need services. The funding for this work is from the National Center for Birth Defects and Developmental Disabilities/Center for Disease Control and Prevention (NCBDDD/CDC) in partnership with the Administration on Disabilities /Administration for Community Living (AoD/ACL).

The team working on the planning study has met with over 60 people. The goal of the meetings is to get input on the planning study and the process for creating an I/DD Health Data Center. Some people we have met with include:

- People with lived experience with I/DD
- Researchers, including research from different countries including Ireland, Scotland, Australia and Canada
- Federal agency representatives
- People from advocacy organizations

Below is information from each group of conversations.

Conversations with People with Lived Experience

On April 1, 2024 the I/DD Counts team hosted two online (virtual) meetings with people who have I/DD. The purpose of the meeting was to get input on the planning study process for an I/DD Health Data Center. We shared information about the purpose of the planning study. We wanted to learn what people with I/DD thought about the planning study process and Center.

In general, they liked the idea of creating an I/DD Health Data Center and thought it was important. Involving people with I/DD in leadership roles and research at the Center was a common theme. It would be important to have people with I/DD employed at the Center. Different options should be available to provide input to the Center including:

- Focus groups
- One-on-one meetings
- Meetings with self-advocacy networks and parent groups
- Online surveys

The group came up with several important ways to get the information and documents into the hands of people with I/DD, researchers, and others who would be using the information about the health of people with I/DD including:

- Sharing things on social media platforms.
- Making sure information is accessible and in plain language.
- Ensuring that information gets translated to other languages.
- Having different ways to share the same information (i.e., written, videos, auditorial).
- Having information written in a way that was easy to understand.

People with I/DD want to have meaningful opportunities to engage in I/DD health research. They should be paid for their time and expertise. This group talked about wanting more opportunities to be part of research initiatives. They want to be part of and co-author materials. They don't want to only be asked to share their story with no meaningful engagement or follow-up.

International Panel Discussions

On April 2, 2024 the I/DD Counts team hosted a virtual meeting with researchers from other countries. There were three main goals of this meeting. The meeting provided an opportunity for:

- Each country to learn from each other on ways to improve population health data for people with I/DD.
- To inform planning efforts to improve health equity data in the US, specific to the population with I/DD.
- To identify potential collaborations for improving population health data.

Countries included in this meeting were Australia, Scotland, Canada and Ireland. During the panel, they talked about how countries are learning more about the health of people with I/DD.

In Ireland, the [IDS-TILDA](#) study looks at how older adults with I/DD are doing health-wise over many years. They make sure people with I/DD are part of the study from beginning to end. In Canada, the [H-CARDD](#) project checks how adults with developmental disabilities get healthcare and use services. They connect health records and social service information to see what they can learn. Australia is also studying different health data to help people with I/DD. They worked on [linking data](#) around the health and wellbeing of people with ID in parts of Australia.

One big idea from all these projects is to involve people with I/DD in designing, collecting, and analyzing the research. Working together is important. Good data can help make better rules and plans to help people with I/DD live healthier all over the world.

Subject Matter Expert Interviews

Throughout April and May, the I/DD Counts held more than 17 subject matter expert (SME) interviews. We talked with different groups of people including people from:

- Federal agencies
- Universities
- Advocacy Organizations
- Researchers

The purpose of these interviews was to learn from people that have been a part of collecting I/DD data. We wanted to learn from them about the work they were doing. We asked questions related to:

- Are there models for collecting and monitoring the health of groups of people that could be a good model to follow?
- How would an I/DD Health Data Center be structured and sustained? In other words, are

there certain activities that would be important? And how can the work of an I/DD Health Data Center continue year after year?

- Who are the essential partners of a Center?
- Are there any promising practices to help us better understand the health of people with I/DD?

We are working to summarize the information that we learned from these interviews. The summaries will help to provide recommendations to the ACL and CDC for the final report. Our next newsletter will have an update from this information.

In-Person Meeting and Poster Session at the American Association on Intellectual and Developmental Disabilities (AAIDD) Conference in Louisville, KY

The I/DD Counts team facilitated a 4 hour in-person meeting at the AAIDD conference on June 10, 2024. There were 10 advocates with lived experience of I/DD that joined the in-person meeting with support for travel and accommodations.

The advocates agreed an I/DD Health Data Center would make people with I/DD more visible in national discussions about health and equity. At this meeting, we spent most of the time talking about what activities an I/DD Health Data Center could do. The I/DD Counts team shared an overview of what we have heard so far through our activities of the planning study.

After discussing and learning more about each individual activity, the advocates voted on the activities they thought were most important for an I/DD Health data center. These were the top 5 activities:

- Provide **technical assistance**.
- Support **advocacy and community engagement**.
- **Create a data repository (to make data available for others to use)**.
- **Provide trainings** to specific groups.
- **Collect data** or information about the health of people with I/DD.

During the AAIDD meeting on June 11th, we had an interactive poster where researchers, providers, and federal employees got to vote on their top activity for the Center. People voted for what they felt was most important and most feasible. We received about 25 responses. People who voted felt that **collecting data was most important**. They felt that **supporting advocacy and community engagement would be the most feasible** activity.

We are working to summarize all information we learned from these conversations. This information will be part of the final report that we write. The report will have recommendations on what is important to consider when creating an I/DD Health Data Center.

Point of Contact:

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Federal Interagency Workgroup (FIW) on I/DD Administrative Data

This workgroup brings together people who work in different federal agencies. Some agencies are collecting data on people with I/DD. They use the data to describe the health of people with I/DD.

We are learning more about people with I/DD in the United States. One way to do this is to use the information about people who use different services. Some services include education and health care. This information is also known as “administrative data.” It’s collected to help provide or “administer” public services.

Each month, participants in the *Federal Interagency Committee on I/DD Administrative Data* come together to review and share information. Members share updates on projects and data sources that help to improve what we know about health for people with I/DD in the United States. They discuss questions that their agencies are considering. The group tracks and shares resources related to I/DD data as well. Recent resources include:

- The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) [2024-2028 Long-Range Plan](#). This provides research activities to do over the next five years. It also shows progress made from the 2018-2023 goals.
- [NIDILRR Toolkit](#). This toolkit provides an overview of NIDILRR and their role. It provides information and resources in one place in a summary format.
- The I/DD Counts team shared what they are learning from discussions about an I/DD Health Data Center. FIW members gave examples of ways to collect and use data.
- The Disability Data Interagency Workgroup (DDIWG) that formed in 2024 by the White House Office of Science and Technology Policy presented. More information on that group is below.

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Disability Data Interagency Working Group (DDIWG)

The DDIWG is a group formed by The White House Office of Science and Technology Policy. There are more than 35 people from different federal agencies that are part of the group. This group focuses on improving disability data at the national level. They focus on disability data more broadly. But they are interested in finding out what the data issues are for the population with I/DD. They have three primary focus areas:

- **Community engagement.** This includes listening sessions and a request for information (RFI). They want input from people outside the group about disability data. The closing period for input was July 15th. The DDIWG will be reviewing all comments submitted. This will help them to develop a Federal Evidence Agenda on Disability Equity.
- **Resources and infrastructure.** There are many projects taking place around collecting disability data. There is not one single place to go to know what is being done. They want to

create a “one-stop shop” for people to find information about disability data.

- **Evidence Agenda on Disability Equity.** This will be available in November. It will be a high-level overview. The focus will be to share what disparities people with disabilities experience. It will also show what needs to happen for better data. It will highlight specific themes of data needs, demographics, etc.

There is an upcoming [virtual conference hosted by the Disability Health Equity Research Network \(DHERN\)](#).

To be connected to the DDIWG, contact:

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Conference Updates

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

- [NACDD Conference](#) (July 23-26, Washington, DC)
- [IASSIDD Conference](#) (August 5-8, Chicago IL)
- [Reinventing Quality](#) (September 15-17, Baltimore MD)

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