I/DD COUNTS Quarterly Newsletter

Date: March 26, 2024

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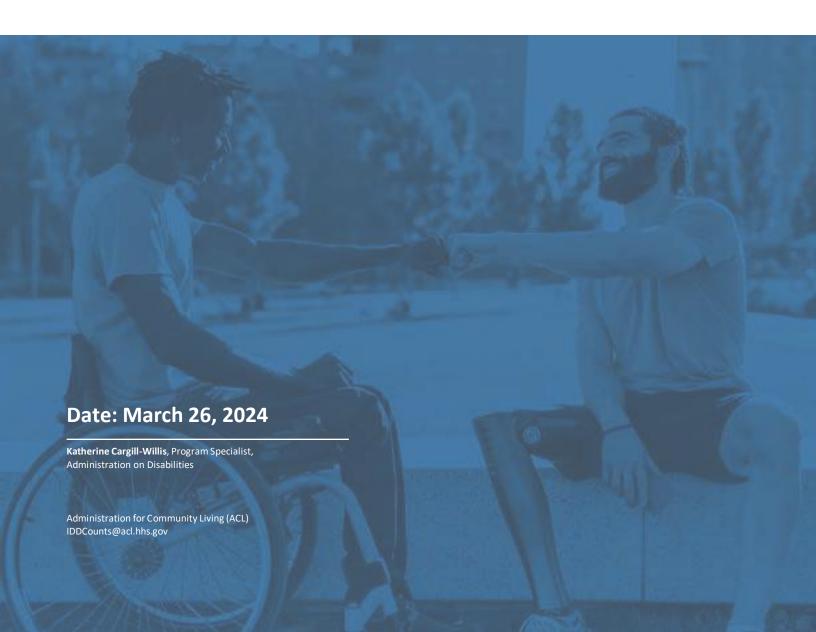
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This newsletter is written in plain language to make the information accessible to as wide a range of people as possible. It provides updates since the last newsletter that was released in November 2023.

March is Developmental Disabilities Awareness month. It is a time to celebrate people with disabilities being a part of our communities. The I/DD Counts project works to show that people with I/DD are important citizens of our country. It is important to find ways to include them in national data to help improve their health and well-being.

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

One of the ways to improve data about people with I/DD is to set up a national coordinating space. This will help to:

- Focus on I/DD health data
- 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 looking at different models to make sure these efforts are coordinated. HSRI is a nonprofit that works to improve systems to make life better for people that need services. The funding for this work is from the Center for Disease Control (CDC) National Center for Birth Defects and Developmental Disabilities within the Centers of Disease Control and Prevention (NCBDDD/CDC) in partnership with the Administration on Disabilities (AoD)/ Administration for Community Living (ACL).

We will meet with people that have experience in this area. This is also called a technical expert panel. We will write a report with the information that we collect. The report will provide recommendations on creating a center to coordinate this information. We will share ideas for things the center should do and data the center should focus on. The recommendations will also include how to coordinate the people and agencies that are focusing on I/DD health data.

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New Paper Published Describing Lessons Learned from I/DD Counts Focus Groups

In October 2023, the I/DD Counts team published a paper describing focus groups that took place in 2020. The focus groups asked people with I/DD how they feel about:

- Having their health information collected
- Using health information to learn how people with I/DD are doing.

The I/DD Counts team held three groups with people with I/DD to gather that information. A total of 16 adults with I/DD joined the groups.

The important messages from the paper are below:

- ***Protecting personal information is important***
    - People with I/DD may not want to share all their information with people that provide support to them. They may not let strangers know that they have a disability. Some doctors or people that work in the medical field have negative attitudes about people with I/DD. This makes it hard to talk with them.
- ***We need better information about the health of people with I/DD***
    - This includes information to make improve health care. It also includes information about what might happen as people with I/DD get older. This is also called longitudinal data. It should include information on mental health. It should also include information on dental health. It is important to know if people have a hard time getting the health care they need.
- ***It's important to gather information about where people live and who they live with***
    - Where people with I/DD live and who they live with can impact their health.
- ***Self-determination and choice are very important***
    - Self-determination means having support to make your own choices. People with I/DD should be able to make their own choices about their care.

These messages are important. They bring up issues that we need to consider when planning for the collection national health data on people with I/DD. The I/DD Counts team hopes to share the information in the paper with:

- Policymakers, or people who make decisions about support
- Advocates, or people that speak up for others
- Support providers, or people that provide support and work at the programs
- Health care providers

This paper is available to purchase. For more details on the study and its findings, see:
Krahn, Cargill-Willis, Bersani, Moore & Johnson. (2023). Recruiting the voices of persons with intellectual and developmental disabilities in policy development: Priorities for health equity data. Intellectual and Developmental Disabilities, (October 2023)

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There are many projects working to improve health data for people with I/DD. Part of the I/DD Counts project is to keep track of them all and encourage connections between projects. I/DD Counts does this with two workgroups:

1. The Federal Interagency Workgroup (FIW) on I/DD Administrative Data
2. The Partners Workgroup

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. They meet monthly to talk about data they are collecting. They work together to improve health related data.

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.

This quarter the workgroup updated an environmental scan of projects. This is a way for us to learn about projects happening with different federal agencies. They are using this environmental scan to:

- Support a planning study
- Be a resource for FIW members
- Be the basis for I/DD Counts quarterly newsletters

This group also talks about different conferences that are taking place. The workgroup shares information on presenting at a conference, where they would be to share updated information related to data collection and projects.

There are more than 30 projects and studies that are focused on improving health data on people with I/DD in the US. We are working to put the projects in a chart that will be available in our next newsletter so that everyone can learn about them. The rest of this newsletter will share highlights from a few of these projects.

Project Funded under Center for Disease Control and Prevention (CDC)

Association of State and Territorial Health Officials (ASTHO): Defining Disability for Syndromic Surveillance (this means doing a better job of making sure we know who has different types of disabilities).

ASTHO is leading a project related to definitions of disability. They want to understand how to support people with disabilities better. They are focusing on times when there is a public health emergency. They are looking at medical records and codes used to bill for medical services. This will help them understand how people use health care. They want to see if they can use certain codes to figure out who has a disability. They also want to see what types of medical care people with disabilities use. Once the project is complete, ASTHO will share what they learned with others.

This project has defined a list of codes. These codes can be used to identify people with impairments in seven areas, including:

- Hearing
- Vision
- Mobility
- Intellectual and Developmental Disabilities
- Cognition and Central Nervous System Disabilities
- Specific Developmental or Learning Disabilities
- Self-Care

Some highlights from national testing:

- On average, there were over 280,000 weekly visits at emergency rooms from people with different disabilities
- Average weekly visits were highest for people that had mobility concerns
- Some people had more than one diagnosis code

Some highlights from state/local testing:

- In general, states report that the codes for disability did a good job identifying who has a disability
- States did find that some people got identified as having a disability who don't really have one. The states have shared their ideas for how to improve the disability codes

ASTHO will finalize the definition of disability and the medical codes they used. When the project is complete, they will share what they learned with others. They will encourage people to use these standard definitions for disability.

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Assistant Secretary for Planning and Evaluation (ASPE)

Improving Data Infrastructure for Person-Centered Outcomes Research on Intellectual and Developmental Disabilities.

In 2022, ASPE [published a report](#) about improving data for research on ID/DD. The report shares some information about their methods and what they learned.

ASPE worked with other organizations to find ways to improve data collection of data for people with ID/DD. They interviewed more than 40 people who are experts in this area. They also put together different panels. After talking with various experts and people with lived experience, they identified 11 opportunities to make ID/DD health data collection better. Five of the most important ways include:

- **Developing a standardized research definition of ID/DD**. This is another way of saying that it's important for everyone to use the same definitions. If we all use the same definition, researchers will be able to get a better picture of people's health from research studies.
- **Advancing data standards for service systems.** This is another way of saying that we need to do a better job of making sure different data systems can "talk" or connect to each other. People with ID/DD often use lots of different services. We can better understand how healthy people with ID/DD are if the data from these different services can be linked.
- **Improving identification of ID/DD at point of care.** Identifying who has ID/DD the first time a person seeks healthcare is important. This can be hard because not everyone wants to share their disability status with a healthcare provider. One potential solution is to develop tools for patients to self-report ID/DD in their medical records.
- **Developing standardized outcome measures**. Data are on the medical outcomes of people with ID/DD; some examples of medical outcomes are well-being, education, employment, and community living. But there are no standard ways to measure these outcomes. Researchers should use the same methods to measure these outcomes. This would help us to understand if the help people receive improves their lives and health.
- **Encouraging Medicaid data use for ID/DD research.** The government has put all state Medicaid records into a national collection of data that researchers can access. But people will do a better job of using the data if there are clear instructions about how to use it to look at health of people with ID/DD.

It is important for people with ID/DD, researchers, and government employees to work together. ASPE has an office called the Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) that is working on these priorities. This office also developed a 10-year strategic plan to help move this work forward. With these projects, people with ID/DD will start to be included more in data.

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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!

- **AAIDD** Conference (June 10-12, Louisville, KY)
- **NACDD** Conference (June 24-26, Washington DC)
- **IASSIDD** Conference (August 5-8, Chicago IL)
- **TASH** Conference (December 5-7, New Orleans, LA)

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