2026 I/DD Counts Data Summit Words to Know

This document explains words and phrases you may hear through the Summit. Many of these words are used when describing the I/DD Counts Roadmap.

A

- **Ableism:** Treating people unfairly because they have a disability.
- **Administration for Community Living (ACL):** A federal government agency.
- **Administrative data:** Information collected by programs or services when people use them. This is sometimes called program data.
- **All-payer claims data:** This is data that comes from both private and public insurance companies about using services. A claim is like a receipt for healthcare services. The claim gets billed to insurance - like after a doctor's visit.
- **Analyze data:** To study information carefully to find patterns or answers.
- **Artificial intelligence:** When a computer program does things that normally need to be done by humans. We call artificial intelligence "AI" for short.
- **Assistant Secretary for Planning and Evaluation (ASPE):** Office that helps design national health and human services policies for the federal government.

B

- **Barriers:** Things that get in the way of what you need or want.
- **Behavioral Health (BH):** the connection between your daily behaviors and how you feel mentally and physically.
- **Benchmarks:** In research and in public health, a benchmark is a target. For example, a state might set a benchmark that they want 90% of all people with IDD in their state to have access to dental care.

C

- **Census:** A count of how many people live in the country. It also includes some descriptions of the people. It happens every 10 years.
- **Centers for Medicare and Medicaid (CMS):** the federal agency that oversees the Medicaid, Medicare and CHIP programs.
- **Characteristics:** Things that describe someone or something. See demographic variables.
- **Children's Health Insurance Plan (CHIP)**: Joint federal and state program that provides low-cost health coverage to children in families whose incomes are too high for Medicaid and too low to buy private insurance.

- **Clinical trials:** research on treatments, medicines or programs. In clinical trials, people try the treatment, medicine or program and researchers see if it improves their health.
- **Comparative Effectiveness Research (CER)**: CER compares the benefits and harms of two or more treatments, programs, or interventions. For example, a CER project might look at whether people with IDD who use self-direction have fewer emergency room visits each year than people who don't use self-direction.
- **Consensus**: An opinion or decision that most people agree with. Not all people agree but most of the people in the group do.
- **Consent:** Saying yes to do something after getting information about it. It is important that you understand what will happen before saying yes. This is often used in research.
- **Coordinating Center of Excellence:** A center that brings different people, groups, and sources of information together in one place. A coordinating center is focused on one or more specific goals.

D

- **Data:** Information that is collected to help us learn about people, services, or health. Sometimes data is numbers but it can also include words such as in stories or interviews.
- **Data agency:** A form of self-determination where an individual understands and takes ownership of their data.

- **Data Dashboard:** an interactive website that shows data on a health topic for a specific group or area. This is often through a map or pictures. Interactive means you can change or filter the data for specific information.
- **Data gaps:** Missing information. Gaps make it harder to understand the full picture.
- **Definitions of IDD:** Different groups often use different definitions of IDD. For example, a state might use one definition to decide who is eligible for getting services. Researchers might use a different definition to figure out how many people in the US have an IDD.
- **Demographic variables:** These are characteristics that describe people. For example, age, race, and marital status. It can also include things about where a person lives and the resources in their community.
- **Dissemination:** Giving out or sharing information. This can be with other people or organizations who need to know about the topic.

F

- **Federal Interagency Workgroup (FIW):** The FIW is a group of people from different federal agencies. They work to improve administrative data on people with IDD.
- **Facilitators:** In research, a facilitator is something that makes another thing more likely to happen. For example, data shows that having a job facilitates people having better health.

- **Focus group:** A way for people to give feedback on a topic.

G

- **Government agencies:** Public offices or departments that do work for the government.
- **Grantees:** In research, a grantee is a group of people who receive funding, or a grant, to work on a specific project. Researchers apply for grants. The strongest application is awarded the grant.
- **Guidelines:** Recommendations or rules for how to do something.

H

- **Home and Community Based Services (HCBS):** Supports and services to help people with disabilities live in their communities.
- **Healthcare Payers:** A company that provides health insurance is a healthcare payer. Medicaid and Medicare are considered healthcare payers.
- **Hospital Encounter Data (HED):** record of when a patient goes to a hospital for medical care.
- **Human Services Research Institute (HSRI):** This is a company that works to make services better for people with disabilities.

I

- **IDD – Intellectual and Developmental Disabilities:** Disabilities that can affect how a person learns, communicates, solves problems, or does everyday activities. This sometimes is also written as ID, IDD, I/DD, ID/DD.
- **I/DD Counts:** A project that is funded by ACL. The project has two goals:
    1. Collect information on **how many people have IDD** in the U.S. Another way of saying this is the **prevalence** of IDD.
    2. Understand the **health of people** with IDD.
- **IDD identifiers:** In survey or administrative data, an IDD identifier is data that can be used to determine who has an IDD.
- **Initiatives:** Plans, activities and strategies that work toward a goal.
- **Infrastructure:** In the I/DD Counts project, infrastructure refers to the data environment. This means where data is stored, how it is gathered, and how this impacts what we learn about health.
- **Insurers:** (see Healthcare Payers)
- **Integrated Dataset on Intellectual and Developmental Disabilities (iDIDD):** A specific data set created by linking three different data sets on people with IDD (support needs, Medicaid spending, life outcomes) in several states.

L

- **Link data:** To connect information from different places so it can be studied together.
- **Linkage studies:** This is using data from different places for the same person. For example, linking data from quality of services to using healthcare.
- **Longitudinal:** Longitudinal research is data that has been collected over time. For example, a research study that collected data on people with IDD from birth to adulthood is a longitudinal study.

M

- **Matched group studies:** This matches groups based on characteristics. Examples of these are age, race and gender. This includes using data from people with and without IDD. When you match, the goal is to learn if there is a real difference between the groups.
- **Medicaid:** A public health insurance program for people who qualify. This often includes people with low income or people with disabilities.
- **Medicare:** A public health insurance program for people that are usually 65 or older. Some people under 65 may qualify with certain disabilities.
- **Minority:** A group of people that have more or less things or opportunities than other groups, based on their characteristics.

N

- **National survey:** A list of questions that are asked to people across the country to learn about a topic.
- **National Health Interview Survey (NHIS):** The NHIS is an in-person survey that asks people different questions about their health. The National Center on Health Statistics manages the survey and the data from the NHIS.

P

- **Patient Center Outcomes Research Institute (PCORI):** PCORI is an independent non-profit organization in the US. Congress created PCORI and gave PCORI money to give out as grants. PCORI funds patient-centered comparative effectiveness research (CER).
- **Planning Study:** A study to gather information about the best way to move forward with a project. The I/DD Counts planning study focused on the best way to create a coordinating center to strengthen IDD data.
- **Policy:** A rule or plan that explains how things are provided. There are often policies around services or how things are paid.
- **Prevalence:** How many people in a group have a certain condition or disability.
- **Privacy:** Keeping personal information safe so it is not shared in the wrong way.
- **Program data:** Information collected by programs or services when people use them. Also known as administrative data.

- **Public health:** The study of the health of communities and populations. Public health leaders are responsible for developing programs and policies to help keep everyone healthy.

Q

- **Quality of life:** How good a person's life is. This can include health, safety, friendships, work, and being part of their community. A person can create their own goals of what a good quality of life looks like.

R

- **Research:** Collecting information to answer a question or solve a problem.
- **Research capacity:** Having the skills, tools, and support needed to do research.
- **Research Identifiable File (RIF**): A file that contains individual identifiers and other private health information. This file is developed by the Centers for Medicare and Medicaid.
- **Researchers:** People with and without disabilities who study questions and use information to learn more about a topic.
- **Roadmap:** A plan that explains steps to reach a goal.

S

- **Scientific research:** Asking a question and using a step by step process to collect information to answer the question.

- **Social determinants of health:** These are things about where a person lives and the resources in their community. These things can have a strong connection to a person's health. For example, if a person lives in a rural community, they might live far away from the nearest hospital.
- **Standards:** A way of doing something so people do things the same way. See also guidelines.
- **Summit:** A meeting where people come together to talk about important issues. People may make a list of activities or things to do that they heard during the meeting.
- **Surveillance:** In IDD health research, surveillance is the regular collection and study of IDD health data.
- **Survey:** A set of questions asked to a group of people to learn about their experiences or opinions.
- **Systems:** In IDD research, systems refers to the big picture of services and supports intended to help people with IDD have good lives. Like how a machine often has lots of gears that work together, a system is the result of how different services work together.

T

- **Transformed Medicaid Statistical Information System (T-MSIS):** A very large national database on Medicaid and CHIP. It includes eligibility, enrollment, and paid claims**.**
- **T-MSIS Analytical Files (TAF)**: T-MSIS data sets designed to help researchers study Medicaid and CHIP.