



Administration for Community Living

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*Advancing independence, integration,  
and inclusion throughout life*

I/DD COUNTS 2023

# **ADVANCING A ROADMAP FOR HEALTH AND EQUITY DATA**

**for Persons with Intellectual and Developmental Disabilities**

**Proceedings of a Summit**

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# INTRODUCTION AND SUMMARY

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## BACKGROUND

The COVID-19 pandemic spotlighted an issue we have known for decades: there are serious data gaps about the health of people with intellectual and developmental disabilities (I/DD).<sup>1</sup>

A first step in addressing these gaps was a U.S. Surgeon General's summit in 2001. It brought national attention to the health disparities of people with I/DD and the need for additional data to inform policymakers and government-funded programs about specific actions that need to be taken. Since 2001, there have been several efforts to address identified gaps and ensure that people with I/DD are recognized and counted in national surveys and in state and federal health and quality monitoring; this work is ongoing.

I/DD Counts was created as a cross-agency initiative to establish and maintain accurate databases on the prevalence and health status of people with I/DD in the United States and its territories. A key goal of this initiative is to improve the collection, analysis, and interpretation of the health-related data of people with I/DD, building on previous work by the Centers for Disease Control and Prevention (CDC).<sup>2,3</sup> In 2019, I/DD Counts began to create the Roadmap for Health Equity Data for Persons with Intellectual and Developmental Disabilities and support action steps to improve data.

Beyond fostering federal collaboration, I/DD Counts has forged partnerships with people with disabilities and families, other community members, researchers, health care entities, and state agencies.

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<sup>1</sup> [Closing the Gap | NICHD - Eunice Kennedy Shriver National Institute of Child Health and Human Development \(nih.gov\)](#)

<sup>2</sup> Krahn, G, Fox, M.H, Campbell, VA, Ramon, I, Jesien, G. (2010). Developing a Health Surveillance System for People with Intellectual Disabilities in the United States. *Journal of Policy and Practice in Intellectual Disabilities*, 7(3); 155-166.

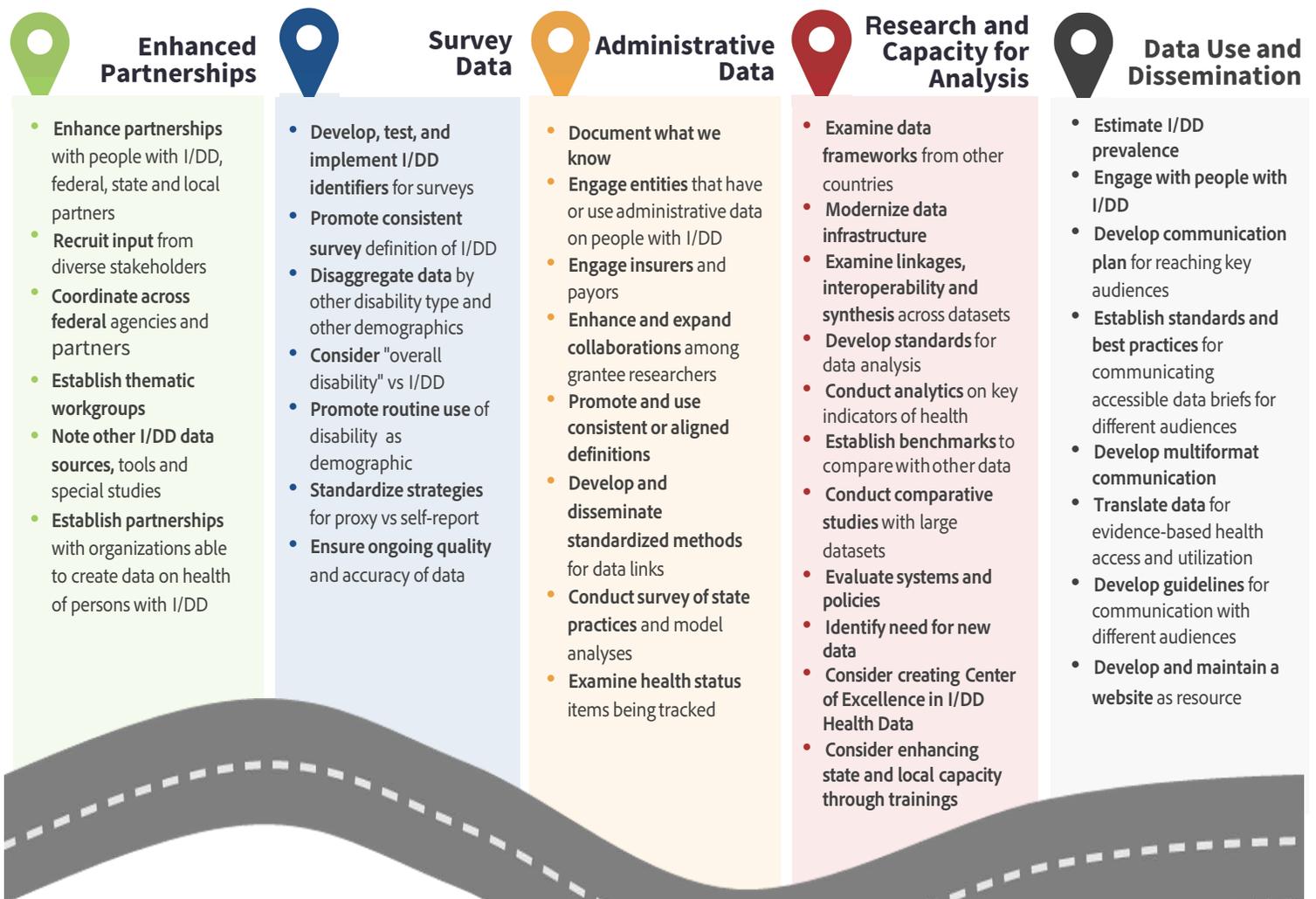
<sup>3</sup> Fox, M.H, Bonardi, A, & Krahn, G.L. (2015). Expanding public health surveillance for people with intellectual developmental disabilities in the U.S. *International Review of Research in Developmental Disabilities*, 48(4), 73-114

# THE ROADMAP

The roadmap lays out a path that will lead to a robust health monitoring system for people with I/DD in the U.S. Once fully established, this monitoring system will be used to inform policies, programs, and projections. The roadmap incorporates what we have learned from efforts in recent years. These include:

- I/DD Data Summits in 2017, 2019 (see summaries at <https://acl.gov/iddcounts>) and 2022
- Collaborations to develop and test questions for national health surveys to better identify the population with I/DD
- Enhanced cross-agency discussions through the establishment of a federal Interagency workgroup on I/DD administrative data
- Focus groups with groups of persons with I/DD, family members, researchers and health care providers, and direct service professionals
- A special issue of *Intellectual and Developmental Disabilities*, 2019, (issue 5) that summarized information to date

Once fully implemented, the roadmap will generate data needed to determine how many people experience I/DD in the US, what their health is like, and what can be done to improve their health. Regular updates throughout this decade will ensure accountability for implementing the Roadmap by 2030.



## ROADMAP UPDATES BASED ON THE SUMMIT 2022

The roadmap was updated following the November 2022 summit organized by the U.S. Department of Health and Human Services agencies. The summit included people from federal, state, advocacy, academic, and clinical organizations, as well as people with I/DD.

The summit organizers noted the progress since the 2019 summit. In particular, the 2022 summit included the following:

- Greater representation of people with disabilities among the panelists and participants
- Broader range of federal agencies represented, with initiatives specific to I/DD reported by more agencies
- A changed policy context, with support for this work in the *President's Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government* <sup>4</sup> which highlights the need for the ability to disaggregate data by populations, such as I/DD, to promote equity. Further, in 2019 the population with I/DD was included as a priority population through the Patient Centered Outcomes Research Initiative (PCORI).<sup>5</sup>
- Expanded awareness of the need for alignment of the definition of I/DD in data that are collected and used by agencies
- Significant interest in cross-agency learning and connections to align efforts.

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<sup>4</sup> [Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government | The White House](#)

<sup>5</sup> [Intellectual and/or Developmental Disabilities | PCORI](#)



# SUMMIT OVERVIEW

This summit is...an opportunity to connect with each other and re-commit to our shared goal: that people with I/DD will have data they need to tell their health story, to advocate for needed health services and ultimately have better health outcomes.

Alison Barkoff,

Acting Administrator and Assistant Secretary for Aging, Principal Deputy Administrator, ACL

## Where and when was the I/DD Counts Summit?

- The summit was organized by I/DD Counts, a cross-agency initiative led by the Administration for Community Living in partnership with advocacy organizations, researchers, and fellow U.S. Department of Health and Human Services partner agencies, including the Assistant Secretary for Planning and Evaluation (ASPE), Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), National Center for Health Statistics, and National Institutes of Health (NIH).
- On November 17th and 18th, 2022, the I/DD Counts Summit engaged an audience of over 70 participants that included individuals with lived experience of I/DD, family members, government officials, health professionals, researchers, and advocacy organizations.
- They participated in-person at the Administration for Community Living as well as virtually through Zoom.

## Why is the I/DD Counts Summit important?

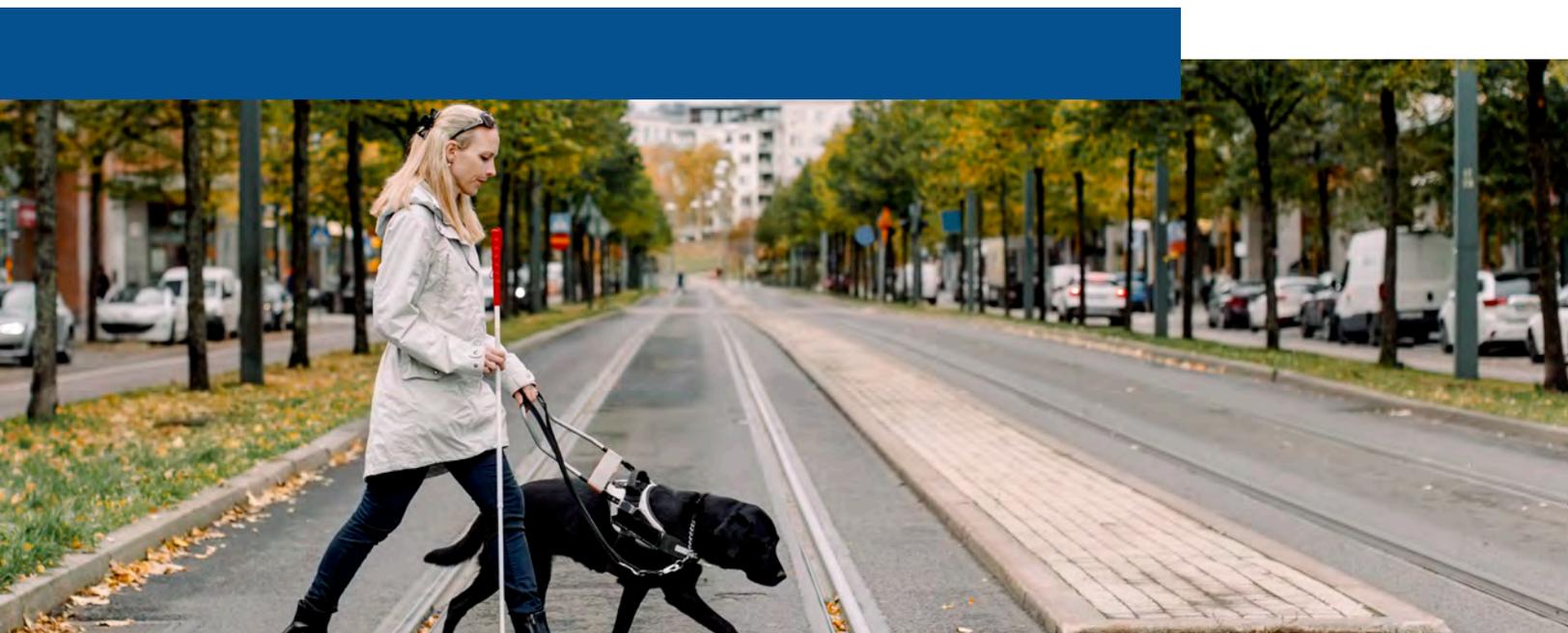
- The goal of the I/DD Counts Summit was to bring together people with disabilities, government leaders, family members, advocates, researchers, and health practitioners.
- Its purpose was to promote dialogue and collaboration on data needed to inform effective policies, collaborations, and programs that will improve health outcomes for people with I/DD.
- The Summit advanced a shared vision and mission for this goal. It identified present and future initiatives for data collection, linkage, and analyses. These actions are reflected in a revised Roadmap for Health Data Equity for Persons with I/DD. These findings are intended to inform efforts to improve data on the health of people with I/DD and provide direction for other work and projects related to improved health data for persons with I/DD.

## How was the I/DD Counts Summit structured?

The 2022 Summit included six panel discussions. Each panel was asked to respond to several key questions. The panels were:

- **Panel I:** Federal government agencies spoke to the “big picture” of why federal agencies need better health data to inform programs and policies.
- **Panel II:** Nongovernmental organizations and advocates described their need for better health data for people with I/DD.
- **Panel III:** Federal agencies provided a more detailed view of current activities for improved data.
- **Panel IV:** Nongovernmental organizations described their current actions to collect better health data on large groups of people with I/DD.
- **Panel V:** Advocacy organizations discussed future needs for communication and knowledge translation to multiple audiences.
- **Panel VI:** Federal agencies, researchers and nongovernmental organizations anticipated future strategies and capacity needs for data management and analysis.

The key themes from these discussions were summarized, and recommendations were included in revisions to the Roadmap for Health Data Equity for Persons with I/DD.



# KEY THEMES

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Key themes from the 2022 I/DD Counts Summit are:

- **Count everyone and make everyone count.** It's a civil right to be counted and included.
- **People with I/DD experience health disparities and inequities.** Efforts to address these inequalities require quality data to be collected and used. There are still gaps in quality data.
- **Communication needs to be improved,** and communication specialists can help. Information and data communicated in writing and verbally need to be accessible to people with I/DD. Ways to do that include using plain language, different communication for different audiences, multiple formats, visual supports, and providing information in different languages, including American Sign Language.
- **People with I/DD need to be involved in all projects about them from the beginning.** Some examples of this are directly asking people about their priorities, expanding the opportunities and the frequency by which people with I/DD can self-report, and learning how people with I/DD understand the standard disability identifier questions.
- **Definitions of I/DD are not consistent** across surveys or administrative datasets. There need to be ways to coordinate data across definitions. One strategy is considering the purposes of the definition – “for what?” –and working to standardize or align definitions. The reasons for the consistency of definition may need to be explained.
- **There have been many new initiatives regarding I/DD health data, but there are still big gaps.** These include being able to disaggregate or separate out by type of disability and other identities (e.g, race, gender) in determining how a disability and its effects change over a person's life.
- **Disability and I/DD should be considered demographic variables.** This would allow analysts to use datasets to understand and report much more about people with disabilities and I/DD. Disability and I/DD identifiers should be included in more datasets beyond health.
- **COVID-19 was a catalyst for improved data.** There were some advances in collecting health data that identified the population with disabilities overall – and I/DD specifically – to understand the health and health risks of people with I/DD. We should maintain the positive changes that were made.

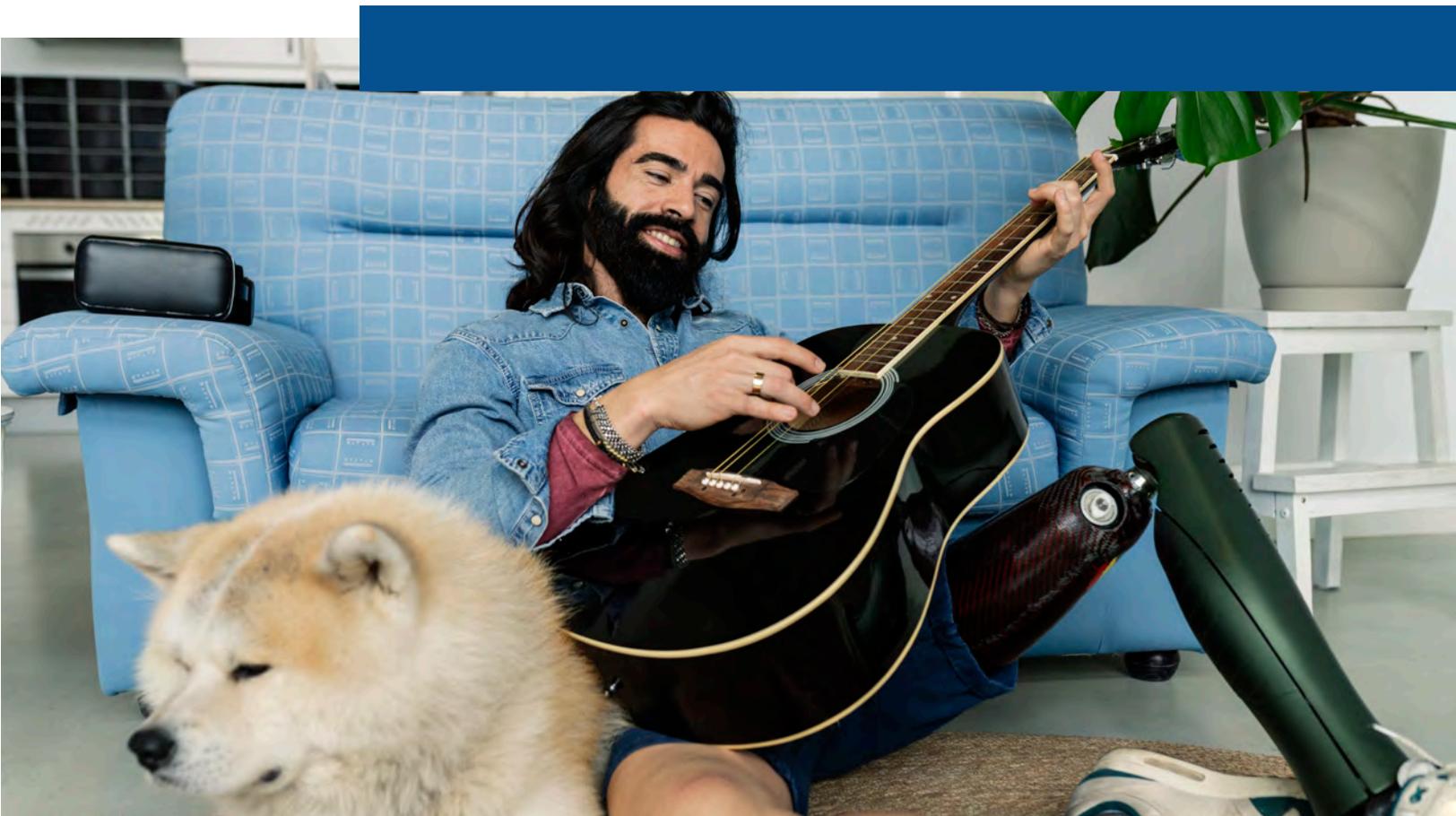
- **Knowing a person has I/DD is important in clinical and support settings.** Health care providers need to know about and understand a person's disability when they are developing care plans. Data should be used to advocate for ongoing training for clinicians and other care providers.
- **Contexts in which people with I/DD live their lives need to be included.** Data are needed to understand and address the social and political determinants of the health of people with I/DD.
- **Quality of life and well-being need to be measured** to have an accurate picture of someone's life. This information should be collected so that it can inform policymakers and program managers.
- **Many people with I/DD are not counted**, especially those not receiving developmental disabilities services. This includes people living with families, employed, and not receiving services, and people who are homeless or people who are in the criminal justice system.
- **There are many promising health data developments**
  - Transformed Medicaid Statistical Information System (T-MSIS) is becoming a way of accessing state-level Medicaid data, but it needs to flag I/DD. Medicare and Medicaid data must be linked to provide a lifespan picture of health care access by persons with I/DD.
  - Increased use of Electronic Health Records.
  - Increased use of data linking, including linking large datasets with national health surveys. (<https://www.cdc.gov/nchs/data-linkage/index.htm>)
  - Increased use of private provider and insurance datasets (e.g., All Payer Claims Databases).
  - New suggestions include connecting with the National Association of Health Data Organizations (NAHDO) and improving access to data from Managed Care organizations.

# SUMMIT PANEL DISCUSSIONS

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The I/DD Counts summit included six panel discussions as detailed in the table below. Each panel was asked to reflect on a topic and respond to several key questions in the facilitated discussion. Panels I and II provided the “big picture” overview of why better health data are needed. Panels III and IV provided a more detailed view of current activities for improved data. Panels V and VI discussed future needs for communication, knowledge translation, and data management and analyses (federal agency, research, and nongovernmental organizations).

Breakout sessions were organized at two points in the summit to facilitate small group dialogue and encourage participants to share their perspectives on key issues and gaps, as well as promising strategies to improve collaboration. Final sessions were devoted to identifying key themes, next steps, and needed revisions to the Roadmap.



# PANEL I

## *What do government leaders need from the data for policy and systems change?*

### MODERATOR

- Jennifer Johnson - *Administration on Disabilities, ACL*

### PANELISTS

- Alison Cernich - *National Institute of Child Health and Human Development, National Institutes of Health*
- LaShawn McIver - *Office of Minority Health, Centers for Medicare & Medicaid Services*
- Tisamarie Sherry - *Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health & Human Services*
- Lisa Wiggins - *National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention*

### PANEL I OVERVIEW

#### **I. Why does your agency need to define I/DD (e.g., eligibility for services, monitor population health, conduct research)?**

Panelists provided reflection and key reasons each agency needs to have a definition including:

- In public health, it is essential to have effective research to drive the core health equity strategy. The COVID-19 Public Health Emergency had a great impact on this population both in terms of access to care and outcomes. It revealed that we did not have adequate data to include specific recommendations in public health guidance, such as vaccination recommendations.
- As system change is underway, panelists discussed efforts to include people with I/DD as a demographic variable in all public health data collection as well as to better understand the health and wellness of people with I/DD.
- All panelists agreed that population definitions are essential for research, which is part of the mission of several agencies represented. Population research requires a definition to describe the sample frame (who is included and who is not included in the research study). Currently, there is no uniform definition of I/DD; research uses different population definitions based on available data and decisions made by researchers. There is a need for guidance and a formal definition to enable research to identify the outcomes of policies, programs, and how they support the population with I/DD.

## **II. *What information does your agency need regarding the health of people with I/DD?***

- To be able to identify health disparities, agencies need information about the intersecting identities of a person with I/DD, such as race/ethnicity, sexual orientation and gender identity. They also need sociodemographic information, wellness indicators, reproductive health data, and information about support needs and outcomes across the lifespan.
- Point-of-care information, or data collected right when someone is receiving care, such as hospital intake or data collected during community-based service delivery, is important to understand the experience of care and the opportunities for linkages of data that is associated with health care encounters.
- The National Institutes of Health (NIH) launched an effort in 2018 to understand what is needed to include people with Down syndrome in research. It includes funding specifically for research focused on this population.
- Panelists discussed concerns about multiple definitions for “health equity.” Different agencies may use different definitions, while researchers use a range of definitions, as well. Foundational work is needed to align these definitions.
- Panelists noted the problem of multiple definitions of I/DD that exist in statutes across the government.

## **III. *What can your agency do, or what are you doing to contribute to better data?***

- The National Institutes of Health (NIH) is evaluating the use of a toolkit and other strategies to assist researchers to better include populations that have been historically marginalized or excluded from research including clinical trials. NIH is funding 13 clinical trials including people with Down syndrome.
- The Assistant Secretary for Planning and Evaluation (ASPE) is launching a \$1.6M project to develop a linked dataset specific to the population with I/DD.
- ASPE has received initial funds to develop a survey on working-age adults with disability.
- Agencies participate in interagency I/DD coordination efforts through the Federal Interagency Workgroup on I/DD Administrative Data.
- CMS's Office of Minority Health is focused on health equity considerations. It recognizes the need to understand population status and has created intentional workgroups across offices to focus efforts.
- CDC has ongoing surveillance efforts to identify the prevalence of autism and other developmental disabilities. Disability status has been added to data collection for COVID-19 monitoring and other health surveillance systems.

# PANEL II

## *What do people with disabilities and advocates need from the data?*

### MODERATOR

- Katherine Cargill-Willis - *Administration on Disabilities, ACL*

### PANELISTS

- Bernard Baker - *Self Advocates Becoming Empowered*
- Tawara Goode - *Georgetown University National Center for Cultural Competence*
- Greg Robinson - *Autistic Self Advocacy Network*
- Marlene Sallo - *National Disability Rights Network*
- Robin Troutman - *National Association of Councils on Developmental Disabilities*
- John Tschida - *Association of University Centers on Disabilities*

### PANEL II OVERVIEW

#### **I. *What information or data do you need as a person with I/DD or a family member?***

- Panelists commented that for people with disabilities to trust the data, data collection and data use, organizers need to include people with disabilities in the design, collection, and reporting of the data.
- Datasets should allow for breaking down the data to understand different experiences by groups within people with disabilities, such as by race and ethnicity.
- Importantly, reports should be clear and easy to understand, presented in plain language and with visuals in inclusive formats. For example, social media posts should include pictures of people and explanations of the data.

#### **II. *Where are the data gaps?***

- The voices and experiences directly reported by individuals with I/DD are not always included in reports and data collection. They should be. For some people who communicate in non-English language or in non-verbal ways (such as using a device or gestures), it is critical to build trust and to keep the process of data collection as simple as possible.
- Specific types of information such as geography, race, ethnicity, and primary language are not easily available in many data reports.
- The data on the prevalence of I/DD are used to fund states, and the data are old. The government should increase funding to get accurate data.
- Since many data analyses include only people who are receiving long-term disability supports, the experiences of people who do not receive supports is not included. This includes many autistic people and other individuals with disabilities who are living in their communities with support from family, friends, or other unpaid supports.

- Measures of environmental well-being should be included, such as housing status, employment status, access to reliable transportation, and social participation.
- The data should examine the inaccessibility/accessibility of health care, the workforce, and the aging I/DD population.
- Updated prevalence data is needed to appropriately fund programs through the DD Act. In some cases, there is not enough funding to support people with I/DD. Lack of funding results in waitlists or gaps in available services.
- We need the ability to identify people with I/DD in other data systems such as those used in the administration of services to refugees, criminal justice, and tribal nations. Panelists raised the need to better understand and identify people with I/DD within the homeless population.
- Organizations and agencies gather data inconsistently on race, ethnicity, and geographical location. Often, they fail to identify multiple cultural identities, which limits the capacity to better serve individuals with I/DD.
- There are gaps in the quality of available data, and the method of gathering data does not consistently consider cultural and language components.

### **III. *What needs does your organization have for data?***

- Advocates stated that individuals with I/DD need to be included in data collection from the beginning in order to have data that can be trusted. When data are released, they should be reviewed and vetted by people with I/DD.
- Available data sets should be as up to date as possible.
- Research and data collection are essential to implement and evaluate policy to understand the intersection of the person in their community and the effect of policy and supports on quality of life.
- Organizations should consider the political determinants of health. They should collect data that links policy to the health outcomes that are important to people with I/DD. Organizations and agencies cannot promote health equity without fully understanding the social and political determinants of the inequities and disparities.
- For understanding the experience of people with I/DD, organizations should consider adopting a framework that examines *availability, accessibility, and acceptability* of supports in order to address cultural and community preferences and norms.

### **IV. *Considering ways in which people with I/DD should be meaningfully included in efforts to improve data equity for people with I/DD, panelists commented that:***

- It is essential to broaden outreach to groups that are not the usual groups, including youth with I/DD who are active on social media and can advocate by showing their daily lives and what is important to them.
- Building and retaining trust is essential.
- Supporting the infrastructure for employment and working to hire and retain people with disabilities is an important step to ensure people are meaningfully included in data discussions. ACL is a good example.

# PANEL III

## **What are government agencies doing to get data on prevalence and health of people with I/DD?**

### **MODERATOR**

- *Alixé Bonardi - Human Services Research Institute, Contractor to Administration on Disabilities, ACL*

### **PANELISTS**

- *Jennifer Bowdoin - Disability and Elderly Health Program Group, Centers for Medicare and Medicaid Services*
- *Tracy King - Eunice Kennedy Shriver National Institute of Child Health and Human Development, National Institutes of Health*
- *Emma Plourde - Office of Behavioral Health, Disability and Aging Policy, HHS Office of the Assistant Secretary for Planning and Evaluation*
- *Cathy Rice - National Center for Birth Defects and Developmental Disability, Centers for Disease Control and Prevention*
- *Julie Weeks - National Center for Health Statistics, Centers for Disease Control and Prevention*

### **PANEL III OVERVIEW**

Further details provided in the accompanying summary document from the Federal Interagency Workgroup.

#### ***I. What are you doing now to improve health data for people with I/DD?***

- The CDC National Center for Health Statistics (NCHS) highlighted two efforts that are underway. The first is work on the development and testing of questions aimed at identifying the population with I/DD in the National Health Interview Survey. The second is the release in October 2022 of a linked federal dataset which covers 10 years of data from national data collection efforts including housing, veterans, and other data files, which create opportunities to explore population identification. See: [NCHS Data Linkage-Activities](#) (cdc.gov).
- The National Institute of Child Health and Human Development at NIH funds many large survey efforts. While these are not designed specifically for population prevalence research, these studies provide important information about sub-groups, including those who have particular I/DD diagnoses.
- The Office of the Assistant Secretary for Planning and Evaluation is engaged in a diverse set of activities around the I/DD population and data including (1) a linked dataset to support the I/DD population identification and research, (2) a public health research project to catalog the various definitions of I/DD used in public research, (3) recent funding to design a survey to identify the I/DD population and priorities for the data structure for the population.

- The National Center for Birth Defects and Developmental Disabilities at CDC is engaged in several coordination efforts and has a number of projects underway, including:
  1. Examining the prevalence of developmental disabilities through the National Survey of Children's Health and, in national adult surveys, using the six standardized questions from the American Community Survey Disability Questions. (They note that these questions do not adequately identify the population with I/DD.)
  2. CDC has a searchable dashboard, "Disability and Health Data System | CDC," which likely includes some people with I/DD. They acknowledge that people with I/DD are not readily identified in the data and are likely underrepresented in the dataset. NCBDD/CDC is currently working to address identifiers of I/DD that could be used.
  3. CDC is working on a project to ensure people with I/DD are identified in records of emergency department visits.
  4. A new project is under consideration that would engage people with I/DD as informants across a range of support needs. The intent is to learn if they feel that they are represented or not represented within the standard disability questions and to elicit descriptions of how to better see themselves as included in those question sets.
  5. A project is funding several state-level sites to utilize state Medicaid data for specific research questions pertaining to disability research.
  
- The CMS Disabled and Elderly Health Program Group described several efforts underway including:
  1. Revising the dataset used for a regularly produced report on long-term supports and services utilization and expenditures to transition to using Medicaid claims and encounter data. This work will serve as a foundation for other work that is underway to use Medicaid claims and encounter data.
  2. Working to identify subpopulations within administrative data, such as those with I/DD.

## ***II. What are the priority issues that need to be addressed?***

- The priority issues have been collected and compiled in recent reports. Key themes that were identified by panelists included:
  - The ability to accurately identify subgroups, including those with I/DD and those with other particular conditions, and geographic distinctions.
  - Data quality, consistency, and usability.
  - Standardized collection of I/DD demographic at the point of care.
  - Best practices for self-identification and self-report (including questions being tested for NHIS) and considering priorities of people with I/DD.
  - Robust data linkages.
  - Across all efforts, clearly document the I/DD definition that is used and encourage movement towards a standardized I/DD definition. Build from recent efforts to use consistent definitions across state-databases and in survey design.

- Consider the experiences of people with I/DD across their lifespan.
- Consider use of health services information from public institutions such as schools to understand the health experiences of youth with I/DD.
- Further development of quality and outcome measures that are meaningful to people who are using services.
- Engage with and build trust with people with I/DD to support participation in studies.

### ***III. What are your directions in the next 5-10 years? What do you want from other agencies?***

- Priority directions included:
  - Using data and resources, we must fill in the current gaps and build a robust body of knowledge.
  - Effective messaging and mainstreaming of the topic to get resources in timely and effective ways.
  - Categorizing opportunities between short-term and long-term goals.
  - Engaging with individuals with I/DD.
  - Continuing to build towards enhanced use of existing (administrative) data.
  - Developing quality measures, working off the current foundation, and maintaining the infrastructure.
  - Better public reporting and availability for use.
  - Including people with I/DD in research and engagement – promote that the research be more relevant to persons with I/DD.
  - Helping researchers understand how to overcome the current barriers and preconceived conceptions that limit the inclusion of people with I/DD in research.
  - Advocating that other agencies collect high-quality data and merge data to work together better – collective data needs a common definition, better data linkages, and better construct perspectives.
  - Organizations need to look at their previous work to identify if the opportunity is in addition to existing work, completed previously, or is new and leads to an opportunity to collaborate.

# PANEL IV

## *What are nongovernment agencies doing to get data on prevalence and health of people with I/DD?*

### MODERATOR

- Andrew Morris - *Contractor to Administration on Disabilities, ACL*

### PANELISTS

- Sheri Larson - *Institute for Community Integration, University of Minnesota*
- Andy Lincoln - *Special Olympics International*
- Mai Pham - *Institute for Exceptional Care*
- Laura Vegas - *National Association of State Directors of Developmental Disabilities Services (NASDDDS)*

### PANEL IV OVERVIEW

#### ***I. What are your organizations currently doing to get data on prevalence and or the health of people with I/DD?***

- Special Olympics maintains the Healthy Athletes System (HAS) database on health screenings of Special Olympics athletes. HAS is considered one of the largest databases on the health of persons with I/DD globally. The HAS system is currently in redesign to include more information on health needs. One challenge is to determine how representative the HAS data system is of the entire population of people with I/DD. Special Olympics is also working with local states and territories to collect data through the Inclusive Health Needs Assessment. Results show that 88% of state staff do not know how many individuals with I/DD are in their service area.
- The Institute for Exceptional Care is working to transform health care for people with I/DD by looking at financing, care coordination, supporting scaled culture change, and preparing clinicians. They host research collaborations to leverage existing data. Health care financing data only identifies 10-25% of people with I/DD based on estimates from NHIS or CDC --the majority of this population is invisible. IEC proposes addressing this through machine-learning algorithms for identification from clinical and social data, focusing on improving care and trust, and multi-stakeholder consensus on health priorities.
- NASDDDS is engaged with HSRI on the National Core Indicators that use quality monitoring systems based on state data and interviews with people with I/DD and their families. They collect health and other data from most states on the populations that are served by state Developmental Disabilities Services. Their work includes self-reported health surveys, survey tools, creating linkages between states, and improving the quality of data.

- The Residential Information Systems Project (RISP) surveys and compiles information from the state I/DD agencies. Further, they use reports published by the CDC in conjunction with census data to estimate the prevalence of I/DD. They estimate that only about 46% of persons with I/DD are served by or are known to the states' DD systems. Their analyses of data from the 2017-2018 National Health Interview Survey suggest that the questions to identify persons with I/DD in the survey are not sensitive or specific enough to adequately capture this population. RISP recommends the inclusion of a question on decision-making. They are currently working with CDC to estimate the prevalence of spina bifida and muscular dystrophy by combining private insurance data with T-MSIS (Medicaid).

## ***II. What are the priority issues that need to be addressed now and in the next 10 years?***

- We need updated prevalence estimates for persons with I/DD; previous estimates are from 1994-95.
- We need greater consistency across states in how data are collected, and improved capacity to stratify data on demographic variables.
- Greater inclusion of people with disabilities who are not served by the DD service systems.
- To understand overall health status, we need revised data structures that better capture demographics (race, ethnicity, poverty, and other social determinants of health), medical diagnoses, and functional limitations.
- We need to adopt a life course approach to data on the health of persons with I/DD to understand health at different ages and understand the health trajectory across the life course.
- Better budget information is needed on costs and needs—we need a compelling business case that communicates to general health care providers and systems that people with I/DD are already in their care every day.

## ***III. What do you need from federal/state agencies and elsewhere to achieve the vision?***

- Collaborate more between government agencies for more standardized approaches and collaborate with nongovernment organizations to maximize data availability and utilization.
- Include people with I/DD in leadership roles in policymaking, research, and training for more useful information.
- Use technology to connect with people and provide faster results.
- Use data to evaluate the impact of policies on experiences and outcomes for persons with I/DD.
- Improve access to managed care organization data. Managed care organizations have a lot of valuable data. Without access to those data, analyses will again be incomplete and biased.
- Include information on and evaluation of setting characteristics.
- We need to drive culture change for health equity to go beyond general health care. The health of people with I/DD needs to be understood in their life contexts.
- Recognize that persons with I/DD are not always part of Medicaid or Medicare but are covered through private insurance as well.
- Understand the implicit biases that prevent better data and better health care.

# PANEL V

## *What is needed for communication/knowledge translation for different audiences?*

### MODERATOR

- Meredith Raymond - *Center for Policy and Evaluation, Administration for Community Living*

### PANELISTS

- Max Barrows - *Green Mountain Self-Advocates of Vermont*
- Dan Berland - *National Association of State DD Directors*
- Zoe Gross - *Autistic Self-Advocacy Network*
- Joe MacBeth - *National Alliance for Direct Service Professionals*
- Maggie Nygren - *American Association on Intellectual and Developmental Disabilities*
- Jason Resendez - *National Alliance for Caregiving*
- Sheryl White-Scott - *Health Practitioner*

### PANEL V OVERVIEW

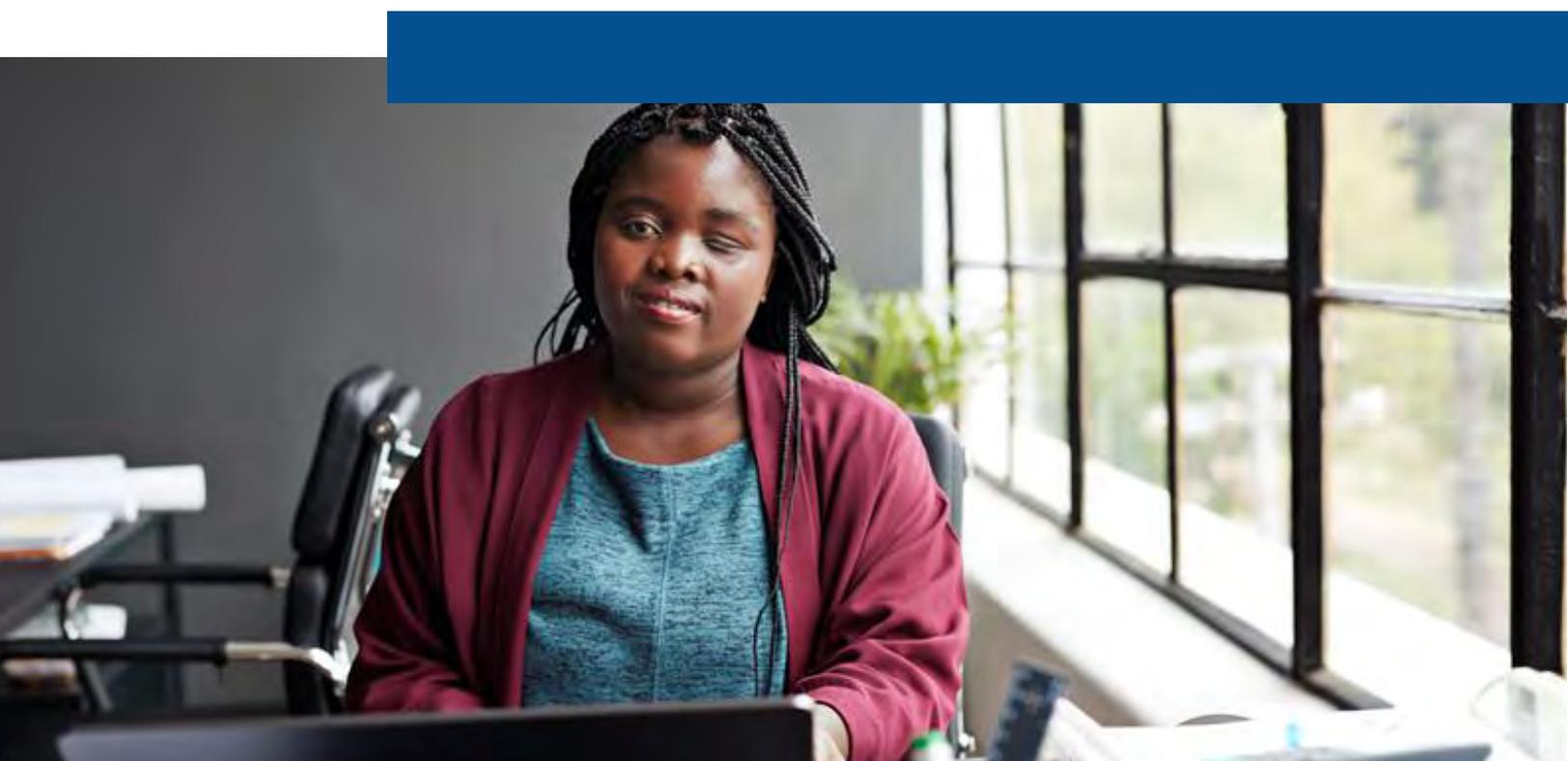
#### **I. What information or data do you need as a person with I/DD or a family member, or as an organization?**

- We need different data for different purposes?
  - Audiences need information at three levels: individual, organization, and systems.
  - Go beyond data on the problems. We need information on solutions.
- Only through data can we expose disability-related inequities.
  - Policy makers need:
    - Actionable data on emergent findings.
    - Cost-prediction data; we need to talk to downstream effects.
    - Geographic breakdown of data so that legislators understand the impacts on their constituents.
    - Real-life stories that best represent the data—use data plus stories.
  - Advocates and families need:
    - Information in ways and on topics they can understand and use:
      - More use of data visualization—graphics is a powerful way of communicating.
      - Materials in plain language and in multiple formats.
    - To know what researchers are saying to see if it reflects people's experiences and if people with I/DD understand the information as intended.
  - Health care providers need:
    - To directly assess and address negative biases of providers that offer quality care to persons with I/DD.
    - Information that is practice-focused and actionable.

- Organizations need:
  - Information that can be distributed to their audiences—organizations can serve as valuable conduits to get information out.
- Direct service professionals need:
  - An understanding of how long-term support services are funded and the necessary data to advocate for their resources.
  - More engagement with researchers and data analysts—Note a Canadian model of monthly dialogue of people with I/DD with researchers.

## ***II. How would you use data information, and in what form is it most useful?***

- Use a multi-pronged approach—e.g., white paper, fact sheets, video blogs, newsletters, journals, different formats for different cultures and audiences.
- Provide information in interesting ways.
- For people with I/DD—
  - Distinguish “need to know” from “nice to know.”
  - Advocacy organizations can present information orally (e.g., via Zoom) and through social media platforms.
  - Provide a way for people with I/DD to report back to researchers.
- Note that most research is incremental; communicators and researchers need to bundle studies to increase their understandability, relevance, and impact.
- Provide enduring ways of information to be shared. This could be to the next group of direct service professionals or self-advocates. Examples are archiving presentations, creating or expanding resource portals, and other training formats so that new direct service professionals and self-advocates can become informed in reliable and consistent ways.



# PANEL VI

## *What are the needed capacities for data management and analyses?*

### MODERATOR

- Gloria Krahn - *Oregon State University, Contractor to Administration on Disabilities, ACL*

### PANELISTS

- Anjali Forber-Pratt - *National Institute on Disability, Independent Living and Rehabilitation Research, ACL*
- Susan Havercamp - *Rehabilitation Research and Training Center on Intellectual Disabilities and Mental Health, The Ohio State University*
- Karly Jerman - *Special Olympics International*
- Henan Li - *Human Services Research Institute, National Core Indicators*
- Suzanne McDermott - *City University of New York, Offices of Disability and Health consortium on Medicaid ID Data*
- Mai Pham - *Institute for Exceptional Care*

### PANEL VI OVERVIEW

#### ***I. What have you learned so far about data and analysis of the health of people with I/DD that others might not know?***

- It is important to work with people with I/DD as research partners.
- We must attend to the state-to-state variability in data — it is important to examine and understand those differences.
- Use the data we currently have but also name the critical inequities and systemic disparities revealed by the data, and in the inequities in data availability.
- Medicaid data shows a big drop-off in people with I/DD around age 45. This is about the age when their parents pass away and survivor benefits for Medicare kick in. This drop-off highlights the importance of linking or combining Medicaid and Medicare data. Otherwise, we will have data that are incomplete in unknown ways.
- Be critical consumers of the data—look deeper to understand what may not be obvious. Ask questions to avoid perpetuating misinterpretations. For example, ask “who is missing?” and “what’s missing?” in the data.
- Attend to how the data are collected, including self-report or proxy-report, and survey or interview methods. The way data is collected and from whom matters.

#### ***II. How do we build or strengthen data management and analytic capacities for state and federal-level data?***

- Hire more data scientists, people skilled at working with the data and systems.
- Build a stronger and more modern data infrastructure. This includes developing a data culture that values and uses the data.

- Teach specifically about health data equity. Understand what the different sources of data are telling you (e.g., teach quartile regression to understand the high user/mid-range/low users of health care).
- Invest in data that allows longitudinal analyses (e.g., through registries).
- Partner with community members from the beginning and throughout the data analysis process. In doing so:
  - Presume competence of persons with I/DD.
  - Invest in empowering the community to be included in the process.
  - Train investigators and institutional review boards (IRBs) on how to include people with I/DD.
  - Create products that allow persons with I/DD to access their data; allow feedback from them.
- Understand and be prepared with stratification and risk-adjustment strategies for conversations with insurers and providers.
- Connect health data with data on other services, such as social services. There are valuable examples of linking different data sets and the new information that can be learned.

### ***III. How do we link data or crosswalk data across differing definitions of I/DD?***

- Try to connect information over time so that you are referring to the same time period.
- Find the amount of data needed to connect the sets (e.g., the number of variables for probability matching).
- When definitions do not align, consider how to include parts of the dataset where the definitions are better aligned. Take steps to better align the data from the beginning.
- Go beyond binary dichotomies (I/DD vs non-I/DD) and work in the “gray zones.”
  - Estimate the likelihood of I/DD based on algorithms.
  - There may be differences in I/DD identification across time—it may be present at the point of care but not always present. The data may not always record I/DD, or the disability may not be consistently present over time.

### ***IV. Do we need a Center of Excellence for I/DD Health Data?***

- We really need a shared conceptual framework to address issues.
- There are advantages to having a single Center of Excellence for leadership and organization. There is also a need for decentralized capacity at state and local levels so that every state has the capacity to analyze data on persons with I/DD.
- University Centers for Excellence in Developmental Disabilities (UCEDDs) were cited as a valuable resource network.
- There is a need for a more constant source of funding to develop and maintain connections with and linkages between groups and individuals with key interest in health equity data for people with I/DD. When funding depends on grant cycles, it can be inefficient and result in lost resources.
- There were different opinions about the agency best positioned to support a Center of Excellence or a network of analysts. Considerations included ACL, CDC, and CMS.
- Consider building a cadre of trained analysts by training through fellowships at different federal agencies.

**We need to keep working on more ways for us to be actively involved in research conducted on us - on all levels. We look forward to a time when more researchers embrace “Nothing About Us Without Us.”**

Max Barrows,  
Outreach Director, Green Mountain Self-Advocates



# NEXT STEPS

Summit participants identified a list of agencies and other groups that are important to include but were not represented at this summit. In the spirit of building coalitions and forming a broader network of groups working to enhance I/DD data, I/DD Counts will explore opportunities to engage and promote I/DD data efforts with other groups. These include health data organizations such as the National Association of Health Data Organizations (NAHDO) and improving access to data from managed care organizations.

Numerous suggestions were made for actions needed in the future. Next Steps are summarized below in the categories of Enhance Partnerships, Survey Data, Administrative Data, Research and Capacity for Analysis, and Data Use and Dissemination

## Enhanced Partnerships

- Enhance partnerships with people with I/DD; federal, state, and local partners; advocacy and self-advocacy groups. Annually determine “Who is Missing?” in our partnerships.
- Ask a broad range of stakeholders to make sure that the communications can be understood and are useful.
- Commit to deep partnerships with people with I/DD and other historically marginalized communities.
  - Pay particular attention to intersectional identities.
  - Take time to build relationships and trust.
- Coordinate across federal agencies and partners on I/DD data.
- Establish greater connection with federal workers with I/DD.
- Note other I/DD data sources, tools, and special studies.
- Establish thematic workgroups to determine best practices.
- Establish partnerships with organizations able to create data on the health of persons with I/DD (e.g., private payers).

## Survey Data

- Develop, test, and implement I/DD identifier questions for national surveys.
  - Pay particular attention to survey trends to move to virtual surveys and how this works (or does not work) for people with I/DD, and the impact of the digital divide.
  - Consider other ways of accessible data collection with technology.
- Promote a consistent survey definition of I/DD.
- Look at ways to disaggregate the data by geographic region, age, race, disability type, sexual orientation/ gender identity, and other demographic variables.
- Promote routine use of disability as a demographic variable.
- Determine where “overall disability” as a demographic is necessary and where more granular analyses by I/DD are possible.
- Standardize strategies for how to support self-reporting by people with I/DD and develop guidelines for how and when to use proxy vs. self-report.
- Ensure ongoing quality and accuracy of surveillance data.

## Administrative Data

- Document what we know now, demonstrate the need to continue current efforts, and identify data gaps.
- Engage entities that have or use administrative data about people with I/DD more broadly.
- Engage insurers and payors.
- Enhance and expand collaborations among grantee researchers.
- Promote use of consistent or aligned definitions of I/DD.
  - Collect and disseminate data definitions for collaborative research.
- Promote routine use of disability variables in administrative data, including the type of disability and age at onset, and identification at different points in time.
- Develop and disseminate standardized methods for data linkages and interpretation.
- Conduct a survey of state practices and model analyses.
- Examine health status items being tracked, including quality of life.

## Research and Capacity for Analysis

- Examine data frameworks from other countries and organizations.
- Modernize the data infrastructure with a conceptual framework and a “culture of data.”
- Examine linkages, interoperability, and synthesis across datasets.
  - Establish specific I/DD flags in linked files such as T-MSIS.
  - Promote linkage of Medicaid and Medicare data.
- Develop standards for data analyses.
- Conduct analytics on key indicators of health and well-being
  - Model and advocate for disaggregation along important variables.
- Establish benchmarks to compare with other data.
  - Identify primary factors (e.g., state) that are important to look at in comparisons.
- Conduct comparative studies with large administrative datasets.
- Evaluate systems and policies for their effects in promoting or hindering health equity.
- Identify the need for new data and long-term studies.
  - Determine the nature of needed longitudinal, lifespan studies.
  - Identify attitudinal and ableist barriers to health equity (such as lack of reasonable accommodations by providers).
- Consider creating a Center of Excellence in I/DD Health Data.
- Consider enhancing state/local capacity through training of researchers conducting analyses and training for researchers to be more inclusive of people with I/DD.

## Data Use and Dissemination

- Estimate prevalence of I/DD through one or more means.
- Engage people with I/DD to ensure the information is relevant, accurate and reaches its intended audiences.
- Develop a communication plan for tailoring information and reaching key audiences.
- Establish standards and best practices for sharing data.
  - Partner with experts in knowledge translation and plain language.
  - Tailor messages for different audiences.
  - Ensure accessibility.
  - Develop multiformat communication.
  - Make messaging actionable, compelling, and interesting.
  - Develop guidelines for communication with different audiences in culturally and linguistically competent ways.
- Translate data for evidence-based health access and utilization.
- Develop and maintain a website that is easy to find and is a resource on health data for people with I/DD.



# LOOKING FORWARD

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The Next Steps provide general directions for what needs to be done and indicate specific actions to take that will result in much needed data. Implementing the steps of the roadmap will require working together across government agencies, advocates, policymakers, health care professionals and researchers. Further it will require commitment, perseverance and resources from agencies and other groups. Once fully implemented, the data resulting from this roadmap will help show how many people experience I/DD in the U.S., what their health is like, and what can be done to improve their health. Regular updates throughout this decade will ensure accountability for implementing the roadmap by 2030.

