Panel 1: IDD Survey Data at a Crossroads

September 21, 2026

Colleen Roche, Moderator

I/DD Counts Summit


Enhance Partnerships
Improve Survey Data
Strengthen Administrative Data
Support Research Capacity
Increase Data Use and Dissemination

Surveys can help us understand people with IDD

- Surveys are questions asked to a group of people to learn about their experiences or opinions.
- Different surveys identify IDD in different ways, so definitions matter
- What progress have we made in using surveys to understand people with IDD?
- What's next?

Panelists

- **Alixe Bonardi**, Human Services Research Institute
- **Julie Weeks**, National Center for Health Statistics
- **Alicia Dixon-Ibarra**, Special Olympics International
- **Ari Ne'eman (pre-recorded)**, Harvard University

- Moderated discussion and audience Q&A

A Shared Goal: Better information about people with IDD

Alixe Bonardi OTR, MHA
Human Services Research Institute

Survey data: steady progress, unfinished work

- Foundational efforts in early 2000s (CDC)
- Data summits in 2017, 2019, 2022. Special Issue of Intellectual and Developmental Disabilities (2019)
- Collaborations with government and funded research studies; develop and test questions for national health surveys, demonstrate IDD health data
- Gathering priorities from people with IDD for health data
- Cross-agency and research partner groups

A word about the terms IDD and I/DD

I/DD Counts is the initiative: efforts to strengthen national health data on people with intellectual and developmental disabilities (IDD).

ID

- Intellectual functioning
- Adaptive behavior
- Developmental onset

DD

- Developmental onset
- Long-term or lifelong impact
- Substantial functional limitations
- Lifelong or extended supports

UMBRELLA TERM

IDD

People with ID, DD, or both.

Distinct and overlapping
Not a third diagnosis
Not one eligibility category

All Means All

We are working to understand the whole population with IDD in the United States.

People with IDD are a part of the whole population in the United States, ***whether or not a particular dataset can identify them.***

Describing the population with IDD

Operational Definitions are the rules applied by researchers to describe how people with ID, DD, IDD, or any group of people, are identified in any dataset.
The rules are based on:

The purpose of identifying people with IDD (e.g. prevalence, comparing health experiences in different groups)
Other factors about the available data (e.g. how the data are collected, data quality, numbers of people identified)

There is not one single source or operational definition we can point to. We need to keep working to be sure people understand how the data do and do not describe people with IDD.

Different datasets fill in different parts of the picture

Each dataset contributes to the picture. No one dataset gives us the whole picture

- Self - report
- Proxy- report
- Diagnoses
- Healthcare data
- Program or Eligibility data

National Surveys

Administrative data

Bringing together information from multiple places helps understand the whole population with IDD.

Better definitions help us see what each source can tell us, who may be missed, and how the pieces fit together.

IDD Data in Surveys:

Developing and implementing the right tools to improve understanding

Julie D. Weeks, Ph.D.

September 21, 2026

2026 IDD Counts Data Summit
IDD Survey Data at a Crossroads

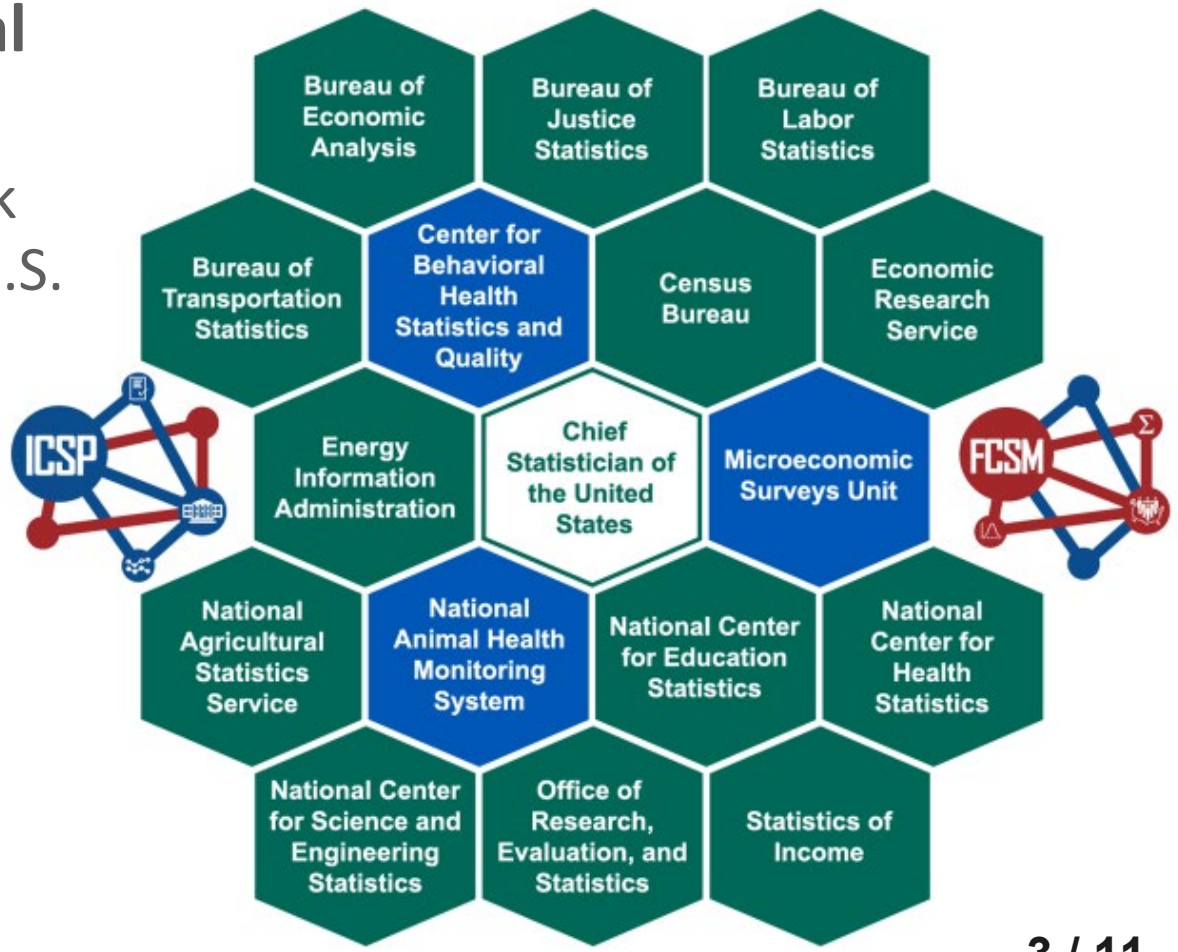
Agenda

- A brief introduction to the National Center for Health Statistics
- Challenges to collecting data on IDD
- Building a partnership and momentum
- A DD Act approach to defining IDD
- Developing and testing the IDD questions
- What can data tell us?

We are a Federal Statistical Agency

We are a principal agency of the Federal Statistical System

- The Federal Statistical System is a network of federal agencies that produce official U.S. statistics
- Statistical agencies provide access to objective, accurate, timely data to foster evidence-based policy
- NCHS is the nation's principal statistical agency responsible for collecting official health statistics



State of Statistics on People with DD

- **Lack of population-level data**
  - 1994-1995 NHIS on Disability
  - No regularly-collected, nationally-representative data
- **Challenges to collecting the data**
  - Varying definitions and purposes: diagnostic, programmatic, surveillance
  - Target population is small
  - Residential characteristics and data collection: community, group quarters, other
  - Person-specific IDD circumstances and participation preferences: self or proxy
- **Needs for data**
  - Understanding of the size, characteristics, and experiences of people with DD
  - Funding: Congress, DHHS determine funding for DD Councils and P&As
  - Inform and monitor policies and programs

Partnership with ACL

- **ACL, NCHS, and ASPE first met in 2015**

  Discuss the feasibility of obtaining an updated DD prevalence
  - Discussions with DHHS (Office of Legislation, Budget Office), partner agencies, UCEDD Directors, the research and disability communities
  - Repeating a supplement would be costly and time-consuming
- **Decisions for moving forward**
  - Add needed questions to the National Health Interview Survey (NHIS)
  - Choice of which definition to use: DD Act (statutory definition)
  - Identify existing questions and gaps
  - Develop, test, fund, implement questions to meet the chosen definition

1. Defining DD for Data Collection

The 2000 Developmental Disabilities Assistance and Bill of Rights Act

The DD Act defines "developmental disability" as a severe, chronic disability that:

(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(i) is manifested before the individual attains age 22;

(ii) is likely to continue indefinitely;

(iii) results in substantial functional limitations in 3 or more of the following areas of major life activity:

1. Self-care
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-direction
6. Capacity for independent living
7. Economic self-sufficiency; and

(iv) reflects the need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other assistance that are of lifelong or extended duration.

2. Identifying the Data Gaps

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3. Developing and Testing the New Data Items

NCHS Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER):

With ACL support, development of 3 new questions:

- Age at onset
- Learning
- Receipt of help with everyday activities

Multiple rounds of cognitive testing included people with IDD, and their family members or proxy:

- Round 1: Fall 2019 (in person)
- Round 2: Spring 2022 (virtual)
- Supplemental round: Winter 2024 (virtual)

Field testing in the NHIS:

- Beginning in 2020

With DHHS/PCORTF, NCBDDD and NCHS support, cognitive testing, qualitative in-depth and feasibility interviews with people with IDD:

- Phase 1: Fall-Spring 2024-2025
- Phase 2: Summer 2025
- Phase 3: Summer 2026 (with Special Olympics International)

What have we learned?

Including people with IDD in the research process is a win-win

"I've had problems throughout my life when I've tried to voice my opinion, people just shut me out. They don't want to listen to nothing I have to say."

"Of course, people still make assumptions based on the way I communicate but I am able to share my thoughts, though not through speech."

Question evaluation is essential to obtaining high-quality data

"I have a lot of difficulty remembering a lot of things. If you tell me too much information at once, it won't register as quick in my brain as you'd think it would […] if you break it down and tell me little by little, then I can repeat it back to you."

"Sometimes, I think a long time ago, I had a diagnosis with some disability that makes it more difficult. "

"You have to explain things to me in a different way. So that I can understand."

"No, I don't think he thinks of himself that way ."

What can data tell us?

Prevalence is important, but not sufficient.

Data can tell us so much more.

People with DD are more likely to:

- *Have health insurance coverage all year.*
- *Have a doctor's office as a usual place of care.*
- *Have had a wellness visit in the past 12 months.*
- *Had a blood pressure check in the past 12 months.*
- *Had a diabetes check in the past 12 months.*

People with DD are more likely to:

- *Be covered by public health insurance.*
- *Have unmet medical care needs.*
- *Have prescription nonadherence.*
- *Have had 2 or more emergency room visits in the past year.*

Source: Weeks, et al. *Forthcoming.*

Thank you!

Special Olympics' Contributions to IDD Survey Data and Measurement

Alicia Dixon-Ibarra, PhD, MPH

Director, Fitness and Health Research

Special Olympics International

Strengthening IDD Health Data Through Special Olympics

Special Olympics Health
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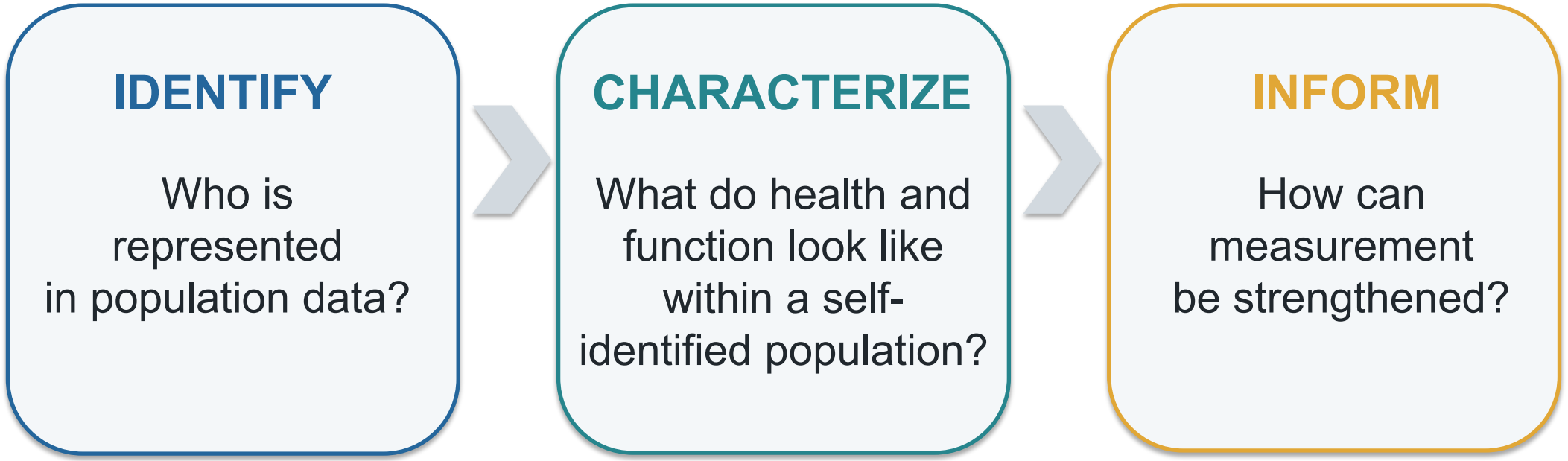

Complementary efforts that reinforce one another

IDENTIFY

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

Strengthen identification of people with IDD in population-based data

Rosemary Collaborative

Advocate

- Promote inclusion of IDD indicators in U.S. and global population-based surveys

Analyze

- Examine identification approaches and health disparities
- Use National Health Interview Survey (NHIS) and National Core Indicators data

CHARACTERIZE

Special Olympics Health
MADE POSSIBLE BY Golisano FOUNDATION

Study health, functioning, and measurement within a self-identified IDD population

Healthy Athletes + Public Health Surveillance

- Embed population-based surveillance questions within Healthy Athletes
- Pair survey indicators with Healthy Athletes screening data
- Compare health outcomes with general-population surveillance benchmarks

Washington Short Set Analyses

- Examine functional limitations among Special Olympics athletes
- Understand how athletes and proxies respond to WG-SS measures
- Compare response patterns with NHIS

Dixon-Ibarra et al. (2026)
Scan for the full article.

INFORM

Generate evidence to strengthen future IDD measurement

PCOR Point of Care Project

- Contribute evidence and lived-experience perspectives
- Supported recruitment into multiple phases of the project

Testing Learning and Support Questions

- Examine supplemental questions designed to better represent ID/DD-specific disability domains
- Assess how questions are interpreted and how well response options reflect athletes' experiences

What can Special Olympics contribute?

Special Olympics Health
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1. A known, self-identified IDD population

2. A bridge to population data

3. A testing ground for better measurement

6 / 7

Special Olympics Health

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THANK YOU.

Different Definitions of Developmental Disability and Implications for Outcomes

Ari Ne'eman, PhD Hailey Clark, BS, BA

Harvard T.H. Chan School of Public Health
JAMA Health Forum 2025;6(12):e255642

How should we define developmental disability?

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- For **adults**, the field still relies on a single **30-year-old** estimate (0.8%, 1994/95 NHIS-D) — most surveys no longer ask adults about diagnosis or the full range of functional impairments.
- In 2022, **HHS called for a standardized definition of DD** to enable data collection at the point of care, outcome measures, and Medicaid claims analysis.

This study

- Examine the **distributive implications** of **4 increasingly comprehensive** diagnosis-based definitions of DD.
- Data: **2023 SIPP** (incl. 18 screener questions and reported diagnoses), augmented with **2019 RISP** to capture people with DD in **institutions / congregate settings** outside SIPP's frame.
- Provide the **first updated adult DD prevalence in $\sim$30 years**, and contextualize each definition with **service use, income support, employment, and impairment acuity**.

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- A **diagnosis-based** approach is consistent with recent childhood DD epidemiology and is far easier to **operationalize consistently in claims / EHR**.
- **The design choice:** which **diagnoses** to include — that is what this paper varies.

The SIPP disability screener: 18 questions

Core functional — all ages (ACS-6)

- Serious difficulty hearing
- Serious difficulty seeing (with glasses)
- Concentrating, remembering, or deciding
- Walking or climbing stairs
- Dressing or bathing
- Doing errands alone

Child-specific

- Developmental condition/delay (ages <5)
- Difficulty playing with other children
- Limitations doing regular schoolwork

Adult-specific

- Difficulty sitting for one hour
- Lifting or carrying 10 pounds
- Using hands/fingers for grasping
- A work-limiting health condition
- Difficulty finding or keeping a job
- Being prevented from working

Long-term & specific conditions

- Long-term health condition limiting daily activities
- **Learning or developmental disability**
- Mental or emotional condition

Learning / developmental disability screener (ages 5+), verbatim

"**Does [name] have a learning or developmental disability?** (This could include conditions such as *dyslexia, ADHD, autism, Down Syndrome, or some other learning or developmental disability.*)"

From screener to diagnosis: the condition question

Condition question — asked of everyone who screens in (ages 5+)

"Earlier you said [name] has difficulty with certain activities *[or: has a work-limiting disability; has a learning or developmental disability or a mental or emotional condition]*. **What condition or conditions [cause these difficulties / does [name] have]?**"

The lead-in adapts to whichever screener(s) the respondent answered "yes." Respondent then reports up to 3 conditions, each selected from a coded answer list (recorded in RCONDBRIDGE / RCONDSUBTYPE). In 2023 the wording was revised to reference all prior "yes" screener items, reducing under-reporting of conditions.

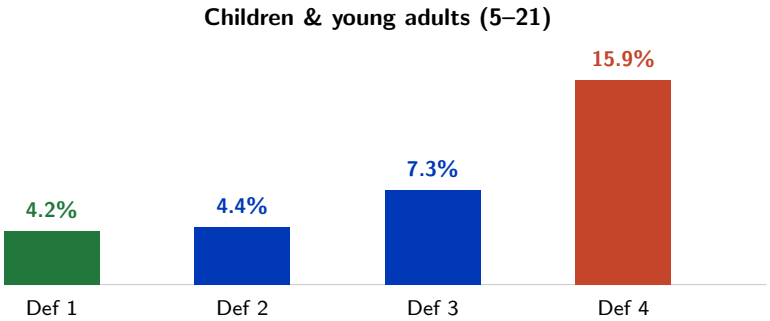
- Diagnoses in Definitions 1–4 (CP, ID, autism, epilepsy, LD/ADHD) are values in that coded list; **Definition 3** adds a "yes" on the LD/DD *screener* **without** a listed LD diagnosis.

Four increasingly comprehensive definitions

Definition	Diagnoses / criteria added
1 (narrowest)	Cerebral palsy, intellectual disability, autism (ASD)
2	+ epilepsy
3	+ LD/DD screener "yes," *without* a learning-disability diagnosis
4 (broadest)	+ learning disability diagnosis (incl. ADD/ADHD)

- Definition 1 reflects the **historical clinical core** of the DD construct.
- Definition 4 approximates the **broadest** diagnostic reading in current use.

Prevalence swings by 3–7× across definitions



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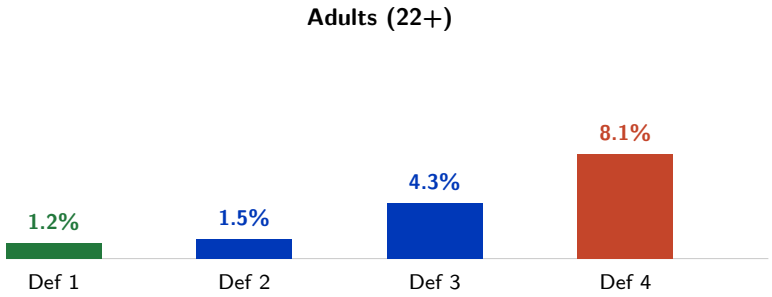


- Children: **4.2%** (Def 1) → **15.9%** (Def 4).
- Adults: **1.2%** (Def 1) → **8.1%** (Def 4) — our updated adult estimate.

A narrower definition captures the service-relevant population (adults)

Adults with DD (22+), %	**Def 1**	Def 2	Def 3	**Def 4**
Known to / served by state DD agency (LTSS)	**33.1**	27.1	9.5	**5.1**
Living in a congregate residential setting	**9.8**	8.1	2.8	**1.5**
Receiving SSI (ASD/ID)	**29.4**	24.2	8.5	**4.5**
Receiving SSDI (ASD/ID)	**30.4**	24.9	8.7	**4.6**

- Under **Def 1**, **33.1%** of adults with DD are known to a state DD agency — state policy changes would be **directly observable** in this population.
- Under **Def 4**, only **5.1%** are — such policy changes are **largely undetectable**.
- Income support is common among adults under **Def 1** (**29.4%** SSI, **30.4%** SSDI) but uncommon under **Def 4** (**4.5%** / **4.6%**); congregate placement falls **9.8%** → **1.5%**.

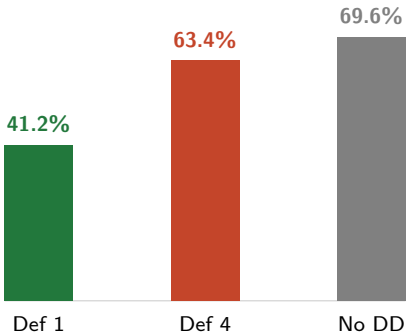
A narrower definition captures the service-relevant population (children)

Children & young adults with DD (5–21), %	**Def 1**	Def 2	Def 3	**Def 4**
Known to / served by state DD agency (LTSS)	**20.4**	19.1	11.6	**5.3**
Living in a congregate residential setting	**1.0**	0.9	0.6	**0.3**
Receiving SSI (ASD/ID)	**14.5**	13.6	8.3	**3.8**

- Under **Def 1**, **20.4%** of children/young adults with DD are known to a state DD agency, vs. only **5.3%** under **Def 4**.
- Congregate residential placement is rare across childhood — **1.0%** (Def 1) → **0.3%** (Def 4).
- SSI receipt (ASD/ID) falls from **14.5%** (Def 1) to **3.8%** (Def 4).

Broader definitions look more like the general population

Employment rate, adults with DD (22+)



Impairment acuity, children/young adults with DD

	Def 1	Def 4
Cognitive impairment	71.8	60.0
Self-care impairment	23.0	7.9
Ambulatory impairment	9.1	3.6
Independent-living impair.	42.2	14.9

(% reporting each impairment)

- As definitions broaden, **employment rises toward the non-DD rate** and **functional-impairment acuity falls**.
- Narrow Def 1 identifies people with **markedly more severe impairment** and more proxy responses.

Definitions are tools — match the tool to the purpose

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- But **DD** is tied to a **publicly funded service system** built — through deinstitutionalization and disability-rights advocacy — to support those at **greatest risk of segregation**.

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- **Insofar as continuity with that purpose is intended, a narrower approach (ID, autism, CP) best identifies** the people impacted by DD policy and at risk of congregate placement and exclusion from work.

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- **Insofar as continuity with that purpose is intended, a narrower approach (ID, autism, CP) best identifies** the people impacted by DD policy and at risk of congregate placement and exclusion from work.
- Prevalence should shift to **diagnosis-based** measurement while service **eligibility** retains a **functional** standard — not everyone with a qualifying diagnosis meets DD service criteria.

Takeaways for policy and research

- Definition choice **substantially** changes DD prevalence and the policy relevance of the identified population.
- A **narrow, diagnosis-based** definition (ID, autism, CP) best tracks the population served by state DD systems and at risk of segregation.
- We provide an **updated adult DD prevalence** to replace 30-year-old data.

Next steps

Operationalize the narrow approach in **claims / EHR** data (adding low-prevalence conditions not visible in SIPP, e.g. spina bifida) toward a **commonly accepted, standardized definition of DD**.

Thank you

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