Different Definitions of Developmental Disability and Implications for Outcomes

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JAMA Health Forum 2025;6(12):e255642

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- 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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- **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.

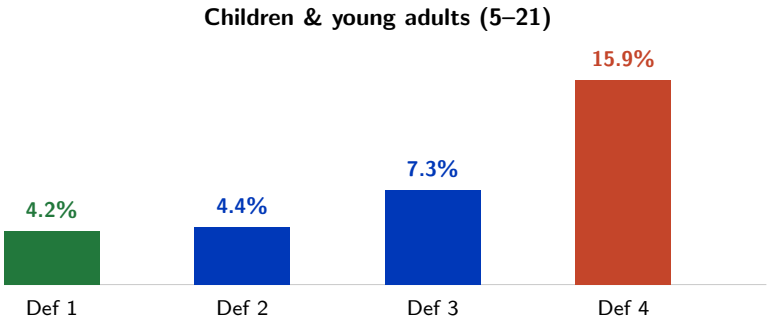
- Diagnoses in Definitions 1–4 (CP, ID, autism, epilepsy, LD/ADHD) are values in that coded list; **Definition 3** adds a "yes" on the LD/DD *screener* **without** a listed LD diagnosis.

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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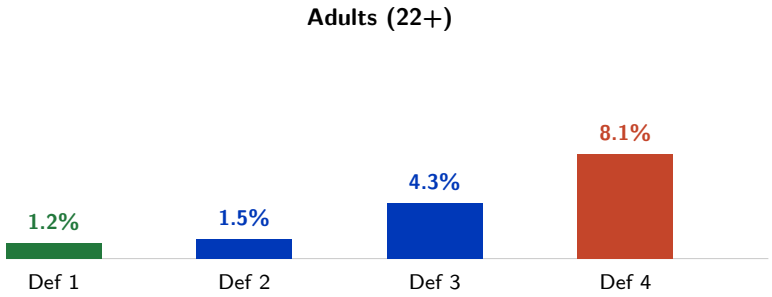


- Children: **4.2%** (Def 1) → **15.9%** (Def 4).
- Adults: **1.2%** (Def 1) → **8.1%** (Def 4) — our updated adult estimate.

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%**.

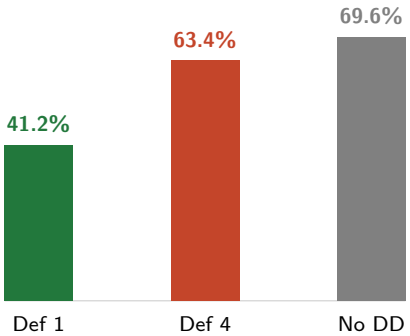
A narrower definition captures the service-relevant population (children)

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.

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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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- 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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JAMA Health Forum 2025;6(12):e255642 · open access (CC-BY)

Appendix: full prevalence estimates (95% CI)

Definition	**Children 5–21** % (95% CI)	**Adults 22+** % (95% CI)
1 (CP, ID, ASD)	4.17 (3.41–5.09)	1.24 (1.01–1.52)
2 (+ EP)	4.44 (3.65–5.38)	1.51 (1.26–1.81)
3 (+ screener, no LD dx)	7.34 (6.32–8.52)	4.32 (3.86–4.82)
4 (+ LD dx)	15.93 (14.43–17.55)	8.10 (7.48–8.77)

Appendix: children/young adults — service & income use

Children/young adults with DD (5–21), %	Def 1	Def 2	Def 3	Def 4
Known to / served by state DD agency	20.35	19.11	11.55	5.32
Living in congregate setting	0.98	0.92	0.56	0.26
Receiving SSI (ASD/ID)	14.53	13.64	8.25	3.80

Appendix: data & methods notes

- **SIPP 2023**, wave 1, month-12 observation; nationally representative of the civilian noninstitutionalized population; updated medical-condition wording only.
- **RISP** (2019, rescaled to 2023) adds people with DD living outside the family/own home or in an ICF/IID — outside SIPP's sampling frame.
- **Assumption:** people eligible for LTSS or in congregate settings fall under Def 1; NCI-IDD supports this (93–95% of adults receiving state DD services meet Def 1).
- **Limitations:** self-reported diagnoses; up to 3 conditions per respondent; birth–21 RISP vs. 5–21 SIPP age misalignment; diagnosis- rather than function-based construct.