



The Center for IDEA  
Early Childhood Data Systems

# What do we Need to Better Understand Special Populations from a National Perspective?

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# Examples of research questions involving children with disabilities

## \* Counts:

- How many are there...?
  - In the US
  - In a program (in child care, in non-licensed care, in Head Start, in State PreK)
  - Unserved? Underserved?

## \* Characteristics

- What are the characteristics of children with disabilities (compared to children without disabilities)?
  - Gender, ethnicity, primary language, household income

## \* Experience and outcomes

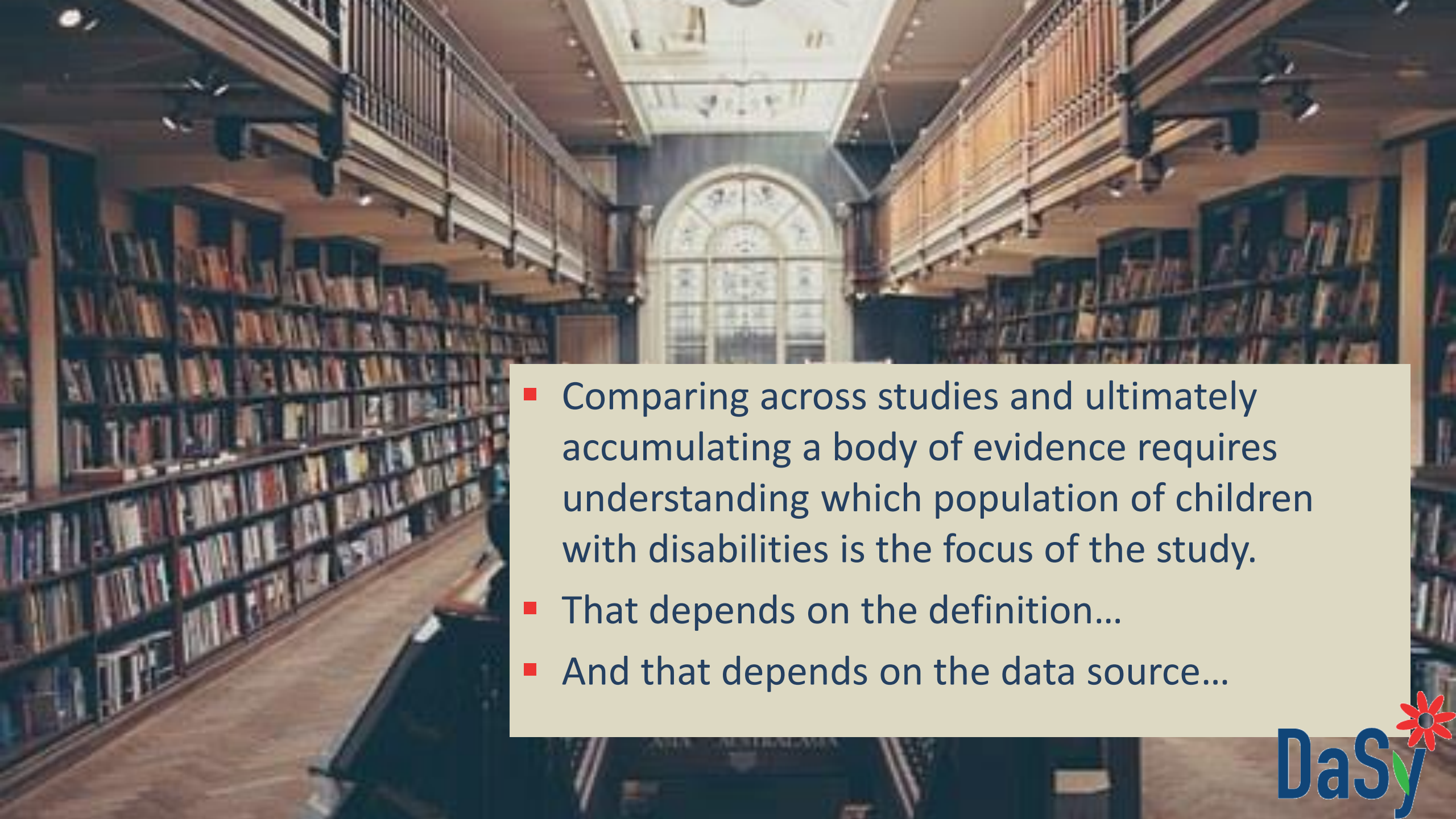
- What does X (outcomes, attendance, use of subsidies, age at enrollment in program, classroom quality, barriers to access) look like for children with disabilities (compared to children without disabilities)?



<http://www.nationalacademies.org/hmd/Reports/2018/opportunities-for-improving-programs-and-services-for-children-with-disabilities.aspx>

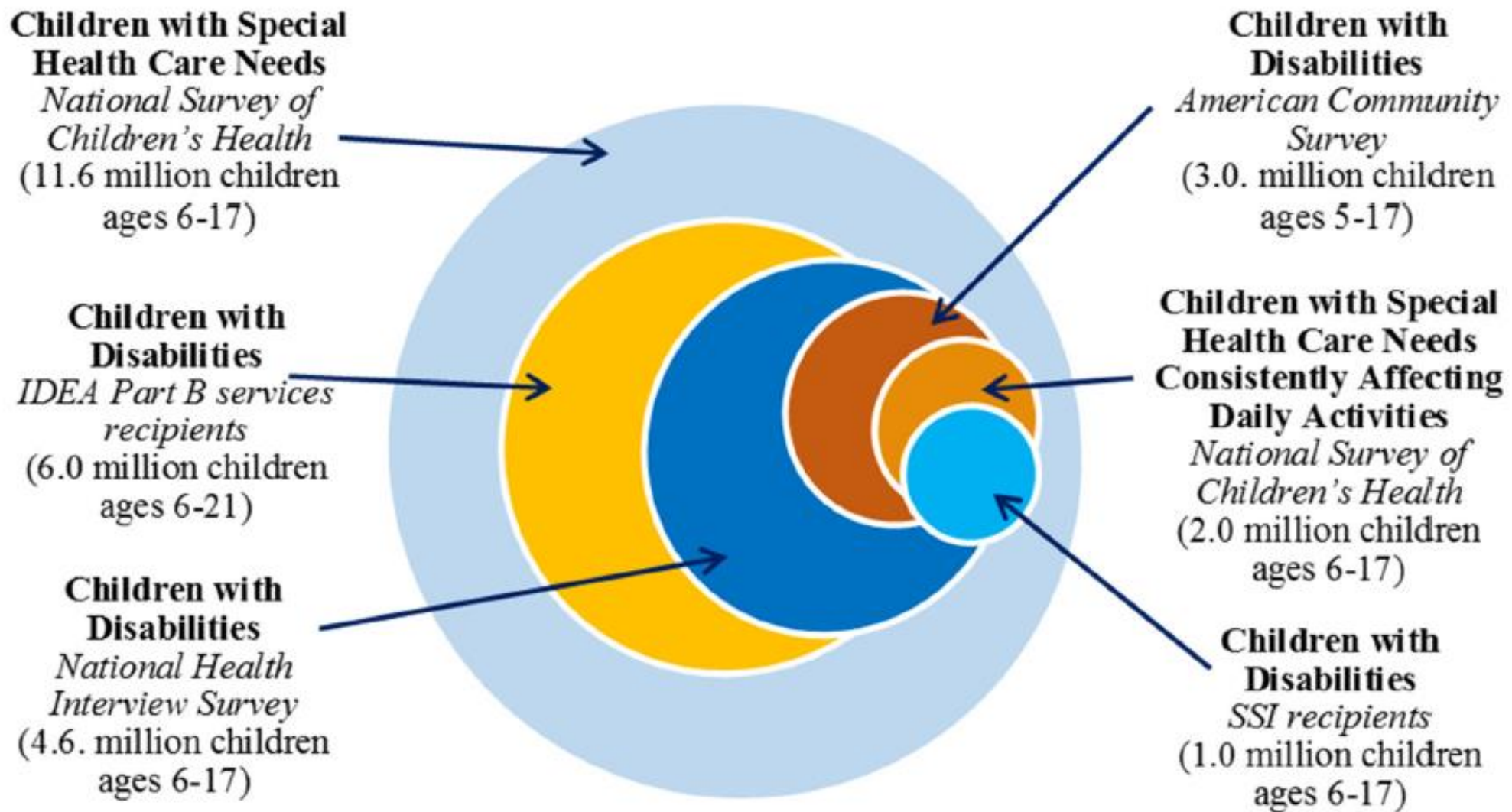
privileged to convene as an interdisciplinary team of experts to assess the benefits of programs and services for children with disabilities and to identify opportunities for improving service delivery.

There is no universally accepted definition of childhood disability. Different conceptual frameworks are used by clinicians, researchers, agencies, service providers, and people with disabilities to understand disability and define disability for purposes of program inclusion, classification, and monitoring. This variability posed a challenge for the committee, as it does for children with disabilities and their families, researchers in the field, and policy makers. The committee recognizes that the nature and severity of disability are not determined solely by underlying medical conditions, but are a function of interaction with the physical world, opportunities, policies, available supports, and social role expectations for children. Therefore,

- 
- Comparing across studies and ultimately accumulating a body of evidence requires understanding which population of children with disabilities is the focus of the study.
  - That depends on the definition...
  - And that depends on the data source...

# Some Sources of Definitions and Data

- Americans with Disabilities Act (ADA)
- Centers for Disease Control (CDC)
- Social Security Administration/Supplemental Security Income (SSI)
- Individuals with Disabilities Education Act (IDEA)
- Maternal and Child Health Bureau – Children with Special Health Care Needs (CSHCN)
- National Health Interview Survey (NHIS)
- National Survey of Children’s Health (MCHB)
- Medical Expenditure Panel Survey (HHS)
- American Community Survey (Census Bureau)
- Survey of Income and Program Participation (Census Bureau)
- Early Childhood Longitudinal Study (Dept. of Education)
- National Household Education Survey (Dept. of Education)



**FIGURE 2-1** Prevalence of childhood disability based on selected definitions.

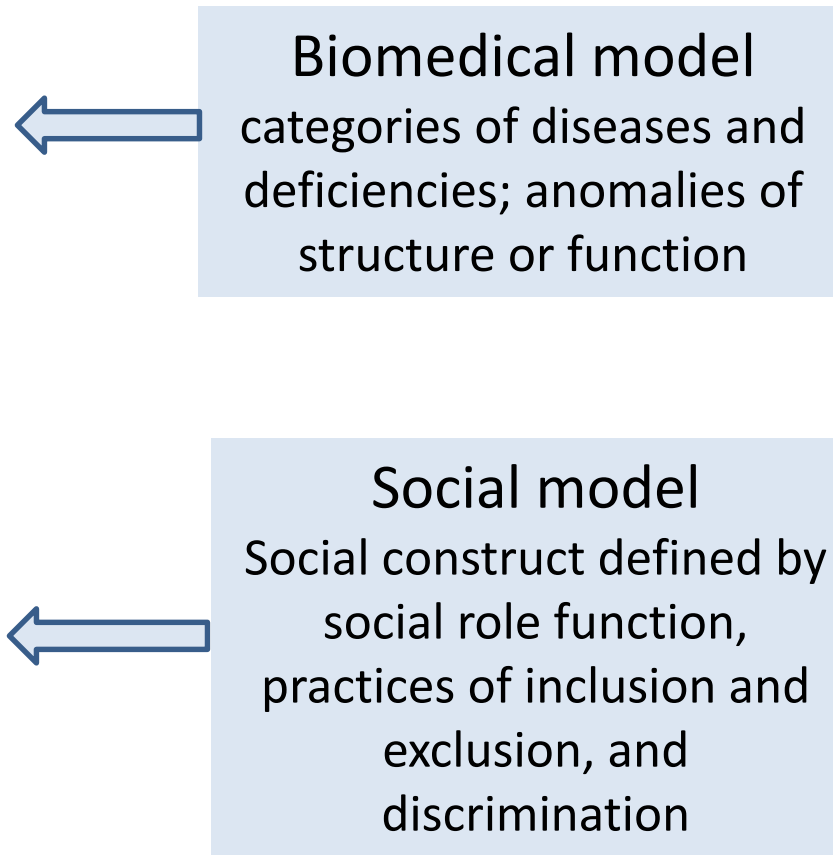
Source: <http://www.nationalacademies.org/hmd/Reports/2018/opportunities-for-improving-programs-and-services-for-children-with-disabilities.aspx>

“An estimated 13–15 percent of children younger than 6 have special needs that may require services, although fewer than 6 percent (about 350,000 infants and more than 750,000 toddlers and preschool-age children) receive special education and related services under the federal Individuals with Disabilities Education Act program.”



Henley, J.R. & Adams, G. (2018). *Insights on access to quality child care for children with disabilities and special needs*. Washington, DC: Urban Institute

“A disability is an environmentally contextualized health-related limitation in a child’s existing or emergent capacity to perform developmentally appropriate activities and participate, as desired, in society”



Disability is the interaction between  
Individual  
and  
Context in which they live



# National Health Interview Survey

Children have a disability if...

- \* Reported to receive special education or early intervention
- \* Experience difficulty walking without equipment
- \* Experience difficulty remembering
- \* or any other limitation

(under 5)

- \* Experience limitations in the kinds or amount of play activities done by other children

(3 and older)

- \* Need help with personal care

# Individuals with Disabilities Education Act (IDEA)

## Eligibility for Section 619 Early Childhood Special Education – Ages 3 - 5

- Child has one or more of 13 conditions
  - Intellectual disability
  - Hearing impairment (including deafness)
  - Speech or language impairments
  - Visual impairments (including blindness)
  - Serious emotional disturbance
  - Autism
  - Orthopedic impairments
  - Traumatic brain injury
  - Other health impairments
  - Specific learning disability
  - Multiple disabilities
  - Deaf-blindness
  - Developmental delay
- Who, by reason thereof, needs special education and related services.
- Applies from ages 3 to 21 (except for developmental delay)

# Child Care and Development Block Grant

The CCDBG considers a child to have a disability if he or she meets at least one of the following criteria:

- (1) meets the definition in section 602 of the Individuals with Disabilities Education Act (IDEA);
- (2) is eligible for early intervention services under part C of IDEA;
- (3) is under 13 years old and eligible for services under Section 504 of the Rehabilitation Act of 1973; or
- (4) is a child with a disability, as defined by the state.

# Researchers define a special needs group

- \* From a study of child care subsidies
- \* Used the Early Childhood Longitudinal Study - Birth Cohort
- \* Children who at 9-months, 2-year, or 4-year data wave were
  - Identified as having an IFSP or IEP, **AND/OR**
  - Had a medically diagnosed disability per birth certificate or parent report, **AND/OR**
  - Scored 1.5 SDs below the mean on social-emotional, motor, or cognitive skills test
    - Motor and cognitive: Bayley Short Form – Research Edition
    - Field administrators rated social-emotional functioning based on child's performance on the BSID

# Disability in young children is not a stable characteristic

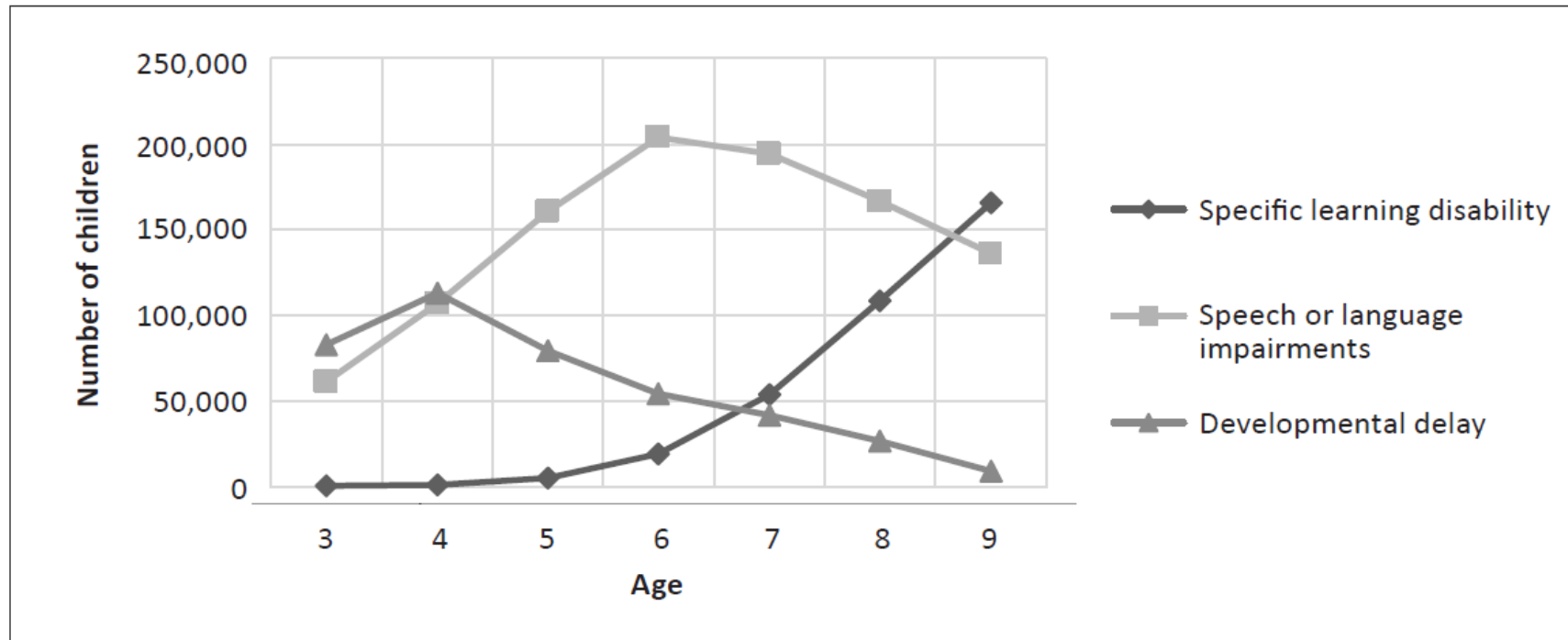


Among young children, there are:

- Children with disabilities who will have their disability(ies) all of their lives.
- Children who have a disability now but will not at some point in the future.
- Children who have a disability now that has not yet been diagnosed.
- Children who don't have a disability now but will be diagnosed with a disability in the future.
- Children who used to have a disability but no longer do.

# The number of children with speech or language impairments increases until age 6 and then drops off.

**Figure 1.** Number of Children Served under IDEA by Age and Disability Category: 2013–14



Source: Data from U.S. Department of Education, ED Facts Data Warehouse, *IDEA Part B Child Count and Educational Environments Collection* (2013–14). Data extracted as of July 3, 2014, from file specifications 002 and 089.



Children with disabilities are an extremely heterogeneous group

- Characteristics, experiences, services, outcomes, etc. will vary by the nature of the child's disability.
- Research needs to have meaningful ways to describe the child's functioning in multiple areas
- Disability categories (e.g., visual impairment) are not sufficient

# Implications for Future Research

- \* Researchers ..
  - Need to clearly present and repeatedly reference the definition/criteria they are using to identify a population of children with disabilities
  - Recognize the program eligibility does not equal all definitions of children with disabilities
  - Be aware of the differences between ever having a disability and having a disability now.
- \* States need to continue to build early childhood integrated data systems (ECIDS) so we will be able to get an accurate picture of participation of children with disabilities in all early childhood programs.
  - And data bases need to include meaningful descriptors of the nature of the child's limitations.
- \* Consensus on a definition would be very helpful.



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# Thank You

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