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*Vincent Campbell:  
Measurement of Disability in Special Populations –  
People with Limited Cognitive Functioning*



# **Measurement of Disability in Special Populations – People with Limited Cognitive Functioning**

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Developmental Disabilities**

**Centers for Disease Control and Prevention**

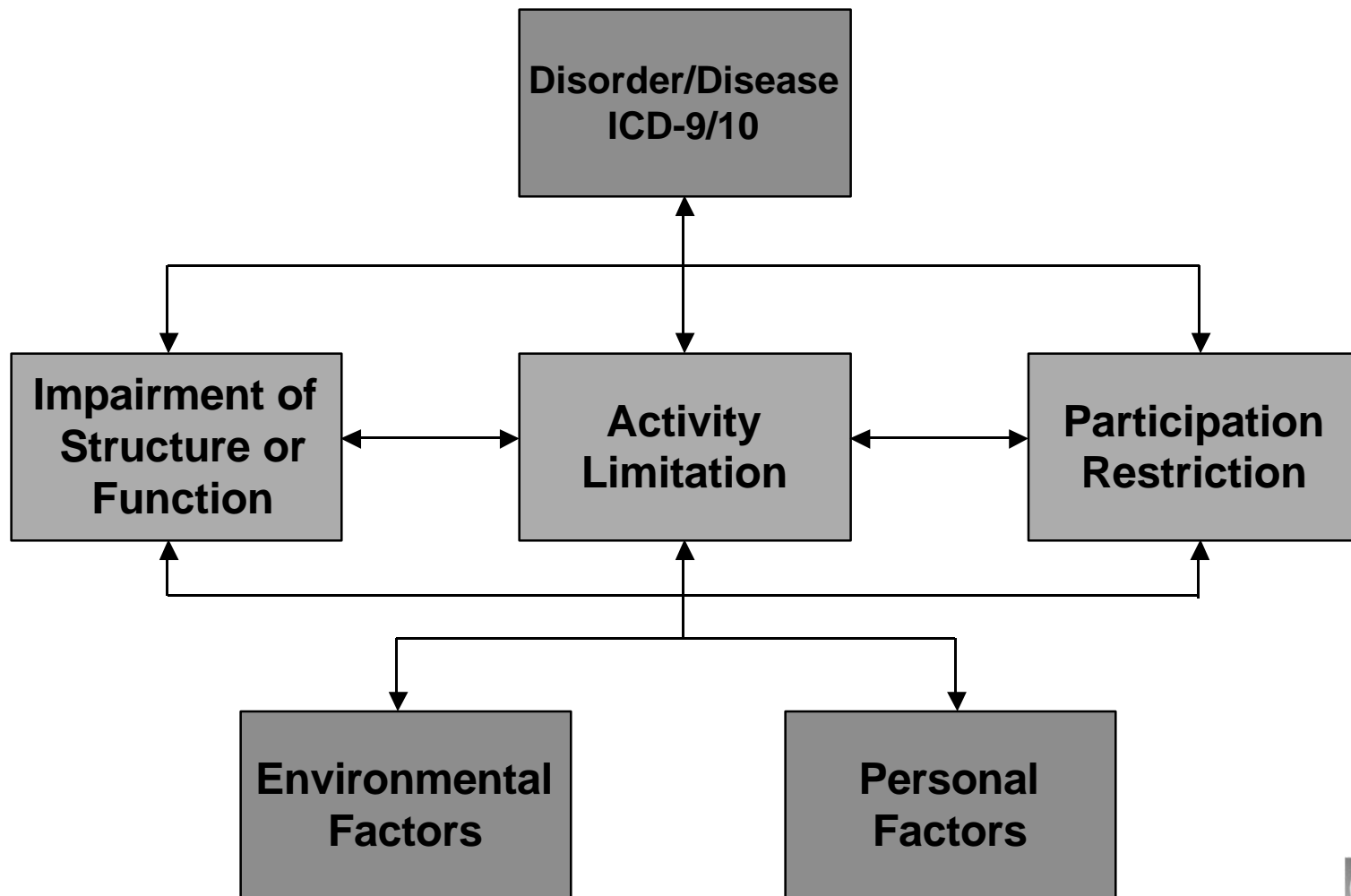


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# ICD-10 Mental Disorder Categories

- **F00-F09 Organic, including symptomatic, mental disorders**
- F10-F19 Mental and behavioural disorders due to psychoactive substance abuse
- F20-F29 Schizophrenia, schizotypal and delusional disorders
- F30-F39 Mood (affective) disorders
- F40-F48 Neurotic, stress-related and somatoform disorders
- F50-F59 Behavioural syndromes associated with physiological disturbances and physical factors
- F60-F69 Disorders of adult personality and behaviour
- **F70-F79 Mental retardation**
- **F80-F89 Disorders of psychological development**
- **F90-F98 Behavioural emotional disorders with onset usually occurring in childhood or adolescence**

# ICFDH Conceptual Model



# ICFDH Impairments - Cognition

## Functions

- Global Mental Functions
  - Orientation
  - Intellectual
- Specific Mental Functions
  - Attention
  - Memory
  - Thought
  - Higher level cognitive
  - Specific mental functions of language
  - Calculation functions
  - others

## Structures

- Structure of the nervous system
  - Structure of the brain

# ICFDH Activity Limitations - Cognition

## **Cognitive activities affected**

- **Learning & applying knowledge**
  - **Basic learning**
  - **Rehearsing**
  - **Learning to read, write, calculate**
  - **Acquiring skills**
  - **Basic learning, NOS**

## **Noncognitive activities affected incidentally**

- *General tasks & demands*
- *Communication*
- *Self care*
- *Domestic life*



# Prevalence - Conditions

## Condition:

- Mental Retardation 0.8%<sup>1, 2</sup>  
0.3%<sup>3</sup> (0.1 - 1.2%)
- Learning disability 1.3%<sup>1</sup>
- Traumatic Brain Injury ~2.0%
- Age-related dementia 0.8%<sup>1</sup> (2.8 – 28%)
- Stroke ~1.4%
- Stroke, dementia, TBI (SC),  
period prevalence, 1991-2000 6.3%

## Activity:

- BRFSS, 12 sites, 1998 (L/R/C) 6.6%

<sup>1</sup> SIPP, 1999

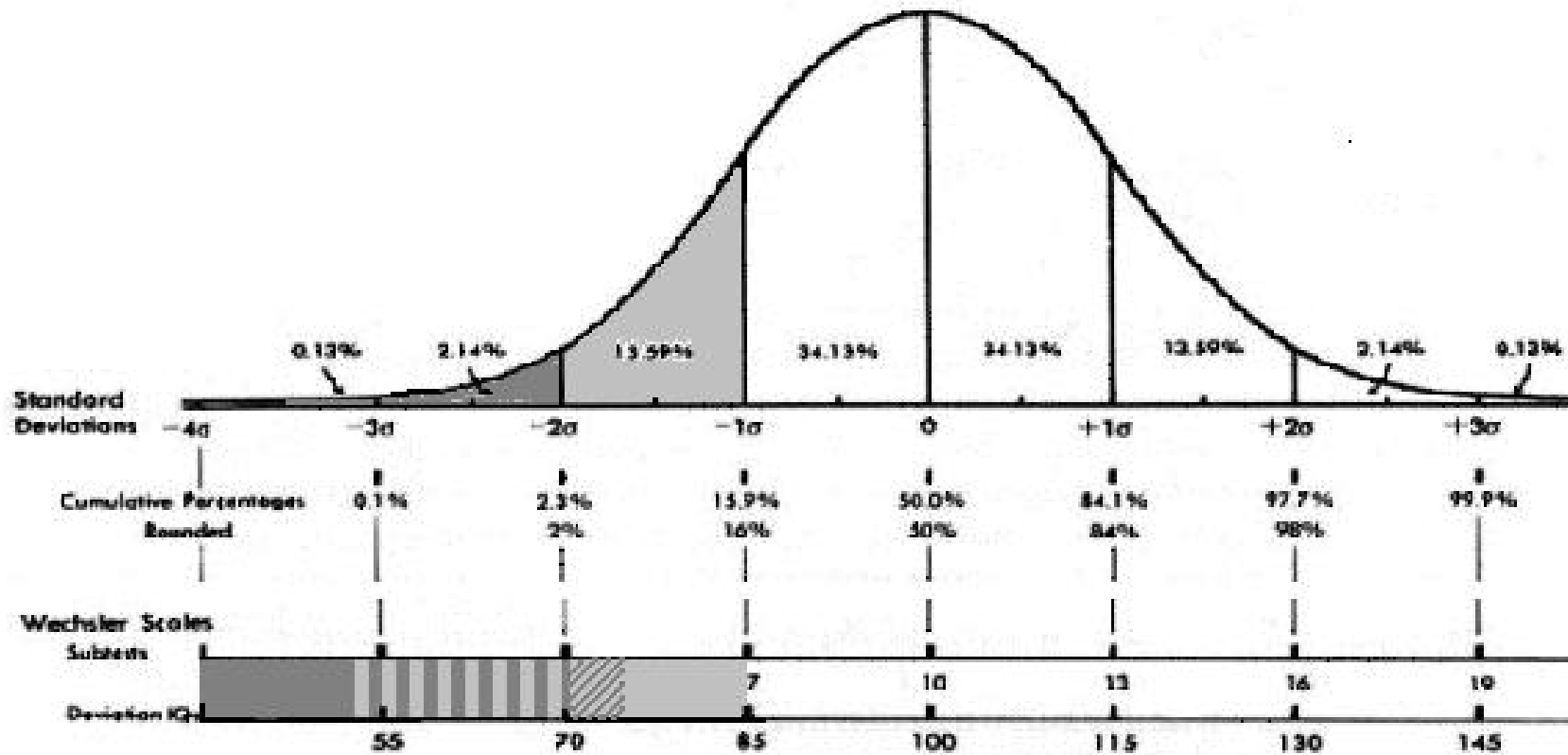
<sup>2</sup> Larson, et al., 2000

<sup>3</sup> NHIS-D1, prevalence of MR

# Mental Retardation

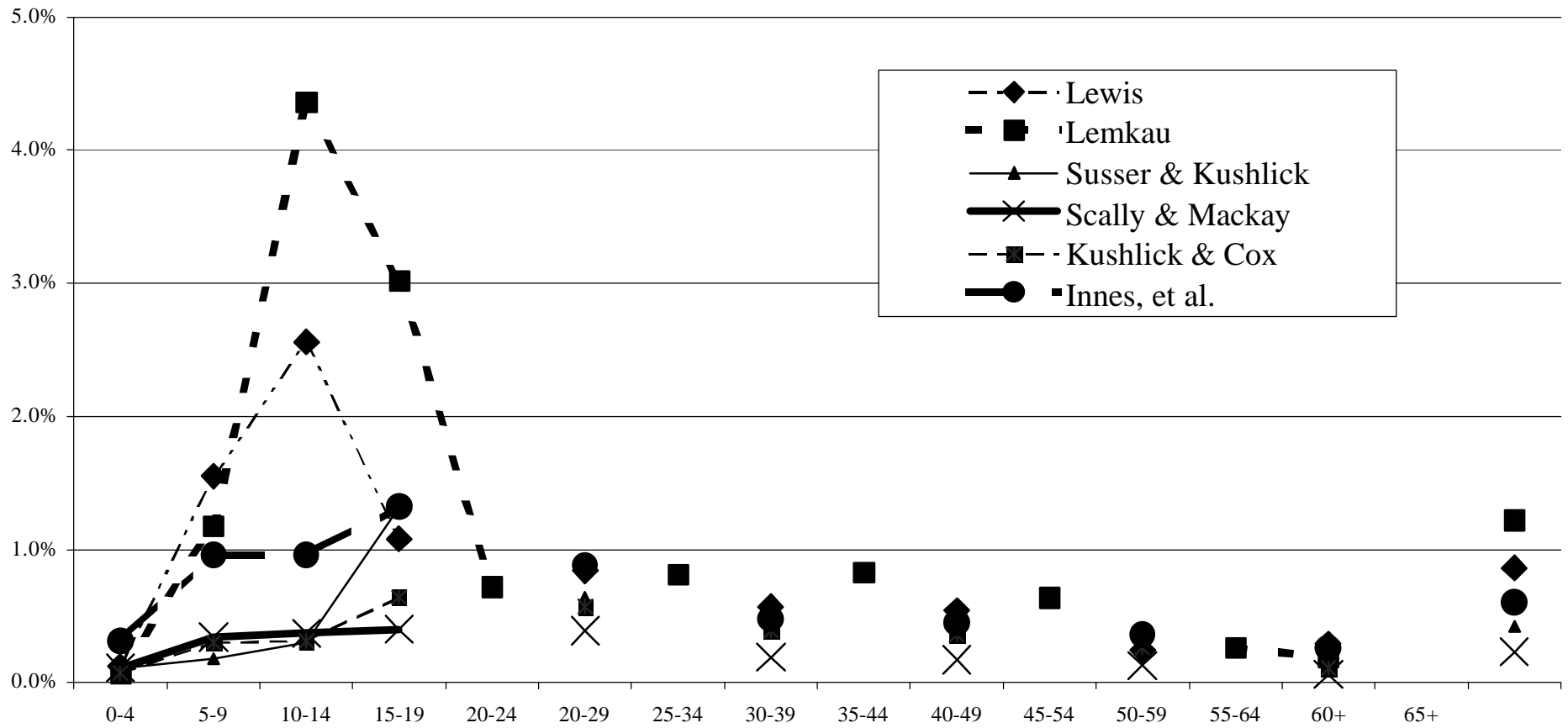
- Socially determined and psychometrically documented
  - Presence of medical condition
  - Comparison with children of similar age
  - School performance
- Multitude of causes
  - Genetic causes
  - Prenatal factors and events
  - Perinatal factors and events
  - Postnatal factors and events
  - Normal distribution

# Distribution of Intelligence (IQ)

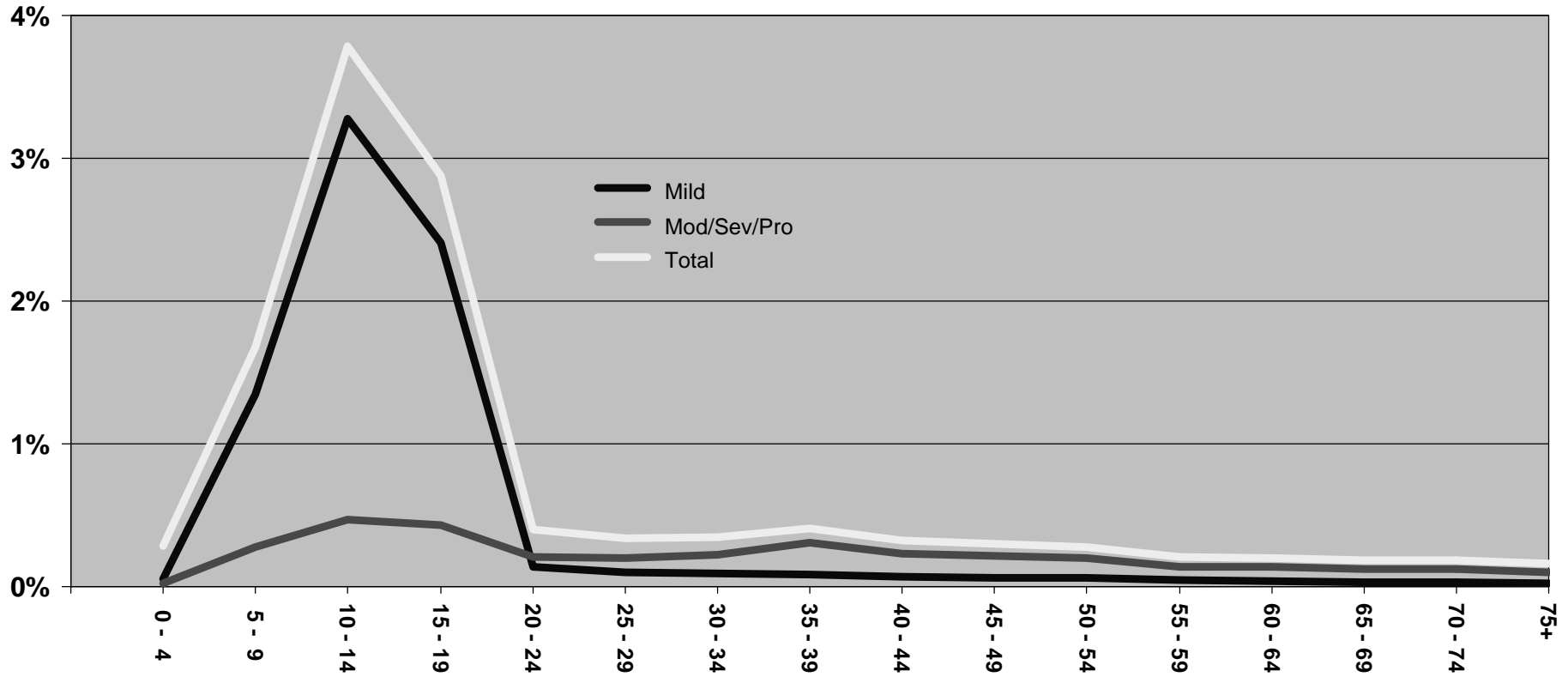


Adapted from The Psychological Corporation, Test service bulletin, 48 (1955).

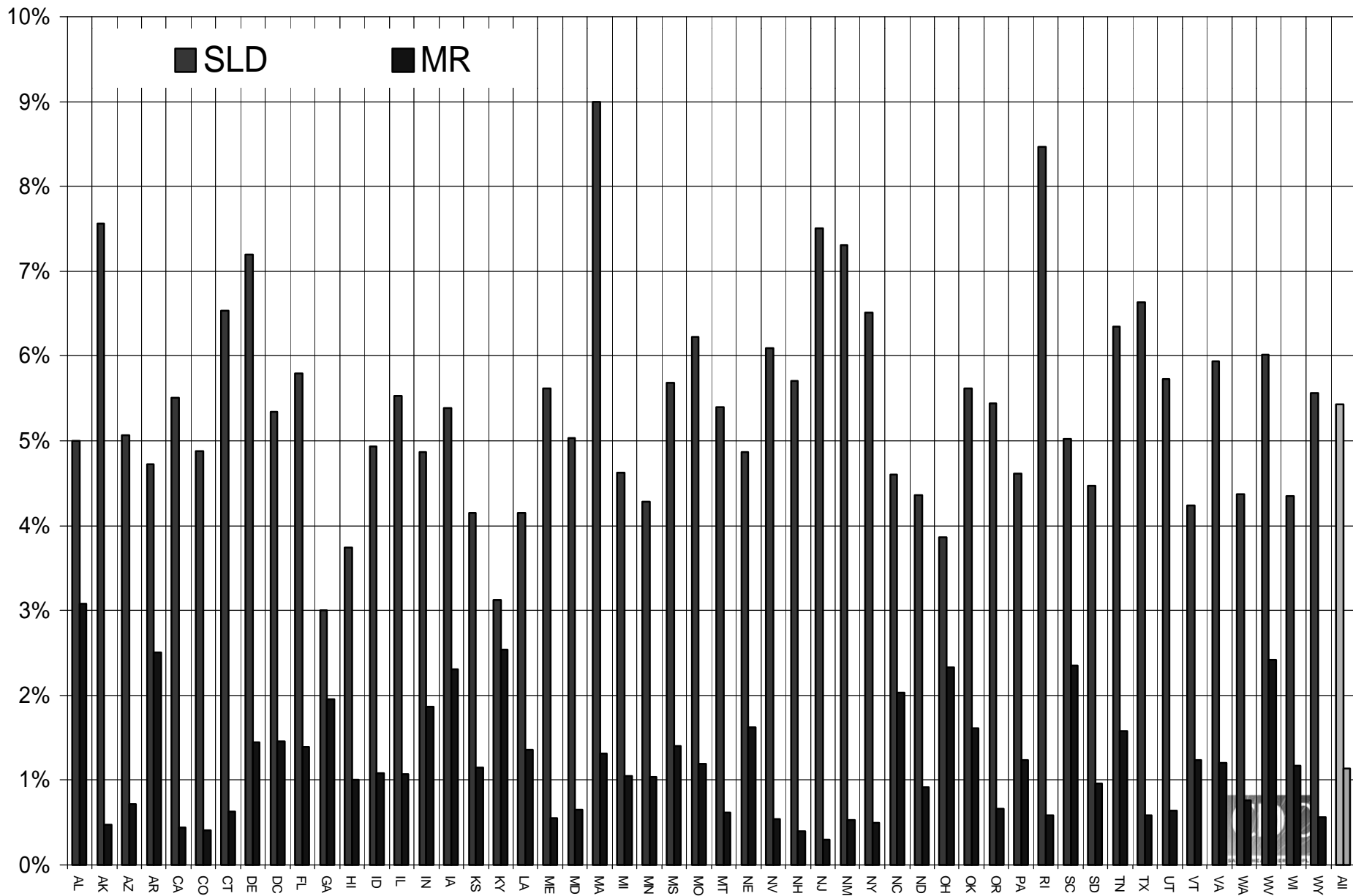
## Life Course Prevalence of Mental Retardation - Reported in Kiely, 1988



## Administrative Prevalence of Mental Retardation Southern State, USA, 1992 & 1993



**Percentage of estimated resident population of children, ages 6-17 years, enrolled in MR or SLD special education by state, United States, 1994-95**



# 10 questions for identification of 'serious' mental retardation – Analysis of results for questions on learning

Cognition		True Condition		Total
		Y	N	
Screen	Y	45	710	755
	N	1	870	871
Total		46	1580	1626

Sensitivity	97.8%
Specificity	55.1%
PV+	6.0%
PV-	99.9%

Type 1 error (false + rate)	44.9%
Type 2 error (false - rate)	2.2%
Prevalence	2.9%

# 2000 US Census

- No disability questions on short form (everyone completes)
- Long form (Approximately 1 in 6 households):

Does this person have any of the following long-lasting conditions:

- a. Blindness, deafness, or a severe vision or hearing impairment?
- b. A condition that substantially limits one or more basic physical activities such as walking, climbing stairs, reaching, lifting, or carrying?

Because of a physical, mental, or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities:

- a. **Learning, remembering, or concentrating?**
- b. Dressing, bathing, or getting around inside the home?
- c. (Answer if this person is 16 YEARS OLD OR OVER.) Going outside the home alone to shop or visit a doctor's office?
- d. (Answer if this person is 16 YEARS OLD OR OVER.) Working at a job or business?

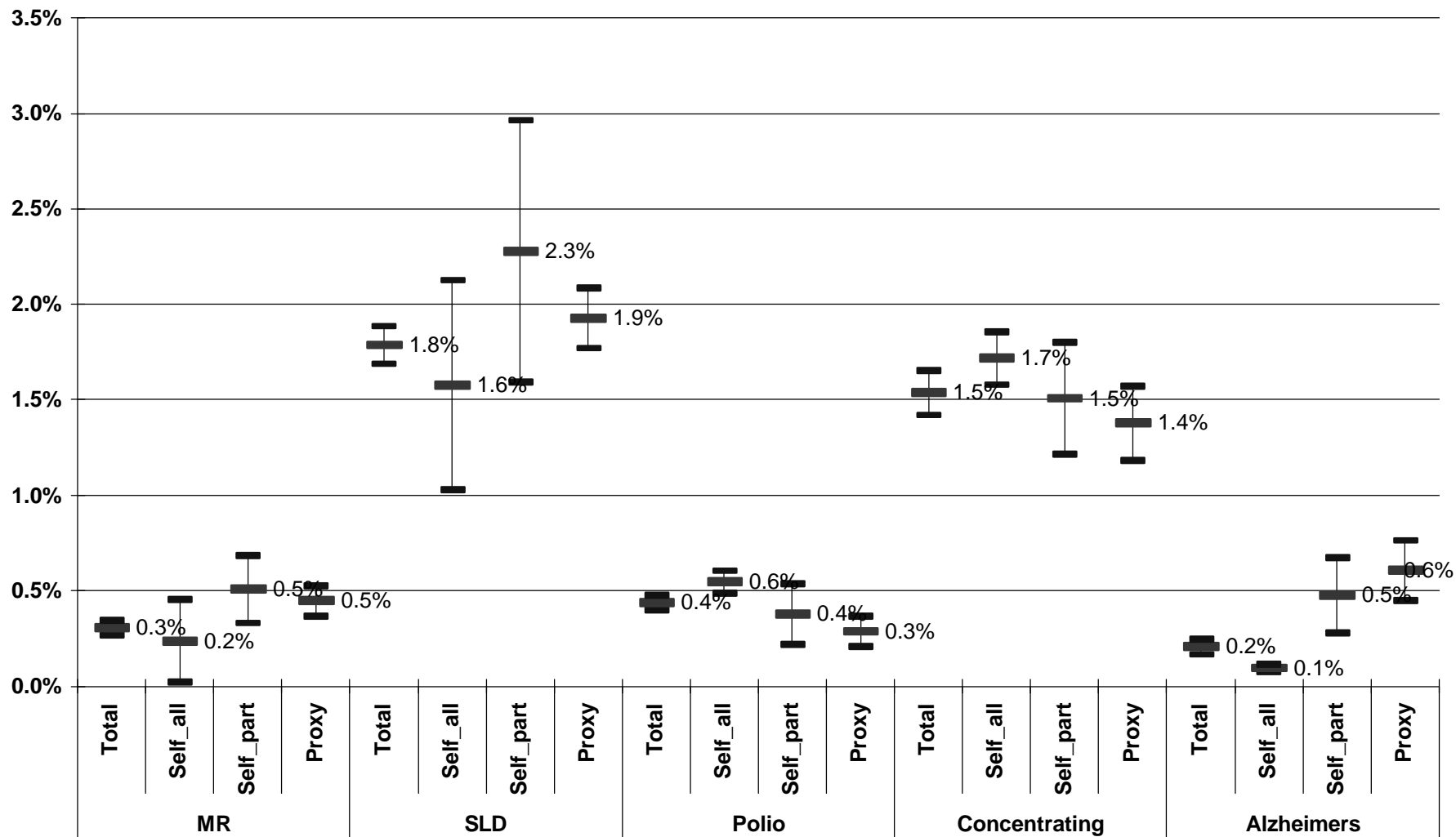




# NHIS-D1 Question on Developmental Disabilities

- I am going to read a list of medical conditions. Tell me if anyone in the family has any of these conditions, even if you have mentioned them before.)
- Does anyone in the family, that is (read names) have – *learning disability, cerebral palsy, cystic fibrosis, Down syndrome, mental retardation muscular dystrophy, spina bifida, autism, hydrocephalus*

# Prevalence of Various Conditions by Respondent Status, National Health Interview Survey-D1, 1994



# Operational Definition of Mental Retardation – NHIS, 1994/1995

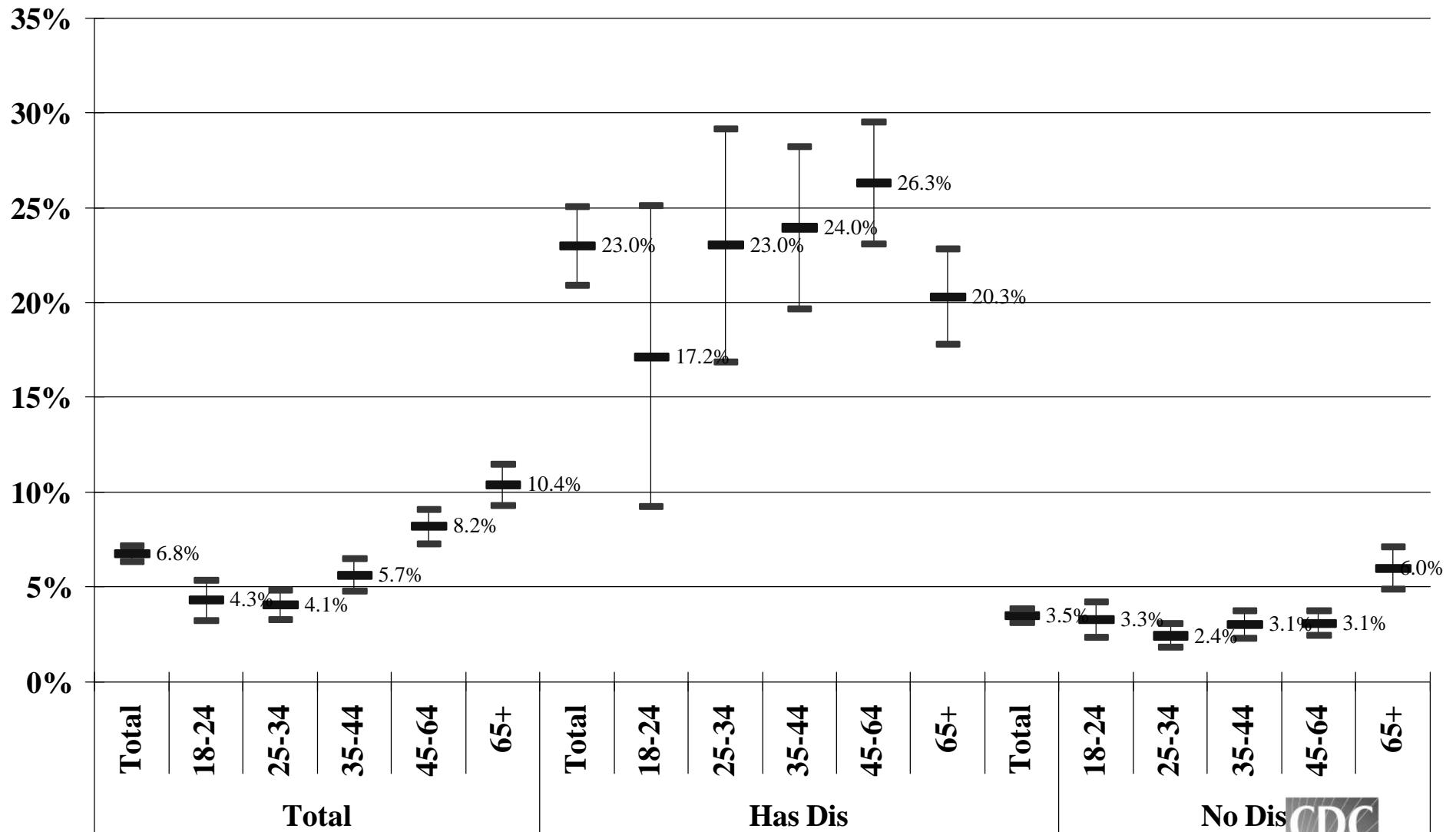
Larson et al., 1999

- If “Yes” to presence of MR
- If MR cause of activity limitation
- If MR cause of limitation in communication, getting along w/ others, ADLs, IADLs, or reason for service
- Acromegaly
- Amino acid transport disease
- Autism
- Branched chain amino acid disturbance
- Cerebral palsy
- Congenital anomaly
- Congenital birth defect
- Congenital CMV
- Congenital hypothyroidism
- Congenital syphilis
- Copper metaboloc disorder
- Deformity of skull

# Operational Definition of Mental Retardation - continued

- Encephalopathy
- Epilepsy
- Hydrocephalus
- Klinefelter's syndrome
- Leukodystrophy
- Lipodosis
- Noxious substance affecting newborn
- Other brain or CNS conditions or deformities
- Other developmental delays
- Reduction deformity of the brain
- Sec chromosome anomaly
- Spina bifida
- Thalassemias
- Tuberos sclerosis
- Unknown congenital or birth injury

# Percent Reporting Trouble Learning Remembering or Concentrating, 1998 BRFSS, 11 States and DC



# Cognitive Components of the Response

(Tourangeau, et al. 2000, p. 8)

## Comprehension

- *Attend to questions and instructions*
- Represent logical form of question
- Identify question focus
- Link key terms to relevant concepts

## Retrieval

- Generate retrieval strategy and cues
- Retrieve specific, generic memories
- Fill in missing details

## Judgment

- Assess completeness and relevance of memories
- Draw inferences based on accessibility
- Integrate material retrieved
- Make estimate based on partial retrieval

## Response

- Map judgment onto response category
- Edit response

# Problems Related to Surveys

Errors of nonobservation – related to coverage, nonresponse and sampling errors (Groves, 1991)

– Coverage

- Inaccessibility of research and surveillance tools for people with disability (Meyers & Andresen, 2000) especially problematic with regard to cognitive limitations
- Many surveys exclude institutional populations

– Nonresponse

- Reluctance to self-identify

# Problems Related to Surveys, Cont'd

## Observational errors - measurement errors (Groves, 1991)

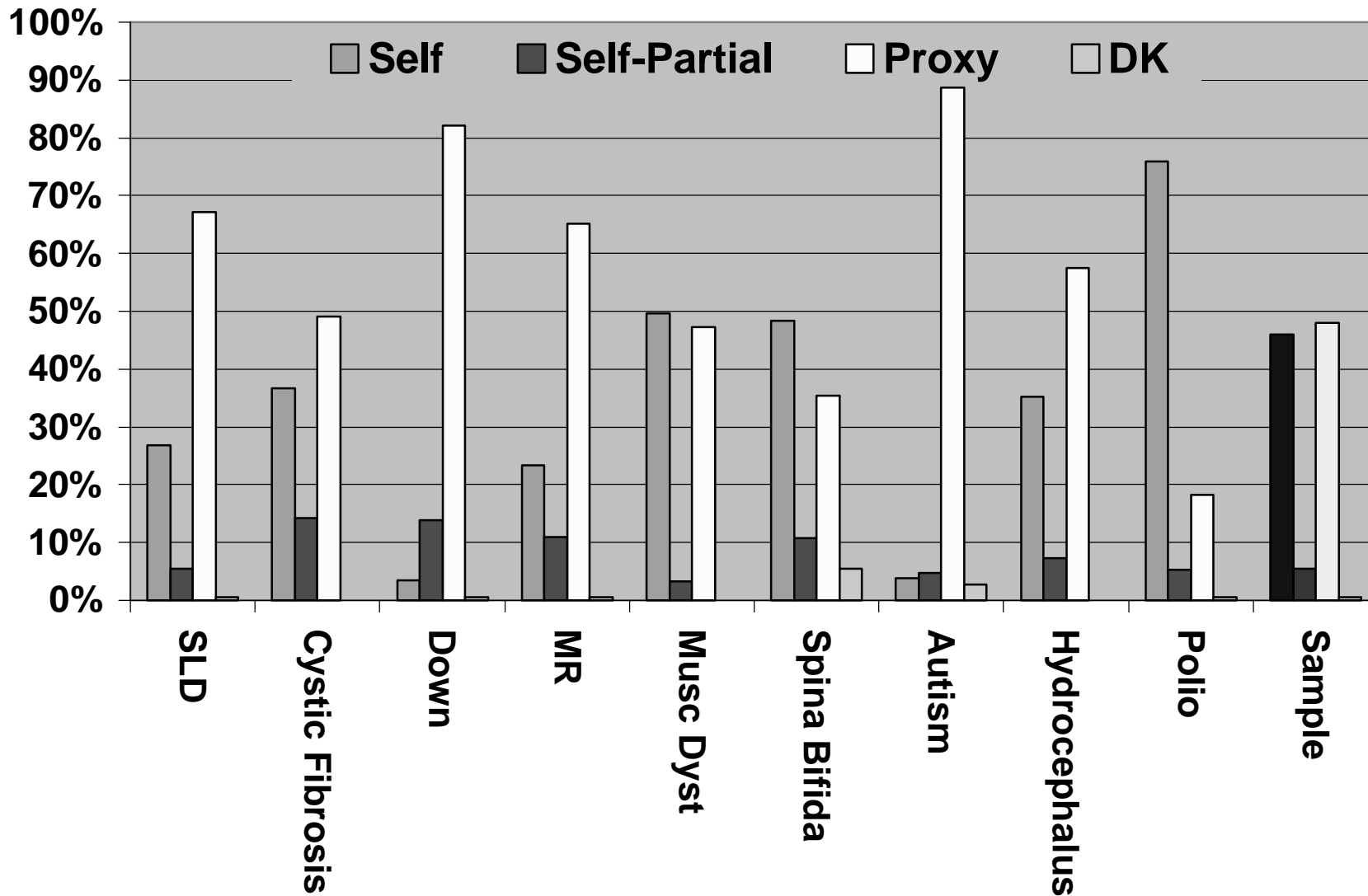
- Interviewer
- Respondent
- Questionnaire – wording or phrasing may be too demanding
- Mode of data collection

## Proxy vs. Self Report

- Todorov & Kirchner (2000) reported differences in response strategies between self and proxy reports for NHIS-D1



## Respondent Status for Conditions (Response = "Yes") NHIS-D1, 1994



# **Response Biases Associated with Limited Cognitive Impairment (i.e., MR)**

- **Responsiveness**
- **Reliability**
- **Consistency**
  - **Acquiescence**
  - **Nay-saying**
  - **Recency**

**(Heal & Sigelman, 1995)**

# Personality Factors Bearing on Survey Responses – Mental Retardation

- Stigma (Dudley, 1997; Edgerton, 1967, 1993; Edgerton & Bercovici, 1976)
- Social/environmental deprivation (e.g., Greenbaum & Auerbach, 1998)
- Experience of failure; outerdirectedness; positive reaction tendencies; negative-reaction tendencies; diminished self-concept (Zigler, et al.)

# Summary

- Cognitive limitation is vaguely defined
- Prevalence estimates vary widely
- People with cognitive limitations are underrepresented in national surveys and census
- Surveys are cognitively demanding
- Behavior of people with cognitive limitations affected by diminished intelligence AND personality patterns
- Alternative survey formats have advantages and disadvantages

# Recommendations

- Incorporate the knowledge and emotions of people with cognitive limitations, and their family and friends, into the survey development process
- Targeted surveys for cognitive limitation – household-based
- Include environmental variables
- Data collection on people in institutional settings
- Additional research into bias of proxy reporting
- Use of alternative question and response formats for people with cognitive limitations

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