Politics, Prevalence, and the Public Interest

Some Historical Notes

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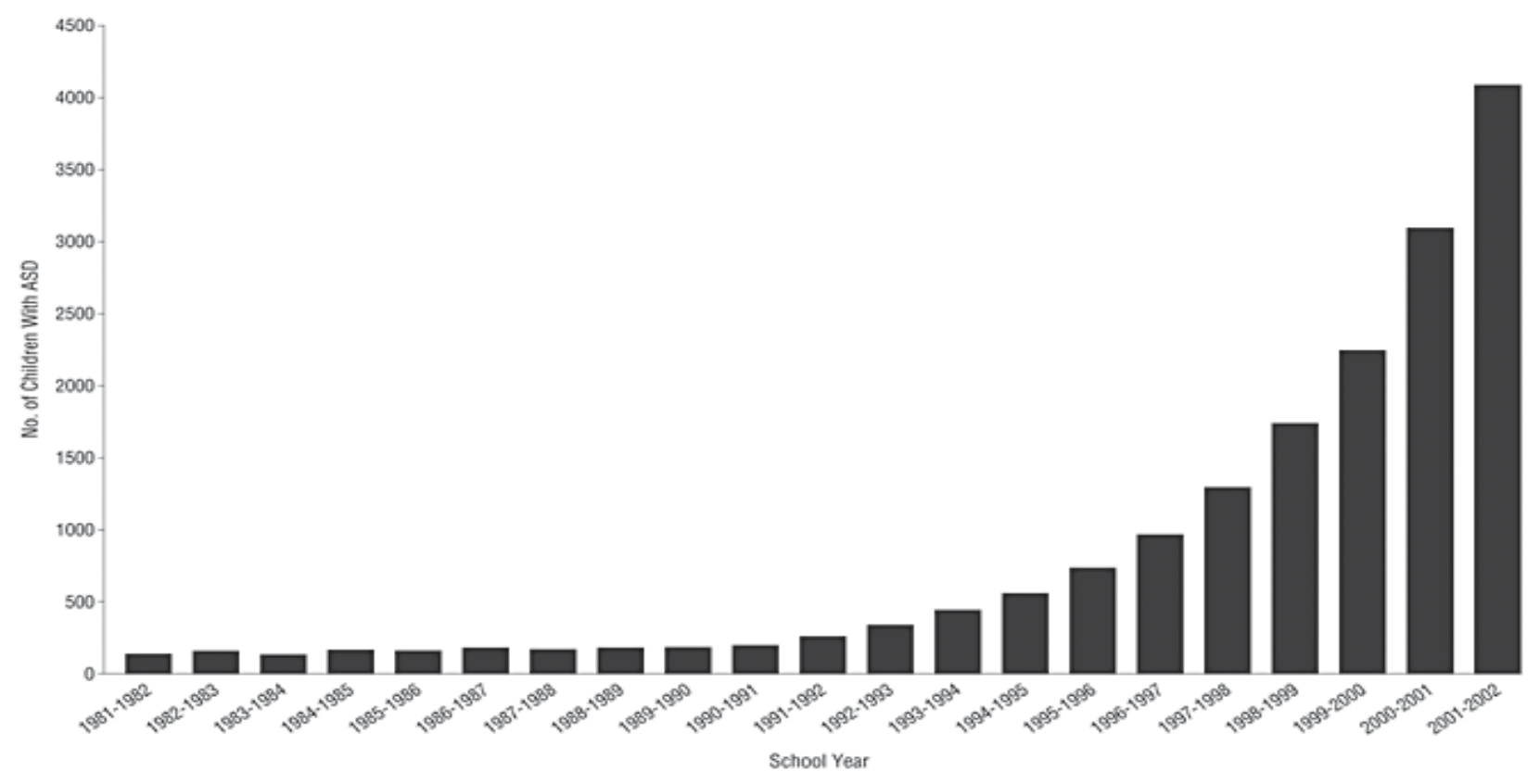
What Do You See?

Number of children classified as having an autism spectrum disorder (ASD) special educational disability in Minnesota from 1981-1982 through 2001-2002



Gurney, et al. Arch Pediatr 2003;157:622-627.

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3 Statements and a Question

1. Data on the prevalence of a condition are often used in political statements.
2. Data on prevalence have (and should have?) consequences for public resources.
3. Prevalence is calculated in a specific political environment. Which influences which? (Empirical research question)

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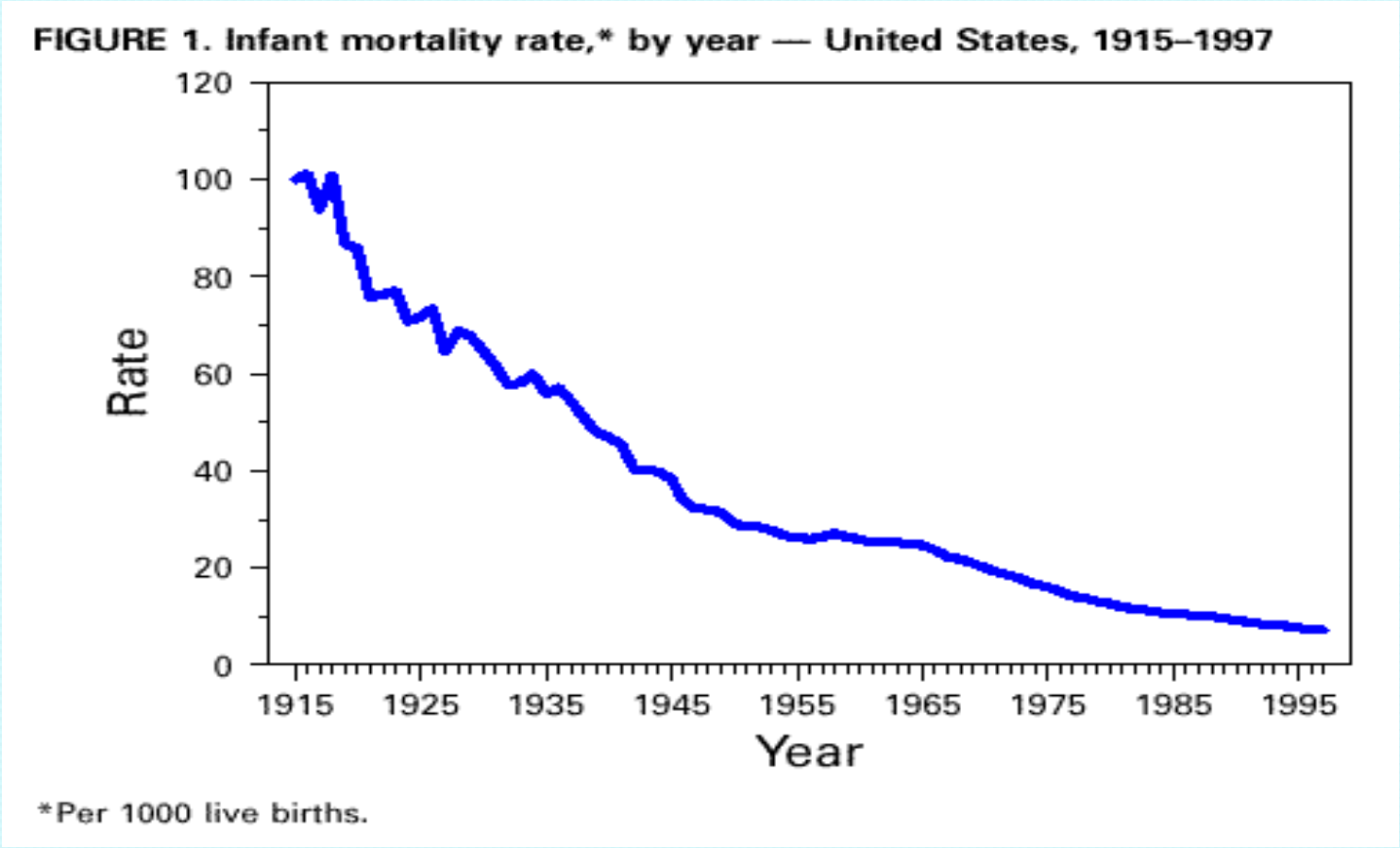
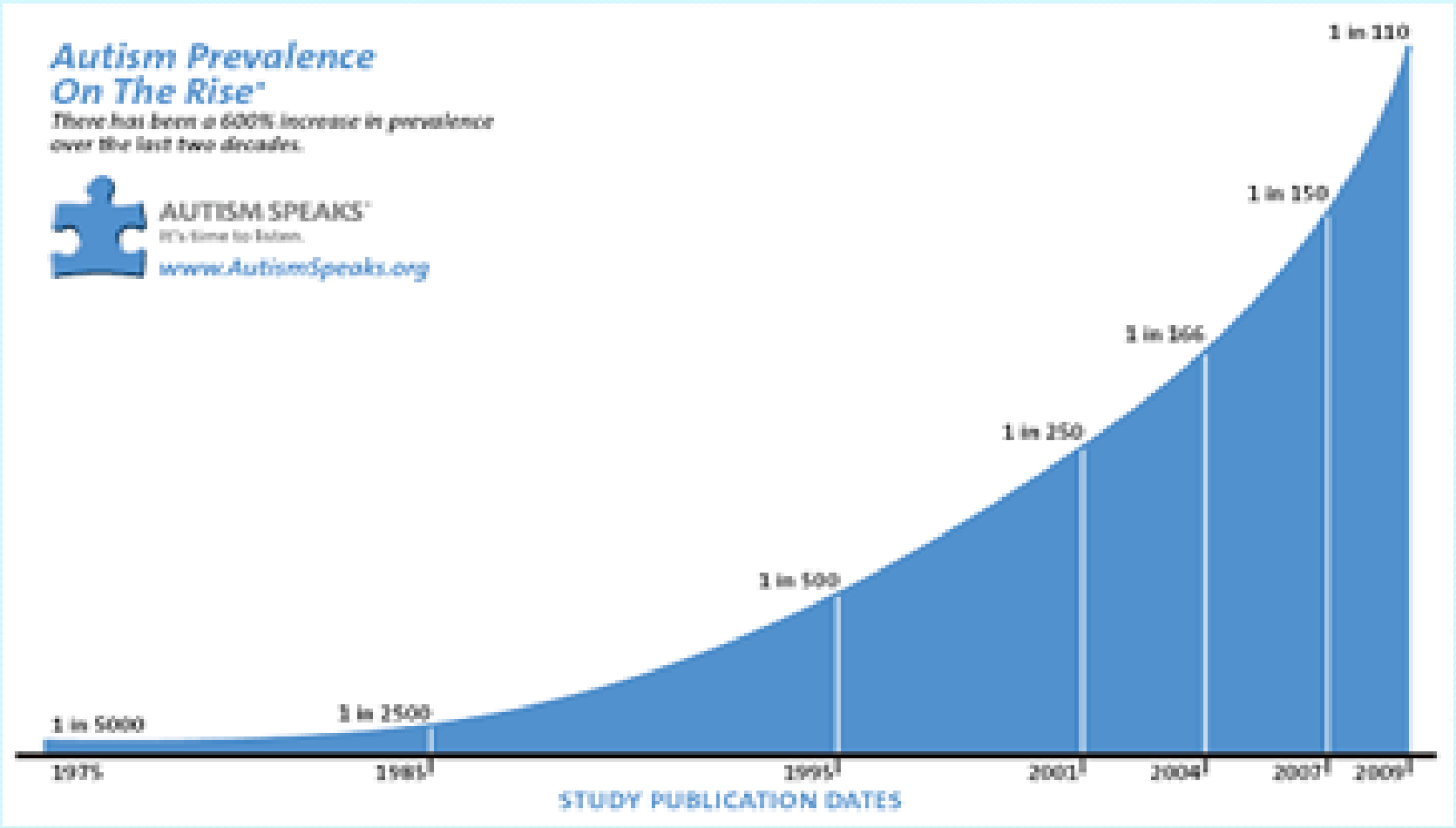
Infant Mortality (US Bureau of Statistics)



Death is a Social Disease (Wm Coleman, 1982)

- Public health statistics has origins in early 1800s France and Great Britain
- Morbidity and mortality linked to social class, environment, etc.
- Since at least the early 1800s, prevalence estimates reflected well-being of a specific location/community
- Early 1900s in US and Europe: infant mortality rate was interpreted as a measure of economic, political, and moral well-being of a community (Brosco, Pediatrics 1999)

Autism Speaks: 2009 Top Research



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1% of children have an ASD

- Different approaches lead to different estimates (e.g. case definition, case finding)
- **As near as we can tell, it's around 1%**
  - Kogan, 2009 - parent report
    - 1/91
  - CDC-ADDM Network, 2009 – record review
    - 1/110

Chronic Conditions of Childhood

Prevalence (per 100)

Learning disability	6.8	Allergies	9.6
ADHD	5.9	Recurrent OM	8.3
Intellectual dis. (MR)	1.5	Asthma	7.2
Autism	**1.0**	Diabetes	0.1
Hearing loss	0.4	Sickle cell	0.1
Visual loss	0.4	Kidney transplant	0.002
Cerebral Palsy	0.3		
Down Syndrome	0.15		

Is there an epidemic of autism?

- - 15% of children in the US have a developmental/behavioral disorder
  - ADHD, Reading disorder, Depression
- > 20% of children in the US live below the Federal Poverty Line
- 30-40% of children do NOT graduate high school on time

Autism is a Public Policy Challenge

- AAP/Bright Futures recommends that pediatric health providers **formally** screen all children for ASDs at 18 and 24 months
- Children who screen positive should be referred for assessment and early intervention (Part C of IDEA)

Implications of Universal Screening

- Best screening tool available is MCHAT
  - Specificity 93-99%
- Using the MCHAT will yield approximately 10-20 "false positives" for every "true positive"
- In Florida, e.g., Part C/Early Intervention may get as many as **10,000 new referrals** per year
  - Personnel/resources not available to help families who are referred with positive screen

Costs of Autism in Florida

- Screening for ASDs is an "unfunded mandate"
  - $2000 - $3000/physician
- Cost to Part C/EI if autism assessments
  - $1-2 million per year
- Cost of providing treatment 25 hrs/week
  - $55 million per year for 1500 children
  - Total budget now for Part C/EI
    - $48 million/year for 37,000 children

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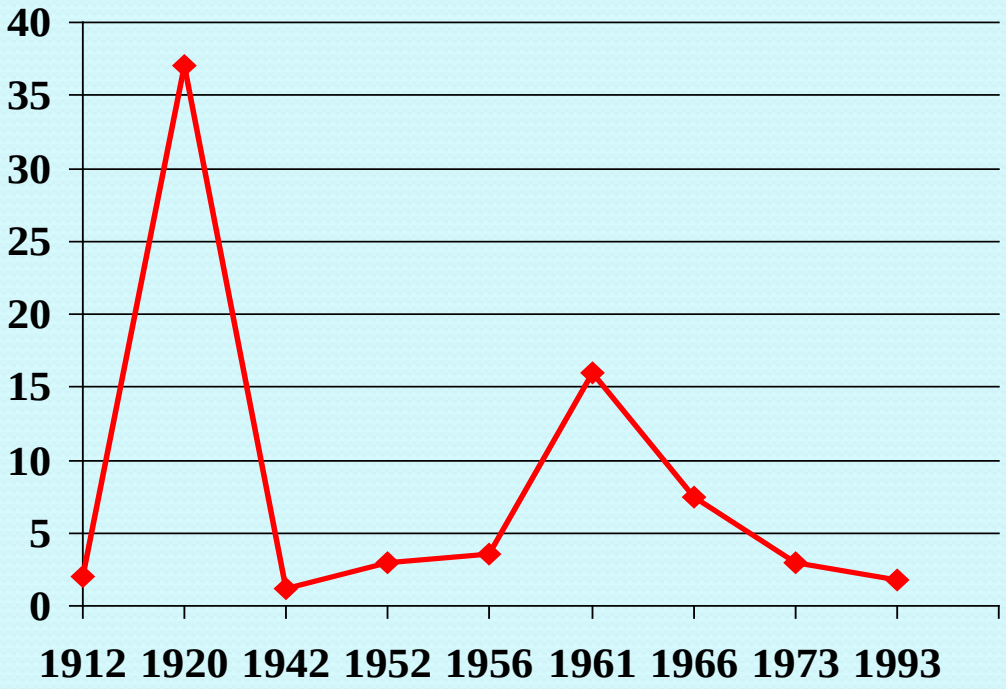
Prevalence of Intellectual Disability

Per 100 population



Brosco, More Than the Names Have Changed , 2008

Why Such Dramatic Variation?

- "Real" change in prevalence of intellectual disability? Unlikely.
- Change in methods of estimating prevalence
  - Case ascertainment
  - Population shifts
  - **Case definition**

Conditions of the Decade

- 1950s – Polio
- 1960s – Mental retardation
- 1970s – Physical disability
- 1980s – ADHD
- 1990s – Learning disabilities
- 2000s – Autism

Conclusion: "ELSI" Issues

- At certain moments in time, estimates of prevalence are political statements
- Prevalence of a condition should be one component in deciding public policy
- Historical record suggests that "social-political milieu" influences estimates of prevalence in ways that researchers likely don't recognize
- Advocacy groups/individual families historically can have great power in deciding policy
- Autism has much in common with other NDD

Bonus Slides

Has the number of children with autism increased since 1980?

Why is this important?

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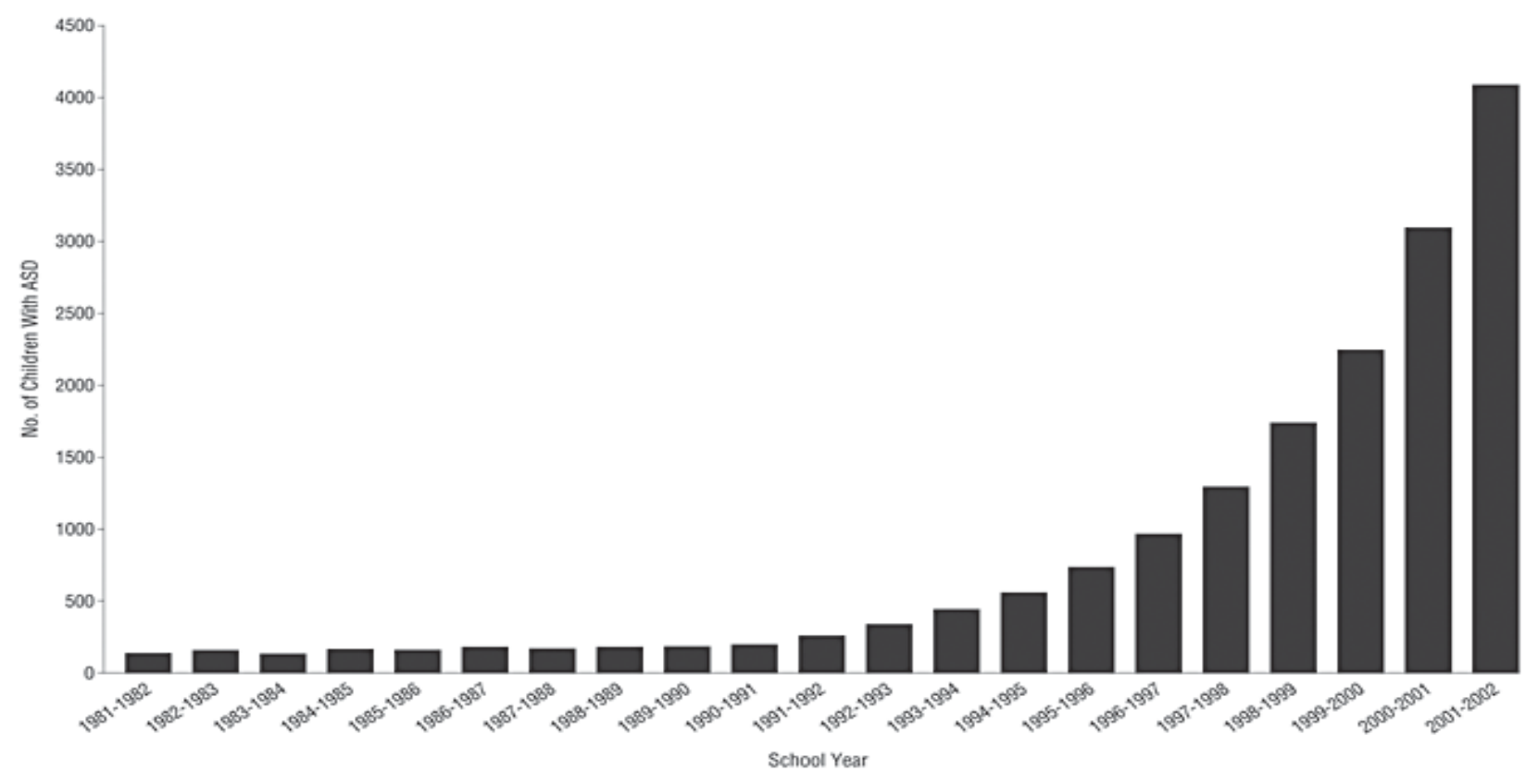

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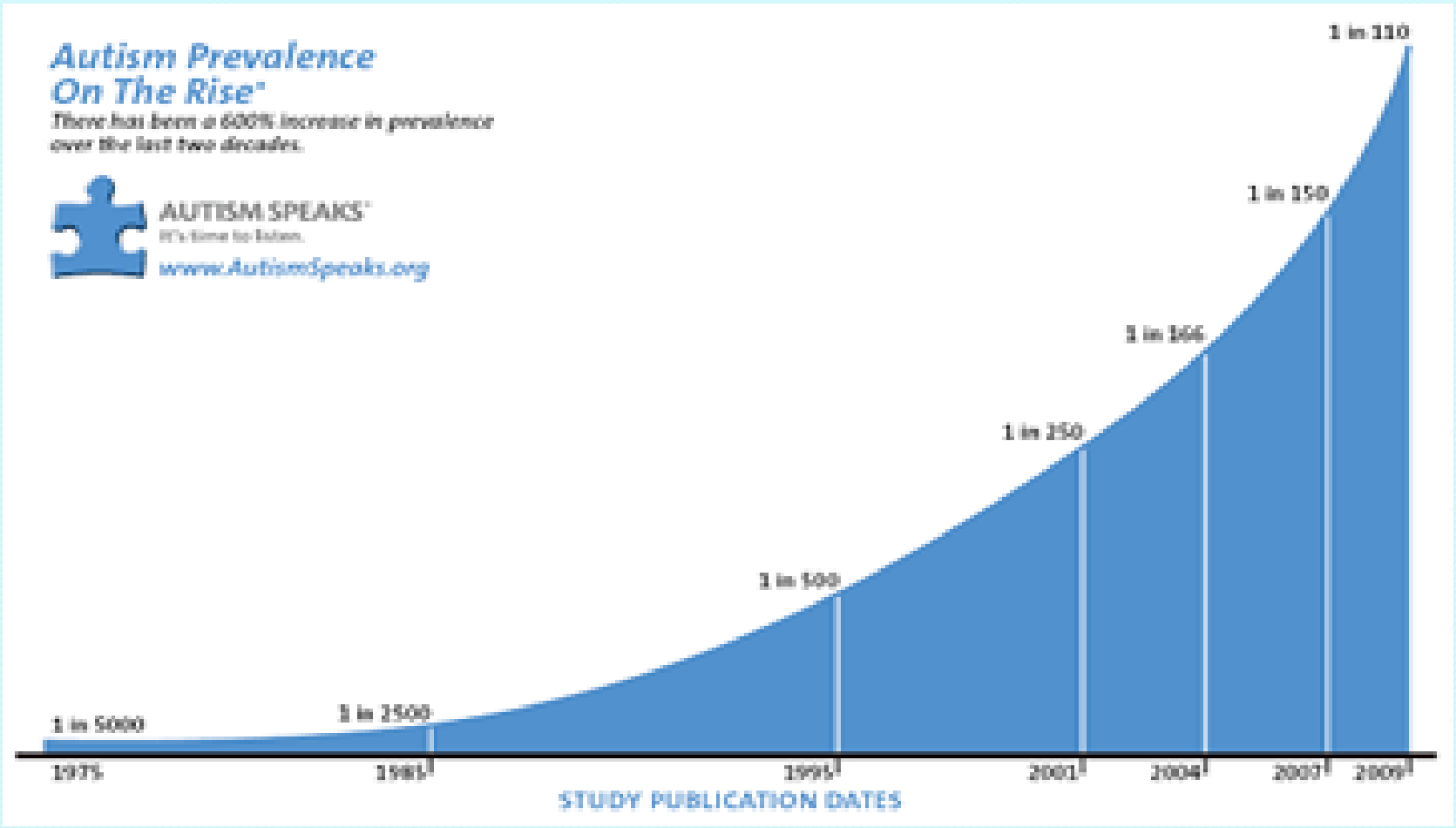


Increase in Population-Based studies?

- Consistent in studies in US, Europe, Japan, etc.
  - Note: low prevalence condition
  - Nearly all studies used different case definition and/or methods of finding

DSM III (1980): Infantile Autism

A. Onset before 30 months of age
B. Pervasive lack of responsiveness to other people
C. Gross deficits in language development
D. If speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, pronominal reversal.
E. Bizarre responses to various aspects of the environment, e.g., resistance to change, peculiar interest in or attachments to animate or inanimate objects

DSM III-R (1987): Autistic Disorder

- "spectrum disorder"
- diagnostic triad
  - "qualitative impairment in reciprocal social interaction"
  - "impairment in communication and imaginative activity"
  - "markedly restricted repertoire of activities and interests"

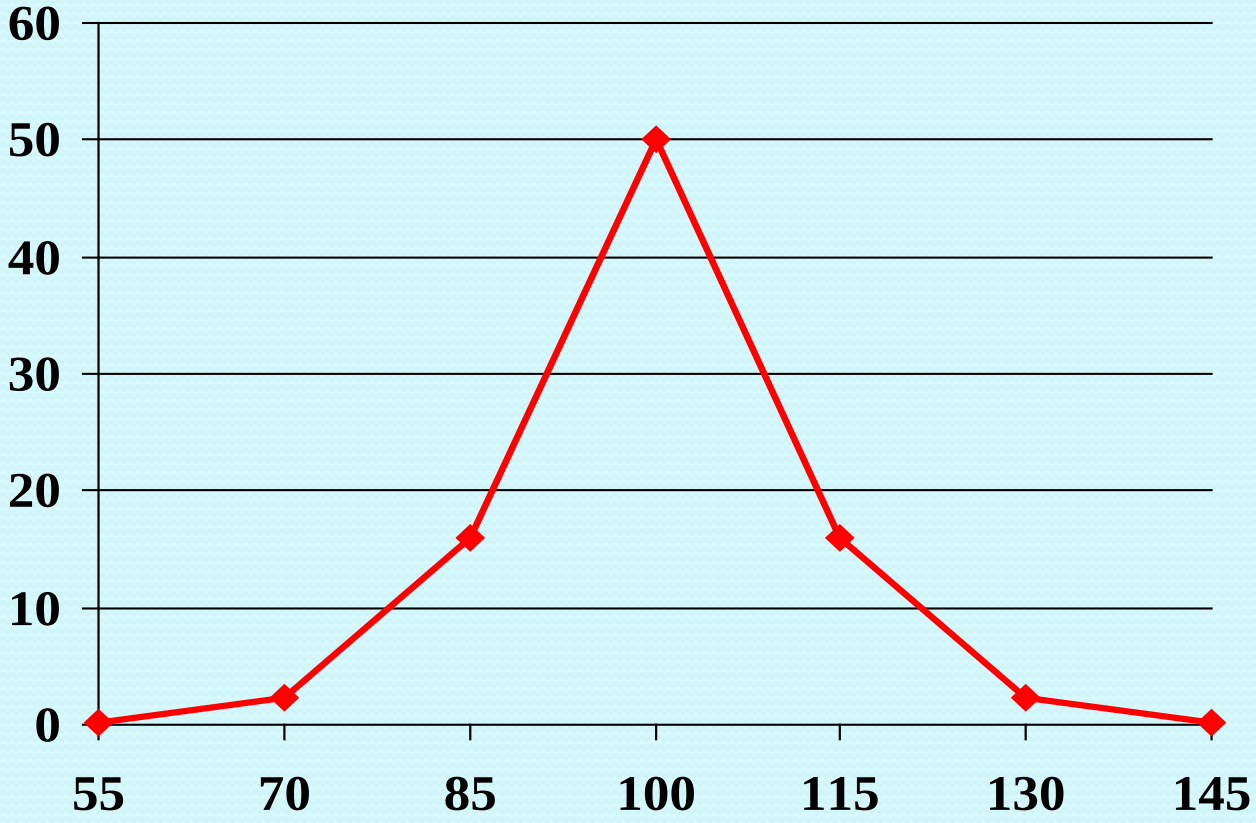
DSM III-R (1987): Autistic Disorder

- "No mode of communication, such as: communicative babbling, facial expression, gesture, mime, or spoken language"
- "No or abnormal seeking of comfort at times of distress"
- "Absence of imaginative activity, such as play-acting of adult roles, fantasy character or animals; lack of interest in stories about imaginary events"

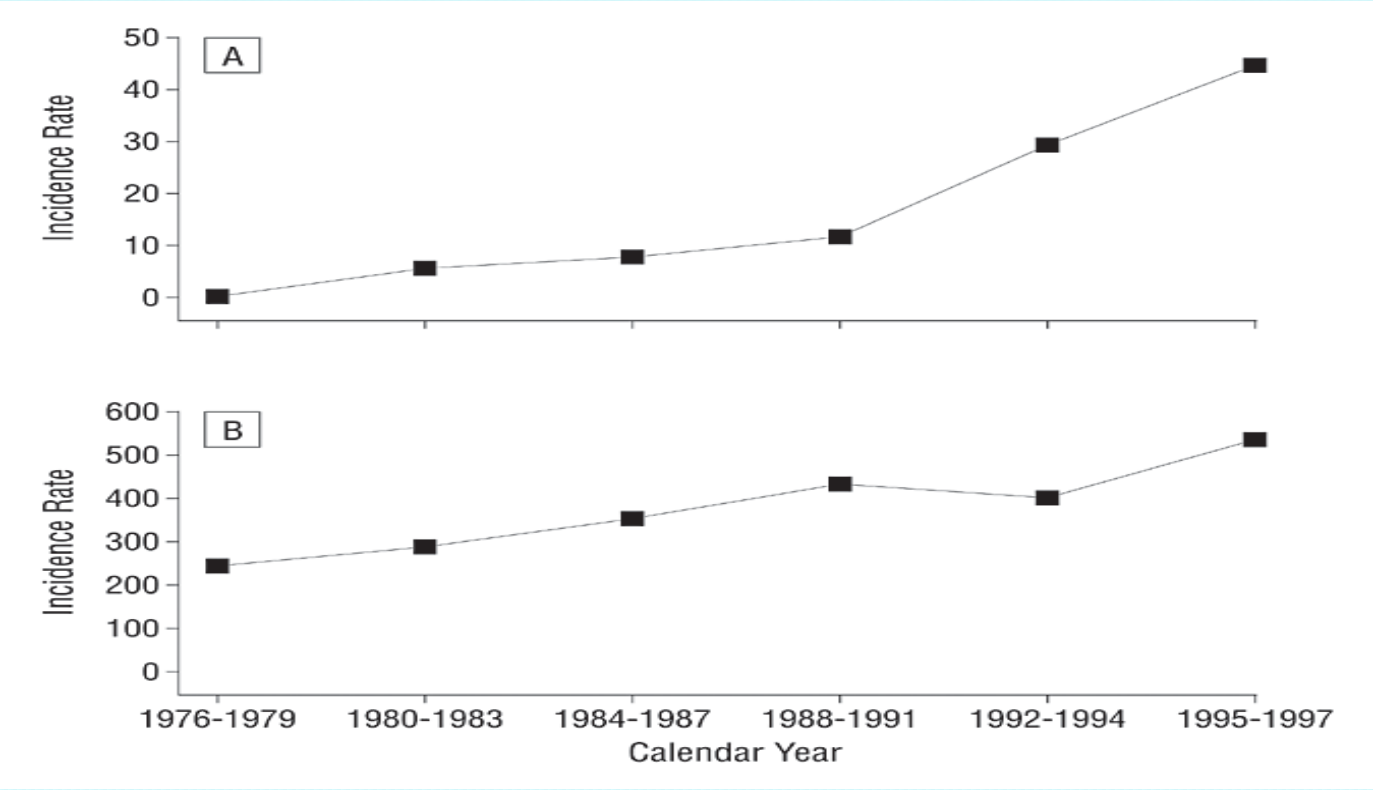
DSM-IV (1994) Autistic Disorder

- "In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation"
- "Failure to develop peer relationships appropriate to developmental level"
- "Lack of varied spontaneous make-believe play or social imitative play appropriate to developmental level"

DSM Since 1980:
Changing "Cut-off" for Defining Autism



Overall age- and sex-adjusted incidence per 100 000 children by period of research-identified autism (A) and all other clinical diagnoses of developmental, neurologic, and psychiatric disorders (B) among residents of Olmsted County, Minnesota, between 1976 and 1997



Barbaresi, W. J. et al. Arch Pediatr Adolesc Med 2005;159:37-44.

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