

Is ASD Increasing?

TriCare Autism Study

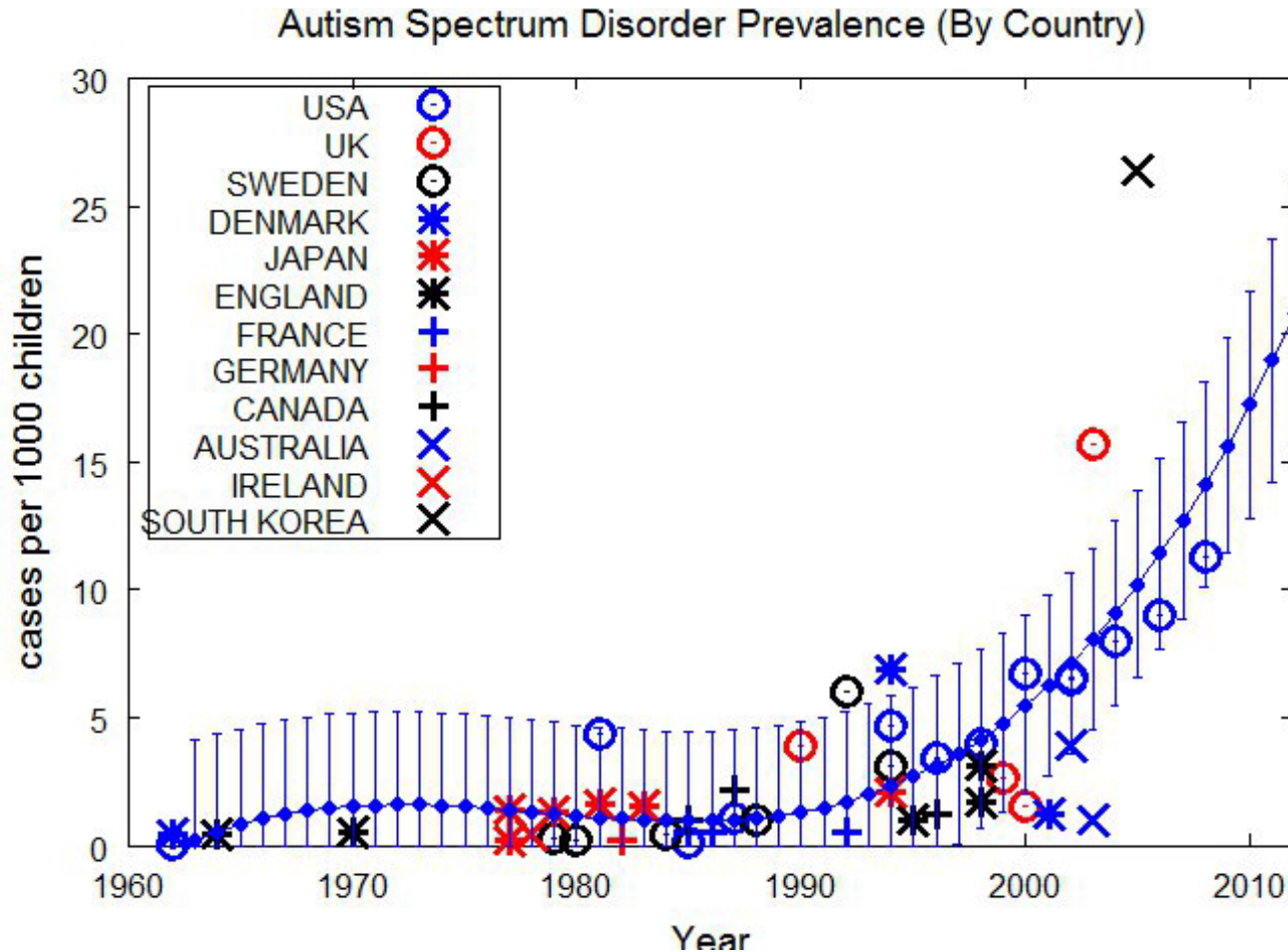
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National Academies Virtual Listening Session
May 10th 2024

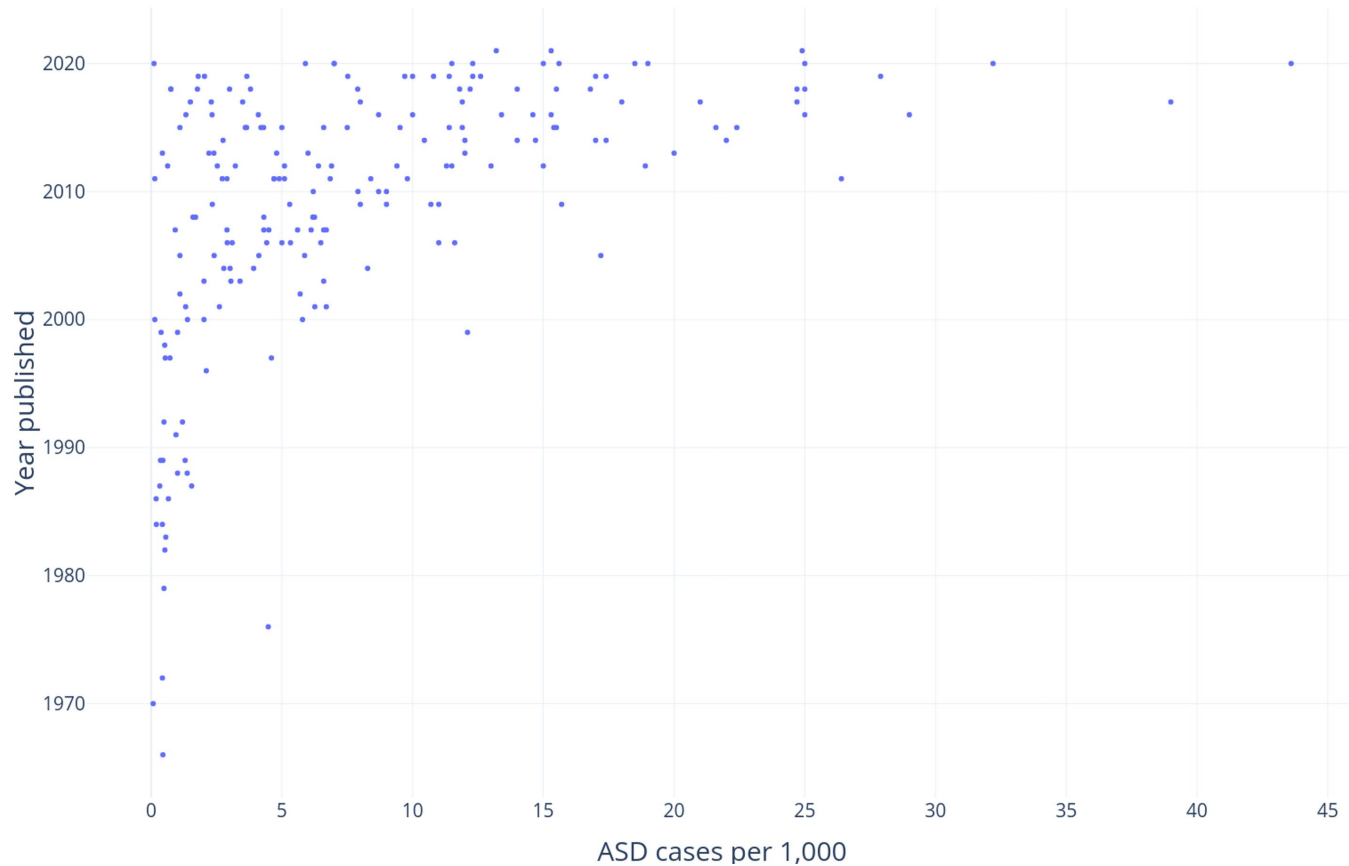
DSM 5 ASD Dx Criteria

- 2 Core Symptom Domains
 - Qualitative Impairments in Social Communication
 - Restricted and Repetitive Behavior (RRB), Interests and Activities
- Onset in Early Childhood

Prevalence Studies of ASD



CDC Prevalence of ASD in US (1970~2020)



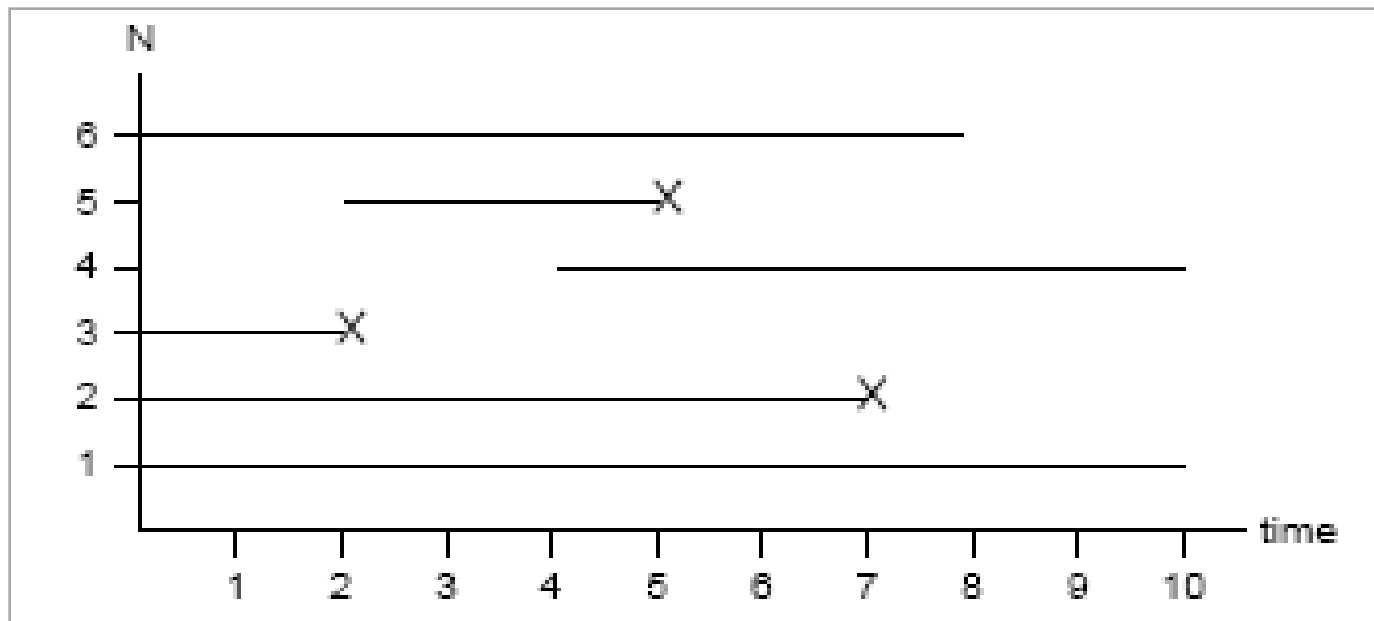
What Frequencies?

- Incidence

- Prevalence

Measures of Disease Frequency

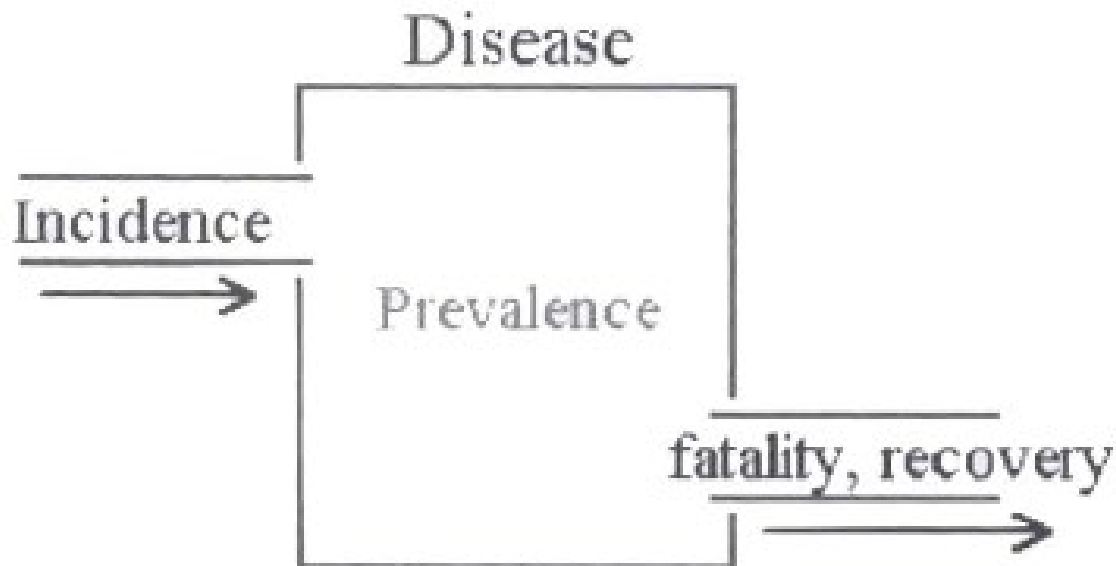
- Incidence =
$$\frac{\text{N of new onsets of diseases}}{\Sigma \text{ observed time across individuals}}$$



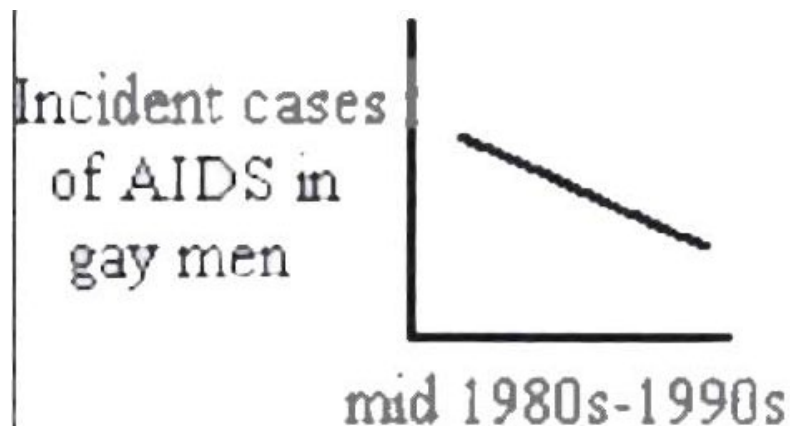
$$\text{Incidence rate} = \frac{0 + 1 + 1 + 0 + 1 + 0}{10 + 7 + 2 + 6 + 3 + 8} = 3 / 36 / \text{time unit}$$

Measures of Disease Frequency

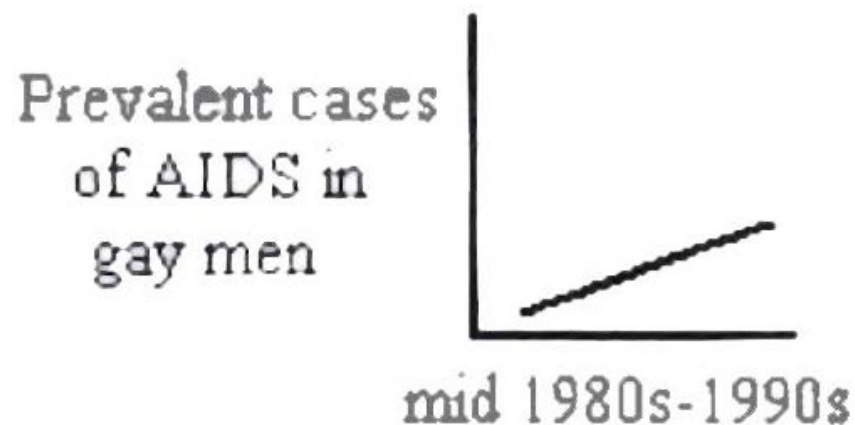
- Prevalence=
$$\frac{\text{N of subjects with disease}}{\text{Population (sample size)}}$$



Relationship between Incidence and Prevalence



- Anti-retroviral treatment
- Reduce high risk behavior



- Treatments prolong life

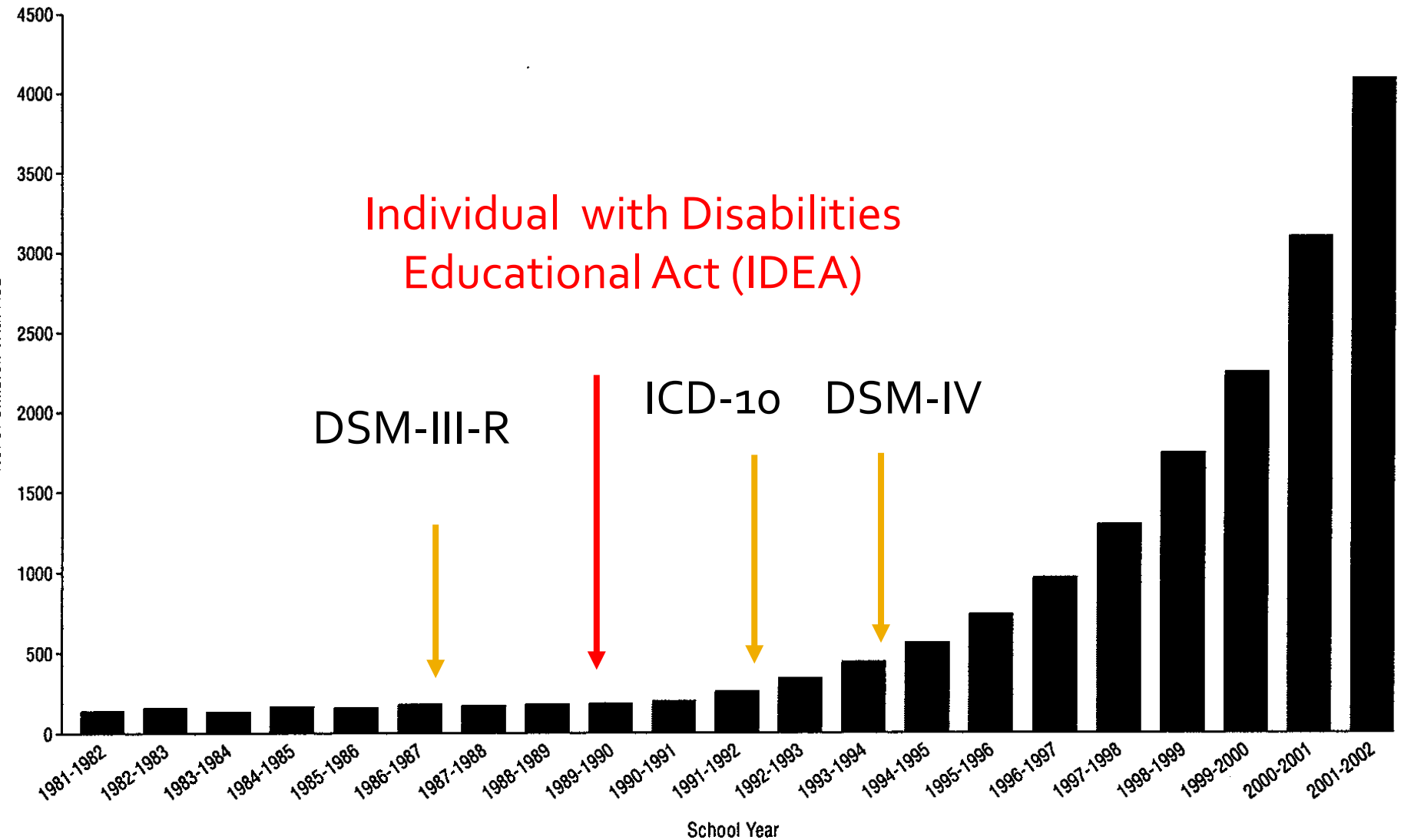
Previous Epidemiological Research of ASD

- Impact of Diagnostic Criteria (Northern Finland)

Age	N	Population	Dx Criteria	Prevalence (/10,000)
15-18	9	39,216	Kanner	2.3
15-18	28	39,216	Autism: ICD10/DSM IV	6.1
15-18	30	39,216	ASD: ICD-10	7.6

Kielinen et al., 2000

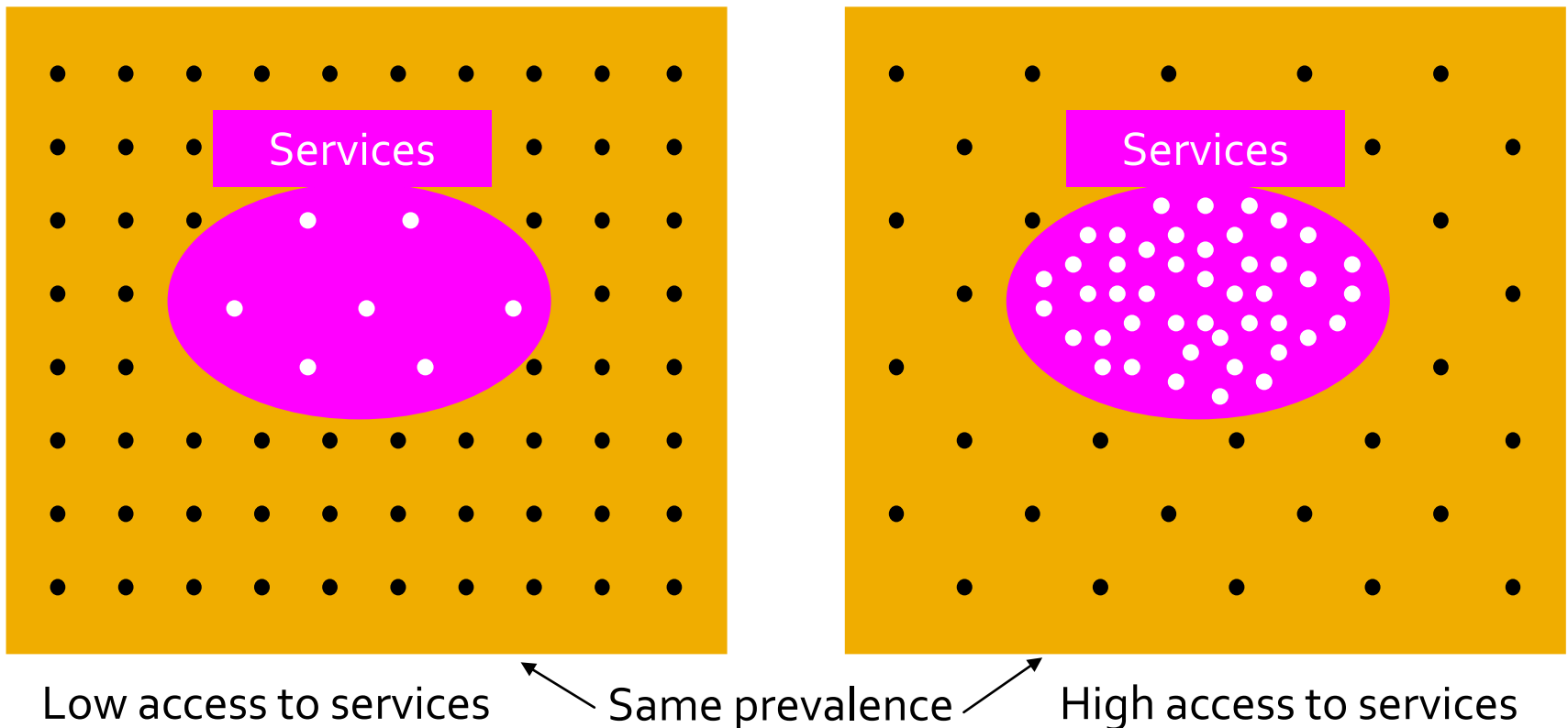
Trends in Minnesota



Gurney et al., 2003

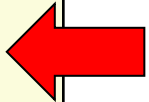
Previous Epidemiological Research of ASD

- Impact of Access to Services

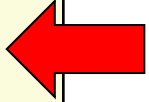


Increase of UK ASD Prevalence

Study (Year)	Location	Source Pop N	Age	Case Source	Prevalence (%)
Baron-Cohen (2009)	Cambridge-shire	11,635	5-9	Special & Main-stream Schools	1.6
Baird (2007)	South East Thames	56,946	9-10	Special need children	1.2
Fombonne (2001)	Stafford-shire	15,500	2.5-6.5	Assessment for Screen (+)	0.6
Baird (2000)	South East Thames	16,235	7	Assessment for Screen (+)	0.5
Taylor (1999)	North Thames	490,000	0-16	Service Records	0.1



x16



Valid and Reliable Measures of Disease Occurrence

- Requirement for valid and reliable prevalence estimates
 - 1) Sufficient size population
 - 2) Inclusion of all the individuals at risk for an outcome
 - 3) Systematic, standardized screening of the population
 - 4) Age for reliable and valid and case ascertainment
 - 5) Diagnoses by standardized research assessments
 - 6) Consistent case identification method over the course

Total Population Approach in Korea



- Ethnically, genetically, environmentally homogeneous population
- One language with almost 100% literacy rate
- 99% children attending compulsory public elementary schools
- Case identification through school system
- Metropolitan Seoul area

Screening Survey: 33 schools, 23,000 children



- Clinical Population
 - Children with prior service history
- Non-Clinical Population
 - Children who were not diagnosed or received services prior to the study

DSM IV ASD Prevalence Estimates

Article

Prevalence of Autism Spectrum Disorders in a Total Population Sample

Young Shin Kim, M.D., Ph.D.

Bennett L. Leventhal, M.D.

Yun-Joo Koh, Ph.D.

Eric Fombonne, M.D.

Eugene Laska, Ph.D.

Eun-Chung Lim, M.A.

Keun-Ah Cheon, M.D., Ph.D.

Soo-Jeong Kim, M.D.

Young-Key Kim, M.D.

HyunKyung Lee, M.A.

Dong-Ho Song, M.D.

Roy Richard Grinker, Ph.D.

Objective: Experts disagree about the causes and significance of the recent increases in the prevalence of autism spectrum disorders (ASDs). Limited data on population base rates contribute to this uncertainty. Using a population-based sample, the authors sought to estimate the prevalence and describe the clinical characteristics of ASDs in school-age children.

Method: The target population was all 7- to 12-year-old children (N=55,266) in a South Korean community; the study used a high-probability group from special education schools and a disability registry and a low-probability, general-population sample from regular schools. To identify cases, the authors used the Autism Spectrum Screening Questionnaire for systematic, multi-informant screening. Parents of children who screened positive were offered comprehensive assessments using standardized diagnostic procedures.

Results: The prevalence of ASDs was estimated to be 2.64% (95% CI=1.91-3.37),

with 1.89% (95% CI=1.43-2.36) in the general-population sample and 0.75% (95% CI=0.58-0.93) in the high-probability group. ASD characteristics differed between the two groups: the male-to-female ratios were 2.5:1 and 5.1:1 in the general population sample and high-probability group, respectively, and the ratios of autistic disorders to other ASD subtypes were 1:2.6 and 2.6:1, respectively; 12% in the general-population sample had superior IQs, compared with 7% in the high-probability group; and 16% in the general-population sample had intellectual disability, compared with 59% in the high-probability group.

Conclusions: Two-thirds of ASD cases in the overall sample were in the mainstream school population, undiagnosed and untreated. These findings suggest that rigorous screening and comprehensive population coverage are necessary to produce more accurate ASD prevalence estimates and underscore the need for better detection, assessment, and services.

(Am J Psychiatry 2011; 168:904-912)

Measures	Prevalence (%)	95% CI
Population		
Total Population	2.64	1.91-3.37
Non-Clinical Population	1.89	1.43-2.36
Clinical Population	0.75	0.58-0.93
ASD Type		
Any ASD	2.64	1.91-3.37
Autistic Disorder	0.94	0.56-1.34
Other Types of ASD	1.70	1.08-2.32
Sex		
Male	3.74	2.57-4.90
Female	1.47	0.60-2.37

1 in 38, 1 in 26 in boys, 1 in 68 girls

Clinical and Non-Clinical ASD Population

	Clinical ASD	Non-Clinical ASD
ASD Subtype Diagnoses	3/4 AD	3/4 Other ASD
SRS T-Score	84 \pm 17	64 \pm 14
Sex Ratio	5:1	2.5:1
Performance IQ	75	98
ID Percentage	59%	16%
RRB	Motor movements Unusual sensory response	Rigid adherence to routine Ritualistic behaviors
BASC Adaptability Score	38 \pm 9	40 \pm 10

Replication of Initial Korea ASD Prevalence Finding



Original article

Screening and direct assessment methodology to determine the prevalence of autism spectrum disorders

Laura A. Carpenter PhD^{a,*}, Andrea D. Boan PhD^{a,b,c}, Amy E. Wahlquist MS^b, Amy Cohen PhD^d, Jane Charles MD^a, Walter Jenner MS^a, Catherine C. Bradley PhD^a

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^b Department of Public Health Sciences, Medical University of South Carolina, Charleston
^c Department of Neurology, Medical University of South Carolina, Charleston
^d Department of Psychology, University of Illinois Urbana-Champaign, Champaign



The Prevalence of Parent-Reported Autism Spectrum Disorder Among US Children

Michael D. Kogan, PhD,^a Catherine J. Vladutiu, PhD, MPH,^a Laura A. Schieve, PhD,^b Reem M. Ghandour, DrPH,^a Stephen J. Blumberg, PhD,^c Benjamin Zablotsky, PhD,^c James M. Perrin, MD,^d Paul Shattuck, PhD,^e Karen A. Kuhlthau, PhD,^d Robin L. Harwood, PhD,^a Michael C. Lu, MD, MPH^f



Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

1 in 36, 1 in 23 boys, 1 in 88 girls

Saito et al. *Molecular Autism* (2020) 11:35
<https://doi.org/10.1186/s13229-020-00342-5>

Molecular Autism

RESEARCH

Open Access



Prevalence and cumulative incidence of autism spectrum disorders and the patterns of co-occurring neurodevelopmental disorders in a total population sample of 5-year-old children

Manabu Saito^{1†}, Tomoya Hirota^{1,2†}, Yui Sakamoto¹, Masaki Adachi³, Michio Takahashi³, Ayako Osato-Kaneda¹, Young Shin Kim², Bennett Leventhal², Amy Shui², Sumi Kato^{1,4} and Kazuhiko Nakamura^{1,3,4}



Open Access

Research

BMJ Open Autism spectrum disorder: updated prevalence and comparison of two birth cohorts in a nationally representative Australian sample

Tamara May,^{1,2} Emma Sciberras,^{2,3} Amanda Brignell,^{1,2} Katrina Williams^{1,2,4}

7-year Cumulative Incidence of ASD

- 10 Consecutive Birth Cohorts
- Screening of 62,135, 7 year old children
- Comprehensive diagnostic assessment for 746 screen positive children
- 402 children with confirmed best-estimate, clinical diagnoses of ASD
- In the process of simulation and modeling to compute 7-year cumulative incidence of ASD

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