The Paul Polani Lecture

A multidisciplinary unit capable of a broad spectrum approach to research aimed at the prevention of neurodevelopmental disorders manifesting as neurological diseases, mental retardation, cognitive,emotional, behavioural or sensory dysfunction

The Paul Polani Lecture

What is the Prevalence of autism and other disorders in the autism spectrum?

How common is autism really?

Autism and disorders of the autism spectrum

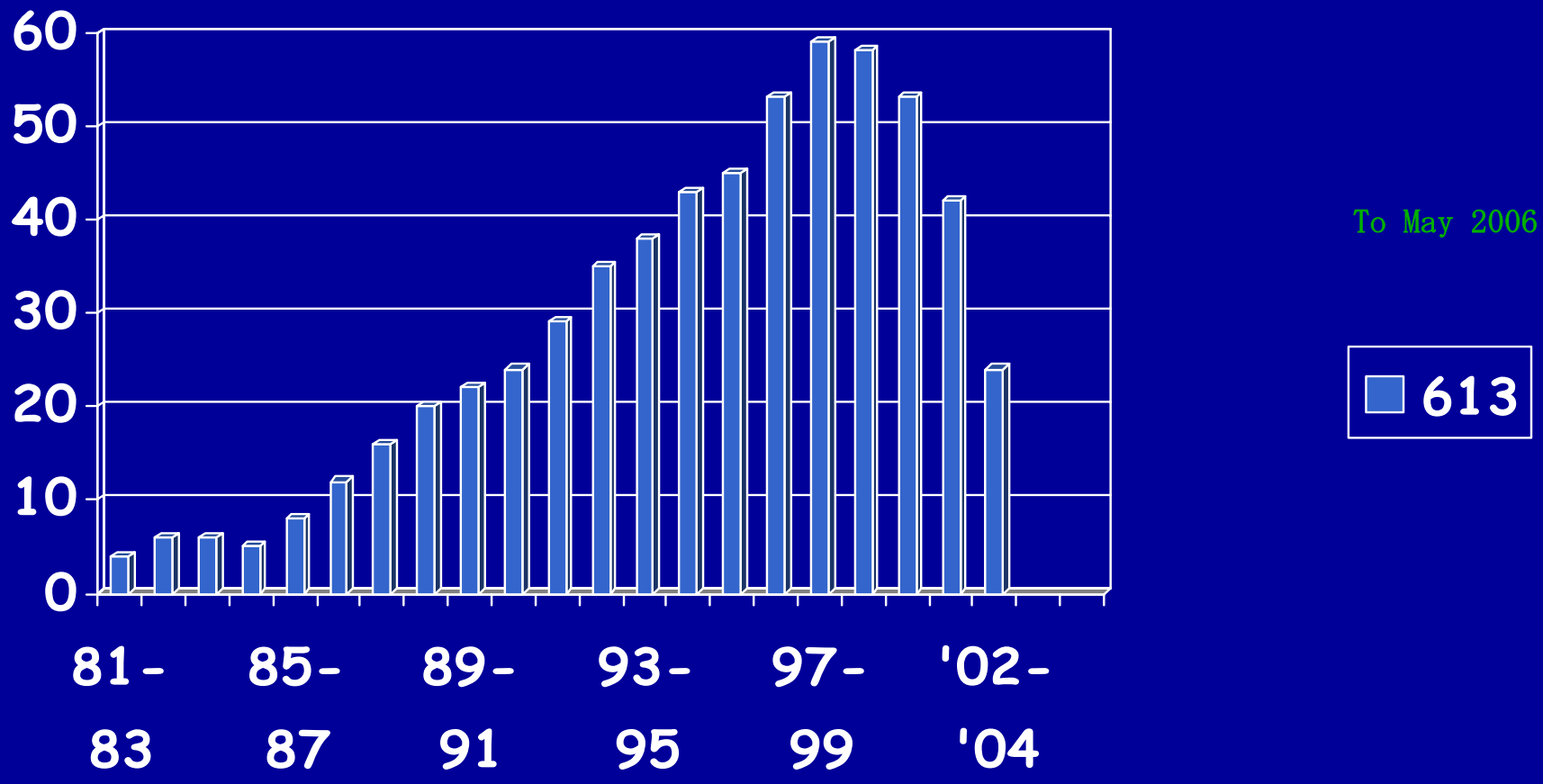
Qualitative impairment in:

- Sociability, empathy and ability to infer what another person is experiencing or thinking
- The communicative use of language and creative imaginative play
- Cognitive & behavioural flexibility and range of interests & activities.
- Other features such as altered sensory responses and stereotyped mannerisms common

Lewisham children & young people with ASD under 25 by their birth year from 1981 at May 2006:

ANNUAL NUMBERS – AVERAGED OVER 3 YEARS

(O'Sullivan & Stevenson)



Question

- What is the current population prevalence of ASD?
- Has there been a true rise in prevalence?
- Are any of the putative environmental factors related to any increase in autism?

Studies of the Prevalence of Autism and Autism spectrum disorders

- literature review: **5/ 10,000** **Fombonne (1998/2001)**

- ***AUTISM***

  16.8 /10,000 Chakrabarti & Fombonne (2001)

- ***AUTISM SPECTRUM DISORDERS***

  58/10,000 CHAT Baird, Cox, Charman et al (2001)

  67.4/10,000 Brick Township, N. Jersey (1998)

  62.6/10,000 Chakrabarti & Fombonne (2001)

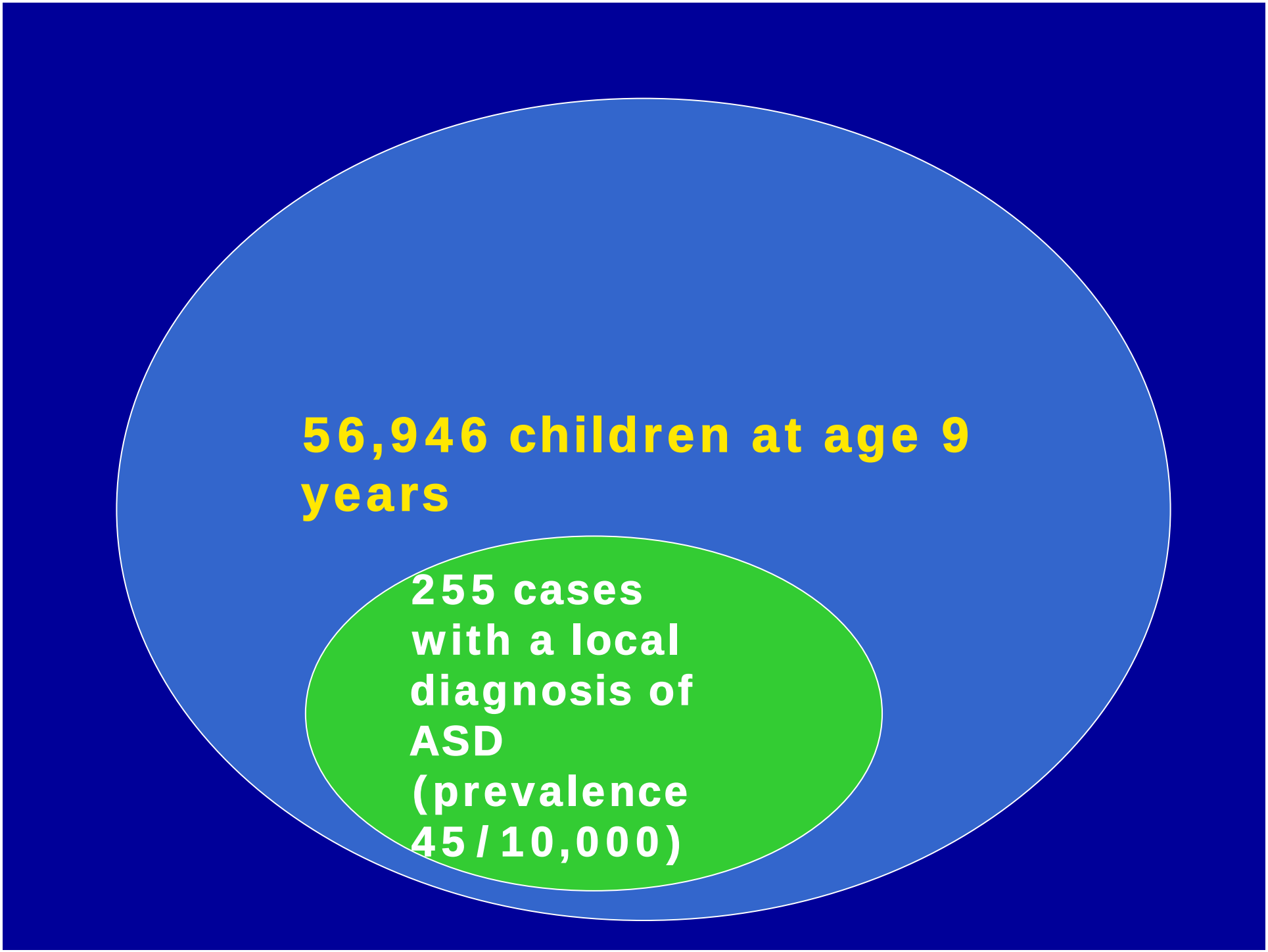
Measuring ASD prevalence

- Existing registers
- Screening of population and selected assessment

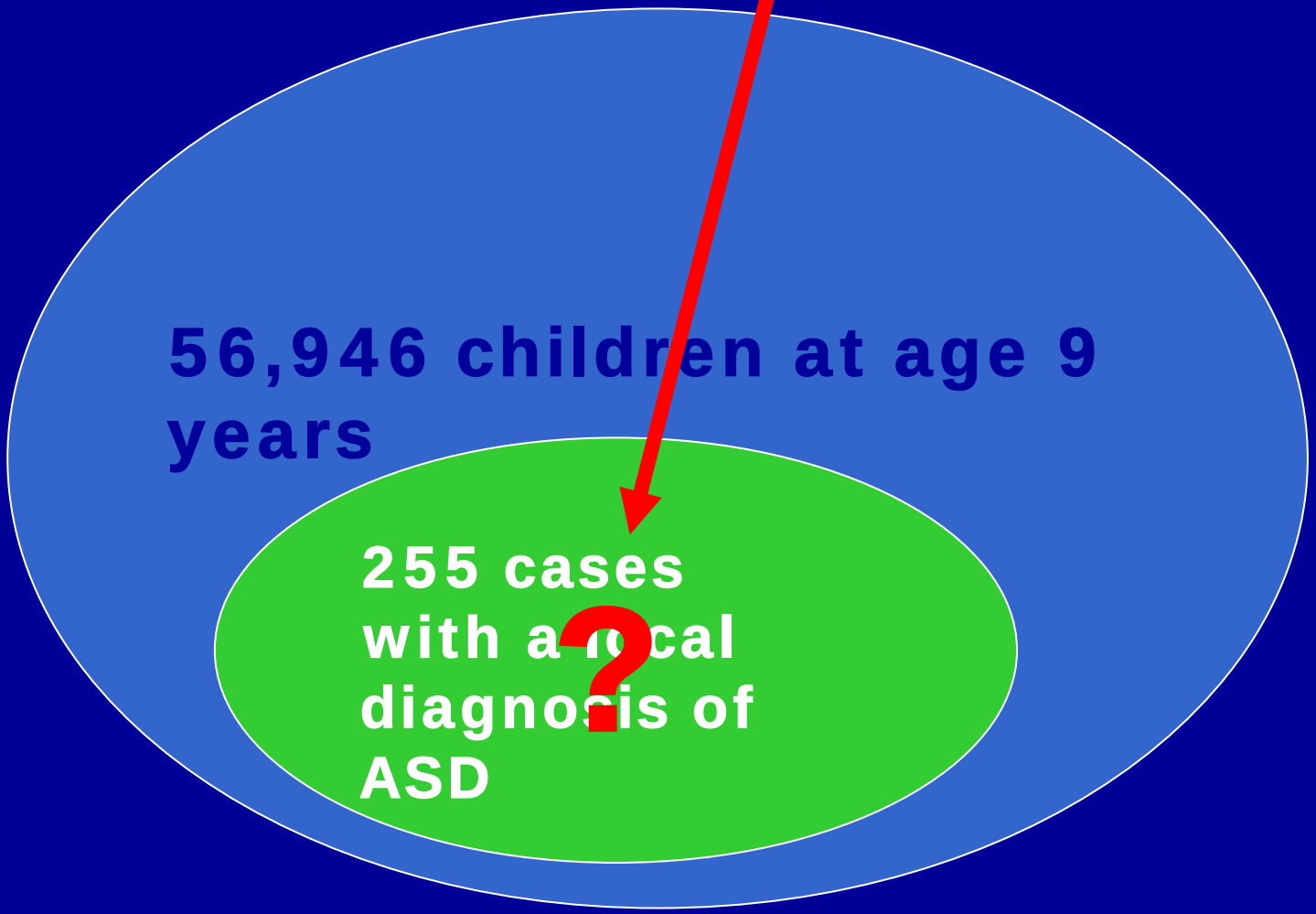
- Variable participation rates
- Age of subjects
- Location-rural/urban
- Inclusion of other diagnoses
- Measures used
- Definition used

Population Cohort of Children in South Thames: The Special Needs and Autism Project (SNAP)

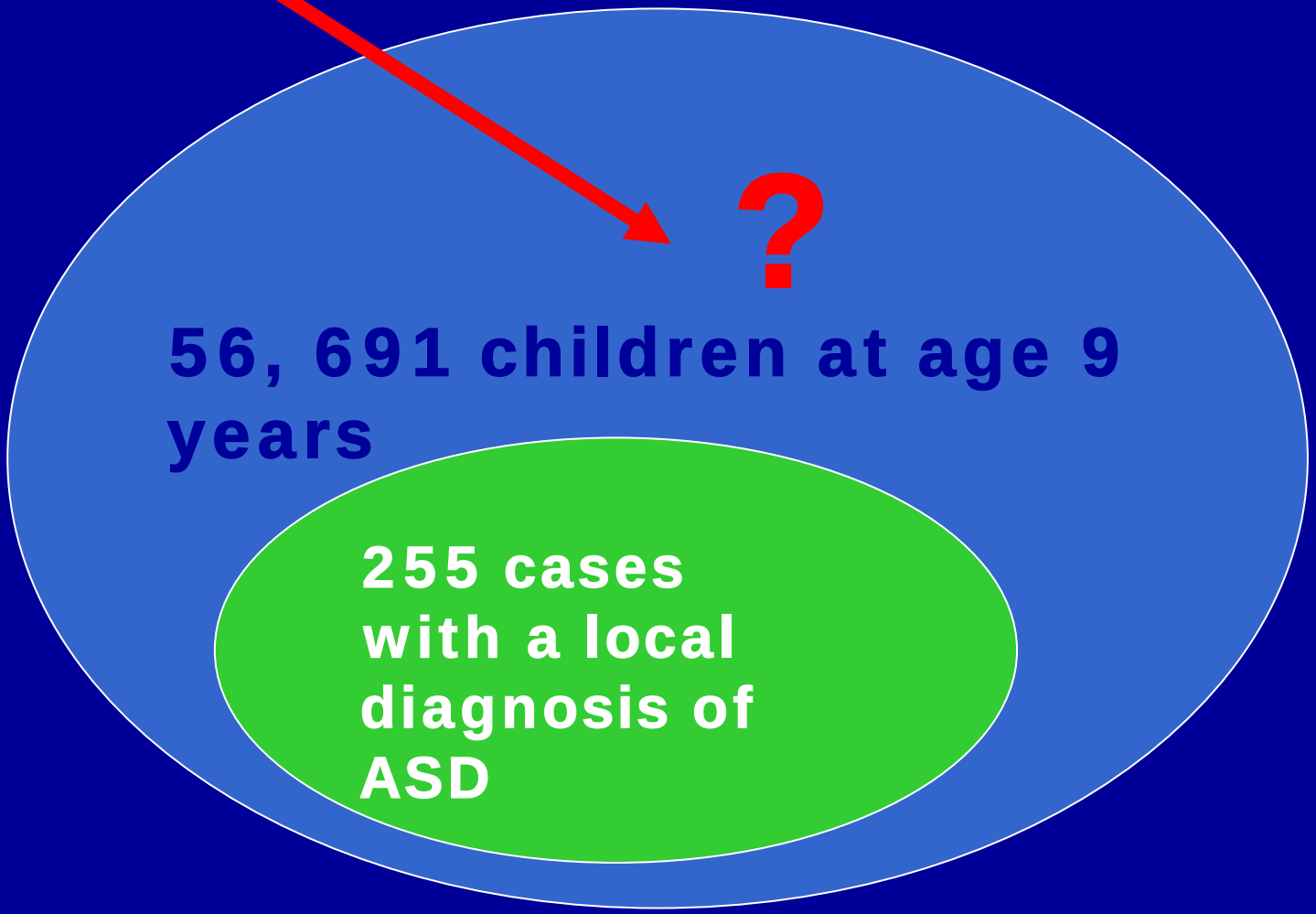
56,946 births (July 1990 – December 1991 incl.)

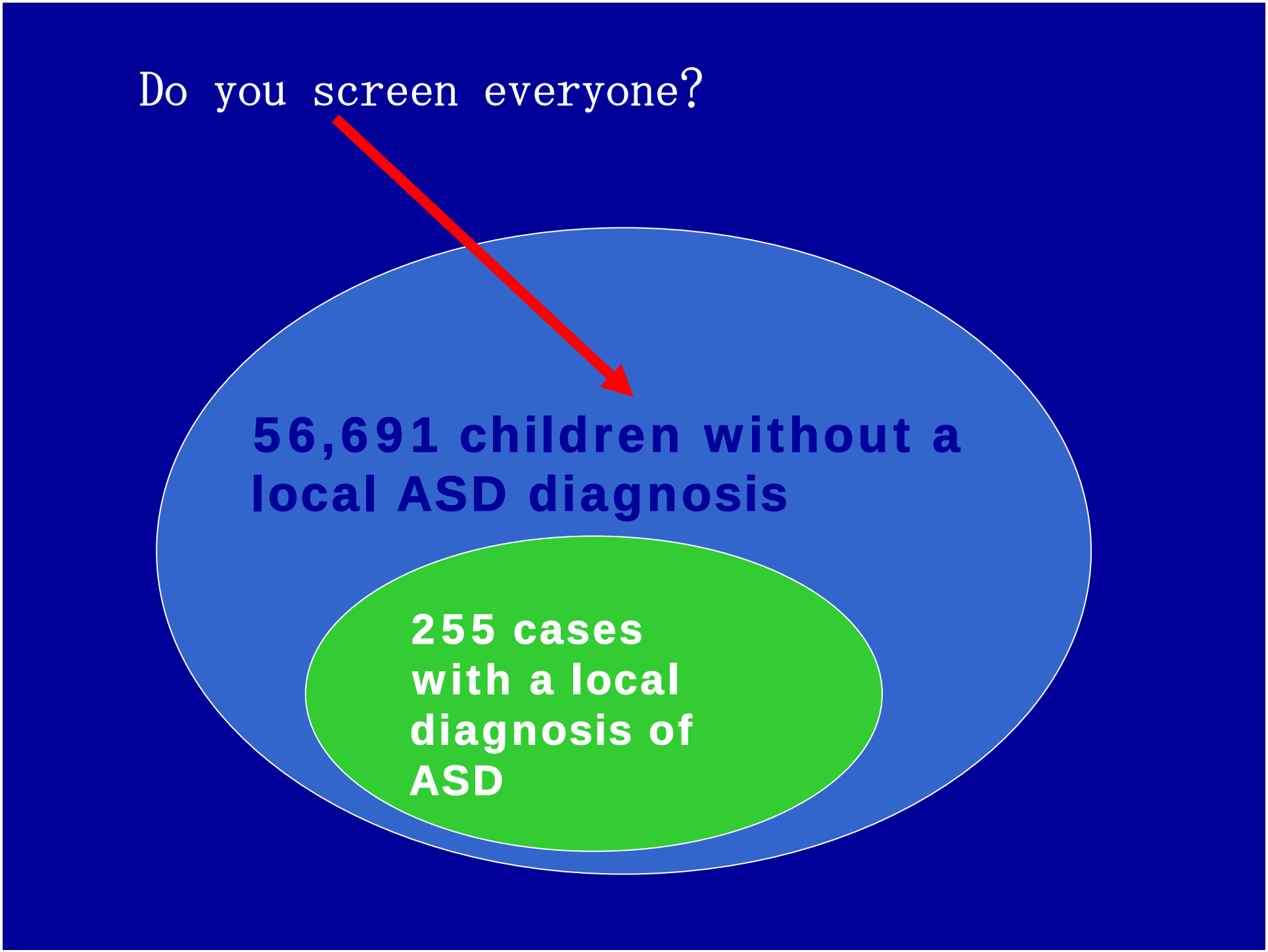

56,946 children at age 9 years
255 cases with a local diagnosis of ASD (prevalence 45/10,000)

How many of those with a local diagnosis are ‘true cases’?

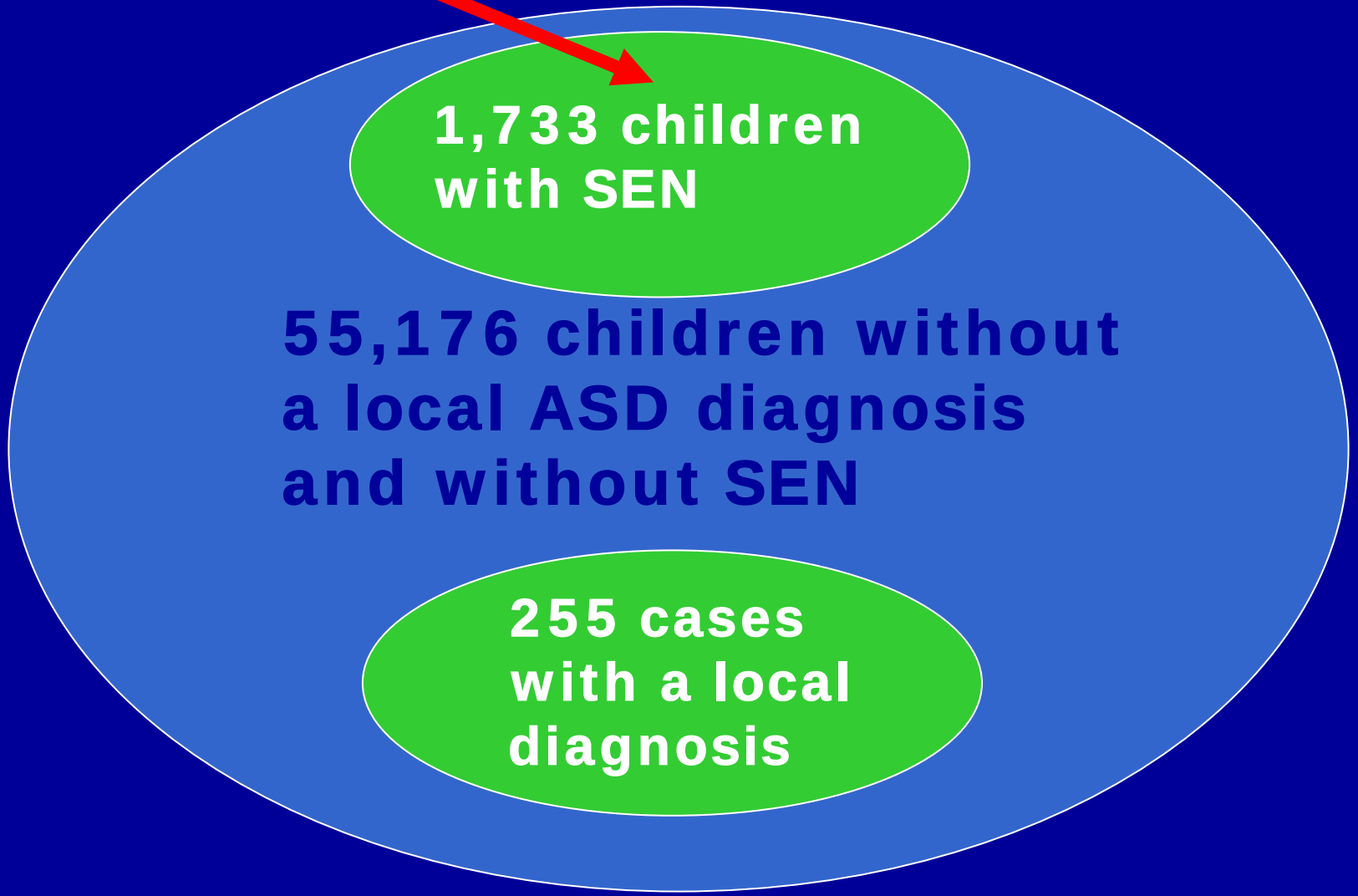


How many undetected cases might there be in the remaining population?




Do you screen everyone?
56,691 children without a local ASD diagnosis
255 cases with a local diagnosis of ASD

Or screen an 'at risk' group with SEN Stateme



Then assess a subsample of screened SEN and locally diagnosed case

Diagnostic process

- Researcher diagnosis
- Each case reviewed by clinical PIs (GB, ES, TC)
  - ADI/ADOS, clinical vignette, IQ and language, teacher reports
- Decision on current presentation made on the basis of ALL available information using ICD-10 criteria

Clinical Diagnoses

- All ASD
- Autism
- ‘Narrow autism’ = ICD childhood autism + ADI 4-5 years + ADOS current autism

Check on accuracy and reliability of diagnosis

- Agreement between research team and clinical PIs
  - On all 255 cases 95% agreement
  - Weighted kappa (autism, ASD, non-ASD) = 0.85
- Agreement between clinical PIs and expert panel
  - 36 random cases seen by 2 from panel of 8 international experts, 93% agreement
  - Weighted kappa (autism, ASD, non-ASD) = 0.75

Diagnostic process

- Rates of autism (33% vs. 42%) and ASD (77% vs. 75%) provide no evidence of systematic over- or under-diagnosis by our consensus

Statistical weighting

- Probability weighting adjusts prevalence estimates for:
  - Differences in sampling proportions and participation in in-depth assessment by SCQ and local diagnosis strata
  - Differential response to SCQ associated with local diagnosis, district, child's sex

Prevalence of ASD per 10,000 population (SNAP) Baird et al

- All ASD
  - 116 (95% CI 90.1-144.8)
- **Autism**
  - 39 (95% CI 29.9-47.8)
- **Other ASD**
  - 77 (95% CI 52.1- 103.3)
- Narrow Autism
  - 25 (95% CI 17-32)

Effects on prevalence rate

- Diagnostic category
- Age at diagnosis: ADI 4-5 ASD prevalence = 143/10,000
- Inclusion of all co-morbid disorders
- Local registers of diagnosis versus ‘at risk’ population screening/assessment 45 v 116/10,000

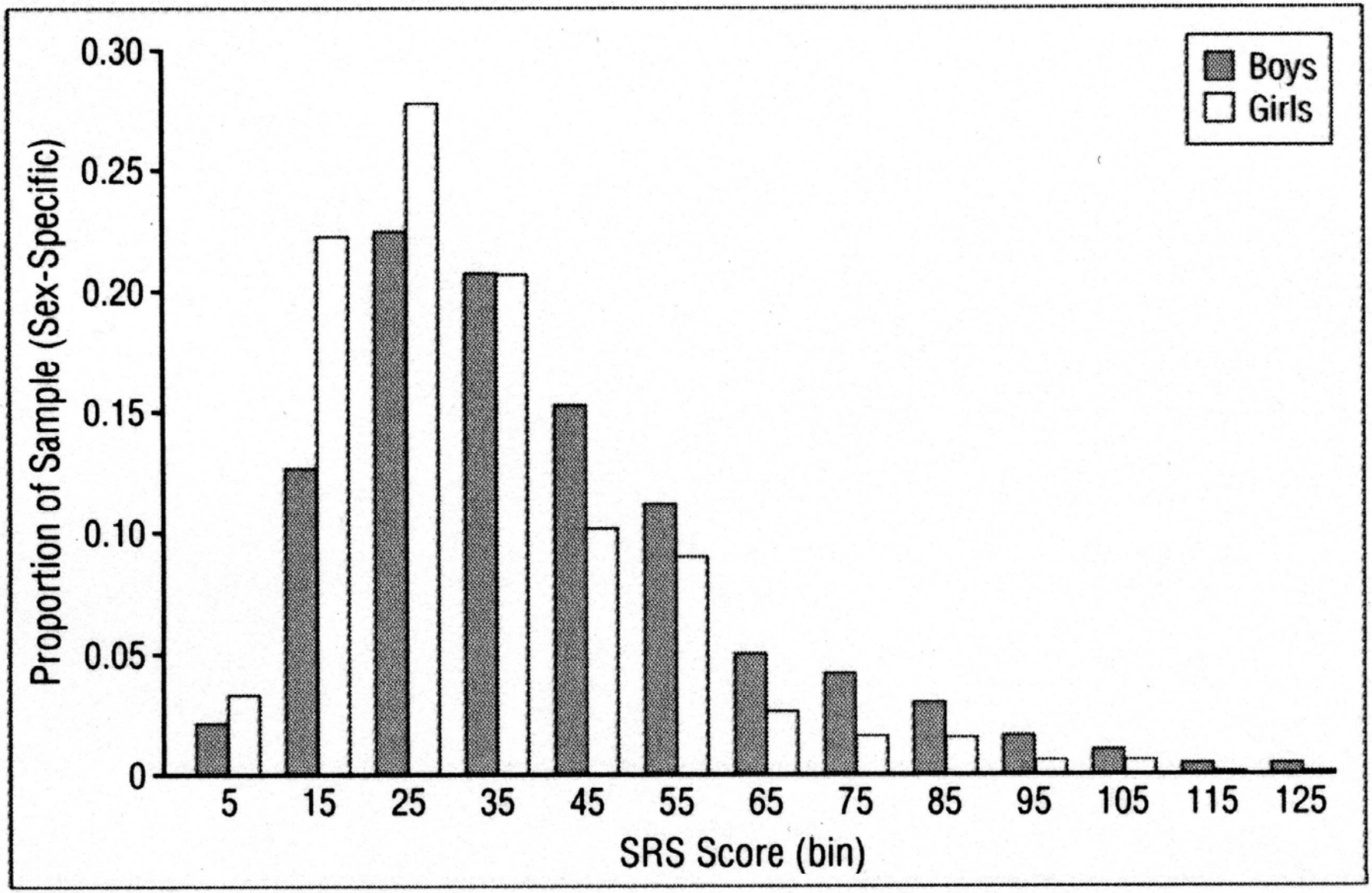
(NB most locally undiagnosed cases had other neurodevelopmental diagnosis e.g. MR, DLD, motor or specific learning problem)

Effects on prevalence

- **Factors that increase prior local identification**:
  - parental education: (OR 5.0)
  - IQ >70: (OR 2.5)
- Factors not independently associated with prior identification:
  - SES or income
  - child sex
  - district (variation)

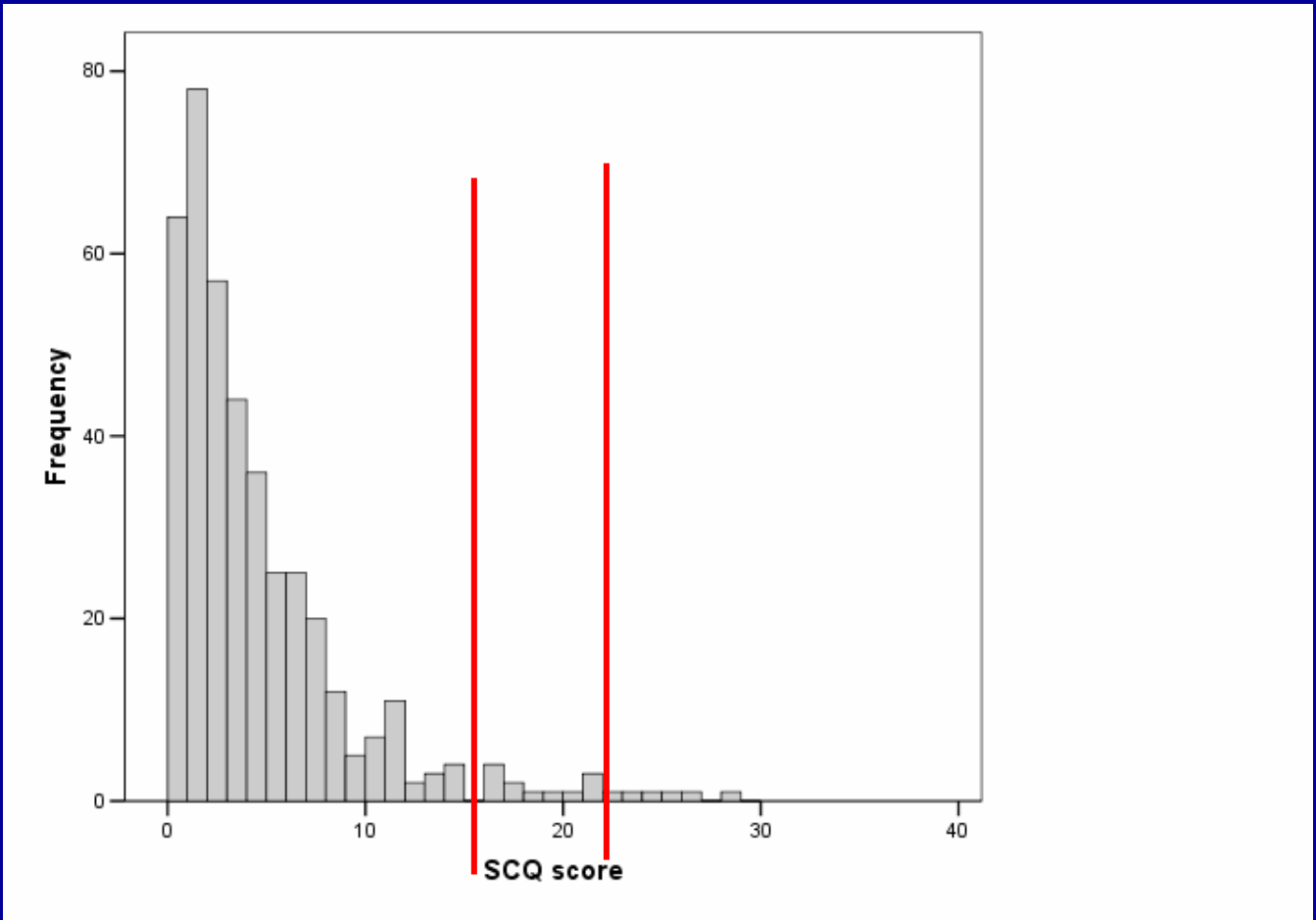
Deriving Categories in Dimensional disorders

Where do you draw the line?



Distribution of Social Responsiveness Scale (SRS) scores as a function of sex (n = 1576).

The SCQ in an unselected (mainstream) population **N=411 (44% return)**



ASD cut-off >=15; autism cut-off >=22

New studies of Autism and ASD Prevalence

- Honda et al. Cumulative incidence rate to age 7 years of 88.5 per 10,000 (2005)

- 2004 ONS British Survey of Child and Adolescent Mental Health age group 5-16 years: 90 per 10,000 **Goodman (2005) (male 1.4% female 0.3%)**

- **Gillberg 2006 80/10,000**

What we still cannot answer

- Has there been a true rise in prevalence?
- Are any of the putative environmental factors related to any increase in autism?

What SNAP and other new studies add

- Approximately 1 in a 100 children has some form of autism spectrum disorder
- Prevalence estimates depend on the strictness with which the diagnostic criteria are applied and the inclusion of other developmental disorders
- Within the same study the prevalence rate varied by greater than a factor of four
- Child and parental characteristics affected whether the child had received a local ASD diagnosis

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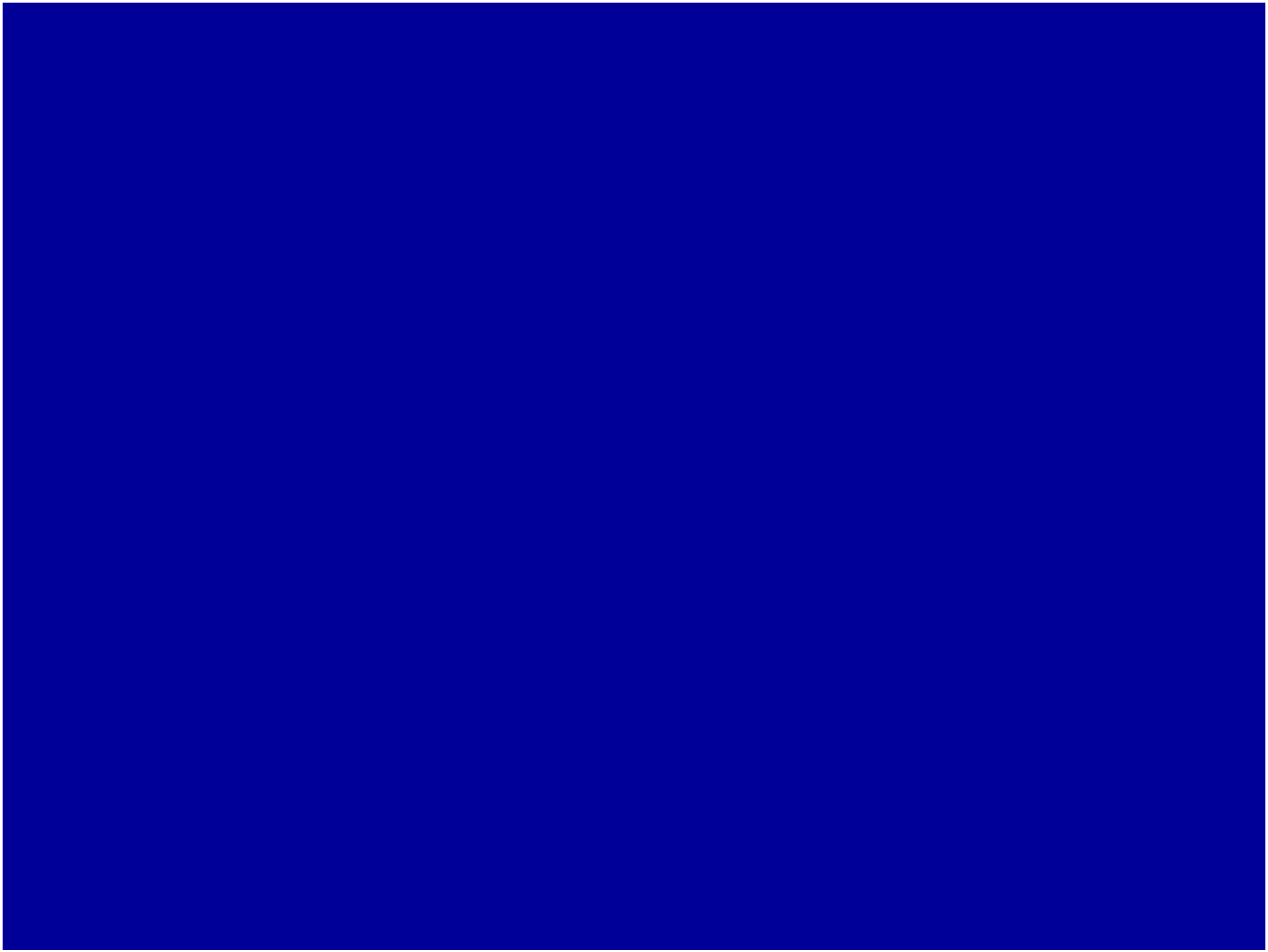
The Special Needs and Autism Project (SNAP)

Funded by: NAAR, Remedi



IQ

- The mean IQ (SD) of all cases with a consensus clinical diagnosis of ASD was 70.1 (24.2), with 56.2% below 70 and 14.7% below 50.
- IQ was lowest for the cases meeting the narrow definition of childhood autism (mean (SD) = 58.9 (19.8)), with 73.2% scoring below 70 and 23.5% below 50.