

Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)

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Summary

Background Recent reports have suggested that the prevalence of autism and related spectrum disorders (ASDs) is substantially higher than previously recognised. We sought to quantify prevalence of ASDs in children in South Thames, UK.

Methods Within a total population cohort of 56 946 children aged 9–10 years, we screened all those with a current clinical diagnosis of ASD (n=255) or those judged to be at risk for being an undetected case (n=1515). A stratified subsample (n=255) received a comprehensive diagnostic assessment, including standardised clinical observation, and parent interview assessments of autistic symptoms, language, and intelligence quotient (IQ). Clinical consensus diagnoses of childhood autism and other ASDs were derived. We used a sample weighting procedure to estimate prevalence.

Findings The prevalence of childhood autism was 38.9 per 10 000 (95% CI 29.9–47.8) and that of other ASDs was 77.2 per 10 000 (52.1–102.3), making the total prevalence of all ASDs 116.1 per 10 000 (90.4–141.8). A narrower definition of childhood autism, which combined clinical consensus with instrument criteria for past and current presentation, provided a prevalence of 24.8 per 10 000 (17.6–32.0). The rate of previous local identification was lowest for children of less educated parents.

Interpretation Prevalence of autism and related ASDs is substantially greater than previously recognised. Whether the increase is due to better ascertainment, broadening diagnostic criteria, or increased incidence is unclear. Services in health, education, and social care will need to recognise the needs of children with some form of ASD, who constitute 1% of the child population.

Introduction

Autism spectrum disorders (ASDs), the common clinical term for the pervasive developmental disorders described in the classification systems,^{1,2} are generally regarded as life-long disorders that have a substantial functional and financial effect on the individual and their family.^{3,4} Individuals with autism put a heavy demand on educational, social, and medical services, and accurate prevalence estimates are needed for the planning of such services. Until the 1990s, the figure of four to five cases of autism per 10 000 people was widely accepted, although as many as 20 per 10 000 children were reported as showing the triad of impairments in social reciprocity, language impairment, and reduced imagination and restricted activities.⁵

Studies have shown increased prevalence estimates for all ASDs of between 30 and 90 cases per 10 000.^{6–11} In addition to a true increase in prevalence, alternative explanations have been proposed, including changing diagnostic criteria, different methods of ascertainment, varying urban, rural, and country location, and population of study, younger age, and inclusion of individuals with average intelligence quotient (IQ) and those with other neuropsychiatric and medical disorders.^{12–14}

Our study is a follow-up to a previous one undertaken in the South Thames region of the UK and reported in a series of studies that began with screening a population of

16 235 children aged 18 months, born within a defined geographic area, for autism. Previously we reported on a follow-up at age 7 years when, by a mixture of direct assessment and case-note review, we estimated the prevalence of all ASDs known to services at that time to be 57.9 per 10 000 (95% CI 42.6–77.0).⁷ We have now extended the population to 56 946 children, screened a high-risk special educational needs group, and directly assessed in depth a sample of 255 children.

Methods

Study population

We studied a population cohort of 56 946 children born between July 1, 1990, and Dec 31, 1991, in 12 districts in South Thames, UK. All children currently resident within those 12 districts with a birthdate within the relevant period were included. The study was approved by the South East Multicentre Research Ethics Committee.

Procedures

The special needs register of the child-health services was used in two ways to identify those with a diagnosis of any ASD and to ascertain the sample to be screened. First, all children on the special needs register with a statement of special educational needs were judged to be at risk for having an unidentified ASD. In the UK, a statement of special educational needs is a legal document issued by

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the local education authority for children who need substantial additional support in school because of learning or behaviour problems. All children who attend special schools, as well as about 2–3% of children attending mainstream schools, have a statement of educational needs. This includes children with learning difficulties and language disorders as well as other medical conditions.

Second, in collaboration with local clinicians, we rigorously searched the registers of children known to child health and speech and language therapy services for those reported as having any current diagnosis of social and communicative impairment or an ASD with or without a statement of special educational needs. In the UK, all children with any significant developmental disorder can be expected to be referred to the child-health services by age 9 years. The speech and language therapy services provide for children both at special schools and mainstream schools and can be expected to involve children who have any problems in communication whether due to a language disorder or a social communication impairment.

We screened all those identified (total statemented group plus all locally diagnosed children) using the social communication questionnaire (SCQ),¹⁵ which is a parent-report questionnaire that asks about characteristic autistic behaviour at present and at age 4–5 years. The questionnaire is based on the autism diagnostic interview-revised (ADI-R)¹⁶ and has established validity with the ADI-R and a diagnosis of autism.¹⁷ Seven additional items were appended to the questionnaire to ascertain family socioeconomic circumstances. Postcode information was used to link an electoral ward socioeconomic deprivation index (Carstairs),^{18,19} and individual car ownership and housing tenure were used to construct a crude income index (from reported income differences^{18,20}). Educational level was defined by the highest academic qualification of either parent.

A two-way stratified random sample of 363 of those children from families who returned the SCQ and who opted in for further assessments was drawn for in-depth clinical assessment. Strata were formed by crossing previous locally recorded clinical ASD diagnosis status by four levels of SCQ score (low score <8, moderately low score 8–14, moderately high score 15–21, high score ≥ 22).

The in-depth measures consisted of the ADI-R¹⁶ and the autism diagnostic observation schedule-generic (ADOS-G)²¹ as the core assessments of autism. Additionally, IQ assessments,^{22–24} language assessments,²⁵ and assessments of adaptive behaviour²⁶ were completed. Informed consent was obtained at the time of assessment. A medical examination was done, but its findings are not relevant to the estimation of prevalence and will be reported separately. Information from teachers about social, communicative, and other behaviour was systematically recorded by use of a telephone interview devised for this study and we were able to look at child-health records for

historical information contemporaneously recorded at varying ages. The ADI-R (audiotaped) and ADOS-G (videotaped) were each undertaken by different researchers. The other assessments were done either on the same or a subsequent occasion by one of the research staff. Immediately after the assessment a vignette was written that incorporated information from the diagnostic and psychometric assessments and any pertinent clinical observations and information.

The ADI-R generates an algorithm score based on behaviours in three domains: social communication; social interaction; and repetitive and stereotyped behaviours. The algorithm codes are based on behavioural descriptions of a child at 4–5 years of age for some items and at any time in their lives for other items. There is an established cut-off for childhood autism.¹⁶ The ADOS-G consists of four modules, each appropriate to different levels of speech and language competence. The schedule is designed to elicit particular behaviours with a number of presses and scores current social communication and social interaction. An algorithm score is generated with established cut-offs both for childhood autism and for all ASDs—ie, including other ASDs.²¹

Two children were excluded from analysis for ADI and ADOS data; both were functioning below 12 months in all respects. However, clinical consensus diagnosis (see below) was achieved for these cases.

The research team scored the assessments and made an initial clinical diagnosis. The principal clinical investigators (GB, ES, TC) reviewed comprehensive clinical material on every case, including ADI and ADOS summary, clinical vignette, psychometric results, and teacher report. The evidence for the presence or absence of each symptom for autism, according to the international classification of diseases 10th revision (ICD-10), was scored as definitely or probably present and recorded. A consensus clinical diagnosis of childhood autism or other ASD was made on the basis of all sources of information: our assessments, earlier locally based assessment, school information, and age of onset of impairments. Any coexisting ICD-10 diagnosis was recorded. Quadratic weighted agreement between initial and consensus diagnostic categories for autism, ASD, and no ASD was 95% with kappa 0.85. Additionally, a narrow autism diagnosis was generated on the basis of the presence of both consensus diagnosis of autism and also fulfilment of the ADI algorithm criteria at age 4–5 years for autism and the (current) ADOS criteria for autism. For 36 randomly selected cases, project consensus diagnoses were compared with those of eight internationally recognised experts with ICD-10 criteria (usually two experts independently rated ADI, ADOS, psychometric findings and a clinical vignette for each case). Project and expert assessments gave similar rates: 33% (95% CI 19–51) vs 42% (27–59) for autism and 77% (61–89) vs 75% (61–85) for ASD, respectively. Quadratic weighted agreement between project consensus and expert diagnostic categories was 93% with kappa 0.77.

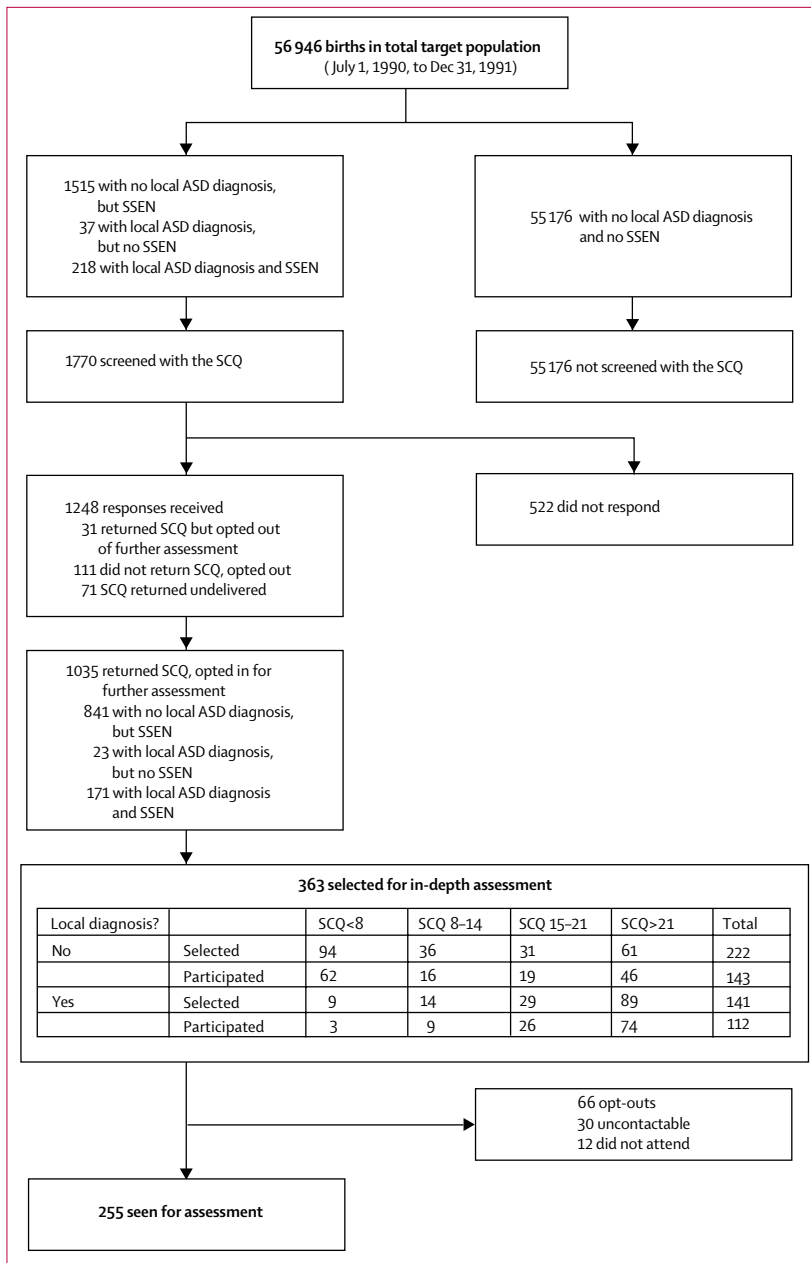


Figure: Case ascertainment
SSEN=statement of special educational needs; SCQ=social communication questionnaire.

Statistical analysis

All reported frequencies are unweighted. All other statistics, such as proportions, percentages, and means are target population estimates calculated by two-steps of inverse probability weighting to take account not only of the differences in sampling proportions across the eight SCQ by previous local ASD diagnosis strata, but also the differential response to the SCQ associated with a previous local diagnosis of ASD, district, and child’s sex. CIs and standard errors were calculated with the linearisation version of the robust parameter covariance matrix as

implemented by the svy procedures of Stata.²⁷ We calculated the population prevalence on the assumption that there were no cases of autism outside of the targeted questionnaire sample. No finite population correction was made.

Role of the funding source

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

The SCQ was mailed to 1770 families with 1270 boys and 500 girls (figure). Mean response rate was 70.5% (range across the 12 districts 57.8–87.6%), with 6% of families declining participation. A total of 1066 SCQs were returned completed (mean return rate 60.2%, range 50.0–76.2% across districts), although 2% of families declined further participation, leaving 1035 who returned the SCQ and opted in for further assessments.

A two-way stratified random sample of children from families who returned the SCQ and who opted in for further assessments was drawn for in-depth clinical assessment. Of the 363 families selected, 66 chose not to participate at this stage, 30 were uncontactable, and 12 did not attend the assessment. A total of 255 children (223 boys, 32 girls) and families (70%) received in-depth assessment, 65 with a low SCQ score, 25 with a moderate-low score, 45 with a moderate-high score, and 120 scoring 22 or greater. Mean age at the time of assessment was 12.0 years (SD 1.1, range 9.8–14.4).

Within this sample of 255 children, 81 were assigned a consensus clinical diagnosis of childhood autism, 53 of whom met the narrower definition of childhood autism (autism criteria on ADI-R at 4–5 and current autism criteria on ADOS). 77 were given a consensus clinical diagnosis of other ASDs and 97 were given a non-ASD consensus clinical diagnosis (table 1). Of the 81 cases that met consensus clinical diagnosis of childhood autism, seven had no delay in language milestones nor evidenced any abnormalities in development and curiosity before the age of 3 years. Although consistent under some interpretations with an ICD-10 diagnosis of Asperger’s syndrome, these seven also fulfilled ICD-10 criteria for childhood autism and will not be reported separately. Of the 77 cases with consensus diagnosis of other ASDs, six met ICD-10 criteria for atypical autism because of late onset, 61 met ICD-10 criteria for atypical autism because of subthreshold symptomatology, seven met ICD-10 criteria for unspecified ASD because of lack of information (incomplete assessment, adopted children for whom early history was not available), and three met ICD-10 criteria for overactive disorder associated with mental retardation and stereotyped movements.

	N*	ADI Soc†	ADI Comm	ADI Rpt	ADOS Soc	ADOS Comm	ICD-10	Male:female ratio	IQ	IQ<70 (%)
Narrow autism	53	24.8 (3.9)	16.9 (3.4)	7.5 (2.2)	10.7 (2.0)	5.5 (1.8)	10.4 (1.5)	5.8:1	58.8 (19.8)	73%
Consensus autism	81	24.4 (4.2)	17.0 (3.6)	7.1 (2.4)	9.4 (2.8)	4.2 (2.3)	9.9 (1.7)	8.3:1	67.9 (24.0)	53%
Other ASD	77	17.6 (6.0)	12.6 (5.2)	4.5 (2.6)	5.2 (3.1)	2.2 (1.8)	5.9 (1.6)	2.4:1	70.1 (24.2)	56%
Total ASD	158	19.8 (6.3)	14.0 (5.2)	5.3 (2.8)	6.6 (3.6)	2.9 (2.2)	7.2 (2.5)	3.3:1	69.4 (24.1)	55%
Non-ASD‡	97	5.4 (4.5)	5.1 (3.6)	1.0 (1.3)	3.2 (3.0)	0.9 (1.3)	1.7 (1.4)	1.5:1	69.3 (18.7)	58%

Data are mean (SD) unless indicated otherwise. *Number of selected cases; missing assessment measures can result in actual sample with data being between N and N-2 for narrow autism, autism, other ASDs, and non-ASD groups, and between N and N-5 for the total ASD group. †Data based on simple weighted estimators. ‡Non-ASD=children with a statement of special educational needs but without an ASD.

Table 1: Summary of screened stated population by consensus ASD diagnoses with ADI-R, ADOS-G, and ICD-10 symptom count scores

Table 2 gives prevalence estimates for narrowly defined autism, consensus diagnosis of autism, other ASDs, and all ASDs for both the total population of children and also for the subpopulation of children already stated for special educational needs or having a local ASD diagnosis.

An ASD diagnosis was locally recorded in 64% of children with narrow autism, 58% of those with a consensus diagnosis of autism, and 23% of those with other ASDs; only 1% of non-ASD stated children had a local ASD diagnosis. Of the 31 children with ASD not locally diagnosed who were assessed, 14 had a developmental diagnosis of language, motor, or specific learning problem, 12 had learning difficulties of moderate or severe degree, and two received an ASD diagnosis subsequent to the start of the study. Multivariate logistic regression on the subsample with a consensus ASD diagnosis indicated the probability that previous local diagnosis was strongly related to the severity of autism (as measured by ICD-10 symptoms), parental education, and more marginally to IQ. The odds of previous identification were increased 5.0 times (95% CI 1.99–12.7) for the 32% of families of stated ASD children with a parent who had completed secondary school education (59% vs 22% identified) and reduced by 0.4 times (0.1–1.2) for the 55% of stated ASD children with an IQ less than 70 (25% vs 45% identified). Although the Carstairs index (of socioeconomic deprivation) was significantly (negatively) related to being a locally identified case (simple OR 0.76 [95% CI 0.61–0.96] $p=0.02$), once parental education was accounted for this association was largely lost (partial OR 0.85 [0.651–1.1] $p=0.2$). No significant associations with previous diagnosis were found for the sex of the child or income index. Although rates of local ASD diagnosis vary by district, once severity, parental education, and IQ were accounted for there was little evidence of variation in rates of identification among true cases (Wald $\chi^2(11)=17.19$, $p=0.1$).

98% of children with a consensus diagnosis of autism met autism criteria on the ADI-R at age 4–5 years, compared with 69% of those with other ASDs and 2% of non-ASD cases. 64% of the consensus autism cases met autism criteria on the ADOS with a further 25% meeting the ASD cut-off on the ADOS. The proportions of other ASD cases meeting autism and ASD cut-offs on the ADOS were 23% and 15%, respectively, and for the non-ASD

	Prevalence in stated population, per 100 (95% CI)	Prevalence in overall population, per 10 000 (95% CI)
Narrow autism	8.0 (5.7–10.3)	24.8 (17.6–32.0)
Consensus autism	12.5 (9.6–15.4)	38.9 (29.9–47.8)
Other ASD	24.8 (16.8–32.9)	77.2 (52.1–102.3)
Total ASD	37.4 (29.1–45.6)	116.1 (90.4–141.8)

*Pooled estimator from weighted sex by previous local ASD diagnosis stratum specific estimates. †All children with a statement of special educational needs or with a previous local ASD diagnosis.

Table 2: Prevalence estimates*

cases the proportions were 4% and 9%, respectively. On instruments measuring severity of autistic symptomatology (ADI-R, ADOS-G, ICD-10 symptom counts), the narrow autism group scored highest, followed by clinical consensus childhood autism, and then other ASDs (table 1).

The mean IQ of all cases with a consensus clinical diagnosis of ASD was 70.14 (SD 24.2), with 56% below 70 and 15% below 50. IQ was lowest for the cases meeting the narrow definition of childhood autism (mean 58.9 [SD 19.8]), with 73% scoring below 70 and 24% below 50.

Discussion

We have estimated the prevalence of autism and related ASDs in children aged 9–10 years using a screening procedure in a high-risk group in a large population followed by careful diagnosis using face-to-face standardised assessments. Our findings accord with those for high prevalence rates from recent studies.^{12,13} Our study did not measure incidence rates, which are more difficult to estimate but which are important in understanding time trends and exploring causality.

Several characteristics of the present study were intended to overcome the limitations of previous research to provide the most accurate prevalence estimate for ASD to date. First, the sample size is sufficient to provide higher precision and is the largest epidemiological study of ASD published that used an active case ascertainment design, excluding database and register studies that have low case ascertainment.¹² Second, prospective ascertainment rather than use of retrospective case-review procedures¹¹ has been shown to be a factor in the variability of prevalence estimation.¹⁵ Serial ascertainment in the same population increases the probability of complete ascertainment. This

study used a multiphase screening design that aimed to assess the validity of ASD diagnoses made by local clinicians and to detect the rate of possible missed cases of ASD in an at-risk sample of children with identified special educational needs, which included various behavioural, learning, and medical problems but not current ASD diagnosis. Several different sources were used for case finding, including the child-health special needs register and discussion with individual local clinicians from paediatrics and speech and language therapy services. All children with statements of special educational needs were included, thus ensuring that comorbid conditions with ASD were included, especially learning difficulties. The prevalence of ASDs based on the count of previous locally identified cases would have been just 44.1 per 10 000. We have shown how population screening of children already recognised to have special educational needs specifically for ASD identifies many more cases, yielding rates of autism of 38.9 and all ASDs of 116.1 per 10 000.

Third, the sample was at an age (9–10 years) when it is likely that all true cases of ASD, or at least those in whom the condition was causing significant functional impairment, would have come to the attention of health and education services. In studies of younger children, not all cases are likely to have come to light to clinicians and services.^{8–10}

Fourth, the study implements a careful diagnostic procedure. Previous research shows that the diagnostic criteria used are an important variable in differing prevalence estimates.^{12,15} In this study, ascertainment by screening was followed by diagnostic assessment with the accepted gold standard practice of reaching a best-estimate clinical consensus diagnosis on the basis of combining information from standard research instruments of parent report, direct observation of the child, and independent information from school teachers. The diagnostic definitions of the research version of ICD-10 were used with clearly defined subgroups and the team was strict in requiring current symptoms for consensus autism. Agreement between the research team and principal clinical investigators was high. Agreement with independent experts was high and in particular provided no evidence for over diagnosis.

We estimated the prevalence rate in the whole population, but the whole population was not screened. The decision not to screen the entire population could mean that some children with an ASD in mainstream schools who do not have a statement of special educational needs will have been missed. However, the Office for National Statistics (ONS) 2005 child and adolescent mental health survey indicated that 97% of children with an ASD had a statement.²⁸ Thus, the current prevalence estimate should be regarded as a minimum figure.

Attrition during the process of engagement in the study could have introduced some bias. Correction was made for the fact that 76% of children who already had a diagnosis of ASD returned the SCQ and agreed to further assessment,

compared with 56% of those without a previous diagnosis of ASD, and also for differential attrition by district and sex of child. Residual bias might have remained nonetheless. Our assessment of children at the age of 9–14 years could have rendered earlier historical recollection of age of onset of symptoms inaccurate, but this was off-set by use of contemporaneous information in the child's health records.

Rather than being deemed relatively rare disorders, ASDs are identified in about 1% of the childhood population aged 9–10 years, although only a third meet ICD-10 criteria for childhood autism and less than a quarter fulfil a narrower definition of autism that requires clinical consensus of autism plus meeting criteria on two established assessment instruments.

Our estimate of the rate of autism is similar to that from our 7-year follow-up of the same cohort⁶ (30.8 per 10 000) and another recent study⁷ (40.5 per 10 000), but is higher than estimates from several other studies (16.8, 22.0, and 21.1 per 10 000, respectively^{8–10}). These studies reported prevalence rates closer to that for our narrower definition of autism (24.8 per 10 000). Our overall ASD prevalence is higher than either that reported by Baird and colleagues⁷ (57.9 per 10 000) or Chakrabarti and Fombonne^{9,10} (62.6 and 58.7 per 10 000, respectively). It is, however, nearer the cumulative incidence rate to age 7 years reported by Honda and colleagues¹⁰ of 88.5 per 10 000 and the 2004 ONS British survey of child and adolescent mental health in which the prevalence of ASD for the age group 5–16 years was 90 per 10 000.²⁶ Services in health, education, and social care should plan to meet the child and family needs of 1% of the child population with some form of ASD.

In the Chakrabarti and Fombonne study,⁹ of the 64 children with ASD, 30% had mental retardation (IQ<70), but this rate varied by disorder subtype, being 67% for children with a diagnosis of autistic disorder and 12% for those with a diagnosis of PDD-nos (pervasive developmental disorder not otherwise specified). In the present study the rates of low IQ were similar across the diagnostic groups, both being a little above a half, although three-quarters of the narrow autism cases had mental retardation, which is similar to the historically accepted figure.¹²

The male to female ratio for all ASDs (3.3:1) is similar to that noted in previous studies, but the ratio for consensus autism (8.3:1) is higher (4.3:1 in Fombonne's review¹²). Sex was not associated with previous diagnosis. Our screening design therefore identified more cases of boys with autism than did previous studies, but not proportionally more cases of boys with other ASDs. However, there was no differential sensitivity to the SCQ screen by sex. One reason may be that the number of boys with statements of special educational needs in the UK is more than double that of girls.²⁹

We found the rate of previous local case identification to be much lower for children of less educated parents. This finding must be a source of concern to service providers; our results suggest that more standardised

approaches to screening and diagnosis could help to reduce this bias.

ICD-10 and DSM-IV diagnostic criteria have been used most commonly in recent prevalence studies but still allow scope for variation in interpretation. Different severity thresholds applied within the same qualitative domains of impairment result in different prevalence rates. Our narrow autism group who met robust criteria of autism on ADI plus ADOS and consensus clinical diagnosis could represent the most reliable and repeatable diagnostic group for studies looking at prevalence over time and place. We postulate that this narrow autism group could represent the older conceptualisation of autism that is commonly associated with mental retardation and occurs four or five times more frequently in boys than in girls. Although a number of putative environmental factors might have contributed to the higher prevalence rates reported in studies published this decade, none has so far been empirically supported.¹³ The consensus diagnosis of autism and, in particular, other ASD cases could be associated with the broadening of diagnostic criteria over time, which might be responsible for the rise in reported prevalence, but other explanations cannot be ruled out, including a true rise in incidence. Children shown in this study to have ASD but who were not locally diagnosed had other coexisting developmental disorders causing significant impairment.

This study emphasises the need for agreed and shared tools and definitions in prevalence and incidence studies and for designs that are not reliant on local systems of case identification that may exhibit educational and other biases.

Contributors

G Baird, E Simonoff, A Pickles, and T Charman planned and designed the study and obtained funding. G Baird, E Simonoff, and T Charman regularly supervised data collection by S Chandler, T Loucas, and D Meldrum. E Simonoff, S Chandler, and T Charman contributed to the data analysis, for which A Pickles had prime responsibility. All authors contributed to the writing and revision of the manuscript for which G Baird is guarantor.

Conflict of interest statement

G Baird has acted as an occasional expert witness for the diagnosis of autism, is President of Afasic, the association of all speech impaired children, and is involved in the National Autistic Society. A Pickles receives royalties from the SCQ and ADOS-G screening and diagnostic instruments. All other authors have no conflicts of interest.

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