

Epidemiology of Autism Spectrum Disorders in Adults in the Community in England

Traolach S. Brugha, MD(NUI), FRCPsych; Sally McManus, MSc; John Bankart, MSc, PhD; Fiona Scott, PhD, CPsychol; Susan Purdon, MSc, PhD; Jane Smith, BSc; Paul Bebbington, PhD, FRCPsych; Rachel Jenkins, MD, FRCPsych; Howard Meltzer, PhD

Context: To our knowledge, there is no published information on the epidemiology of autism spectrum disorders (ASDs) in adults. If the prevalence of autism is increasing, rates in older adults would be expected to be lower than rates among younger adults.

Objective: To estimate the prevalence and characteristics of adults with ASD living in the community in England.

Design: A stratified, multiphase random sample was used in the third national survey of psychiatric morbidity in adults in England in 2007. Survey data were weighted to take account of study design and nonresponse so that the results were representative of the household population.

Setting: General community (ie, private households) in England.

Participants: Adults (people 16 years or older).

Main Outcome Measures: Autism Diagnostic Observation Schedule, Module 4 in phase 2 validated against the Autism Diagnostic Interview–Revised and Diagnostic Interview for Social and Communication Disorders in phase 3. A 20-item subset of the Autism-Spectrum Quo-

tient self-completion questionnaire was used in phase 1 to select respondents for phase 2. Respondents also provided information on sociodemographics and their use of mental health services.

Results: Of 7461 adult participants who provided a complete phase 1 interview, 618 completed phase 2 diagnostic assessments. The weighted prevalence of ASD in adults was estimated to be 9.8 per 1000 (95% confidence interval, 3.0-16.5). Prevalence was not related to the respondent's age. Rates were higher in men, those without educational qualifications, and those living in rented social (government-financed) housing. There was no evidence of increased use of services for mental health problems.

Conclusions: Conducting epidemiologic research on ASD in adults is feasible. The prevalence of ASD in this population is similar to that found in children. The lack of an association with age is consistent with there having been no increase in prevalence and with its causes being temporally constant. Adults with ASD living in the community are socially disadvantaged and tend to be unrecognized.

Arch Gen Psychiatry. 2011;68(5):459-466

Author Affiliations:

Department of Health Sciences, University of Leicester, Leicester (Drs Brugha, Bankart, and Meltzer and Ms Smith); National Centre for Social Research, London (Ms McManus and Dr Purdon); Autism Research Centre, Department of Psychiatry, University of Cambridge, Cambridge (Dr Scott); Department of Mental Health Sciences, University College London, London (Dr Bebbington); and Institute of Psychiatry, Kings College London, London (Dr Jenkins), England.

AUTISM SPECTRUM DISORDERS (ASDs) are neurodevelopmental disorders characterized by impairment of reciprocal social interaction and communication and restricted repetitive behaviors.¹ They have persisting negative effects on learning and development of independence in adulthood.² In 2007, the yearly cost to society of each adult with ASD in Great Britain was estimated to be £90 000.³ Adults with ASDs are more likely to be recognized and supported if they also have severe intellectual disability; those with higher levels of functioning tend to be overlooked in the community.⁴

In childhood, ASDs are associated with intellectual disability and male sex. More recent surveys⁵⁻⁷ report higher prevalence estimates. In children, the median

rate in 16 surveys published between 1966 and 1991 was 4.4 per 10 000 population; the median rate in 16 surveys published between 1992 and 2001 was 12.7 per 10 000.⁶ In 3 recent large regionwide or national community surveys⁸⁻¹⁰ of children and adolescents in England, the prevalence of ASD was approximately 10 per 1000. It is not known whether this reported increased prevalence reflects case finding changes or increasing incidence due to newly emerging causes. Among intellectually disabled adults (<0.5% of the overall adult population), a rate of 75 per 1000 was obtained from an intellectual disability case register¹¹ that incorporated identification from direct observation, detailed case records, and interviews with caregivers. Although adults with ASD have been studied across a range of age groups,¹²

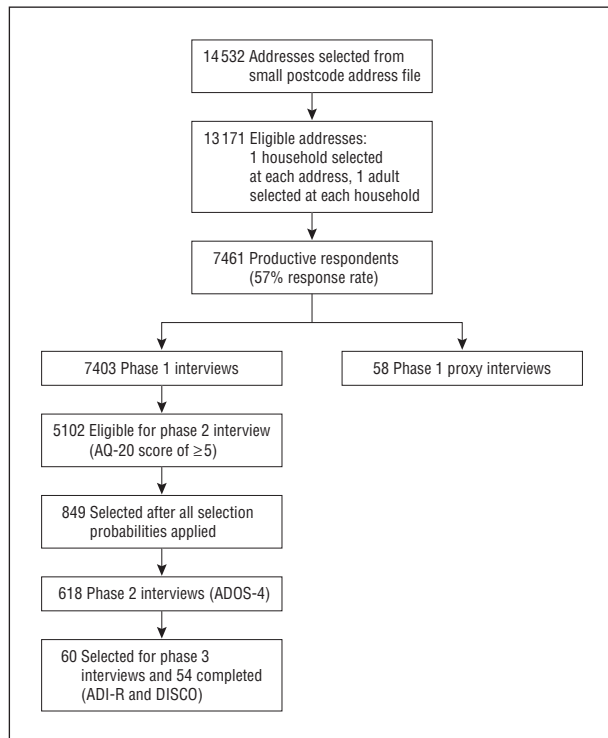


Figure 1. Multistage sampling procedure and the multiphase assessment procedures in general population assessment of autism spectrum disorder. Detailed findings for the third validation phase will be presented elsewhere and are summarized in the text. ADI-R indicates Autism Diagnostic Interview–Revised; ADOS-4, Autism Diagnostic Observation Schedule, Module 4; AQ-20, Autism-Spectrum Quotient; and DISCO, Diagnostic Interview for Social and Communication Disorders.

there is no information about community prevalence across the age range in that population. Adults in Great Britain who have responded to postal and online surveys¹³ stating that they have ASD are more often male (2:1), rarely 65 years or older, and rarely in full-time employment. They tend to have been given a diagnosis of high-functioning autism or Asperger syndrome, with only 1 in 5 in receipt of psychological or psychiatric services.

Cases of ASD in surveys of children have been identified using direct observation and collateral descriptions of behavior (from parents and teachers),⁵⁻⁷ techniques that are less feasible in adults. We used a multiple-phase design: an initial screening phase of adults in the community, a direct observation second phase, and developmental interviews of collateral informants in a third phase.

We hypothesized that, in the community, the rate of ASDs in early adulthood would be similar to that reported in older children but that far fewer cases would be found among older adults, particularly those in the retirement age range. We also hypothesized that adults with ASDs would be more likely to be male and disadvantaged socioeconomically and less likely to be receiving support from mental health services than adults with other mental disorders.

METHODS

The third national Adult Psychiatric Morbidity Survey in England, carried out in 2007,¹⁴ used a stratified 2-phase design

based on a random probability sample. Postcode sectors (on average, 2550 households) were stratified on the basis of a measure of socioeconomic status within a regional breakdown (**Figure 1**). All primary sampling units were then further stratified on the basis of the proportion of adults employed in non-manual labor jobs and sorted by the proportion of households without a motor vehicle based on 2001 UK Census data (<http://www.statistics.gov.uk/about/data/methodology/specific/population/PEMethodology/>). Next, postal sectors were sampled from each stratum with a probability proportional to size; 519 postal sectors were selected, with 28 delivery points randomly selected in each (yielding 14 532 delivery points). Interviewers visited these to identify private households in England containing at least 1 adult (16 years or older) (Figure 1). Ethical approval for the study was obtained from the Royal Free Medical School Research Ethics Committee, London, England.

To estimate the prevalence of ASD among adults in the community, a subset of questions from a self-report autism trait screening questionnaire, the Autism-Spectrum Quotient (AQ),¹⁵ was used in phase 1. This tool was used to select participants for a second-phase evaluation using detailed clinical assessments based on module 4 of the Autism Diagnostic Observation Schedule, Module 4 (ADOS-4).¹⁶ The 50-item AQ and a recently published¹⁷ factor analytically derived 28-item AQ have been validated cross-culturally.¹⁸ For each phase 1 respondent, the probability of selection for phase 2 diagnostic assessment was calculated from respondents' answers to screening questions in the phase 1 questionnaire^{14,19} as the highest of 4 disorder-specific probabilities (ASD, psychosis, borderline personality disorder, and antisocial personality disorder).

The higher the score on the phase 1 screens, the greater the likelihood of being selected for phase 2. The selection process for a third validation phase is described in the next section.

MEASURES

We used stepwise logistic regression to develop a 20-item subset of the 50-item AQ, using previously gathered diagnostic clinic and control data.^{15,19} The 20-item version (AQ-20) was administered to all phase 1 respondents to generate a probability of selection for the detailed phase 2 diagnostic assessment. Phase 1 respondents also completed questionnaires covering physical and mental health, socioeconomic factors, use of mental health services,¹⁴ and willingness to take part in further interviews. Predicted verbal IQ (V-IQ; range estimate, 70-130) was derived using the National Adult Reading Test²⁰; V-IQ was the only method for estimating IQ available in the 2007 Adult Psychiatric Morbidity Survey, although its validity in community cases of ASD is untested. National Centre for Social Research interviewers conducted fieldwork from October 2006 through December 2007. A few of the selected respondents were incapable of undertaking the interview alone because of mental or physical incapacity. For them, the option of a proxy interview with another member of the household or someone else who knew them well was available (Figure 1). The information collected was insufficient for selection probabilities to be calculated, and respondents interviewed by proxy were therefore ineligible for phase 2 interviews.

Phase 2 ASD assessments were based on the ADOS-4, a face-to-face clinical assessment of current behavior consistent with a diagnosis of ASD. It consists of tests termed *presses* that evaluate communication, reciprocal social interaction, creativity, imagination, and stereotyped and restricted interests. The ADOS-4 incorporates algorithms for ASD,²¹ applied to selected ADOS-4 ratings corresponding to *DSM-IV*²² criteria for pervasive developmental disorder. Phase 2 interviewers were experienced in psychological research and received an induc-

tion and training program, run by a senior research psychologist (J.S.), a psychiatrist (T.S.B.), and a qualified ADOS-4 trainer (F.S.). Training experience was gained through assessing adults living in the community, including students, and working age and older adults who had a clinician-determined diagnosis of an ASD such as Asperger syndrome. Interviewing in the field did not commence until the 4 interviewers achieved at least 90% agreement on ratings of jointly observed ADOS-4 examinations. During fieldwork, interviewers received supervision sessions and prepared ASD case vignette reports. They took part in debriefing after the interviews to add further contextual information.

A threshold of 10 or greater on the ADOS-4 total score is recommended for identifying cases of autism,²¹ provided it includes scores of at least 3 on the Communication domain and at least 6 on Reciprocal Social Interaction. To our knowledge, for the first time in a community sample and in older adults,¹⁹ we validated this threshold for determining a case of ASD using the ADOS-4, with 54 assessments carried out by the senior research psychologist in a third study phase (Figure 1). These assessments included developmental interviews with family members or other suitable informants of second-phase respondents, half of whom had a high probability of having ASD. The Autism Diagnostic Interview–Revised²³ and the Diagnostic Interview for Social and Communication Disorders²⁴ were administered. The appropriateness of using a threshold of 10 or greater was tested using models based on predicting cases of ASD from these 2 tools (details of these assessments and of clinical consensus diagnoses will be reported separately).

ANALYSIS

Survey data were weighted to take account of study design and nonresponse so that the results were representative in terms of age, sex, region, and area characteristics of the household population 16 years or older in England.¹⁴ First, sample weights were applied to take account of the different probabilities of selecting respondents in different-sized households. Second, to reduce household nonresponse bias, a household-level weight was calculated from a logistic regression model using interviewer observation and area-level variables (using 2001 UK Census data) available for responding and nonresponding households. The nonresponse weight for each household was calculated as the inverse of the probability of response estimated from the model multiplied by the household's selection weight. Finally, weights were applied using the techniques of calibration weighting based on age, sex, and region to weight the data to represent the structure of the national population, by taking account of differential nonresponse between regions and age × sex groups. The population control totals used were the Office for National Statistics 2006 midyear household population estimates.²⁵ Phase 2 weights were designed to generate condition-specific phase 2 data sets representative of the population eligible for phase 2 by virtue of that particular condition. Combining the phase 2 weighted data with the phase 1 weighted data for the noneligible group thus gives data representative of the whole adult population. Because incomplete response could bias survey estimates, we investigated possible nonresponse bias: we compared the probability of ASD (phase 1 AQ-20 score) between geographic regions by regional response rate and by each respondent's willingness to take further part in the survey.

Weighted prevalence estimates were determined using an ADOS-4 threshold of 10 or greater (PROC SURVEYFREQ, version 9.1; SAS Institute, Inc, Cary, North Carolina) and for comparison a range of thresholds from 7 or greater to 13 or greater. The distribution of AQ-20 and ADOS-4 scores was examined

using histograms. The small number of people identified as having ASD (in terms of the number of ADOS-4 cases found) means that caution is required in interpreting the population distribution of ASD. Variation in prevalence of ASD by other characteristics was examined in univariable and multivariable weighted logistic regression models (PROC SURVEYLOGISTIC, version 9.1; SAS Institute, Inc) and by examining the predicted probability of being a case as a function of continuously measured characteristics (age and V-IQ). The sample for these analyses consisted of phase 1 respondents with a near zero probability of ASD (AQ-20 score <5, classified as non-ASD cases) together with all respondents who completed a full ADOS-4 in phase 2. Phase 1 respondents with an AQ-20 score of 5 to 20 who were not administered a phase 2 assessment were excluded as unknowns and accounted for in the weighting.

RESULTS

Of the 13 171 households identified as potentially eligible in the Adult Psychiatric Morbidity Survey, 4075 refused; 7461 individuals in the households (56.6%) provided a complete phase 1 interview. Of these, 849 people were selected for phase 2 interviews; 62 refused and no contact was made with 157, leaving 630 participants (74.2%) who completed phase 2 assessments (Figure 1). Full ADOS-4 assessments were carried out in 618 participants. Nonresponse bias was investigated by comparing the proportion scoring 13 or greater on the AQ-20 in the 5 regions with the highest response rate and the 6 regions with the lowest response rate in phase 1: it was 1.1% and 1.2%, respectively; using weighted data, it was 1.1% and 1.3%. Refusal to take part by participants selected for a phase 2 interview was 24% overall: the proportion of those who refused and scored 13 or greater on the AQ-20 was 24.3% among individuals with an AQ-20 score of 0 to 12 and 23.3% among those with an AQ-20 score of 13 to 20. Neither comparison gave any indication that survey participation was associated with having ASD. The ADOS-4 threshold of 10 or greater for ASD was supported by models based on predicting cases of ASD from the phase 4 Diagnostic Interview for Social and Communication Disorders and Autism Diagnostic Interview–Revised developmental assessments (details will be reported separately).

Using the validated threshold of a score of 10 or greater on the ADOS-4 to indicate a case of ASD, we determined that the overall prevalence of ASD in the English population of individuals 16 years or older was 9.8 per 1000 population (95% confidence interval [CI], 3.0-16.5). **Table 1** includes the unweighted and weighted numbers of cases and weighted estimates for ADOS-4 cut-offs from 7 or greater to 12 or greater. The estimated V-IQ of our ASD cases ranged from 70 (and less) to 100.

UNIVARIABLE MODELS

The rate of ASD among men (18.2 per 1000; 95% CI, 4.2-32.2) was much greater than among women (2.0 per 1000; 95% CI, 0.0-4.3). This difference was statistically significant in a weighted univariable logistic model (**Table 2**). **Figure 2** depicts the association with age using the weighted prevalence of ASD according to the

diagnostic ADOS-4 threshold of 10 or greater. The predicted probability of ASD suggested a gradual decrease with increasing years, although the trend was not significant (odds ratio, 0.99; 95% CI, 0.94-1.04; $P=.55$); assuming that this is the true odds ratio, for every extra year of age, the odds of ASD would decrease by 1%. The lower limit of the 95% CI suggests a decrease in the odds of 6% with every increasing year of age. In a univariable model, the predicted probability of ASD (ADOS-4 ≥ 10)

was inversely related to V-IQ score (odds ratio, 0.94; 95% CI, 0.87-0.99; $P=.04$); for every unit increase in V-IQ score, the odds of ASD decreased by 6.0%.

Having ASD was significantly associated with living in accommodation rented from a social landlord (local authority or housing association) rather than from a private landlord or owned by the participant or other member of the household (Table 2). The presence of ASD was higher in participants without any educational qualifications than in those with university-level qualifications (Table 2).

The presence of ASD was significantly associated with being single (Table 2). A relative preponderance of ASD in more deprived local areas (wards) was close to being statistically significant ($P=.06$; Table 2). There was no overall association between equalized household income and the presence of ASD; in participants living in households with the highest income, ASD was less frequent than among those with the lowest incomes, which was close to being statistically significant ($P=.06$; Table 2). No significant association was identified between household composition and ASD. People who did not know whether they received state benefits had higher odds of having ASD (Table 2); there was insufficient information to determine whether receiving benefits was associated with ASD. Among working-age participants (aged 16-64 years), we found no significant association with economic activity. We had insufficient data to evaluate

Table 1. Weighted Cumulative Estimates of Respondents per 1000 Population for ADOS-4 Cut-offs

| ADOS-4 Cut-off | Unweighted Base (n = 2828) | Weighted Base (n = 7333) | Weighted Estimate Rate per 1000 Population (95% CI) |
|----------------|----------------------------|--------------------------|---|
| ≥ 7 | 32 | 108 | 14.7 (7.0-22.5) |
| ≥ 8 | 26 | 88 | 12.0 (4.9-19.1) |
| ≥ 9 | 20 | 75 | 10.2 (3.4-17.0) |
| $\geq 10^a$ | 19 | 72 | 9.8 (3.0-16.5) |
| ≥ 11 | 16 | 65 | 8.9 (2.2-15.5) |
| ≥ 12 | 12 | 47 | 6.4 (0.6-12.3) |
| ≥ 13 | 10 | 44 | 6.0 (0.2-11.8) |

Abbreviations: ADOS-4, Autism Diagnostic Observation Schedule, Module 4; CI, confidence interval.

^aA threshold of 10 or greater on the ADOS-4 total score is recommended for a case of autism, including scores of at least 3 on the Communication domain and at least 6 on Reciprocal Social Interaction.

Table 2. Univariable Candidate Predictors of Presence of ASD^{a,b}

| Univariable Predictor | Overall P Value | Comparison Group vs Reference Group | OR (95% CI) | P Value for Selected Comparison |
|--|-----------------|---|---------------------|---------------------------------|
| Sex | .001 | Male vs female | 9.14 (2.37-35.15) | .001 |
| Marital status | .02 | Single vs not single | 4.70 (1.22-18.02) | .02 |
| Tenure | .002 | Social vs owner | 11.23 (2.86-43.48) | <.001 |
| | | Social vs private | 5.85 (1.06-32.26) | .04 |
| Equalized household income ^c | .17 | Low vs high | 5.60 (0.90-34.62) | .36 |
| | | Moderate vs high | 2.40 (0.36-15.93) | .31 |
| Highest educational qualification ^d | .01 | None vs degree/HND, college, university | 11.63 (2.33-58.83) | .003 |
| | | None vs A-level/GCSE, school | 2.37 (0.61-9.18) | .21 |
| Employment status | .88 | Out of work vs in work | 1.86 (0.16-21.28) | .62 |
| | | Out of work vs inactive | 1.55 (0.14-16.95) | .72 |
| Receipt of benefits ^e | .04 | Does not know vs none | 13.33 (1.59-111.11) | .02 |
| | | Does not know vs yes | 4.67 (0.37-58.82) | .23 |
| Index of Multiple Deprivation ^f | .06 | High vs medium vs lowest, ordinal | 2.34 (0.96-5.69) | .06 |
| Verbal IQ, NART ^g | .04 | Continuous | 0.94 (0.87-0.998) | .04 |
| Age | .55 | Continuous | 0.99 (0.94-1.04) | .55 |

Abbreviations: ADOS-4, Autism Diagnostic Observation Schedule, Module 4; ASD, autism spectrum disorder; AQ-20, 20-item Autism-Spectrum Quotient; CI, confidence interval; GCSE, General Certificate of Secondary Education; HND, Higher National Diploma; NART, National Adult Reading Test; OR, odds ratio.

^aFor total scores on the ADOS-4 with a threshold of 10 or greater (n = 2854). The reference category for OR reporting is always the second category. For example, men have 9.14 times the odds of ASD than women.

^bModels in phase 1 carried out on respondents with a low probability of having ASD (AQ-20 <5) and on all respondents who completed ADOS-4 in phase 2.

^cHousehold income was established by means of a show-card on which banded incomes were presented. Equalized income is adjusted to take account of the number of people living in the household. To derive this, each household member is given a score depending, for adults, on the number of adults cohabiting or not cohabiting and, for dependent children, their age. The total household income is divided by the sum of the scores to provide the measure of equalized household income. Respondents were then allocated to the equalized household income quintile to which their household had been allocated.

^dRespondents who reported foreign qualifications or qualifications that could not be classified were excluded.

^eReceipt of any benefit other than state pensions, child benefit, Working Tax Credits, or maternity-related benefits. Social fund grants and housing benefits were included.

^fThe Index of Multiple Deprivation 2007 combines a number of indicators chosen to cover a range of economic, social, and housing issues into a single deprivation score for each small area in England. This allows each area to be ranked relative to one another according to its level of deprivation in the form of an ordinal variable.

^gAn estimate of verbal IQ was derived using the NART score. Respondents who did not speak English as their first language, who had eyesight problems, or who stated that they had dyslexia were excluded from the base.

associations with ethnic groups. Each analysis using the ADOS-4 threshold of 10 or greater in Table 2 was repeated with the cut-off of 7 or greater. The statistically significant associations for sex and tenancy for an ADOS-4 threshold of 10 or greater were also found when the threshold was 7 or greater; those for other associations were also in the same direction but no longer statistically significant.

Because most (15 of 19) of the phase 2 cases with an ADOS-4 threshold of 10 or greater were in male participants, the weighted univariable logistic model (Table 2, males and females combined) was repeated in males only. The findings were unaltered.

MULTIVARIABLE MODELING

Multivariable backward stepwise logistic modeling was performed using the 8 most significant and borderline significant univariable predictors listed in Table 2 (analysis conducted on both sexes), producing 3 significant predictors after removal of nonsignificant variables with the use of backward selection (Table 3). Men had nearly 9 times the odds of having an ASD diagnosis compared with women ($P = .002$). For every unit increase in the level of education, the odds of ASD decreased by 55% ($P = .049$). Those in social housing had a significantly higher odds of having ASD compared with those who owned their home ($P = .03$). Index of Multiple Deprivation, single marital status, receipt of welfare benefits, household income, and V-IQ were not associated (Table 3). Finally, age (continuous) was added to the model. However, its inclusion did not improve the fit of the model (odds ratio, 0.98; 95% CI, 0.94-1.02; $P = .36$).

USE OF SERVICES

Service use for mental or emotional problems was compared between participants with and without ASD. These data are not shown in a table because the base number for people with ASD was too small to make meaningful statistical comparisons (19 cases were identified in the 2007 Adult Psychiatric Morbidity Survey sample). Nevertheless, there was no evidence of increased use of services for mental or emotional problems by people with ASD in the preceding month or year. None of the cases found in this study had previously been given a formal autism assessment or diagnosis.

COMMENT

Autism spectrum disorder affects approximately 1% of the adult English household population. There was no evidence of a statistically significant reduction in prevalence of ASDs as a function of age. Prevalence was greatest in men, in those living in social housing, and in those with the lowest educational qualifications. Adults with ASD appear to be largely unrecognized. To our knowledge, there are no previous systematic community surveys of adults with which to compare these findings.

The survey was based on the most validated investigator-rated diagnostic instruments available for study-

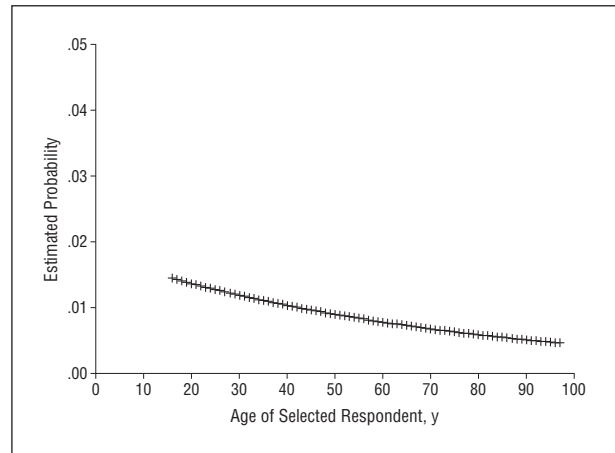


Figure 2. Predicted values of autism spectrum disorder (ASD) by age. P value for age as a continuous predictor of ASD ($P = .55$), using the recommended score threshold of 10 or greater on the Autism Diagnostic Observation Schedule, Module 4.

Table 3. Weighted Multivariable Model Candidate Predictors of Presence of Autism Spectrum Disorder^a

| Predictor ^b | OR (95% CI) | P Value for Specific Comparison | P Value Overall |
|------------------------|------------------|-----------------------------------|-------------------|
| Sex | | | .002 |
| Male vs female | 8.62 (2.2-34.5) | .002 | |
| Educational level | | | .049 |
| Continuous | 0.45 (0.21-0.99) | .049 | |
| Housing tenure | | | .02 |
| Social vs owner | 6.1 (1.7-21.7) | .03 | |
| Social vs private | 2.5 (0.4-15.1) | .98 | |

Abbreviations: CI, confidence interval; OR, odds ratio.

^a $n = 1875$.

^b Nonsignificant predictors: Index of Multiple Deprivation, single marital status, receipt of welfare benefits, household income, and verbal IQ.

ing the prevalence of ASD in adults. However, a number of study limitations should be considered. The number of cases we identified was small, but our sampling strategy, as well as our approach to weighting, means that we could account for the low specificity and sensitivity of our phase 1 screening measure. Because we screened people from across a wide range of AQ-20 score strata, our prevalence estimate is probably reliable. The cost and the burden of including ADOS-4 assessments during phase 1 would have been unsustainable. There is thus a need to develop improved phase 1 screening. Sampling excluded institutional residents and adults with intellectual disability severe enough to prevent them from participating in the assessment. A definitive estimate of prevalence in the whole adult population would require additional sampling in those populations. The association with low intellectual ability in our household sample suggests that our sampling and interviewing methods did not exclude any but the most severely intellectually disabled adults. The 57% response rate in phase 1 was disappointing. Response rates in surveys have been declining in most countries during the past decade.²⁶ However, our estimates were weighted to take account of differences between census data and the profile of the partici-

pants. Sensitivity analyses showed no evidence of a non-response bias; reluctance to cooperate was not associated with a higher phase 1 AQ-20 score. This finding is supported by recent research showing that nonresponse rate alone is a weak predictor of nonresponse bias and by recent studies suggesting that changes in nonresponse rates do not necessarily alter survey estimates.²⁷ Furthermore, the phase 2 weighting took account of variation in response rate by phase 1 AQ-20 score, age, and sex. Bias in prevalence estimation can be eliminated if an assumption of missingness at random within these adjustment cells is justified.²⁸ In a missingness-at-random situation, missingness depends on demographic or other characteristics that can be adjusted for using weighting. If, after such adjustment has been made, missingness is not related to the survey outcome, missing data can be said to be missing at random. Given our sensitivity analyses and the absence of any other information to the contrary, it is plausible that within age, sex, region, and AQ-20 score groups (the variables upon which our weighting was based), our missing data situation approximates reasonably well to missingness at random. We found nothing in the literature on nonresponse bias pertaining to ASD specifically; nonresponse has been linked to psychopathologic factors in some studies,²⁹ but it is not clear in which direction the overall burden of bias lies.

The small number of cases identified (n=19) limited our ability to identify possible associations. For example, although the prevalence of ASD appeared greater in adults living in the most deprived localities and in those in the lowest household income groups (Table 2), these associations were not statistically significant; however, such associations cannot be ruled out given the wide confidence intervals. Nevertheless, the study was powered to generate a prevalence estimate within a prespecified 95% CI, rather than to test hypotheses associating ASD status with particular attributes.

For practical reasons, large surveys of adults usually preclude the involvement of collateral informants capable of describing the respondent's behavior over time, including in childhood. Our principal in-depth outcome measure, the ADOS-4, is limited to direct observation in an artificial context. However, detailed assessments in a supplementary third phase sample (to be reported separately) and using well-established developmental interviews showed good agreement with the ADOS-4. Intellectual ability is an important factor in determining the outcome of ASD in adulthood²; our measure of V-IQ was limited and has not been validated for community-living adults with ASD. However, educational level achieved is regarded as a good index of ability and was more strongly associated with ASD in our multivariable model. Our assessment methods provided insufficient information for subtyping ASD, but our cases were likely to be Asperger syndrome, pervasive developmental disorder—not otherwise specified, and autistic disorder.²²

The weighted prevalence of 9.8 per 1000 population in adults is essentially the same as recently reported⁸⁻¹⁰ in systematic surveys of children up to age 15 years. Two of these childhood surveys also used age-standardized versions of the same diagnostic instrument, the ADOS.^{8,10}

This overall rate can be contrasted with that of other mental disorders contributing significantly to the global burden of disease in adulthood. Thus, the prevalence of ASD is approximately twice that of psychosis and half that of current depressive episodes assessed in the same survey.¹⁴ Some research and public health purposes may require the use of cut-off points or an ordinal scale or dimensional description of the burden of a disorder. The distribution of ADOS-4 cases (Table 1) suggests continuity rather than discontinuity above and below the diagnostic threshold as found in psychiatric disorders such as depression.³⁰ Our validation study does not recommend using a cut-off point of 7 or greater (Table 1) on the ADOS-4, although the developers²¹ have suggested that this might be acceptable in combination with other detailed clinical information. The higher estimated prevalence in men vs women was based on the ADOS-4. The self-report AQ-20 used in phase 1 suggested a smaller sex difference in those with high scores. This variability is in line with childhood studies⁷ showing that the sex difference is less when subthreshold forms of the condition are studied. It could also indicate differences between instruments in the identification of the less common female form of autism, although this seems less likely. Some degree of heterogeneity is likely to underlie the behavioral presentation of our autism prevalence cases; such heterogeneity may cause problems in the design and interpretation of community treatment trials.³¹

Our survey lacked the statistical power to examine small but possibly clinically and etiologically important differences between cohorts in rates of ASD according to age. Our CI for age is consistent with a percentage increase in prevalence of 4% or a percentage decrease of 6% per year of age. Small reductions of prevalence with age could be explained by increased mortality in autism³² or by older respondents being less available to participate in a household survey because of loss of family support or increased use of institutionalization. However, based on the literature reviewed earlier, we would expect substantially lower rates in earlier birth cohorts (older respondents) if rates of ASD have been rising considerably during recent decades, and we would also expect lower rates in younger adults than in recent childhood surveys using the ADOS-4. We did not find this. Overall, our findings suggest that prevalence is neither rising nor falling significantly. This favors the interpretation that methods of ascertainment have changed in more recent surveys of children compared with the earliest surveys in which the rates reported were considerably lower. Our data suggest that the causes of autism appear to be temporally constant and that recent apparent rises in rates of diagnosis must therefore reflect better survey case finding rather than some new environmental toxin. However, we urge caution and the need for independent replication of this first set of adult community survey findings. Whether using cross-sectional survey or cohort³³ sampling designs, further work with adults is needed to improve the specificity and sensitivity of self-report measures of ASD.

The finding that adults with ASD are socially disadvantaged, at a lower educational level, less able intellectually, and apparently unrecognized by mental health ser-

vices is of potential public health importance. This is in a country with well-established social, educational, welfare, and health care services funded from taxation. Research is also needed in lower-income countries where clinical experience suggests that ASD is prevalent and disabling. Participants with ASDs were less likely to know about a key aspect of their financial circumstances, namely, whether they are receiving state financial benefits (Table 2). This is in line with the clinical observation that many people with ASD are ill equipped to manage their finances. Previous work^{34,35} shows that adults with mental health disorders receive more attention from services because these problems are recognized needs. However, we found no statistically significant increase in use of the services among adults with ASD. The cases identified in this survey were apparently not clinically recognized; the underrecognition of ASDs was also apparent in a recent national audit⁴ of support for more able adults with autism from local government and the national health service in England. This audit also makes a reasoned economic argument for increasing the identification of adults with ASD and for supporting them to obtain and maintain appropriate paid employment. The characteristics of our community survey cases appear to differ from those of adults who have responded to postal and online surveys stating that they have an ASD,¹³ emphasizing the importance of systematic case finding for public health information. Formal comparison of community and clinically diagnosed cases is not yet possible. However, it would appear that cases are often underdiagnosed in elderly individuals, those with lower levels of functioning, those in paid employment, and men.

There are no effective medical treatments for ASD, particularly in adulthood. Adults with ASD have enduring problems with communication and social understanding. However, social care services are being developed to support them, based on the principle that staff recognize and accept the presence of the condition and learn how to understand and communicate with those who have it. This might, for example, improve access to sustained paid employment.³⁶ In our clinical experience, providing this sort of social care to adults with a diagnosis of ASD leads to improvements in quality of life and reductions in the inappropriate use of high-cost hospital services.

To our knowledge, we have demonstrated for the first time in the general population that the rate of ASD is not significantly associated with age, suggesting that the causes of autism are temporally constant. A great deal more research should be directed at the epidemiology and care of adults with this condition.

Submitted for Publication: November 12, 2010; accepted November 30, 2010.

Correspondence: Traolach S. Brugha, MD(NUI), FRCPsych, Department of Health Sciences, University of Leicester, Leicester General Hospital, Gwendolen Rd, Leicester LE5 4PW, England (tsb@le.ac.uk).

Author Contributions: Dr Brugha had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Financial Disclosure: None reported.

Funding/Support: This study was supported by the National Health Service Information Centre for Health and Social Care and Department of Health; autism follow-up was supported by the National Institute for Health Research and Department of Health Policy Research Programme.

Role of the Sponsor: The scope of the topics covered in the Adult Psychiatric Morbidity Survey was determined in discussion with the funders before fieldwork commenced. The funders took no part in determining the results reported in this article. The authors are solely responsible for the article and its contents.

Additional Contributions: Acknowledgment for the advice and support of groups and individuals can be found elsewhere.¹⁹

REFERENCES

1. Wing L. The autistic spectrum. *Lancet*. 1997;350(9093):1761-1766.
2. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *J Child Psychol Psychiatry*. 2004;45(2):212-229.
3. Knapp M, Romeo R, Beecham J. *Economic Consequences of Autism in the UK*. London, England: Mental Health Foundation and Autism Speaks; 2007.
4. National Audit Office. *Supporting People With Autism Through Adulthood*. London, England: National Audit Office; 2009.
5. Fombonne E. Epidemiological surveys of autism and other pervasive developmental disorders: an update. *J Autism Dev Disord*. 2003;33(4):365-382.
6. Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders. *J Clin Psychiatry*. 2005;66(suppl 10):3-8.
7. Newschaffer CJ, Croen LA, Daniels J, Giarelli E, Grether JK, Levy SE, Mandell DS, Miller LA, Pinto-Martin J, Reaven J, Reynolds AM, Rice CE, Schendel D, Windham GC. The epidemiology of autism spectrum disorders. *Annu Rev Public Health*. 2007;28:235-258.
8. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*. 2006;368(9531):210-215.
9. Green H, McGinnity A, Meltzer H, Ford T, Goodman R. *Mental Health of Children and Young People in Great Britain, 2004*. Basingstoke, England: Palgrave Macmillan; September 2005.
10. Baron-Cohen S, Scott FJ, Allison C, Williams J, Bolton P, Matthews FE, Brayne C. Prevalence of autism-spectrum conditions: UK school-based population study. *Br J Psychiatry*. 2009;194(6):500-509.
11. Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry*. 2007;190:27-35.
12. Risi S, Lord C, Gotham K, Corsello C, Chrysler C, Szatmari P, Cook EH Jr, Leventhal BL, Pickles A. Combining information from multiple sources in the diagnosis of autism spectrum disorders. *J Am Acad Child Adolesc Psychiatry*. 2006;45(9):1094-1103.
13. National Autistic Society. *I Exist: The Message From Adults With Autism*. London, England: National Autistic Society; 2008.
14. McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R. *Adult Psychiatric Morbidity in England, 2007: Results of a Household Survey*. London, England: NHS Information Centre for Health and Social Care; 2009.
15. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The Autism-Spectrum Quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev Disord*. 2001;31(1):5-17.
16. Lord C, Risi S, Lambrecht L, Cook EH Jr, Leventhal BL, DiLavore PC, Pickles A, Rutter M. The Autism Diagnostic Observation Schedule—Generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord*. 2000;30(3):205-223.
17. Hoekstra RA, Vinkhuyzen AAE, Wheelwright S, Bartels M, Boomsma DI, Baron-Cohen S, Posthuma D, van der Sluis S. The construction and validation of an abridged version of the Autism-Spectrum Quotient (AQ-short) [published online August 10, 2010]. *J Autism Dev Disord*.
18. Wakabayashi A, Baron-Cohen S, Wheelwright S, Tojo Y. The Autism-Spectrum Quotient (AQ) in Japan: a cross-cultural comparison. *J Autism Dev Disord*. 2006;36(2):263-270.
19. Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart

- J. *Autism Spectrum Disorders in Adults Living in Households Throughout England—Report From the Adult Psychiatric Morbidity Survey 2007*. Leeds, England: NHS Information Centre; 2009.
20. Nelson HE, Willison J. *National Adult Reading Test (NART)*. 2nd ed. Windsor, England: NFER-Nelson; 1991.
 21. Lord C, Rutter M, DiLavore PC, Risi S. *Autism Diagnostic Observation Schedule: ADOS Manual*. Los Angeles, CA: Western Psychological Services; 2002.
 22. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 4th ed. Washington, DC: American Psychiatric Association; 1994.
 23. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview—Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *J Autism Dev Disord*. 1994;24(5):659-685.
 24. Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *J Child Psychol Psychiatry*. 2002;43(3):307-325.
 25. Office for National Statistics. 2006 Mid-year household population estimates. London, England: Office for National Statistics; 2007. <http://www.statistics.gov.uk/about/data/methodology/specific/population/PEMethodology>. Accessed June 2, 2009.
 26. de Leeuw ED, de Heer W. *Trends in Household Survey Nonresponse: A Longitudinal and International Comparison: Survey Nonresponse*. Hoboken, NJ: Wiley & Sons; 2002:44-51.
 27. Groves RM. Nonresponse rates and nonresponse bias in household surveys. *Public Opin Q*. 2006;70(5):646-675. doi:10.1093/poq/nfl033.
 28. Groves RM, Dillman D, Eltinge J, Little RJA, eds. *Survey Nonresponse*. New York, NY: John Wiley & Sons Inc; 2002.
 29. Eaton WW, Anthony JC, Tepper S, Dryman A. Psychopathology and attrition in the epidemiologic catchment area surveys. *Am J Epidemiol*. 1992;135(9):1051-1059.
 30. Melzer D, Tom BD, Brugha TS, Fryers TF, Meltzer H. Common mental disorder symptom counts in populations: are there distinct case groups above epidemiological cut-offs? *Psychol Med*. 2002;32(7):1195-1201.
 31. Spence SJ, Thurm A. Testing autism interventions: trials and tribulations. *Lancet*. 2010;375(9732):2124-2125.
 32. Pickett JA, Paculdo DR, Shavelle RM, Strauss DJ. 1998-2002 Update on "causes of death in autism." *J Autism Dev Disord*. 2006;36(2):287-288.
 33. Susser E, Bresnahan M. Epidemiologic approaches to neurodevelopmental disorders. *Mol Psychiatry*. 2002;7(suppl 2):S2-S3.
 34. Brugha TS, Bebbington PE, Singleton N, Melzer D, Jenkins R, Lewis G, Farrell M, Bhugra D, Lee A, Meltzer H. Trends in service use and treatment for mental disorders in adults throughout Great Britain. *Br J Psychiatry*. 2004;185:378-384.
 35. Bebbington PE, Meltzer H, Brugha TS, Farrell M, Jenkins R, Ceresa C, Lewis G. Unequal access and unmet need: neurotic disorders and the use of primary care services. *Psychol Med*. 2000;30(6):1359-1367.
 36. Howlin P, Alcock J, Burkin C. An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*. 2005;9(5):533-549.

Correction

Errors in Degree, Name, Honorific, Affiliations, and Funding/Support. In the Original Article titled "Trends in Antipsychotic Use in Dementia 1999-2007" by Kales et al, published in the February 2011 issue of the *Archives* (2011;68(2):190-197), an author's degree, another author's name, another author's honorific, an affiliation, and the Funding/Support line contained errors. Dr Claire Chiang's degree should be PhD, not MD; Rosalindo Ignacio should be Rosalinda V. Ignacio; and Ms Cunningham should be Dr Cunningham. The first affiliation should read Veterans Affairs Health Services Research and Development Center for Clinical Management Research, Serious Mental Illness Treatment, Resource, and Evaluation Center, Ann Arbor, Michigan. In the "Methods: Study Cohort" section, the data source should be listed as the Serious Mental Illness Treatment, Resource, and Evaluation Center. In addition, the Funding/Support line should read: This study was supported by grant R01-MH081070-01 from the National Institute of Mental Health; and the Serious Mental Illness Treatment, Resource, and Evaluation Center, Ann Arbor, Michigan. This article was corrected online.