



# Autism Spectrum Disorders in adults living in households throughout England

## *Report from the Adult Psychiatric Morbidity Survey 2007*

Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J

A survey carried out for The NHS Information Centre for health and social care  
by the National Centre for Social Research,  
the Department of Health Sciences, University of Leicester, and  
the Autism Research Centre, University of Cambridge

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**For queries about the report:**

**Mail, telephone & e-mail**

The NHS Information Centre  
1 Trevelyan Square, Boar Lane, Leeds LS1 6AE  
General enquiries: 0845 300 6016  
E-mail: [enquiries@ic.nhs.uk](mailto:enquiries@ic.nhs.uk)

NHS IC Responsible Statistician  
Bethan Thomas, Statistical Head of Surveys  
Contact via [enquiries@ic.nhs.uk](mailto:enquiries@ic.nhs.uk), tel: 0845 300 6016

**For hard copy requests:**

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The Publications Officer  
National Centre for Social Research  
35 Northampton Square, London EC1V 0AX  
Telephone orders/General enquiries: 020 7549 7006  
E-mail: [info@natcen.ac.uk](mailto:info@natcen.ac.uk)

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## Foreword

Autism Spectrum Disorders (ASD) are lifelong developmental disabilities that affect the way a person communicates and relates to people around them. There is a lack of epidemiological research on adults with ASD, so knowledge about the level of unmet need for services among adults with ASD and their families is sparse and inhibits the planning of provision.

This report presents the prevalence and correlates of ASD, the first such estimates to be produced with a random probability general population sample anywhere in the world. At the NHS Information Centre, we are committed to providing quality and timely information to monitor the health of the population in England, and this includes supporting the development of new and innovative methods such as these.

The data reported on here were collected as part of the 2007 survey of adult psychiatric morbidity in England (APMS 2007).

Again, this demonstrates the ability of the NHS Information Centre to provide appropriate information befitting of national concerns to improve care received and the targeting of resources effectively.



**Tim Straughan**

Chief Executive

The NHS Information Centre for health and social care

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We would first like to thank all the respondents who so generously gave up their time to participate in this survey and to acknowledge the enormous professionalism and commitment of the NatCen and University of Leicester interviewers.

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Advice on assessment of Autism Spectrum Disorder during study planning was provided by: Dr Akio Wakabayashi, Prof Anne Le-Couteur, Prof Christine Lord, Dr Tom Berney, Dr Digby Tantam, Prof Simon Baron-Cohen, Dr Judith Gould, Dr Lorna Wing and Dr Fiona Scott.

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Sally McManus led on the first phase of the APMS and had overall responsibility for the survey.

## Notes

1. The data used in this report have been weighted. A specific weighting variable was used for all analyses of ASD (Aspergerwt2): this variable incorporates the main survey weight (wt\_inst1) plus makes further adjustment for the ASD assessment process. The weighting is described briefly in Chapter 2 and in more detail in Chapter 3. Both unweighted and weighted sample sizes are shown at the foot of each table. The weighted numbers reflect the relative size of each group in the population, not numbers of interviews conducted, which are shown by the unweighted bases.
2. The prevalence of ASD in this report is presented as percentages to one decimal place, which is equivalent detail to reporting rates per thousand. While rates per thousand are often used in more specialist literature, we decided to use percentages because these are more accessible for to a wider readership and flow better when cited in the text. To convert from a percentage to a rate per thousand, simply move the decimal point one place to the right.
3. The following conventions have been used in tables:
  - no observations (zero value)
  - 0 non-zero values of less than 0.045% and thus rounded to zero
  - [] used to warn of small sample bases, if the unweighted base is less than 40.
4. Because of rounding, row or column percentages may not add exactly to 100%.
5. A percentage may be quoted in the text for a single category that aggregates two or more of the percentages shown in a table. The percentage for the single category may, because of rounding, differ from the sum of the percentages in the table.
6. 'Missing values' occur for several reasons, including refusal or inability to answer a particular question. In general, missing values have been omitted from all tables and analyses.
7. The term 'significant' refers to statistical significance (at the 95% level) and is not intended to imply substantive importance. Unless otherwise stated, differences mentioned in the text have been found to be statistically significant at the 95% confidence level. Standard errors that reflect the complex sampling design and weighting procedures used in the survey have been calculated and used in tests of statistical significance. A table giving the standard errors for the ASD estimate is shown in Chapter 3.

## 1.1 Background to the Adult Psychiatric Morbidity Survey 2007

The community-based psychiatric morbidity survey series is the primary data source for monitoring trends in England's mental health. Previous surveys in this series were carried out by the Office for National Statistics, and were commissioned by the Department of Health, Scottish Executive and National Assembly for Wales. They covered a wide range of different population groups, including:

- Adults living in private households: aged 16 to 64 in 1993<sup>1</sup> and aged 16-74 in 2000;<sup>2</sup>
- Residents of institutions providing care and support to people with mental health problems;<sup>3</sup>
- Homeless adults;<sup>4,5</sup>
- Adults with a psychotic disorder;<sup>6,7</sup>
- Prisoners and young offenders;<sup>8,9,10</sup>
- Young people in local authority care;<sup>11</sup>
- Children and adolescents;<sup>12,13</sup> and
- Carers.<sup>14</sup>

The Adult Psychiatric Morbidity Survey 2007 (APMS 2007) is the third survey of psychiatric morbidity in adults living in private households. It was carried out by the National Centre for Social Research (NatGen) in collaboration with the University of Leicester, and was commissioned by the NHS Information Centre for health and social care and funded by the Department of Health.

APMS 2007 retains the same core questionnaire coverage and methodological approach as the 1993 and 2000 surveys, to enable the analysis of change over time. However, the latest survey also included a number of new topics to reflect emerging policy priorities. A key addition to the 2007 survey was the inclusion of a measure of Autism Spectrum Disorder (ASD). This measure includes Asperger Syndrome, although different subtypes of ASD can not be distinguished from the data. ASD is the focus of this topic report.

## 1.2 Aims of the APMS 2007 survey

A specific objective of APMS 2007 was to estimate the prevalence of ASD among adults, using diagnostic criteria, and to identify the nature and extent of social disadvantage associated with ASD. This includes broadly gauging the level and nature of service use in relation to mental health problems, with an emphasis on primary care.

It should be noted that presence of ASD is known to be higher in the learning disabled population, and a sample of private households of this kind is likely to under-represent adults with the condition, who are more likely to be living in a communal or institutional setting. Moreover, adults with severe functional impairment who do live in private households may be less able (or willing) to respond to surveys.

### 1.3 Overview of the APMS 2007 survey design

Fieldwork was carried out between October 2006 and December 2007. A two-phase approach was used for the assessment of several disorders.

The phase one interviews were carried out by NatGen interviewers. These included structured assessments and screening instruments for mental disorders, as well as questions about other topics, such as general health, service use, risk factors and demographics. These interviews lasted about 90 minutes on average.

The phase two interviews were carried out by clinically trained research interviewers employed by the University of Leicester. A sub-sample of phase one respondents were invited to take part in the second phase interview to permit assessment of ASD, psychosis, and borderline and antisocial personality disorder. The assessment of these conditions requires a more detailed and flexible interview than was possible at the first phase, and the use of some clinical judgement in ascertaining a diagnosis.

Details of the sample design and methods are provided in Chapter 3. Methods and results for the other disorders assessed on the survey are described in the main survey report, which can be downloaded from the NHS IC website.

The phase one and two interviews were also components of a wider programme of work that the University of Leicester has been leading on. The aims of this wider work have been to adapt existing ASD assessment tools and evaluate their performance in a community setting. The report of this methodological development work is reproduced in full in Appendix C.<sup>16</sup>

### 1.4 Coverage of this report

This report presents data on the presence of ASD, based on the data collected at phases one and two of APMS 2007. These findings were not included in the initial survey report. Estimated disorder prevalence is presented by age, sex, ethnic group, marital status, highest educational qualification, equivalised household income, economic activity status, receipt of benefits, housing tenure, area level deprivation and predicted verbal IQ. The level and nature of treatment and service use is considered, although the sample size means that this cannot be explored in detail.

### 1.5 Access to the data

As with the previous general population surveys, a copy of the 2007 APMS dataset will be deposited at the UK Data Archive. Copies of anonymised data files can be made available for specific research projects. Information on this process is available at the data archive website ([www.data-archive.ac.uk](http://www.data-archive.ac.uk)).

A list of the derived variables used in this report can be found in Appendix B.

### 1.6 Ethical clearance

Ethical approval for APMS 2007 was obtained from the Royal Free Hospital and Medical School Research Ethics Committee.<sup>17</sup>

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## Summary

- Autism Spectrum Disorders (ASDs) are developmental disorders characterised by impaired social interaction and communication, severely restricted interests and highly repetitive behaviours.
- This chapter presents data on the prevalence and correlates of ASD among adults living in the English general population. This is the first time such data have been collected in any country.
- In the phase one interview ASD was screened for using a 20 item version of the Autism Quotient (AQ-20). In the phase two interview, assessments were carried out by clinically trained interviewers using the Autism Diagnostic Observation Schedule (ADOS) with a subset of respondents with medium to high AQ-20 scores. The results were weighted to generate a prevalence rate for the population as a whole.
- The recommended threshold of a score of 10 or more on the phase two ADOS assessment was used to indicate a case of ASD.
- Using this recommended threshold score on the ADOS, 1.0% of the adult population had ASD. The rate was higher in men (1.8%) than women (0.2%), which fits with the profile found in childhood population studies.
- 19 cases were identified in the phase two sample. Only a subset of phase one respondents was selected to take part in a phase two interview. Had all respondents completed a phase two interview, we estimate that 72 cases would have been identified in the sample as a whole. The small unweighted base size means caution with interpretation is required. Rates are shown for all adults and separately for men, but not separately for women due to small numbers.
- People who were single were more likely to be assessed with ASD than people of other marital statuses combined. This was evident among men: 4.5% of single men were assessed with ASD.
- ASD was associated with educational qualification. The rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (2.1%).
- Likelihood of a positive assessment for ASD varied with tenure and the level of deprivation in the local area. Those living in accommodation rented from a social landlord were the most likely to have ASD. This was strongly evident among men: 8.0% of men in social housing were identified with ASD.
- Being of low predicted verbal IQ was also associated with presence of ASD.
- There was no indication of any increased use of treatment or services for mental or emotional problems among people with ASD.

## 2.1 Introduction

Autism Spectrum Disorders (ASDs) are developmental disorders characterised by widespread abnormalities of social interaction and communication, as well as severely restricted interests and highly repetitive behaviours.<sup>1</sup> As with other mental and behavioural disorders, they probably exist on a continuum. Presence of ASD can have a negative impact on learning and, at the more severe end of the spectrum, on the ability to live independently in adulthood.<sup>2</sup> Adults with the condition often experience isolation and adverse experiences such as being bullied and socially excluded.

ASD is known to be strongly associated with the presence of learning disabilities and it has been estimated that 7.5% of adults with a learning disability may also have ASD.<sup>3</sup> The costs to society, including to individuals and families, of ASD in adulthood has been estimated at £90,000 per annum per adult.<sup>4</sup> Quantifying a total cost of ASD is problematic because there have been no reliable estimates of the number of adults in England with the condition. APMS 2007 is the first general population probability sample survey in any country to have assessed ASD in adults.<sup>5</sup>

ASD has been assessed among children and young people, and two recent, large-scale surveys estimated the prevalence of childhood ASD to be around 1%, and higher in boys than girls.<sup>6</sup> ASDs are more apparent and easier to study in children, in part because diagnosis should include presence of symptoms in childhood and parent and teacher observations of this are more likely to be accurate and available for this group.

The number of reported cases of ASD increased steeply throughout the 1990s. It is likely that this was due to changes in public awareness of the condition, different diagnostic definitions and practices, availability of services and referrals, and earlier age at diagnosis.<sup>7</sup> The current evidence available does not rule out the possibility that the prevalence of ASD has increased.<sup>8</sup>

## 2.2 Definition and assessment

### 2.2.1 Autism Spectrum Disorder (ASD)

The concept of Autism gained recognition in the mid 20th Century and is still evolving.<sup>9</sup> It remains unclear whether ASDs comprise one condition or a range of similar inter-related neuro-developmental conditions, with separate subtypes (such as Autism, Asperger syndrome and High Functioning Autism). Experts have achieved a broad consensus on what constitutes the category of Autism Spectrum Disorder (ASD), and the diagnostic criteria set out in the fourth Diagnostic and Statistical Manual (DSM-IV) and the International Classification of Disease (ICD-10) are very similar.<sup>10</sup> Both systems use the term Pervasive Developmental Disorders (PDD) and require information on early childhood development for diagnosis.

### 2.2.2 Assessment of ASD

#### *Case assessment of ASD*

In surveys of ASD in childhood, information on behaviour and early development has been collected from parents and teachers. For adults, the ideal scenario would involve assessments of directly observed current behaviour and information on both early development and on current day to day functioning over an extended period. This is not a practical option for a large general population survey of adults, and so the assessment process on APMS 2007 was based on a combination of self-report data collected at the phase one interview and a semi-structured assessment carried out by a clinically trained research interviewer at the phase two interview, conducted alongside assessments of psychosis and personality disorder. This multi-stage case assessment for ASD is similar in structure to that used on APMS 2007 for the assessment of psychosis and personality disorders and includes the following:<sup>11</sup>

- A. Phase one AQ-20 self-completion screen
- B. Selection of cases for phase two assessment
- C. Phase two ADOS assessment of a subset of cases
- D. Weighting to adjust for selection probabilities and non-response.

**A Phase one interview: Autism Quotient**

The full Autism Quotient, here referred to as the AQ-50, is one of few fully structured questionnaires designed to capture signs of ASD in respondents.<sup>12</sup> The other two questionnaires are either longer<sup>13</sup> or require data to be collected from a collateral informant, such as a parent.<sup>14</sup> A clinical diagnosis can not be derived from the AQ-50; it is a screening tool designed to identify potential underlying autistic traits. However, the AQ-50 has been shown in clinical populations to have good correspondence with an ASD diagnosis at a clinic.

The full AQ consists of 50 items; to minimise respondent burden on the already long APMS 2007 questionnaire, a shorter 20 item version was derived using data collected by two of the AQ authors in the development of the full schedule. Details of the modelling undertaken to select the best subset of items are given in a separate technical report which is reproduced in Appendix C.<sup>15</sup> The AQ-50 questionnaire is composed of items designed to assess five broad dimensions: social functioning, imagination, communication, attention switching and attention to detail. The 20 adopted items selected by the modelling procedure as the best predictors of a positive ASD assessment spread quite evenly across these categories: six were social functioning items; four, communication; four, attention to detail; three, attention switching; and three, imagination. This short version of the questionnaire is referred to here as the AQ-20.

The 20 items selected were mostly phrased positively, where agreement with the item was indicative of an ASD trait. The original AQ-50 had sought a balance of positive and negative agreement items to avoid agreement bias, therefore the following three items were rephrased from the original and the scoring was reversed:

**Figure 2A**

Figure 2A	
Reversed items in the AQ-20	
Original wording in AQ-50	Revised wording in AQ-20
I would rather go to a <i>library</i> than a <i>party</i>	I would rather go to a party than a <i>library</i>
I <i>don't particularly</i> enjoy reading fiction	I <i>particularly</i> enjoy reading fiction
I find it <i>hard</i> to make new <i>friends</i>	I find it <i>easy</i> to make new friends

Because none of the AQ-50 items ask about the impact of ASD traits on functioning, five new questions were constructed. One was asked for each of the AQ dimensions that a respondent screened positive for. These questions, and the ones that make up the AQ-20, were discussed by an expert panel and tested in the cognitive piloting conducted as part of the APMS 2007 development work. The final version of the AQ-20 and the impact questions is reproduced in Appendix A.

A score was generated for each respondent based on their responses to the AQ-20. Each response indicative of ASD was given one point, so that the AQ-20 generated a score of between zero and twenty where a higher score indicated greater likelihood that the person may have ASD. Items 1, 2, 3, 4, 6, 9, 10, 15, 17 and 18 drew a point for 'definitely agree' or 'slightly agree'; and items 5, 7, 8, 11, 12, 13, 14, 16, 19 and 20 for 'definitely disagree' or 'slightly disagree'.

The AQ-20 is a self-completion questionnaire, and it was administered via a laptop computer in the phase one interview. Because it is a screening questionnaire and not a diagnostic measure, a clinical assessment was included in the phase two interview.

## **B Selection of cases for phase two assessment**

A subsample of phase one respondents was invited to take part in a second phase interview. Respondents' probabilities of selection for phase two were determined by their responses to questions at phase one, including their score on the AQ-20. Those with a higher AQ-20 score had a higher chance of being selected. How the phase two sample was constructed is described in detail in Chapter 3.

## **C Phase two assessment: Autism Diagnostic Observation Schedule (ADOS)**

The second phase interviews were carried out by clinically trained research interviewers from the University of Leicester. The assessment of conditions such as ASD required a more flexible interview than was possible at the first phase, and the use of judgement in rating clinical criteria for diagnostic classification.

The Autism Diagnostic Observation Schedule (ADOS), Module 4, was completed with 618 respondents at phase two (98% of phase two respondents). It is a widely recommended 'gold standard' clinical research assessment instrument for autistic disorders that is used to collect information on adult functioning.<sup>16</sup> It is a semi-structured clinical assessment of whether current behaviour is consistent with a diagnosis of an autistic disorder.

The ADOS and its algorithm have been validated in previous clinic based testing, but prior to APMS 2007 they had rarely been used with older adults or in a general population setting.<sup>17</sup> The methods and results of a quality assurance and validation study undertaken are reported on elsewhere. That study found the ADOS performed well, and its results have informed the case threshold used in this report.

The ADOS consists of a series of tasks that evaluate communication, reciprocal social interaction (social functioning), creativity, imagination and stereotyped interests and restricted interests. These tasks are rated. The ADOS ratings that correspond to DSM-IV criteria were summed to produce an overall score. A score of seven or more is the threshold used to identify an inclusive category of 'non specific PDD'. The recommended threshold of 10 or more is applied in this report to indicate a case of ASD.

## **D Weighting to adjust for selection probabilities and non-response**

For the designation of an ASD outcome the following approach was used:

- For those with a phase one AQ score of five or more and who had an ADOS assessment, the results of the ADOS were used.
- Those whose responses at phase one placed them in stratum one were assumed to not have the disorder, regardless of whether or not an ADOS assessment was completed.
- Those with a phase one AQ score of five or more but who did not have an ADOS assessment (e.g. due to non-selection, refusal or non-contact) were excluded from the analysis, and a weighting strategy was applied to take account of their absence. The weighting strategy meant that the ADOS results for the respondents assessed at phase two were weighted to reflect the profile of all respondents identified as eligible for a phase two assessment.

## **2.3 Results**

### **2.3.1 ASD, by age and sex**

The overall prevalence of ASD, using the threshold of a score of 10 on the ADOS to indicate a positive case, was 1.0% of the adult population in England (equivalent to a rate of 10 per thousand). A total of 19 cases was identified, because only a sub-sample of respondents was selected for a phase two interview. This small base means that great caution is required in interpreting the population distribution of ASD (particularly among women). Had all respondents gone through to a phase two interview, we estimate that about 72 cases would have been identified in the sample as a whole.

The rate among men (1.8%) was higher than that among women (0.2%), which fits with the

profile found in clinic based research and in childhood population studies. This difference (as are all the differences highlighted in the text of this report) was statistically significant.

Table 2A

Table 2A			
Prevalence of ASD (ADOS 10+), by sex			
All adults	2007		
	Sex		
	Men	Women	All
	%	%	%
ASD (ADOS score of 10+) <sup>a</sup>	1.8	0.2	1.0
Base (unweighted)	1114	1740	2854
Base (weighted)	3517	3841	7358

<sup>a</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data.

Analysis of ASD by age is quite unstable when age is grouped into narrow bands of 10 years or less, due to the small number of productive cases identified in the sample. However, when analysed by three broad bands of 20-30 years each, a slight downward trend with increasing age appeared to be evident but was not significant. Because no significant variation in rate by broad age group was evident, it was not deemed necessary to age standardise the subsequent tables in this report.

Table 2B

Table 2B			
Prevalence of ASD (ADOS 10+), by age			
All adults	2007		
	Age group		
	16-44	45-74	75+
	%	%	%
ASD (ADOS score of 10+) <sup>a</sup>	1.1	0.9	0.8
Base (unweighted)	1351	1227	276
Base (weighted)	3638	3135	584

<sup>a</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data.

### 2.3.2 Variation in screening positive for ASD by other characteristics

The small number of productive cases of ASD identified meant that it was sensible to restrict the tables in this chapter to showing data in three columns, to avoid instability in the estimates. Using broader bands can mask some of the extremes and some associations become non-significant. Prevalence estimates are shown for all adults and separately for men, but not separately for women, due to the small number of women identified with ASD in the sample.

#### Ethnic group

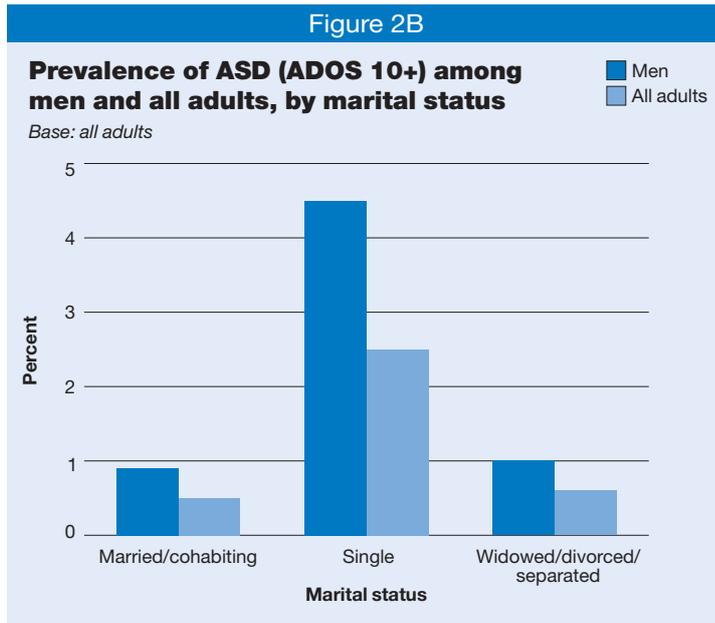
None of the 19 cases of ASD identified in the APMS 2007 sample was a respondent from a minority ethnic group. However, due to the small number of minority ethnic respondents in the sample as a whole, caution is required in interpreting whether or not ASD is associated with ethnic group.

#### Marital status

People who were single (and had never been married) were more likely to be assessed with ASD than people of all other marital statuses combined (i.e. those who were either currently married or cohabiting or who had been married in the past). This pattern was evident

among men only: 4.5% of single men were assessed with ASD compared with 0.9% of those married or cohabiting and 1.0% of those widowed, divorced or separated.

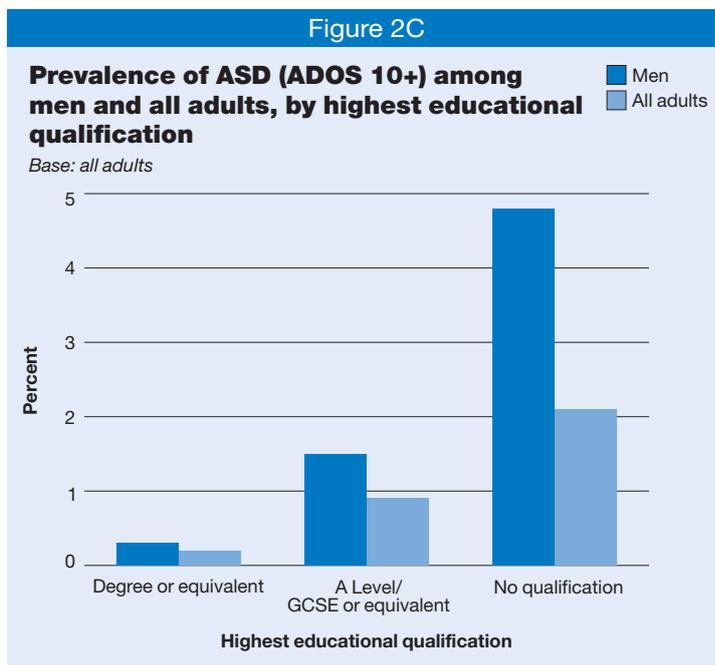
Table 2.1, Figure 2B



### Highest educational qualification

Presence of ASD was associated with the highest educational qualification that people had achieved. Overall, the rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (2.1%). This pattern was evident among men.

Table 2.2, Figure 2C



### Equivalent household income

See the Glossary for a definition of equivalent household income and how it was derived.

While the likelihood of having ASD appeared to increase among men as household income decreased, this was not significant (when analysis was run using household income grouped into tertiles).

Table 2.3

### Economic activity status

See the Glossary for a definition of economic activity and how it was derived. This analysis

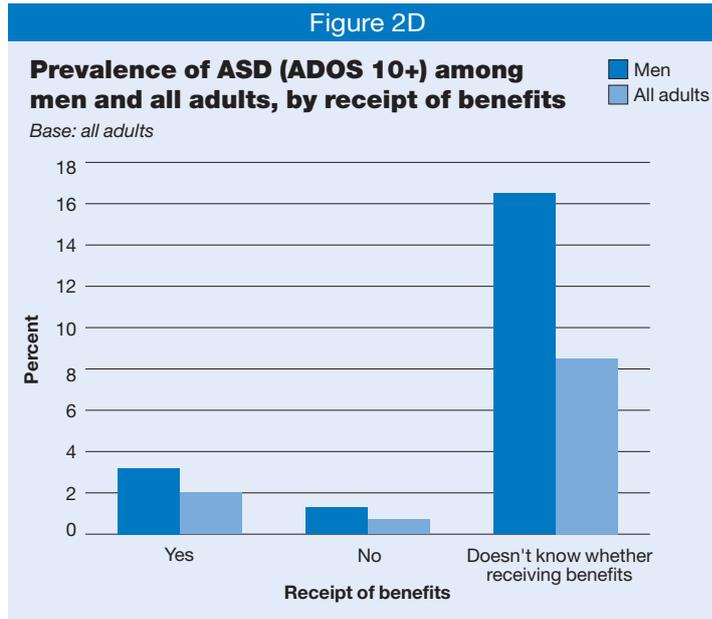
was run on those aged 16-64, to exclude people who are retired constituting most of the economically inactive group.

No significant variation in rate of ASD by economic activity status was found. **Table 2.4**

**Receipt of benefits**

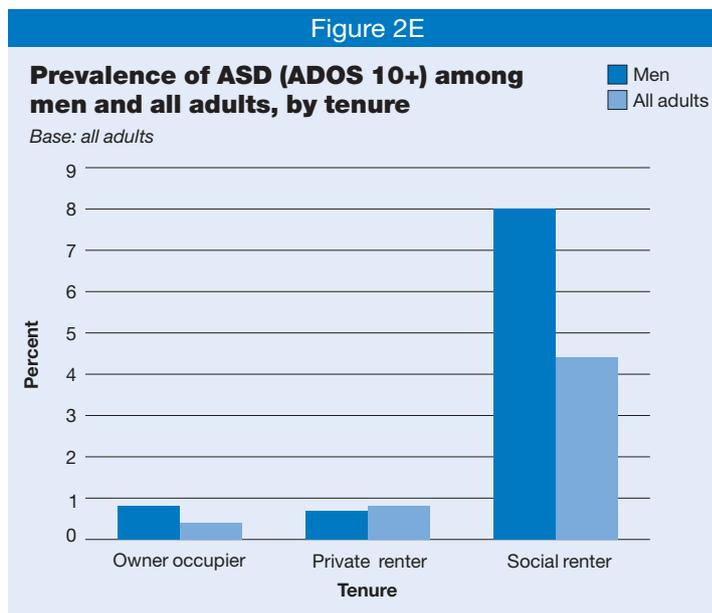
See the Glossary for a list of which benefits were included in the derivation of this variable.

While no significant variation was evident between those who were and were not in receipt of benefits, 16.5% of those who did not know whether or not they were receiving any such state aid did assess positive for ASD. While the base for those responding 'don't know' was small, this does suggest that people with ASD may lack skills in financial awareness. A similar pattern was evident for questions about debt, where 23% of men answering 'don't know' were assessed as having ASD (data not shown). **Table 2.5, Figure 2D**



**Housing tenure**

Likelihood of a positive assessment for ASD varied with the tenure status of people's homes. Those living in accommodation which was rented from a social landlord were the most likely to have ASD. This was evident among men: 8.0% of men in social housing were identified with ASD. **Table 2.6, Figure 2E**

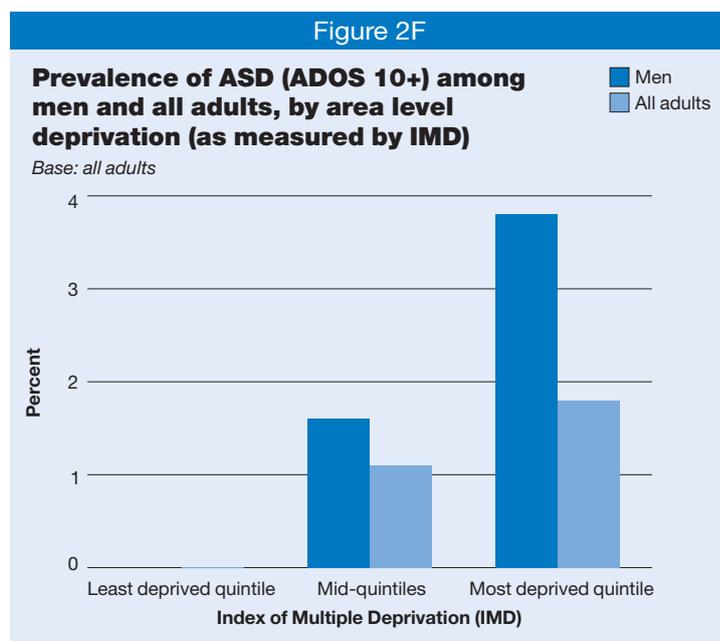


### Area level deprivation

The Index of Multiple Deprivation (IMD) 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 others according to its level of deprivation.

The IMD quintiles were regrouped into three, with the least deprived group containing one quintile, the most deprived group containing one quintile and the other three grouped into a middle category. Using this approach, ASD was found to be significantly associated with how deprived the area is that people live in. In areas with an IMD score indicative of higher deprivation, the ASD rate was highest.

Table 2.7, Figure 2F



### Predicted verbal IQ

A prediction of verbal IQ (V-IQ) was derived using respondents' scores on the National Adult Reading Test (NART), conducted at phase one. How this score was converted to a prediction of verbal IQ is outlined in Appendix A. Respondents with a V-IQ score of between 70 and 85 could be considered to be of 'borderline intelligence': this is the minimum IQ considered to be required for someone to function normally and independently without the assistance of support services. It should be noted that the authors are not aware of any validation work that has assessed the use of the NART as a way of predicting Verbal IQ, or the correspondence of Verbal IQ with general intelligence, specifically among people with ASD.

The prevalence of ASD was only 0.4% in those with a V-IQ above 100. People with the lowest V-IQ score (70-85) were much more likely to have ASD (2.7% of all adults, 4.3% of men) than those in higher scoring V-IQ groups.

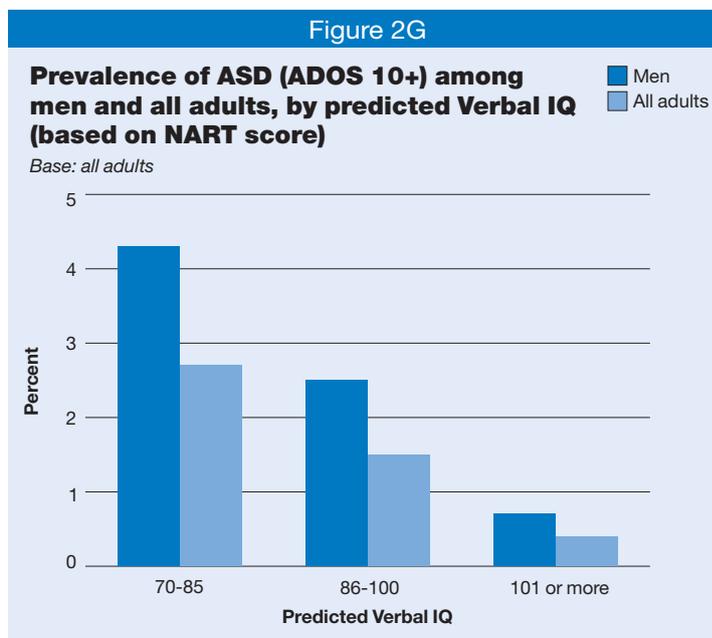
Table 2.8, Figure 2G

### 2.3.3 Treatment and service use

Respondents were asked about any treatment they were receiving for a mental or emotional problem around the time of the interview. This included the use of a range of different types of psychoactive medication and counselling or other talking therapies. The drugs that were asked about are listed in the Glossary. Questions covering use of health, community and day care services in the past year were also included. More detailed definitions of these, including variation in the timescales referred to, are also provided in the Glossary.

Rates of treatment and service use were compared between people with and without ASD. These data are not shown in a table because the base size for people with ASD is very small: just 19 positive cases. However, the main finding from these data is that there is no

Figure 2G



indication of any increased use of treatment or services for mental or emotional problems among people with ASD. If anything, it appears that rates of treatment and service use for a mental health reason may be lower for this group, although it must be emphasised that the treatment data can only be considered as, at best, indicative.

## 2.4 Discussion

The overall prevalence of ASD in adults in England was estimated to be 1.0%. Rates were higher in men than women and no association with age was found. The lack of an association with age means that the data provide no support for there being an increase in prevalence in recent decades.

Perhaps most important of all is the finding that adults with ASD are socially disadvantaged, less well educationally qualified, less able intellectually and possibly under-supported by services. Much of this could be alleviated with greater involvement of existing established social, educational, welfare and health care services.

While our data did not demonstrate that adults with ASD are more likely to be receiving state financial benefits than adults without ASD, it did indicate that people with ASD are less likely to know the answer to this and other similar questions. This is in line with the clinical observation that many are ill equipped to manage their own finances. Previous work shows that adults with mental disorders receive attention from services because mental health problems are recognised needs.<sup>20</sup> But this recognition of need does not extend to adults with ASD. The findings of this survey are mirrored by the National Audit Office report on support for more able adults with autism from local government and the national health service in England.<sup>21</sup> The NAO report also makes a reasoned economic argument for increasing the identification of adults with ASD, and supporting them to obtain and maintain appropriate paid employment.

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 for supporting them are being developed within Local Authorities in some parts of England, which are based on the principle that carers and health and social care staff can recognise 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.<sup>22</sup> Clinical experience of providing informed social care of this kind to adults given a diagnosis of ASD leads to improvements in quality of life and reductions in inappropriate use of high cost hospital services.

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## Tables

- 2.1 Prevalence of ASD (ADOS 10+) among all adults and men only, by marital status
- 2.2 Prevalence of ASD (ADOS 10+) among all adults and men only, by highest educational qualification
- 2.3 Prevalence of ASD (ADOS 10+) among all adults and men only, by equivalised household income
- 2.4 Prevalence of ASD (ADOS 10+) among all adults and men only, by economic activity status
- 2.5 Prevalence of ASD (ADOS 10+) among all adults and men only, by receipt of benefits
- 2.6 Prevalence of ASD (ADOS 10+) among all adults and men only, by housing tenure
- 2.7 Prevalence of ASD (ADOS 10+) among all adults and men only, by Index of Multiple Deprivation (IMD)
- 2.8 Prevalence of ASD (ADOS 10+) among all adults and men only, by predicted Verbal IQ

**Prevalence estimates are shown for all adults and separately for men, but not separately for women due to the small number of women identified with ASD in the APMS sample.**

Table 2.1

**Prevalence of ASD (ADOS 10+) among all adults and men only, by marital status***All adults<sup>a</sup>* 2007

ASD (ADOS score of 10+) <sup>b</sup>	Marital status		
	Married/cohabitating	Single	Widowed/divorced/separated
	%	%	%
Men	0.9	4.5	1.0
All adults	0.5	2.5	0.6
<i>Base (unweighted)</i>			
<i>Men</i>	642	276	196
<i>All</i>	1614	564	676
<i>Base (weighted)</i>			
<i>Men</i>	2141	902	475
<i>All</i>	4635	1601	1122

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

Table 2.2

**Prevalence of ASD (ADOS 10+) among all adults and men only, by highest educational qualification***All adults<sup>a</sup>* 2007

ASD (ADOS score of 10+) <sup>b</sup>	Highest educational qualification <sup>c</sup>		
	Degree (incl. teaching, nursing, HND)	A Level/GCSE or equivalent	No qualification
	%	%	%
Men	0.3	1.5	4.8
All adults	0.2	0.9	2.1
<i>Base (unweighted)</i>			
<i>Men</i>	340	449	247
<i>All</i>	882	1132	680
<i>Base (weighted)</i>			
<i>Men</i>	1055	1329	836
<i>All</i>	2160	2628	2071

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

<sup>c</sup> Respondents who reported foreign qualifications or qualifications that could not be classified were excluded from the base.

Table 2.3

**Prevalence of ASD (ADOS 10+) among all adults and men only, by equivalised household income***All adults<sup>a</sup>* 2007

ASD (ADOS score of 10+) <sup>b</sup>	Equivalised household income <sup>c</sup>		
	Highest income	Middle income	Lowest income
	%	%	%
Men	0.4	0.9	3.3
All adults	0.3	0.7	1.6
<i>Base (unweighted)</i>			
<i>Men</i>	388	271	237
<i>All</i>	884	722	674
<i>Base (weighted)</i>			
<i>Men</i>	1030	1004	1067
<i>All</i>	2071	1788	2322

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

<sup>c</sup> See the Glossary for a definition of equivalised household income.

Table 2.4

**Prevalence of ASD (ADOS 10+) among all adults and men only, by economic activity status***Aged 16-64<sup>a</sup>* 2007

ASD (ADOS score of 10+) <sup>b</sup>	Economic activity status		
	In employment	Unemployed	Economically inactive
	%	%	%
Men	1.6	[1.9]	3.3
All adults	0.9	1.6	1.5
<i>Base (unweighted)</i>			
<i>Men</i>	688	37	161
<i>All</i>	1671	72	547
<i>Base (weighted)</i>			
<i>Men</i>	2161	247	520
<i>All</i>	4429	291	1215

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

Table 2.5

<b>Prevalence of ASD (ADOS 10+) among all adults and men only, by receipt of benefits</b>			
<i>All adults</i> <sup>a</sup>		2007	
ASD (ADOS score of 10+) <sup>b</sup>	Whether in receipt of state benefits <sup>c</sup>		
	Yes	No	Don't know
	%	%	%
Men	3.2	1.3	[16.5]
All adults	2.0	0.7	8.5
<i>Base (unweighted)</i>			
<i>Men</i>	181	910	19
<i>All</i>	440	2360	43
<i>Base (weighted)</i>			
<i>Men</i>	748	2726	29
<i>All</i>	549	3258	56

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

<sup>c</sup> See the Glossary for a description of how the receipt of benefits variable was derived.

Table 2.7

<b>Prevalence of ASD (ADOS 10+) among all adults and men only, by Index of Multiple Deprivation (IMD)</b>			
<i>All adults</i> <sup>a</sup>		2007	
ASD (ADOS score of 10+) <sup>b</sup>	Index of Multiple Deprivation (IMD) <sup>c</sup>		
	Least deprived quintile	Mid-three quintiles	Most deprived quintile
	%	%	%
Men	-	1.8	3.8
All adults	-	1.1	1.6
<i>Base (unweighted)</i>			
<i>Men</i>	191	704	219
<i>All</i>	541	1771	542
<i>Base (weighted)</i>			
<i>Men</i>	540	2425	552
<i>All</i>	1331	4725	1302

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

<sup>c</sup> The 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 their level of deprivation. <http://www.communities.gov.uk/communities/neighborhoodrenewal/deprivation/deprivation07/>

Table 2.6

<b>Prevalence of ASD (ADOS 10+) among all adults and men only, by housing tenure</b>			
<i>All adults</i> <sup>a</sup>		2007	
ASD (ADOS score of 10+) <sup>b</sup>	Tenure		
	Owner occupiers	Private renters	Social renters
	%	%	%
Men	0.8	0.7	8.0
All adults	0.4	0.8	4.4
<i>Base (unweighted)</i>			
<i>Men</i>	757	155	188
<i>All</i>	2010	336	477
<i>Base (weighted)</i>			
<i>Men</i>	2473	525	502
<i>All</i>	5355	1039	929

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

Table 2.8

**Prevalence of ASD (ADOS 10+) among all adults and men only, by predicted Verbal IQ**

People with English as their first language<sup>a</sup>

2007

ASD (ADOS score of 10+) <sup>b</sup>	Predicted Verbal IQ <sup>c</sup>		
	70-85 %	86-100 %	101+ %
Men	4.3	2.5	0.7
All adults	2.7	1.5	0.4
<i>Base (unweighted)</i>			
Men	154	260	616
All	310	716	1638
<i>Base (weighted)</i>			
Men	599	1031	1644
All	1043	1994	3684

<sup>a</sup> Data are not presented separately for women due to the small number of women in which ASD was identified.

<sup>b</sup> See Section 2.2 for a definition of ASD and a description of how the variable was derived from weighted phase one and two data. The base (total sample) consists of all respondents with a near zero probability of being ASD positive (a phase-one AQ-20 score of less than 5) and respondents who completed an ADOS assessment at phase-two.

<sup>c</sup> An estimate of Verbal IQ was derived using the National Adult Reading Test (NART) score. Respondents who did not speak English as their first language, who had eyesight problems, or who volunteered that they were dyslexic were excluded from the base. The methodology for converting the NART error score to a predicted Verbal IQ is summarised in the Glossary and described in detail in Appendix A.

## 3.1 Introduction

The Adult Psychiatric Morbidity Survey 2007 (APMS 2007) is the third in a series of general population surveys of adult mental health. The previous surveys were conducted by ONS in 1993 and 2000, and covered England, Scotland and Wales. The 2007 survey was carried out by NatCen, covered England only and removed the upper age limit to participation (which was 64 in 1993 and 74 in 2000). Like the preceding surveys, APMS 2007 consisted of two phases, with the second phase interview being conducted with a sub-sample of phase one respondents by clinically trained interviewers coordinated by the University of Leicester. Core topics have been covered in every survey wave, such as anxiety and depression, psychosis and substance use disorders.

The key new topic covered in 2007 was the assessment of Autism Spectrum Disorder (ASD), which has not been measured in a general population sample of adults before. This chapter summarises the general methodological approach of phase one and phase two of APMS 2007. A more detailed technical report, focusing on the rationale for and development of the ASD assessment procedures adopted and the outcomes of related corroborative work undertaken in this area is reproduced in Appendix C.<sup>1</sup>

This chapter provides a description of the survey methodology used on APMS 2007, including accounts of the:

- Sample design for the phase one and phase two interviews;
- Fieldwork procedures;
- Survey response;
- Weighting strategies; and
- Data analysis approach used in this report.

More detailed survey methodology is provided in the main report, which can be downloaded from the NHS Information Centre website.<sup>2</sup>

## 3.2 Sample design

### 3.2.1 Overview of the sample design

The sample for APMS 2007 was designed to be representative of the population living in private households (that is, people not living in communal establishments) in England. People living in institutions are more likely than those living in private households to have ASD, however this group was not covered in the survey reported on here and this should be borne in mind when considering the survey's account. At the time of the 2001 Census, 2% of the English population aged 16 years or over were resident in a communal establishment.

The survey adopted a multi-stage stratified probability sampling design. The sampling frame was the small user Postcode Address File (PAF). The small user PAF consists of those Royal Mail delivery points which receive fewer than 50 items of mail each day. Therefore, most large institutions and businesses are excluded from the sample but some small businesses and institutions may receive fewer than 50 items each day and thus be sampled. Once the interviewer has verified that an address does not contain a private

household, such addresses are recorded as ineligible. The very small proportion of households living at addresses not on the PAF (less than 1%<sup>3</sup>) were not covered by the sample frame.<sup>4</sup>

A stratified multi-stage random probability sample was used for the phase one interview, involving two stages of sample selection: the sampling of the primary sampling units (PSUs) followed by the sampling of addresses within the selected PSUs. The approach to drawing a sample is outlined below: please see the main report for details.<sup>2</sup>

### **3.2.2 Selection of primary sampling units (PSUs)**

The PSUs were individual or groups of postcode sectors. In the first stage of sampling, the postcode sectors were stratified on the basis of a measure of socio-economic status within a regional breakdown. First, postcode sectors were divided into regions based on Strategic Health Authority (SHAs).<sup>5</sup> All the PSUs within each SHA were then further stratified on the basis of the proportion of people in non-manual classes and sorted by the proportion of households without a car based on 2001 Census data.<sup>6</sup> Then postal sectors were sampled from each stratum with a probability proportional to size (where size is measured by the number of delivery points). In this way a total of 519 postal sectors were selected in England.

Table 3.1

### **3.2.3 Sampling addresses and households**

In the second stage of sampling 28 delivery points were randomly selected within each of the selected postal sectors. Interviewers visited to identify private households with at least one person aged 16 or over. At addresses with more than one household, interviewers used multi-household selection grids to select a single household.

### **3.2.4 Sampling one adult per household**

One adult aged 16 years or over was selected for interview in each household.<sup>7</sup> In households where there was more than one person aged 16 years or over, one was selected at random for interview.

### **3.2.5 Eligible addresses**

Out of the 14,532 addresses in the original sample, 12,694 (87%) were found to include at least one private household, 1,318 (9%) were non-residential addresses, and 520 (4%) were addresses of unknown eligibility. After making adjustments for the proportion of addresses of unknown eligibility that would in practice have been eligible, there was an estimated combined base of 13,171 known eligible and probable eligible addresses for the phase one interview.<sup>8</sup>

### **3.2.6 Sampling procedures for the phase two interviews**

#### **Overview**

For each phase one respondent, the probability of selection for a phase two assessment was calculated as the maximum of four disorder-specific probabilities:

- Psychosis probability;
- ASD probability;
- Borderline personality disorder probability; and
- Antisocial personality disorder probability.

The probabilities were based on respondents' responses to screening questions in the phase one questionnaire. These disorder-specific probabilities are summarised below, and described in more detail in the main survey report.

As an example of their use: a person with a psychosis score of zero, an ASD score of five, a borderline personality disorder score of four, and an adult antisocial personality score of two and a conduct disorder score of three (corresponding to stratum 3 for antisocial social

personality disorder) would have had the following four disorder-specific ‘probabilities’ for selection:

- Psychotic disorder: 0
- ASD: 0.021
- Borderline personality disorder: 0.25
- Antisocial personality disorder: 0.18.

Given that the highest of these four probabilities is 0.25, the probability that the respondent was selected for a phase two interview was 0.25.

**Figure 3A**

Figure 3A	
<b>Calculation of disorder-specific probabilities of selection for a phase two interview</b>	
<b>Psychotic disorder</b>	
<i>Number of phase one psychosis criteria met</i>	<i>Probability of selection for phase two</i>
0	0
1+	1
<b>ASD</b>	
<i>Score at phase one ASD self-completion questionnaire</i>	<i>Probability of selection for phase two</i>
0-4	0
5	0.021
6	0.022
7	0.022
8	0.025
9	0.029
10	0.25
11	0.61
12+	1
<b>Borderline personality disorder</b>	
<i>Score at phase one self-completion SCID-II screen</i>	<i>Probability of selection for phase two</i>
0-3	0
4	0.25
5	0.40
6	0.52
7	0.63
8	1
9	1
<b>Antisocial personality disorder</b>	
<i>Stratum assigned according to phase one self-completion SCID-II screen</i>	<i>Probability of selection for phase two</i>
1 (or aged 16/17)	0
2	0.13
3	0.18
4	0.29
5	0.38
6	0.54
7	0.76
8	1
9	1

### 3.3 Topic coverage

The questionnaire covered a range of psychiatric and behavioural disorders and topics related to individual circumstances and experiences. These are listed in the main survey report, alongside the full phase one questionnaire.

### 3.4 Fieldwork procedures

#### 3.4.1 Training and supervision of interviewers

##### *Phase one interviewers*

The NatCen interviewers were briefed on the administration of the survey. Topics covered on the one-day survey-specific training included questionnaire content, confidentiality and respondent distress. All interviewers were accompanied by a project supervisor during the early stages of their fieldwork. Routine supervision of 10% of interviewer work was carried out.

##### *Phase two interviewers*

The phase two interviewers were recruited and co-ordinated by the University of Leicester. They were all interviewers experienced in psychological research, and several had worked on APMS 2000. Phase two interviewers received an extensive induction and training programme, run by a senior research psychologist and a psychiatrist assisted by a full time ADOS trainer from Cambridge University. They also received training sessions from NatCen on using Computer Assisted Interviewing (CAI). Whilst in the field, phase two interviewers received regular supervision sessions and technical support.

The ADOS specific training programme was developed based on the types of people with ASD that interviewers were likely encounter in field, including students, and working age and older adults living in the community with a clinician determined diagnosis of Asperger syndrome or High Functioning Autism. The format and content of this training programme was developed following advice and comment from the most experienced research active UK based trainers and from investigators involved in the original development of the instrument. Interviewing in field did not commence until the team of four interviewers was achieving substantially above 90% agreement on ratings of jointly observed ADOS examinations.

The fieldwork of the research psychologists was supervised by a senior research psychologist and a psychiatrist who had conducted earlier surveys in the psychiatric morbidity programme. The supervising psychologist observed a subset of field work interviews in respondents' own homes. At the midpoint of phase two fieldwork all interviewers met again with the ADOS trainer and a second equally experienced ADOS trainer who had not been involved in their training to conduct an inter-rater reliability session.

#### 3.4.2 Proxy interviews and people with severe learning disability

If the selected respondent was not capable of undertaking the interview alone, for reasons of mental or physical incapacity, the option was available for a 'proxy' interview conducted with another member of the family, a carer or another person who knew the selected respondent well. The 58 proxy interviews conducted were short (mostly less than half an hour), and only included questions that were current and factual rather than subjective. The information collected was not sufficient for selection probabilities to be calculated, and therefore selected respondents interviewed via a proxy respondent were not eligible for a phase two interview.

Because the survey had no upper age limit, many of the selected respondents interviewed via a proxy respondent were very elderly. Some selected respondents interviewed in this way may have been adults with learning disability at the severe or profound level, because

they would not have been able to take part in the full APMS 2007 interview directly. This was in part because phase one interviewers were not trained in how to manage such situations and because the APMS 2007 questionnaire would not have been appropriate. The prevalence of ASD among adults with learning disability is known to be elevated, one estimate places the ASD rate at 7.5% among this group.<sup>9</sup>

### 3.4.3 Other fieldwork details

Please see the main survey report for details of:

- Piloting and questionnaire development
- Quality control procedures
- Advance letters sent to respondents
- Making contact
- Collecting the data
- Token of appreciation (given for participation in both phase two and phase two)
- Help-lines, thank you letters and examples of fieldwork documents.

## 3.5 Survey response

### 3.5.1 Response at phase one

9% of sampled addresses were ineligible because they contained no private households, while 4% were addresses of unknown eligibility (see Section 3.2.5). This left an estimated base of 13,171 known eligible or probable eligible households for the phase one interview. The proportion of selected adults who agreed to take part in an initial interview is shown in Figure 3B. At the phase one interview, 57% of those eligible agreed to take part in an interview. This included 50 partial interviews where the respondent completed the service use and CIS-R modules, but did not reach the end of the interview.

Figure 3B

Figure 3B		
Response rates of adults at initial interview (phase one)		
	Number	%
<b>Set sample of households</b>	<b>13,171</b>	<b>100</b>
Refusals	4,075	31
Non-contacts (known eligible)	499	4
Non-contacts (estimated eligible)	471	4
Other unable/unproductive	664	5
<b>Co-operating adults</b>	<b>7,461</b>	<b>57</b>
<b>Co-operating adults</b>	<b>7,461</b>	<b>100</b>
Full interviews	7,353	99
Partial interviews	50	1
Proxy interviews	58	1

### 3.5.2 Response at phase two

7461 respondents provided a productive phase one interview. Of these 58 were proxy respondents and therefore not eligible for the phase two interview (see Figure 3E). A probability of selection was calculated for each respondent based on their answers to the phase one screening questions on psychosis, Asperger syndrome, and personality disorder: as outlined in Section 3.2.6. 5,329 respondents had a probability of selection of greater than zero: 4050 of these also agreed to be recontacted for a phase two interview (76%). After the application of the highest of the four disorder specific sampling fractions, 849 respondents were selected for a phase two interview. Phase two interviews were conducted with 630 of these (74%).

Figure 3C

Figure 3C

<b>Response rates of adults at clinical interview (phase two)</b>		
	<b>Number</b>	<b>%</b>
Productive respondents	7,461	
– excluding proxies	7,403	
<b>Eligible for phase two based on phase one responses</b>	<b>5,329</b>	<b>100</b>
- eligible and agreed to recontact	4,050	76
<b>Selected for phase two after sampling fractions applied</b>	<b>849</b>	<b>100</b>
- phase two interview conducted	630	74
- refusals	62	7
- non contacts	54	3
- not issued to field due to time constraints	103	12
<b>Phase two interviews</b>	<b>630</b>	<b>100</b>
- SCAN interview completed <sup>a</sup>	628	100
- SCID interview completed	606	96
- ADOS interview completed	618	98

<sup>a</sup> Scan data are not present for all 630 cases, as were lost for two respondents.

## 3.6 Weighting the data

### 3.6.1 Weighting the phase one data

The survey data were weighted to take account of non-response, so that the results were representative of the household population aged 16 years and over. Weighting occurred in four steps.

*First*, sample weights were applied to take account of the different probabilities of selecting respondents in different sized households.

*Second*, to reduce household non-response bias, a household level weight was calculated from a logistic regression model using interviewer observation and area-level variables (collected from Census 2001 data) available for responding and non-responding households. The dependent variable was whether the household responded or not. The independent variables considered for inclusion in the model were the presence of any physical barriers to entry to the property (e.g. a locked common entrance or the presence of security staff), Government Office Region, Index of Multiple Deprivation 2004 (IMD 2004) quintiles,<sup>10</sup> population density (number of persons per hectare), percentage of persons of non-white ethnic background, percentage of households owner-occupied, and the percentage of adults in a non-manual occupation.

Not all the variables were retained for the final model: variables not strongly related to the propensity of households to respond were dropped from the analysis. The variables found to be related to response were Government Office Region, whether there were entry barriers to the selected address, and the percentage of households owner-occupied. The model shows that the propensity for a household to respond was lower in the West Midlands, East of England, London, South East and the South West (relative to the North East), higher for households with no physical barriers to entry to the property, and higher in areas where a relatively high percentage of households were owner-occupied.

The non-response 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. The full model is given in Table 3.2.

**Table 3.2**

*Thirdly*, weights were applied using the techniques of calibration weighting<sup>11</sup> based on age,

sex and region to weight the data to represent the structure of the national population, and to take account of differential non-response between regions and age-by-sex groups. The population control totals used were the Office for National Statistics (ONS) 2006 mid-year household population estimates. Tables 3.3 and 3.4 show the control totals used. As a result of the calibration, the APMS 2007 weighted data matches exactly the estimated population across these three dimensions. This is shown in Table 3.5. **Tables 3.3 to 3.5**

Finally, the phase one survey weight was multiplied by an ASD sampling weight, to produce the definitive weighting variable used in this report (aspergerwt2). This process is described in Section 3.6.2.

### **3.6.2 Weighting the phase two data**

The phase two interview data has a set of survey weights different from those generated at phase one. The phase two weights were designed to generate condition-specific phase-two datasets that were representative of the population 'eligible' for phase two by virtue of that particular condition. Combining the phase-two weighted data with the phase-one weighted data for the non-eligible group thus gives data representative of the whole adult population.

The calculation of the phase two weights was relatively straightforward. They account for two factors:

1. Not all those eligible for phase two were selected with equal probability (those with higher screening scores at phase two were more likely to be selected, and those with potential co-morbidities were selected with, on average, higher probabilities than those with single disorders);
2. Some of those selected for phase two declined to take part. This introduces the possibility of phase two non-response bias. Attempts have been made to minimise the risk of this by including a non-response adjustment to the weights that ensures that those responding match those selected in terms of sex, age-group and screening score for the disorder in question.

The weights relating to the second phase dataset were calculated as two components. The first comprised the selection weights, which were calculated, for each person as the inverse of their probability of selection for phase two, multiplied by their phase one weight. The second component was the non-response adjustment, calculated as the inverse of the modelled probability of responding at phase two (having been selected). The modelling was based on a weighted logistic regression, with the weights in the model being the selection weights.

## **3.7 Data analysis and reporting**

### **3.7.1 Introduction**

APMS 2007 was a cross-sectional survey of the general population. While it allows for associations between ASD and personal characteristics and behaviour to be explored, it is important to emphasise that such associations cannot be assumed to imply causality.

A list of the variables used in the analysis in this report is provided in Appendix B: all will be included in the final archived dataset.

### **3.7.2 Weighted and unweighted bases**

As outlined in Section 3.6 above, all the data presented in Chapter 2 of this report are weighted (with aspergerwt2) to account for likelihood of selection and non-response. Both weighted and non-weighted bases are given in each table. The unweighted bases are presented to show the number of respondents included. The weighted base shows the relative size of the various sample elements after weighting, reflecting their proportions in the English population, so that data from different columns can be combined in their correct

proportions. The absolute size of the weighted base has no particular significance, since it has been scaled to the achieved sample size.

### 3.7.3 Age-standardisation

Because presence of ASD was not found to be significantly associated with age broadly banded, it was not considered necessary to age-standardise the data in the tables in this report.

### 3.7.4 Standard analysis breaks

ASD was analysed by a series of socio-demographic breaks: age, sex, ethnicity, marital status, housing tenure, equivalised household income, highest educational qualification, employment status, receipt of benefits and area level deprivation. These are defined in the Glossary at the end of this report, including how they were derived. In addition, prevalence of ASD was examined in relation to estimated Verbal IQ. This variable is also described in the Glossary.

#### *Treatment and service use*

When looking at treatment and service use, respondents assessed with ASD were compared with those assessed as without ASD. Because of the small base size for people with ASD in APMS 2007 sample size, these analyses are not presented in this report. However the distribution that was observed is discussed, in a general way, in the text.

### 3.7.5 Sampling errors and design factors

The percentages quoted in the main report are estimates for the population based on the information from the sample of people who took part in this survey. All such survey estimates are subject to some degree of error. The confidence interval (CI) is calculated from the sampling error, which is a measure of how such a survey estimate would vary if it were calculated for many different samples. If the survey were repeated many times, such a 95% CI would contain the true value 95% of the time. For this survey, a multi-phase stratified design was used, rather than a simple random sample, and the sampling errors need to reflect this.

The effect of a complex sample design on estimates is quantified by the design factor (deft). It is the ratio of the standard error for a complex design to the standard error which would have resulted from a simple random sample.

The sampling errors, design effects and confidence intervals (CIs) for ASD prevalence can be found in Table 3.6. These calculations were carried out using the statistical package SPSS.

**Table 3.6**

### References and notes

- 1 Brugha T, McManus S, Meltzer H, Purdon S, Scott F, Baron-Cohen S, Wheelwright S, Smith J, Bankart J (2009) Development and testing of methods for identifying cases of Autism Spectrum Disorder among adults in the Adult Psychiatric Morbidity Survey 2007 The NHS Information Centre.
- 2 McManus S, Meltzer H, Brugha T, Bebbington P & Jenkins R McManus S (Eds.) (2009) Adult Psychiatric Morbidity in England, 2007. Results of a household survey. London: The NHS Information Centre for health and social care.
- 3 Dodd T (1987) 'A further investigation into the coverage of the Postcode Address File' Survey Methodology Bulletin no 21 OPCS.
- 4 Addresses selected for all NatCen surveys in the last three years were excluded from the sampling frame. However, because they have been selected at random in the first place, this does not introduce selection bias. The benefit of this procedure is to reduce the burden of surveys on the public, which, it is hoped, will help to maintain response in the long term.
- 5 The sample design (implemented April 2006) used the structure for health administration in England which came into effect on 1 July 2003. There were 28 SHAs which were constituted from groups of local authorities.

- 6 The NS-SEC (National Statistics Socio-economic Classification) measure relating to household reference persons (the person in whose name the accommodation is owned or rented) does not easily lend itself to a manual/non-manual breakdown. Hence the social grade measure available for all persons aged 16 and over in households was used, where non-manual was defined by social classes AB (higher and intermediate managerial/administrative/professional) and C1 (supervisory, clerical, junior managerial/administrative/ professional).
- 7 In 2000 one adult aged 16 to 74 years was interviewed per household.
- 8 See McManus et al (2009) for details.
- 9 Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. (2007) Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Brit J Psychiatry*: 190:27-35.
- 10 IMD 2004 is a measure of multiple deprivation at the small area level.  
<http://www.communities.gov.uk/archived/general-content/communities/indicesofdeprivation/216309/>
- 11 The calibration weighting was carried out iteratively in the CALMAR SAS macro.

## Tables

- 3.1 Regional stratifiers used and number of PSUs selected
- 3.2 Final response model
- 3.3 2006 mid-year household population estimates for adults in England, by age and sex
- 3.4 2006 mid-year household population estimates for adults in England, by Government Office Region
- 3.5 Weighted and unweighted sample distribution, by Government Office Region, age and sex
- 3.6 True standard errors and 95% confidence intervals for ASD (ADOS 10+)

Table 3.1

**Regional stratifiers used and number of PSUs selected**

Regional stratifier	Strategic Health Authority <sup>a</sup>	Delivery Point Count	Number of PSUs selected
1	Norfolk, Suffolk and Cambridgeshire	993,067	24
2	Bedfordshire and Hertfordshire	692,132	16
3	Essex	716,697	18
4	North West London	723,877	17
5	North Central London	495,489	12
6	North East London	638,329	15
7	South East London	666,114	16
8	South West London	554,970	13
9	Northumberland, Tyne & Wear	633,663	15
10	County Durham and Tees Valley	512,894	12
11	North and East Yorkshire and Northern Lincolnshire	730,673	18
12	West Yorkshire	919,293	22
13	Cumbria and Lancashire	856,005	20
14	Greater Manchester	1,109,392	27
15	Cheshire & Merseyside	1,050,407	25
16	Thames Valley	888,735	21
17	Hampshire and Isle of Wight	773,709	18
18	Kent and Medway	698,001	17
19	Surrey and Sussex	1,136,614	27
20	Avon, Gloucestershire and Wiltshire	954,049	23
21	South West Peninsula	717,566	17
22	Dorset and Somerset	552,905	13
23	South Yorkshire	567,408	14
24	Trent	1,200,485	28
25	Leicestershire, Northamptonshire and Rutland	678,179	17
26	Shropshire and Staffordshire	643,446	15
27	Birmingham and the Black Country	979,455	23
28	West Midlands South	666,013	16
	<b>England</b>	<b>21,749,567</b>	<b>519</b>

<sup>a</sup> Created in 2002, there were originally 28 strategic health authorities (SHAs). On July 1 2006, this number was reduced to 10. We used the original SHA boundaries to stratify the sample by region.

Table 3.2

<b>Final response model</b>					
Variable	Base	Odds ratio	Standard error	P-value	95% confidence interval
<b>Government Office Region (&lt;0.001)</b>					
North East	679	(baseline)			
North West	1,779	0.88	0.095	0.168	0.73-1.06
Yorkshire & the Humber	1,328	0.83	0.098	0.059	0.69-1.01
East Midlands	1,107	0.86	0.102	0.134	0.70-1.05
West Midlands	1,349	0.78	0.098	0.012	0.65-0.95
East of England	1,456	0.76	0.097	0.005	0.63-0.92
London	1,647	0.58	0.096	<0.001	0.48-0.70
South East	2,040	0.75	0.093	0.002	0.63-0.90
South West	1,309	0.73	0.099	0.001	0.60-0.88
<b>Barriers to entry at selected address</b>					
One or more barriers to entry	1,349	(baseline)			
No barriers	11,345	1.38	0.061	<0.001	1.22-1.55
<b>Percentage of households in area owner-occupied<sup>a</sup></b>					
	12,694	1.00	0.001	0.003	1.00-1.01

<sup>a</sup> The odds of a household responding increased by 1.004 (to 3 decimal places) per one unit increase in the percentage of households owner-occupied, adjusting for the other variables in the model.

Table 3.3

### 2006 mid-year household population estimates for adults in England,<sup>a</sup> by age and sex

Age group	Men N	Women N
16-24	2,898,211	2,798,318
25-34	3,292,746	3,329,246
35-44	3,840,530	3,902,973
45-54	3,208,291	3,272,812
55-64	2,908,582	3,014,655
65-74	1,960,670	2,167,516
75 and over	1,437,592	2,145,871
<b>Total</b>	<b>19,546,622</b>	<b>20,631,391</b>

<sup>a</sup> Office for National Statistics (ONS) 2006 mid-year household population estimates. (<http://www.statistics.gov.uk/about/data/methodology/specific/population/PEMethodology/>)

These figures are estimates: they are provided to enable others to replicate our process.

Table 3.4

### 2006 mid-year household population estimates for adults in England,<sup>a</sup> by Government Office Region

Government Office Region	N
North East	2,040,387
North West	5,410,995
Yorkshire & the Humber	4,074,538
East Midlands	3,463,025
West Midlands	4,226,702
East of England	4,433,773
London	5,970,247
South East	6,472,410
South West	4,085,936
<b>Total</b>	<b>40,178,013</b>

<sup>a</sup> Office for National Statistics (ONS) 2006 mid-year household population estimates. (<http://www.statistics.gov.uk/about/data/methodology/specific/population/PEMethodology/>)

These figures are estimates: they are provided to enable others to replicate our process.

Table 3.5

**Weighted and unweighted sample distribution, by Government Office Region, age and sex**

	Population	Unweighted respondents	Respondents weighted by selection weight only	Respondents weighted by un-calibrated non-response weight	Respondents weighted by final weight
	%	%	%	%	%
<b>Government Office Region</b>					
North East	5.1	5.9	5.8	5.3	5.1
North West	13.5	14.8	14.4	13.6	13.5
Yorkshire & the Humber	10.1	10.8	10.6	10.2	10.1
East Midlands	8.6	9.2	9.5	9.0	8.6
West Midlands	10.5	10.7	10.9	10.8	10.5
East of England	11.0	11.5	11.8	11.8	11.0
London	14.9	10.8	10.7	12.8	14.9
South East	16.1	16.1	16.3	16.3	16.1
South West	10.2	10.2	10.1	10.2	10.2
<b>Age and sex</b>					
Male 16-24	7.2	3.7	5.1	5.2	7.2
Male 25-34	8.2	5.6	6.0	6.1	8.2
Male 35-44	9.6	8.3	8.5	8.6	9.6
Male 45-54	8.0	6.7	7.1	7.2	8.0
Male 55-64	7.2	7.7	8.0	7.9	7.2
Male 65-74	4.9	6.2	6.1	6.0	4.9
Male 75+	3.6	5.1	4.5	4.4	3.6
Female 16-24	7.0	4.0	5.0	5.0	7.0
Female 25-34	8.3	8.3	8.1	8.3	8.3
Female 35-44	9.7	10.8	10.9	10.9	9.7
Female 45-54	8.1	8.6	9.4	9.3	8.1
Female 55-64	7.5	9.5	9.6	9.5	7.5
Female 65-74	5.4	7.6	6.2	6.2	5.4
Female 75+	5.3	8.0	5.6	5.6	5.3
<b>Total</b>	<b>40,178,013</b>	<b>7,462</b>	<b>7,462</b>	<b>7,462</b>	<b>7,462</b>

Table 3.6

**True standard errors and 95% confidence intervals for Autism Spectrum Disorder (ASD: ADOS 10+)**
All adults<sup>a</sup>

2007

Base	Characteristic	%	Sample size	Weighted sample size	True standard error	95% confidence interval <sup>b</sup>	Deft
<b>Men</b>	Presence of ASD	1.8	1114	3517	0.7	0.8 - 3.9	1.99
<b>Women</b>	Presence of ASD	0.2	1740	3814	0.1	0.1 - 0.6	0.99
<b>All adults</b>	Presence of ASD	1.0	2854	7358	0.3	0.5 - 2.0	1.89

<sup>a</sup> Consists of all respondents with a phase one AQ score of 0-4, plus all respondents with an AQ score of 5 or more and a phase two ADOS score.

<sup>b</sup> Produced using SPSS v15. Other statistical software packages may produce slightly different estimates of confidence intervals.

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**Contents**

A1 Assessment of ASD

A2 Assessment of predicted Verbal IQ

**A1 Assessment of ASD**

The two-phase approach to the assessment of ASD is described in Chapters 2 and 3. This appendix reproduces the questions in the short version Autism Quotient (AQ-20) that were selected from the longer AQ-50 and describes how they were scored.<sup>1</sup> This screening instrument was used to stratify respondents according to their likelihood of having ASD to inform their selection probability for a clinical phase two assessment. The second phase assessment tool, which required clinical judgement and was administered by a trained research interviewer, was the semi-structured Autism Diagnostic Observation Schedule (ADOS). The documentation of this interview is under copyright and cannot therefore be reproduced in this report. Details however can be obtained from the authors of the ADOS.<sup>2</sup>

**Autism Quotient (AQ-20) and impact on functioning questions**

The items in the AQ-20 are reproduced in this appendix, with the responses indicative of ASD in bold. Some of these items were changed from those in the original AQ-50, in order to retain a balance of agree and disagree responses attracting scores. The items that changed are listed in the table below, in both the original and revised format:

Figure A	
Reversed items in the AQ-20	
Original wording in AQ-50	Revised wording in AQ-20
I would rather go to a <i>library</i> than a <i>party</i>	I would rather go to a <i>party</i> than a <i>library</i>
I <i>don't particularly</i> enjoy reading fiction	I <i>particularly</i> enjoy reading fiction
I find it <i>hard</i> to make new friends	I find it <i>easy</i> to make new friends

A score was generated for each respondent based on their responses to the AQ-20. Each response indicative of ASD was given one point, so that the AQ-20 generated a score of between zero and twenty where a higher score indicated greater likelihood that the person may have ASD. Items 1, 2, 3, 4, 6, 9, 10, 15, 17 and 18 drew a point for 'definitely agree' or 'slightly agree'; and items 5, 7, 8, 11, 12, 13, 14, 16, 19 and 20 for 'definitely disagree' or 'slightly disagree'.

After the AQ-20, new questions designed to assess the impact of different domains of ASD on social functions are shown.

<sup>1</sup> Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. (2001) The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-function autism, males and females, scientists and mathematicians. *J Autism Dev Disorder* February;31(1):5-17.

<sup>2</sup> Lord C, Rutter M, Le Couteur A. (2002) The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. *J Autism Dev Disord*. 30:205-223.

## AQ-20 ITEMS

### ASK ALL

#### Intro

The following statements are about the kind of person that you are, and the way you prefer to do things. You might find some of the statements a bit odd, but please answer all of them to the best of your ability, even if some of them don't seem to apply to you.

#### 1. ASover

I prefer to do things the same way over and over again.

- 1 **Definitely agree**
- 2 **Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

#### 2. ASsound

I often notice small sounds when others do not.

- 1 **Definitely agree**
- 2 **Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

#### 3. ASpolite

Other people frequently tell me that what I've said is impolite, even though I think it is polite.

- 1 **Definitely agree**
- 2 **Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

#### 4. ASdates

I am fascinated by dates.

- 1 **Definitely agree**
- 2 **Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

#### 5. ASsocsit

I find social situations easy.

- 1 Definitely agree
- 2 Slightly agree
- 3 **Slightly disagree**
- 4 **Definitely disagree**

#### 6. ASdetail

I tend to notice the details that others do not.

- 1 **Definitely agree**
- 2 **Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

#### 7. ASparty

I would rather go to a party than a library.

- 1 Definitely agree
- 2 Slightly agree
- 3 **Slightly disagree**
- 4 **Definitely disagree**

### 8. ASpeople

I find myself drawn more strongly to people than to things.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

### 9. ASstalk

When I talk, it isn't always easy for others to get a word in edgeways.

- 1 Definitely agree**
- 2 Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

### 10. ASstory

When I'm reading a story, I find it difficult to work out the characters intentions.

- 1 Definitely agree**
- 2 Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

### 11. ASread

I particularly enjoy reading fiction.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

### 12. ASfriend

I find it easy to make new friends.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

### 13. ASlisten

I know how to tell if someone listening to me is getting bored.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

### 14. ASdomore

I find it easy to do more than one thing at once.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

### 15. ASphone

When I talk on the phone, I'm not sure when it's my turn to speak.

- 1 Definitely agree**
- 2 Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

**16. ASface**

I find it easy to work out what someone is thinking or feeling just by looking at their face.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

**17. ASinform**

I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc).

- 1 Definitely agree**
- 2 Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

**18. ASplan**

I like to plan any activities I participate in carefully.

- 1 Definitely agree**
- 2 Slightly agree**
- 3 Slightly disagree
- 4 Definitely disagree

**19. ASsococc**

I enjoy social occasions.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

**20. ASdob**

I am not very good at remembering people's date of birth.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree**
- 4 Definitely disagree**

**Assessment of social functioning:**

**IF ATTENTION SWITCHING SCORE=2 AND TOTAL AQ SCORE>=8 THEN**

**ImpactAS**

You've said that you prefer to (*do things the same way each time/plan activities carefully*).

Are your important daily routines, work or study ever affected by of this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF ATTENTION TO DETAIL SCORE>=2 AND TOTAL AQ SCORE>=8 THEN**

**ImpactAD**

You've said that you are particularly good at things like (*noticing small sounds when others do not/remembering details like dates*).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF COMMUNICATION SCORE $\geq$ 2 AND TOTAL AQ SCORE $\geq$ 8 THEN**

**ImpactCn**

You've said that you sometimes have difficulties (*knowing how and when to speak/being told that you are impolite*).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF SOCIAL FUNCTIONING SCORE $\geq$ 2 AND TOTAL AQ SCORE $\geq$ 8 THEN**

**ImpactSS**

You've said that you (*may avoid social situations or find them difficult/find yourself drawn strongly to things*).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF IMAGINATION SCORE $\geq$ 2 AND TOTAL AQ SCORE $\geq$ 8 THEN**

**ImpactIm**

You've said that you (*take a particular interest in facts about things but not in characters in stories*).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

## **A2 Assessment of predicted Verbal IQ**

Sight reading irregularly spelled words is thought to be a reasonable estimate of intellectual functioning because this task correlates well with Verbal IQ.<sup>3</sup> An estimate of Verbal IQ (V-IQ) was derived using the National Adult Reading Test (NART), which was administered on phase one of APMS 2007.<sup>4</sup> To introduce the test, the interviewer said:

'The next set of questions are about something completely different, and involve reading different words.

First, I would like you to look at this card.

In a moment I will ask you to start reading the words on the card. Begin with the first word on the top row and go from left to right along the row, and then on to the second row.

Please pause after each word – wait until I say OK before going on to the next. Don't worry if you don't recognize a word. Have a guess at how it is said.

We will stop before the end of the list.'

The interviewer then presented the respondent with an show card on which 50 words were printed in relatively large font, these are reproduced in Table A.

<sup>3</sup> Franzen M (2000) Reliability and validity in neuropsychological assessment. Second edition: Critical Issues in Neuropsychology.

<sup>4</sup> Nelson HE and Willison J. (1991) National Adult Reading Test (NART). Windsor: NFER-Nelson; Report No.: 2nd Edition.

Table A

**Words in the National Adult Reading Test (NART)**

CHORD	COURTEOUS	HIATUS	FACADE	GAUCHE
ACHE	RARIFY	SUBTLE	ZEALOT	TOPIARY
DEPOT	EQUIVOCAL	PROCREATE	DRACHM	LEVIATHAN
AISLE	NAIVE	GIST	AEON	BEATIFY
BOUQUET	CATACOMB	GOUGE	PLACEBO	PRELATE
PSALM	GAOLED	SUPERFLUOUS	ABSTEMIOUS	SIDEREAL
CAPON	THYME	SIMILE	DETENTE	DEMESNE
DENY	HEIR	BANAL	IDYLL	SYNCOPE
NAUSEA	RADIX	QUADRUPED	PUERPERAL	LABILE
DEBT	ASSIGNATE	CELLIST	AVER	CAMPANILE

If respondents did not know a word, they were asked to guess how they thought the word should be pronounced. The correct phonetic pronunciation of each word was presented on the laptop computer for the interviewer, and the interviewer coded whether or not the respondent's pronunciation matched that on their screen. While some allowance was made for regional dialects, the words on the NART had been selected because they should vary relatively little. The test was stopped after four incorrect responses in a row.

Respondents whose first language was not English were not asked to do the NART, and those who volunteered to the interviewer that they were dyslexic or had eyesight problems were excluded from the analysis.

Each correct item was given a point, and a 'NART error score' was generated by subtracting the number of correct items from 50. This score can then be converted into the revised Wechsler Adult Intelligence Scale (WAIS-R) for an estimate of Verbal IQ (VIQ).<sup>5</sup>

The equation used for this conversion was:

Predicted WAIS-R Verbal IQ = 127.4 – 1.14 x NART error score.

Respondents with a V-IQ score of between 70 and 85 were estimated to be of 'borderline intelligence'.

<sup>5</sup> Wechsler D. (1987) Wechsler Adult Intelligence Scale – Revised, New York: The Psychological Corporation.

# Appendix B

## Derived variables used in this report

# B

### Contents

- B1 Autism Spectrum Disorder
- B2 Predicted Verbal IQ
- B3 Socio-demographic variables
- B4 Psychoactive medication currently used
- B5 Talking therapies and service use
- B6 Variables accounting for survey method

Detailed and current documentation for all the archived variables will be available from the UK Data Archive when the APMS 2007 dataset is deposited (see <http://www.data-archive.ac.uk/>).

### B1 ASD variable

<b>Com10pl</b>	ADOS 10+, to be used with 'aspergerwt2'
Value	Label
1	present
2	absent

### B2 Predicted Verbal IQ variable

<b>IQVBEST3G</b>	Predicted Verbal IQ grouped into three
Value	Label
1	70-85
2	86-100
3	101 or more

### B3 Socio-demographic variables

<b>RESPSEX</b>	Sex of selected respondent
Value	Label
1	Male
2	Female

<b>AGE30YR</b>	Age of selected respondent in 30 year age bands
Value	Label
1	16 - 44
2	45 - 74
3	75+

<b>ETHNIC4</b>	Ethnic origin of selected respondent in four categories
Value	Label
1	White
2	Black
3	South Asian (Indian, Pakistani or Bangladeshi)
4	Mixed or other
<b>EDQUAL3</b>	Highest educational qualification of selected respondent in three categories (with foreign and other qualifications excluded)
Value	Label
1	Degree/Teaching, HND, Nursing
2	A Level/GCSE or equivalent
3	No qualifications
<b>RESMARDF</b>	Marital status of selected respondent
Value	Label
1	Married/Cohabiting
3	Single
4	Widowed/Divorced/Separated
<b>DVILO3A</b>	ILO employment status of selected respondent in three categories
Value	Label
1	In Employment
2	Unemployed
3	Economically Inactive
<b>NEWTEN</b>	Tenure status of respondent's accommodation
Value	Label
1	Owner occupier
2	Social renter
3	Private renter
<b>QIMD3</b>	IMD quintiles grouped into three
Value	Label
1	Least deprived quintile
2	Middle three quintiles
3	Most deprived quintile
<b>EQINV3</b>	Equivalised household income grouped into three
Value	Label
1	Lowest income tertile
2	Middle income tertile
3	Highest income tertile
<b>Anybens</b>	Respondent in receipt of any benefits
Value	Label
1	Yes
2	No

## B4 Psychoactive medication

<b>ANYMED</b>	Current use of any psychoactive medication
Value	Label
1	Yes
2	No

## B5 Talking therapies and service use

**ANYTHER** Currently having any counselling or therapy

Value Label

1 Yes

2 No

**TRTMENT** Currently in receipt of any medication, counselling, or therapy treatment

Value Label

1 Yes

2 No

**DAYCOMYR** Used a day activity centre in past year

Value Label

1 Yes

2 No

**ANYCCAR** Any community care service in past year

Value Label

1 Yes

2 No

**ANYHLCA** Received any health care for mental health or emotional reason (past year from GP, past quarter from hospital)

Value Label

1 Yes

2 No

**ANYDACA** Received any day care service in past year

Value Label

1 Yes

2 No

## B6 Variables accounting for survey method

**WT\_INTS1** Survey weight for phase one data (including the AQ)

**POINT** Primary sampling unit

**STRATA** Stratification variable

**ASPERGERWT2** Weighting variable for use with the ADOS 10+ variable (com10pl), takes account of phase one and phase two weighting

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# Development and testing of methods for identifying cases of ASD



Development and testing of methods for identifying cases of Autism Spectrum Disorder among adults in the Adult Psychiatric Morbidity Survey 2007

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**Authors:** <sup>1</sup>Brugha Traolach, <sup>2</sup>McManus Sally, <sup>1</sup>Meltzer Howard, <sup>2</sup>Purdon Susan, <sup>3</sup>Scott Fiona, <sup>4</sup>Baron-Cohen Simon, <sup>3</sup>Wheelerwright Sally, <sup>1</sup>Smith Jane, <sup>1</sup>Bankart John

<sup>1</sup>Department of Health Sciences, University of Leicester, <sup>2</sup>National Centre for Social Research (NatCen), London, <sup>3</sup>Autism Research Unit, University of Cambridge.

Correspondence: Traolach S Brugha MD(NUI), FRCPsych, Professor of Psychiatry, Department of Health Sciences, University of Leicester, Leicester General Hospital, Gwendolen Road, Leicester LE5 4PW, United Kingdom. Email: [tsb@le.ac.uk](mailto:tsb@le.ac.uk)

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## Summary

As no reliable methods for conducting studies of the epidemiology of Autism Spectrum Disorders (ASD) in adult general population samples have been developed, a methodological programme was instigated to create a suitable screening instrument. The instrument would need to be able to screen for traits of all types of ASD among people with a level of cognitive functioning sufficient to enable participation in a general population survey. Further work may be required for screening to be inclusive of those with the lowest levels of functioning and who may be more likely to be living in a communal setting. This report describes the approach taken to the adaptation and validation of existing ASD assessment tools to develop a process for the epidemiological measurement of ASD among adults in the general population living in private households.

The programme of methodological development work consisted of several stages: modification of an ASD screening tool to use in a survey, three phases of the Adult Psychiatric Morbidity Survey (APMS) 2007 and analyses of the data collected:

- A subset of twenty out of fifty items on the self report Autism Quotient (AQ) was selected in order to predict efficiently which adults would be likely to have an autism spectrum disorder in a specialist diagnostic clinic.
- A random probability sample of adults aged 16 or over throughout England was administered the best discriminatory twenty items from this short-version AQ (phase one). Respondents with higher AQ scores at phase one, completed second and third phase data collections for the purposes of comparison and validation (APMS survey phases one, two and three).
- The instruments selected for the subsequent survey phases were the informant based Diagnostic Interview for Social and Communication Disorders (DISCO, covering life long development) and the Autism Diagnostic Observation Schedule (ADOS).
- The data analyses used to evaluate these methods will be reported on more fully in later academic outputs.

## Background

Autistic spectrum disorders (ASDs) (such as Autism, Asperger Syndrome and High Functioning Autism) are either one or a range of closely related developmental disorders characterised by impairment of reciprocal social interaction and communication and the presence of restricted repetitive behaviours (Wing, 1997), with negative impacts on learning and the development of independence in adulthood (Howlin et al. 2004). ASDs exist on a continuum (or spectrum) of severity and often co-exist with learning difficulties; different types of ASD can be associated with different levels of impact on social functioning. On average, the yearly cost to society, of each adult with ASD in Great Britain has been estimated at £90,000 including personal and training costs (Knapp et al. 2007).

The concept of Autism was first written about in accessible form in the mid 20th Century and is still evolving (Frith, 1991). Experts have been able to achieve a consensus on what constitutes the category of ASD in the form of two very similar sets of international definitions or diagnostic criteria (American Psychiatric Association, 1994; World Health Organization, 1993). Both systems employ the phrase, Pervasive Developmental Disorders (PDD), but this has not been widely adopted by clinicians or service users and carers. Both sets of diagnostic criteria also require information on early childhood development. In two recent, large scale, region-wide and national surveys among children and young people the prevalence of ASDs has been shown to be about 1% (Baird et al. 2006; Green et al. 2005), although estimates will vary with the population studied and the assessment tools used. Rates in childhood are strongly associated with the presence of learning difficulties and disability.

In this report three stages of developmental work are described to identify adults in the community with ASD. They are: (i) the creation (with any necessary adaptation) of a self report questionnaire to be suitable for use in an adult household survey where information from other sources is not routinely available, (ii) the systematic collection of data on ASD characteristics in a large scale general population survey (Adult Psychiatric Morbidity Survey (APMS) 2007 phase one); and (iii) follow-up evaluations in subsequent survey phases using an established research diagnostic instrument used in clinical settings and analyses of the data collected.

The data from the second and third survey phases were used to evaluate the initial phase, self report, survey measure. Thus, the inclusion of clinical diagnostic instruments made it possible to estimate the prevalence and epidemiology of ASD among those with a higher level of functioning and living in private households from the first phase self-report data, provided that the instrument was good at identifying (i.e. demonstrated at least good sensitivity) potential ASD cases. The second and third phase data also provided information for choosing the most appropriate threshold required for prevalence estimation based on the phase one instrument. Where a respondent scores at or above this 'threshold' level, ASD is thought highly likely to be present.

The third survey of adult psychiatry morbidity (APMS 2007) (McManus et al. 2009) was an ideal vehicle for this data collection, being a large scale national general population survey employing a random probability sampling approach and covering the full adult age range.

## Methods

### Project design

The project consisted of three phases of survey data collection and three pieces of analysis. These are described below and in Figure 1.

**Modification of survey screening tool:** a case-control design was used to analyse self report data from the fifty item Autism Quotient, in order to identify a subset of 20 questions for use in epidemiological research (see Section 1.4).

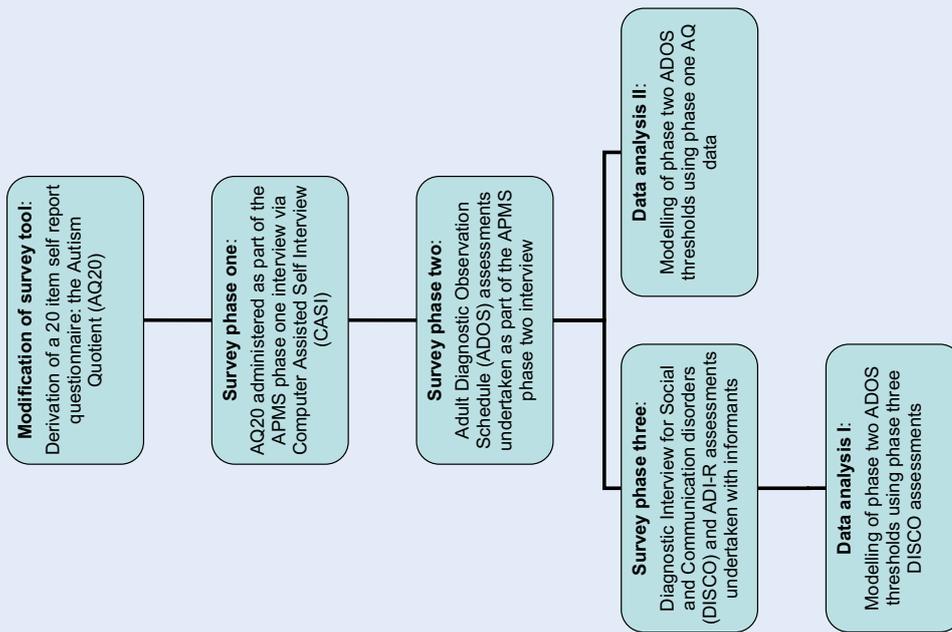
**Survey phase one:** these questions were included in the first phase of the general population, psychiatric morbidity survey (APMS 2007), which used stratified random sampling (see Section 1.5).

**Survey phases two and three:** depending on the answers to the AQ20, subsamples of survey respondents were included in later phases of data collection using clinical diagnostic assessments of ASD (APMS 2007 phases two and three) (see Sections 1.5 and 1.6).

**Data analyses:** the data collected in the three phases of survey fieldwork were analysed to explore how well the different measures of ASD corresponded and to identify the best ADOS threshold score (see Sections 1.7 and 1.8).

Figure 1 illustrates the different studies and phases of data collection undertaken.

Figure 1: A breakdown of the survey phases and data analyses in the ASD project



## Measures

### Clinical Diagnostic Assessments

There are three widely recommended, 'gold standard' clinical research assessment instruments for ASDs that are used to collect information on adult functioning:

- Adult Diagnostic Observation Schedule (ADOS) (Lord et al. 2002b);
- Diagnostic Interview for Social and Communication Disorders (DISCO) (Wing et al. 2002); and
- Adult Diagnostic Interview – Revised (ADI-R) (Lord et al. 1994).

### Current Functioning: the Adult Diagnostic Observation Schedule (ADOS)

The Adult Diagnostic Observation Schedule (ADOS) provides a direct face to face clinical assessment of whether the respondent exhibits current behaviour consistent with a diagnosis of an autistic disorder. The ADOS was originally developed to examine children and then modified for use with older children and adults. In adults the ADOS takes up to ninety minutes to administer. The ADOS assessment consists of various tests comprising set situations (termed 'presses') that evaluate communication, reciprocal social interaction (social functioning), creativity, imagination and stereotyped and restricted interests. Respondents are also asked about their knowledge and understanding of social relationships, emotions, and daily living responsibilities. Algorithms for autism spectrum disorder and for autism are incorporated in the ADOS (Lord et al. 2002a). Selected ADOS ratings that correspond to DSM-IV (American Psychiatric Association, 1994) criteria for Pervasive Developmental Disorder (PDD) are summed to a total score for Communication and Reciprocal Social Interaction to which two thresholds are applied for non specific PDD (ADOS 7+) and for Autism (ADOS 10+). However the authors stipulate that the final clinical diagnosis should where possible take account of other available information. The ADOS does not include an assessment of childhood development or of behaviour outside the examination setting (i.e. in the community), which is recommended (where feasible) in a comprehensive autism diagnostic assessment (based for example on the ICD-10 or DSM-IV diagnostic criteria).

### Diagnostic Interview for Social and Communication Disorders (DISCO)

The DISCO and ADI-R are considered to be the reference assessments of childhood and adult behaviours present in ASDs. The DISCO includes an extensive assessment of current functioning that collects information sufficient for establishing the presence of Autism Spectrum Disorder in an adult (Leekam et al. 2002). It can generate diagnoses without requiring information on childhood development. Information on adult functioning could be provided by a sibling, partner, carer so that most criteria for Autism Spectrum Disorder are covered apart from the ICD-10 and DSM-IV criteria that require additional information on the age at which the respondent first achieved spoken language. The DISCO is now increasingly used in the National Health Service (NHS) to assess adults with a possible ASD. The DISCO also evaluates a range of subtypes of the autism spectrum and related developmental disorders such as disorders of speech.

### Autism Diagnostic Interview – Revised (ADI-R)

The alternative available developmental assessment instrument, the ADI-R, is used widely in research settings and in childhood assessments in health services in the UK and elsewhere.

The purpose of the ADI-R is the same as the DISCO, which is to provide a profile of childhood and current behaviour necessary for an assessment of an ASD. The items in the ADI-R were compared with those covered in the DISCO. Both cover child and current functioning behaviour that describe impaired functioning. The ADI-R appears to focus mainly on core autism features omitting some behaviours that occur in the broader spectrum as seen in cases of Asperger Syndrome and High Functioning Autism, which are more completely covered by the longer DISCO assessment. The diagnostic algorithm for the ADI-R current version requires information on childhood behaviour in order to provide diagnostic output.

### Self report ASD questionnaires

In order to meet data quality requirements in surveys: validity, reliability, portability, and to minimise respondent burden, a self report questionnaire was needed that could predict ASD caseness. It also had to be brief and easy for survey respondents to comprehend and to complete. Only one such questionnaire, the Autism Quotient (AQ) was identified in the published literature (Baron-Cohen et al. 2001), which met these criteria. Although a 78 item questionnaire has recently been described in the literature, the Ritvo Autism and Asperger's Diagnostic Scale (RAADS), it takes one hour to complete and there is only preliminary published data on prediction of ASD caseness (Ritvo et al. 2008).

The AQ was designed to be completed by the target respondent on paper or online. AQ items are designed to evaluate the following five ASD dimensions: social skill, communication, imagination, attention switching and attention to detail. Therefore it can be regarded as a measure of underlying autistic traits and not a measure of autistic pathology. The 50 item AQ has been found to be useful for screening adults referred for diagnostic assessments at tertiary care clinics (Baron-Cohen et al. 2001). The AQ does not generate a clinical diagnosis.

## Modification of survey tool:

### Selection and derivation of a short self-report ASD questionnaire suitable for use in large scale adult surveys

In order to make the Autism Quotient feasible in a large scale survey covering a wide range of mental and behavioural disorders (McManus et al. 2009), a shorter 20 item version of the AQ was derived from the 50 item AQ questionnaire using data previously collected with the AQ covering the same psychological dimensions (Baron-Cohen et al. 2001). Extra questions were added to assess impact on functioning in regard to the five ASD dimensions (McManus et al. 2009).

The samples used to derive the shorter set of AQ items were 1761 Cambridge University undergraduates, none of whom were considered to be ASD cases, although it is likely that a very small proportion would have been undiagnosed 'cases', and 304 clinical cases diagnosed with ASD living in the East of England. The methods used have been described previously (Baron-Cohen et al. 2001). The 20 item AQ was derived from the full 50 item version using this previously obtained clinical and volunteer sample data. Thus a 'normal'

population of controls and a clinical population of diagnosed cases were available. The aim was to find the best subset of predictors which would discriminate between these cases and controls. It was decided that a total number of items not exceeding 20 would be most appropriate for the purposes of reducing screening time to a reasonable duration.

There were several choices of statistical modelling, including best subsets regression, stepwise regression, backward stepwise regression and forward stepwise regression (all binary logistic regression methods).

**Table 1: The full 50 item Autism Quotient a**

Item Number	Item Name
1	Prefer with Others
2	Doing Same Way
3	Picture in Mind
4	Absorbed Lose Sight
5	Notice Small Sounds
6	Strings of Information
7	Say I'm Impolite
8	Imagine Story Characters
9	Date Fascination
10	Track Conversations
11	Social Situations Easy
12	Notice Details
13	Library or Party
14	Make Up Stories
15	Drawn to People
16	Very Strong Interests
17	Enjoy Social Chat
18	Word in Edgeways
19	Fascination with Numbers
20	Characters' Intentions
21	Enjoy Fiction
22	Hard Make Friends
23	Notice Patterns
24	Theatre or Museum
25	Daily Routine
26	Keep Conversation Going
27	Read Between Lines
28	Whole Picture
29	Remember Phone Numbers
30	Notice Small Changes
31	Tell if Bored
32	More than One

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33	Talk on Phone
34	Enjoy Being Spontaneous
35	Point of Joke
36	Looking at Face
37	Interruption Switch
38	Good Social Chat
39	Going On and On
40	Enjoy Games Pretending
41	Collect Information Categories
42	Be Someone Else
43	Plan Activities
44	Enjoy Social Occasions
45	People's Intentions
46	New Situations Anxious
47	Enjoy New People
48	Good Diplomat
49	Remember Dates of Birth
50	Easy Children Pretending

<sup>a</sup> See Appendix A for details of the items retained in the AQ20.

## Survey phases one and two: AQ20 and ADOS fieldwork

The APMS 2007 was carried out by the National Centre for Social Research (NatCen) in collaboration with the University of Leicester (McManus et al. 2009), and was commissioned by The NHS Information Centre for health and social care and funded by the Policy Research Programme in the Department of Health. The main aim of this survey was to collect data on mental health among adults aged 16 and over living in private households in England. Previous research in this field has focused on samples of people in contact with treatment or services, and so has excluded those with unrecognised, undiagnosed and untreated conditions. It should also be noted, however, that as a survey of people living independently in private households, presence of the disorder could have had an impact on likelihood of survey participation. This is hard to measure due to the lack of data that can be collected on survey non-respondents. Certainly those who were not able to participate in the survey without assistance were not included, nor were those living in a communal or institutional setting.

The APMS survey data collection comprised two elements: lay interviews for common mental disorders and clinical interviews to assess ASD, psychosis and personality disorder.

Before conducting the survey, newly introduced questions (including the AQ-20) were subject to cognitive testing. Cognitive testing methods provide social researchers with both theories and tools to develop better survey instruments and questionnaires. (Collins, 2003)

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The focus is on ensuring that questions are clear and can be understood by all respondents as intended. The cognitive pilot was conducted in two waves with 21 respondents. In the first wave it was identified that the AQ questions needed an introduction which highlighted that while 'you might find some of the statements a bit odd... please answer all to the best of your ability, even if some don't seem to apply to you.' This wording was tested in the second wave of cognitive piloting and found to work well.

The survey lay interviews included structured assessments serving diagnostic criteria and screening instruments for a range of mental disorders (including the AQ-20), as well as questions on topics such as general health, service use, risk factors and demographics. A subsample of these respondents was invited to take part in a follow up interview. These interviews were carried out by clinically trained research interviewers. The assessment of conditions such as psychosis, ASD and personality disorder require a more unstructured interview and the use of clinical judgement in rating clinical criteria was required for diagnostic classification.

The Autism Diagnostic Observation Schedule (ADOS), Module 4, was used throughout this second assessment phase of 618 Adults. The Diagnostic Interview for Social and Communication disorders (DISCO) and ADI-R were carried out in a later third phase subset of second phase respondents who agreed to be followed up.

## Sample design

### Phase one sample design

A stratified multi-stage, random probability sample was used (McManus et al. 2009), sampling primary sampling units (PSUs), followed by sampling addresses within the selected PSUs. The PSUs were individual or groups of postcode sectors. A postal sector contains on average 2,550 households. Small postal sectors are grouped with contiguous sectors so that each group contains at least 500 delivery points.

The PSUs were stratified on the basis of a measure of socio-economic status within a regional breakdown. First, postcode sectors were divided into regions based on Strategic Health Authority (SHAs). All the Primary Sampling Units (PSUs) within each SHA were then further stratified on the basis of the proportion of persons in non-manual classes and sorted by the proportion of households without a car based on 2001 Census data. Then postal sectors were sampled from each stratum with a probability proportional to size (where size is measured by the number of delivery points). In this way a total of 519 postal sectors were selected in England.

In the second stage of sampling, 28 delivery points were randomly selected within each of the selected postal sectors. This yielded a total sample of 14,532 delivery points. Interviewers visited the 14,532 addresses to identify private households with at least one person aged 16 and over. When visited by an interviewer, 1,318 of the selected addresses were found not to contain private households. These addresses were thus ineligible and were excluded from the survey sample. Within each of these eligible households, one person was randomly selected to take part in the survey.

For each phase one respondent, the probability of selection for a phase two assessment was calculated as the maximum value of four disorder specific probabilities: psychosis probability; ASD probability; borderline personality disorder probability; and antisocial personality disorder probability. The probabilities were based on respondents' responses to screening questions in the phase one questionnaire (McManus et al. 2009).

The phase one interviews covered non psychotic disorders (CIS-R (Lewis et al. 1992)), personality disorder (SCID-II screening questionnaire (Williams et al. 1992)) and screening questionnaires for ADHD (Kessler et al. 2005), Eating disorders (Morgan et al. 1999), and ASD (the 20 item version of the AQ described in Section 1.4 (Asperger Self Completion Questionnaire (McManus et al. 2009))). Because none of the twenty AQ items enquired specifically about effects on functioning, five new questions were constructed for the survey (McManus et al. 2009). These asked about interference with functioning in relation to each of the five underlying dimensions of the AQ listed earlier.

The phase one survey fieldwork took place throughout one calendar year (2007). If the selected survey respondent was not capable of undertaking the interview alone, then the option was available for a 'proxy' interview to be conducted with another member of the family, a carer or another person who knew the selected respondent well (McManus et al. 2009).

### Phase two sample design

For each phase one respondent, the probability of selection for a phase two assessment was calculated as the greatest of the specific probabilities of four disorders: psychosis; ASD; borderline personality disorder; and antisocial personality disorder. The probabilities were based on respondents' responses to screening questions in the phase one questionnaire, with a higher score indicating a higher likelihood of being selected for the follow-up (McManus et al. 2009).

## Phase two diagnostic measures

The phase two interviews comprised the ADOS Module 4 (Lord et al. 2002a), the survey format of the Schedules for Clinical Assessment in Neuropsychiatry (SCAN) (Brugha and Nienhuis, 1998; Wing et al. 1990) primarily covering psychotic disorders and which included extensive ratings of observed mood, speech, behaviour; and the SCID-II semi-structured interview (Williams et al. 1992) covering the sections for antisocial and borderline personality disorder. The phase one and phase two interviews both involved computer assisted personal interviewing (CAPI). In phase one, sensitive information was collected by self-completion, also using laptop computer (CAS).

Phase two interviews took place in the respondent's own home and lasted for at least 90 minutes. All ADOS ratings were intended to be completed as soon as possible after the interview in accordance with the developers of the instrument (Lord et al. 2002a). Ethical approval was obtained for all phases of the APMS.

### Training and supervision of phase one and phase two interviewers

Phase one (NatCen) interviewers who were selected to work on the first phase of the survey were generally experienced interviewers, many of whom had worked previously on health-related surveys. Interviewers were fully briefed on the administration of the survey. Topics covered included introducing the survey, questionnaire content, confidentiality and respondent distress. All interviewers were accompanied by a project supervisor during the early stages of their fieldwork to ensure that the interviews were administered correctly. Routine supervision of 10% of interviewer work was carried out subsequently.

The phase two interviewers were experienced in psychological research, and several had worked on APMS 2000. Phase two interviewers received an extensive induction and training programme, run by a senior research psychologist and a psychiatrist assisted by a full time ADOS trainer. They also received training sessions from NatCen on using Computer Assisted Interviewing (CAI). Whilst in the field in phase two interviewers received regular supervision sessions and technical support with use of laptops.

A number of quality control measures were built into the survey process, both at data collection and to check on the quality of phase one and phase two interviewer performance. The phase two interview is less structured and requires clinical skills and judgement. The field work of the research psychologists was supervised by a senior research psychologist and psychiatrist who had conducted earlier surveys. The supervising psychologist observed a subset of field work interviews in respondents' own homes. At the midpoint of phase two fieldwork all interviewers met again with the ADOS trainer and a second equally experienced ADOS trainer who had not been involved in their training to conduct an inter-rater reliability session.

### Survey phase three: DISCO and ADI-R fieldwork

Five pilot phase three interviews were carried out with the cooperation of consenting adults identified through local voluntary groups and who had been previously assessed for possible Autism Spectrum Disorder (usually either Asperger Syndrome or High Functioning Autism), and with the assistance of survey respondents chosen at random, living within 1-2 hours of Leicester, whose ADOS total score was under 7 and who gave consent.

Phase three respondents all completed an ADOS at phase two, gave consent to the next phase and had an informant such as a partner, carer or parent available and willing to take part. Consents were obtained by telephone and interviews conducted in the home of the informants throughout England in the third phase of the survey.

Thirty respondents who scored high on the ADOS (Communication and Reciprocal Social Interaction Total  $\geq 7$ ) and a randomly selected group of thirty respondents who were negative on the ADOS (controls; ADOS < 7) were selected for DISCO interviews (Wing *et al.* 2002). If the informant was a parent who was able to recall childhood functioning at about age five years, items from the ADI-R that are required for classification purposes were also fully coded.

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All the interviews were carried out by a senior research psychologist with clinical experience in assessing adults with a wide range of mental disorders, including adults referred with possible ASD. She was trained in the use of the DISCO, having previously been a trained user of the ADI-R and the ADOS. The interviewer was only informed of the contact details, age and gender of the sampled respondent.

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## Data analysis I: Examination of the agreement between the DISCO and ADOS assessments

The agreement between the ADOS and the DISCO was assessed. Data from the 60 people who completed the DISCO provided sufficient precision to find a kappa of 0.6 with a 95% confidence interval extending 0.22 in either direction (assuming a 2-tailed hypothesis and that expected true proportion of successes = 70%, (nQuery v 2.0) (Elashoff, 1997)).

## Data analysis II: Examination of the use of self-report questions to predict ADOS assessments according to ADOS diagnostic threshold

Only the AQ-20 was completed by all survey phase one respondents. The aim of this data analysis was to relate AQ20 to ADOS data using non-parametric (Spearman's) correlation and a range of modelling procedures.

All of the AQ20 variables were entered into a general linear model to find significant predictors of ADOS. A backward stepwise method was used to eliminate non-significant predictors at the 5% level. Once the final set of predictors had been selected, a regression equation was available for predicting the prevalence of ADOS in the respondents from the first phase (all of whom had completed an AQ20).

95% confidence intervals were calculated with SAS Proc Surveyfreq (see [http://post.queensu.ca:8080/SASDoc/getDoc/em/statua.hlp/surveyfreq\\_sec2.htm](http://post.queensu.ca:8080/SASDoc/getDoc/em/statua.hlp/surveyfreq_sec2.htm)). These 95% CIs take into account the complex sample design used for the survey and the results apply to the entire study population.

A best subsets logistic regression was carried out to find the best subset of AQ-20 items for predicting ADOS in the sample of 618 phase two respondents.

## Discussion

A subset of twenty out of fifty items on the self report Autism Quotient was selected for use in epidemiological surveys to predict efficiently (identify) which adults are likely to be found to have an autism spectrum disorder (ASD). The AQ-20s were systematically collected in a random probability sample of adults aged 16 or over throughout England. A random subset of respondents, selected with probability increasing with AQ score, completed second and third phase data collections with the ADOS, ADI-R and DISCO respectively. Analyses were carried out to test the AQ-20 and the ADOS, which will be reported elsewhere.

There were a number of study limitations, including that:

- Case and control data used to derive the 20 item AQ data were drawn from normal student populations and clinical populations respectively, which may have imposed greater heterogeneity on these samples.
- People with levels of functioning insufficient to participate in a general population survey were excluded from the sample, as were those living in communal or institutional settings.
- The number of childhood developmental assessments that could be completed was small.

There is no other body of comparable research on adults. The diagnostic instruments used are similar to those used in a recent large scale survey of children aged approximately 10 years by Baird and colleagues and the probability sampling of the general population used by Green and colleagues (Baird et al. 2006; Green et al. 2005). The present methods are therefore felt by the authors to be to the highest standard achievable at present. However this is a first methodological development of its kind in the autism field and it is to be hoped that future surveys could build and improve on the present procedures.

In conclusion methods have been developed that are feasible and that provide the possibility of generating fairly representative data on the epidemiology of autism spectrum disorder on able adults in the general population.

## Appendices

### APPENDIX A The AQ20 items and impact questions

Autism Quotient (AQ-20) and impact on functioning questions

ASK ALL

Intro

The following statements are about the kind of person that you are, and the way you prefer to do things. You might find some of the statements a bit odd, but please answer all of them to the best of your ability, even if some of them don't seem to apply to you.

ASover

I prefer to do things the same way over and over again.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASound

I often notice small sounds when others do not.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASpolite

Other people frequently tell me that what I've said is impolite, even though I think it is polite.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASdates

I am fascinated by dates.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASocsit

I find social situations easy.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASdetail

I tend to notice the details that others do not.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASparty

I would rather go to a party than a library.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASpeople

I find myself drawn more strongly to people than to things.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASlaik

When I talk, it isn't always easy for others to get a word in edgeways.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASstory

When I'm reading a story, I find it difficult to work out the characters' intentions.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASread

I particularly enjoy reading fiction.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASifriend

I find it easy to make new friends.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASlisten

I know how to tell if someone listening to me is getting bored.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASuomore

I find it easy to do more than one thing at once.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASphone

When I talk on the phone, I'm not sure when it's my turn to speak.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASface

I find it easy to work out what someone is thinking or feeling just by looking at their face.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASinform

I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc).

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASplan  
I like to plan any activities I participate in carefully.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASsococc  
I enjoy social occasions.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

ASdob

I am not very good at remembering people's date of birth.

- 1 Definitely agree
- 2 Slightly agree
- 3 Slightly disagree
- 4 Definitely disagree

**IMPACT QUESTIONS**

**IF DVassc >=2 AND DVTotal >=8 THEN**

ImpactAS

You've said that you prefer to (do things the same way each time/plan activities carefully).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF DVasdc >=2 AND DVTotal >=8 THEN**

ImpactAD

You've said that you are particularly good at things like (noticing small sounds when others do not/remembering details like dates).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF DVChsc >=2 AND DVTotal >=8 THEN**

ImpactCh

You've said that you sometimes have difficulties (knowing how and when to speak/being told that you are impolite).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF DVSSsc >=2 AND DVTotal >=8 THEN**

ImpactSS

You've said that you (may avoid social situations or find them difficult/find yourself drawn strongly to things).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

**IF DVimsc >=2 AND DVTotal >=8 THEN**

ImpactIm

You've said that you (take a particular interest in facts about things but not in characters in stories).

Are your important daily routines, work or study ever affected by this?

- 1 To a great extent
- 2 To some extent
- 3 A little bit
- 4 Not at all

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# Glossary of survey terms and definitions

<b>Adults</b>	Adults were defined as people aged 16 and over.
<b>Autism Diagnostic Observation Schedule (ADOS)</b>	The phase-two ASD assessments were based on the ADOS (Module-4), which is a direct face to face clinical assessment of current behaviour consistent with a diagnosis of an ASD. It consists of psychological tests termed 'presses' that evaluate communication, reciprocal social interaction, creativity, imagination and stereotyped and restricted interests. Algorithms for ASD form part of the ADOS.
<b>Autism Quotient (AQ)</b>	A 20 item subset of a self completion questionnaire, the 50 item Autism Spectrum Quotient, was developed using previously gathered diagnostic clinic and control data. The 20 item version (AQ-20) was used for all phase-one respondents to produce a probability of selection for a detailed phase-two diagnostic assessment. It is a screening tool, and cannot provide a diagnosis.
<b>Autism Spectrum Disorders (ASDs)</b>	Autism Spectrum Disorders (ASDs) are neuro-developmental disorders characterised by impairment of reciprocal social interaction and communication alongside the presence of restricted repetitive behaviours, with persisting negative impacts on learning and on the development of independence in adulthood.
<b>Benefits</b>	'Receipt of any benefit' included all benefits asked about other than state pensions, child benefit, Working Tax Credits, or maternity related benefits. Social fund grants and housing benefit were also included.
<b>Borderline intelligence</b>	See <b>Verbal IQ</b> .
<b>Community care services</b>	Community care services included the following in the past year: a psychiatrist, psychologist, community psychiatric nurse, community learning difficulty nurse, other nursing services, social worker, self help/support group, home help/homecare worker or outreach worker.
<b>Current treatment for a mental or emotional problem</b>	Current treatment for a mental or emotional problem included currently receiving any medication, counselling or therapy, or both medication and counselling.
<b>Day care services</b>	Day care services included community mental health centre, day activity centre, sheltered workshop and other nursing services in the past year.
<b>Depot injection</b>	Medication used in the treatment of psychosis and given by injections on a monthly basis are sometimes termed depot injections.
<b>DSM-IV (Diagnostic and Statistical Manual of Mental Disorders)</b>	The Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) is a manual that categorises currently recognised mental health disorders.

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**Educational level**

Educational level was based on the highest educational qualification reported and was grouped as follows:

*Degree*

Degree (or degree level qualification)  
NVQ Level 5

*Teaching, HND, Nursing*

Teaching qualification  
HNC/HND, BRC/TEC Higher, BTEC Higher, City and Guilds  
Full Technological Certificate, Nursing Qualifications  
(SRN, SCM, RGN, RM, RHV, Midwife)  
NVQ Level 4

*A Level or equivalent*

A levels, SCE Higher  
ONC/OND/BEC/TEC not higher  
City and Guilds Advanced/Final Level  
BTEC National  
GNVQ (Advanced Level)  
Youth Award - Platinum  
NVQ Level 3

*GCSE or equivalent*

GCSE (Grades A-C)  
O level passes (Grade A-C if after 1975)  
CSE (Grades A-C)  
CSE Grade 1  
SCE Ordinary (Bands A-C)  
Standard Grade (Level 1-3)  
SLC Lower  
SUPE Lower or Ordinary  
School Certificate or Matric  
City and Guilds Craft/Ordinary Level  
BTEC First  
GNVQ (Intermediate Level)  
NVQ Level 2  
Youth Award - Gold  
CSE Grades 2-5  
GCE O level (Grades D & E if after 1975)  
GCSE (Grades D,E,F,G)  
SCE Ordinary (Bands D & E)  
Standard Grade (Level 4,5)  
Clerical or Commercial qualifications  
Apprenticeship  
GNVQ (Foundation Level)  
NVQ Level 1  
Youth Award - Bronze or Silver  
CSE Ungraded

*Foreign/other qualifications*

*No qualifications*

For the analyses in this report, those with a degree or a teaching, HND or nursing qualification were combined; A Levels and GCSEs were combined; and those with foreign or other qualifications were excluded.

---

**Economic activity/  
employment status**

Economically active people are those over the minimum school-leaving age who were working or unemployed in the week before the week of the interview. These people constitute the labour force.

### **Employed**

This category includes people aged 16 and over who, in the week before the week of the interview, worked for wages, salary or other form of cash payment such as commission or tips, for any number of hours. It covers people absent from work in the reference week because of holiday, sickness, strike or temporary lay-off, provided they had a job to return to with the same employer. It also includes people attending an educational establishment during the specified week if they were paid by their employer while attending it, people who worked in Government training schemes and unpaid family workers.

People are excluded if they have worked in a voluntary capacity for expenses only, or only for payment in kind, unless they worked for a business, firm or professional practice owned by a relative. Full-time students are classified as 'working', 'unemployed' or 'inactive' according to their own reports of what they were doing during the reference week.

### **Unemployed people**

This survey used the International Labour Organisation (ILO) definition of unemployment. This classifies anyone as unemployed if he or she was out of work in the four weeks before interview, or would have been but for temporary sickness or injury, and was available to start work in the two weeks after the interview. Otherwise, anyone out of work is classified as economically inactive.

The treatment of all categories in this survey is in line with that used in the Labour Force Survey (LFS).

### **Economically inactive**

The 'economically inactive' group includes students, and those looking after home, long term sick or disabled, or retired.

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## **Ethnicity**

Respondents identified their ethnicity according to one of fifteen groups. For analysis purposes these groups were subsumed under four headings: white, black, South Asian and other.

White	White – British White – Irish Any other white background
Black	Black – Caribbean Black – African Any other black background
South Asian	Indian Pakistani Bangladeshi
Other	Chinese Mixed – white and black Caribbean Mixed – white and black African Mixed – white and Asian Any other mixed background Other

Due to the heterogeneous nature of the 'other' ethnic group, which includes people of various mixed ethnic origins and Chinese, this category is generally not referred to in the text or charts in the chapters. It is included on tables for completeness.

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## **Equivalent household income**

Making precise estimates of household income, as is done for example in the Family Resources Survey, requires far more interview time than

available to this survey. Household income was thus established by means of a show card (see the main report) on which banded incomes were presented. Information was obtained from the selected respondent, although they were encouraged to seek further information from the household reference person when this was someone other than the respondent.

Initially the respondent was asked to state their own aggregate gross income, and were then asked to estimate the total household income including that of any other people in the household. Household income can be used as an analysis variable, but there has been interest in using measures of equivalised income that adjust income level to take account of the number of people in the household. Methods of doing this vary in detail: the starting point is usually an exact estimate of net income, rather than the banded estimate of gross income obtained in the APMS 2007. The method used in the present report utilises the widely used McClemens scoring system, described below.

1. A score was allocated to each household member, and these were added together to produce an overall household McClemens score. Household members were given scores as follows:

First adult	0.61
Spouse/partner	0.39
Other second adult	0.46
Third adult	0.42
Subsequent adults	0.36
Dependant aged 0-1	0.09
Dependant aged 2-4	0.18
Dependant aged 5-7	0.21
Dependant aged 8-10	0.23
Dependant aged 11-12	0.25
Dependant aged 13-15	0.27
Dependant aged 16+	0.36

2. The equivalised income was derived as the annual household gross income divided by the McClemens score. Where information on annual household gross income was not available, this was replaced with annual individual gross income.
3. This equivalised annual income was attributed to all members of the household.
4. Households were ranked by equivalised income, and tertiles q1 – q3 were identified. Because incomes were obtained in banded form, there were clumps of households with the same income spanning the tertiles. It was decided not to split clumps but to define the tertiles as ‘households with income up to q1’, ‘over q1 up to q2’ etc.

Equivalised household income tertiles and corresponding income groups:

- Lowest quintile <£14,057
- Middle quintile >=£14,057 < £29,826
- Highest quintile >=£29,826

5. All individuals in each household were allocated to the equivalised household income tertile to which their household had been allocated. Insofar as the mean number of people per household may vary between tertiles, the numbers in the tertiles will be equal. Inequalities in numbers are also introduced by the clumping referred to above, and by the fact that in any sub-group analysed the

proportionate distribution across tertiles will differ from that of the total sample.

<b>Health care services</b>	The health care services used variables included an inpatient stay or outpatient visit in the past quarter, or spoken with a GP in the past year, for a mental or emotional reason. The time frame therefore varied and so it is important to note that this variable does not represent all health care services used in the past year.																																																																				
<b>ICD-10</b>	The International Classification of Diseases and Related Health Problems 10th Revision (ICD-10) is a classification system for diseases and signs, symptoms, abnormal findings, complaints, social circumstances and external causes of injury or diseases, as classified by the World Health Organisation (WHO).																																																																				
<b>Income</b>	See <b>equivalised household income</b> .																																																																				
<b>Index of Multiple Deprivation (IMD 2007)</b>	The 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 their level of deprivation. <a href="http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/">http://www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/</a>																																																																				
<b>Marital status</b>	Respondents were categorised according to their self-reported legal marital status, this included a code for whether the respondent was in a legally recognised Civil Partnership with someone of the same sex.																																																																				
<b>Medications</b>	Current use of specific psychoactive medications was asked about using a series of showcards. These included all the most commonly prescribed preparations used in the treatment of mental health problems. Both generic and brand names were shown. Depot injections used in the treatment of psychosis were also included. Individual medications were grouped into the following categories: <table border="1" data-bbox="619 1234 1412 1912"> <thead> <tr> <th><b>Drugs used in the treatment of psychosis</b></th> <th><b>Anti-depressants</b></th> <th><b>Hypnotics</b></th> <th><b>Anxiolytics</b></th> </tr> </thead> <tbody> <tr> <td>Largactil</td> <td>Prozac</td> <td>Planpak</td> <td>Valium</td> </tr> <tr> <td>Stelazine</td> <td>Lustral</td> <td>Mogadon</td> <td>Ativan</td> </tr> <tr> <td>Haldol</td> <td>Seroxat</td> <td>Buspar</td> <td>Librium</td> </tr> <tr> <td>Risperdal</td> <td>Efexor</td> <td><b>Drugs used in the treatment of ADHD</b></td> <td><b>Any medication</b></td> </tr> <tr> <td>Zyprexa</td> <td>Nardil</td> <td>Ritalin</td> <td>Included</td> </tr> <tr> <td>Clozaril</td> <td>Manerix</td> <td>Strattera</td> <td>whether the</td> </tr> <tr> <td>Priadel</td> <td>Tofranil</td> <td>Not all drugs</td> <td>respondent</td> </tr> <tr> <td>Dolmatil</td> <td>Anafranil</td> <td>used in the</td> <td>was taking any</td> </tr> <tr> <td>Seroquel</td> <td>Prothiad</td> <td>treatment of</td> <td>of the</td> </tr> <tr> <td>Abilify</td> <td>Sinequan</td> <td>ADHD were</td> <td>psychoactive</td> </tr> <tr> <td>Depixol</td> <td>Cipramil</td> <td>asked about,</td> <td>medications</td> </tr> <tr> <td>Modecate</td> <td>Zispen</td> <td>only two of the</td> <td>listed,</td> </tr> <tr> <td>Clopixol</td> <td></td> <td>most commonly</td> <td>including</td> </tr> <tr> <td>Risperdal consta</td> <td></td> <td>prescribed</td> <td>depot</td> </tr> <tr> <td></td> <td></td> <td>preparations</td> <td>injections.</td> </tr> <tr> <td></td> <td></td> <td>were included.</td> <td></td> </tr> </tbody> </table>	<b>Drugs used in the treatment of psychosis</b>	<b>Anti-depressants</b>	<b>Hypnotics</b>	<b>Anxiolytics</b>	Largactil	Prozac	Planpak	Valium	Stelazine	Lustral	Mogadon	Ativan	Haldol	Seroxat	Buspar	Librium	Risperdal	Efexor	<b>Drugs used in the treatment of ADHD</b>	<b>Any medication</b>	Zyprexa	Nardil	Ritalin	Included	Clozaril	Manerix	Strattera	whether the	Priadel	Tofranil	Not all drugs	respondent	Dolmatil	Anafranil	used in the	was taking any	Seroquel	Prothiad	treatment of	of the	Abilify	Sinequan	ADHD were	psychoactive	Depixol	Cipramil	asked about,	medications	Modecate	Zispen	only two of the	listed,	Clopixol		most commonly	including	Risperdal consta		prescribed	depot			preparations	injections.			were included.	
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<b>P value</b>	A p value is the probability of the observed result occurring due to chance alone. A p value of less than 5% is conventionally taken to indicate a statistically significant result ( $p < 0.05$ ). It should be noted that																																																																				

the p value is dependent on the sample size, so that the large sample differences or associations which are very small may still be statistically significant. Results should therefore be assessed for their importance on the magnitude of the differences or associations as well as the p value itself.

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**Verbal IQ (V-IQ)**

An estimate of predicted Verbal IQ (V-IQ) was derived using the National Adult Reading Test (NART). A V-IQ score of 70-85 was used to indicate borderline intelligence. Respondents who did not speak English as their first language, who had eyesight problems, or who volunteered that they were dyslexic were excluded from the base.

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This report presents the findings of the first ever survey of Autism Spectrum Disorder among people aged 16 and over living in private households in England. The survey covered a range of types of psychiatric disorder, was commissioned by the NHS Information Centre for health and social care, and is one of a series of surveys of mental health in different population groups.

ASD prevalence is presented by age, sex, ethnicity, marital status, tenure, equivalised household income, employment status, area level deprivation and the level and nature of treatment and service use.

### **Department of Health Sciences, University of Leicester**

[www2.le.ac.uk/departments/health-sciences](http://www2.le.ac.uk/departments/health-sciences)

The Department of Health Sciences at the University of Leicester is a research-led department with established strengths across epidemiology, medical statistics, public health, primary care, health services research, and psychiatry. Structured to support innovative multidisciplinary and multi-method solutions to research questions, it conducts high quality scientific research that can inform policies and practices aimed at securing people's health and well-being.

### **National Centre for Social Research**

[www.natcen.ac.uk](http://www.natcen.ac.uk)

The National Centre for Social Research (NatCen) is an independent institute specialising in social survey and qualitative research for the development of public policy. Research is in areas such as health, housing, employment, crime, education and political and social attitudes. Projects include ad hoc, continuous and longitudinal surveys, using face to face, telephone and postal methods; many use advanced applications of computer assisted interviewing.

### **Autism Research Centre**

[www.autismresearchcentre.com](http://www.autismresearchcentre.com)

The mission of the Autism Research Centre (ARC) is to understand the biomedical causes of autism spectrum conditions, and develop new and validated methods for assessment and intervention. The ARC fosters collaboration between scientists in Cambridge University and outside, to accelerate this mission.

### **The NHS Information Centre for health and social care**

[www.ic.nhs.uk](http://www.ic.nhs.uk)

The NHS Information Centre is England's central, authoritative source of health and social care information. Acting as a 'hub' for high quality, national, comparative data, it delivers information for local decision makers, to improve the quality and efficiency of care.

### **Policy Research Programme, Department of Health**

[www.dh.gov.uk/en/Researchanddevelopment/Policyresearchprogramme/index.htm](http://www.dh.gov.uk/en/Researchanddevelopment/Policyresearchprogramme/index.htm)

The Policy Research Programme is a national programme of research dedicated to providing an effective evidence base for policy-making in the Department of Health. It covers all aspects of the Department's policy-making activity and works alongside other national research programmes and the National Institute for Health Research.