Estimating the Prevalence of Autism Spectrum Conditions in Adults:

Extending the 2007 Adult Psychiatric Morbidity Survey

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Executive Summary

This report, "Estimating the prevalence of autism in adults: Extending the 2007 Adult Psychiatric Morbidity Survey", presents the prevalence of autism among adults aged 18 years and over. Data from the 2007 Adult Psychiatric Morbidity Survey (APMS 2007)[1] has been combined with data from a new study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments in Leicestershire, Lambeth and Sheffield. For this latter study, 290 adults were recruited between August 2010 and April 2011. The overall response rate for the new survey was 20 per cent in private households (83 interviews). Sixty four per cent of communal care establishments approached took part in the study. Among these, the response rate for individual participants was 69 per cent (207 interviews).

The study comprised a relatively small sample with limited geographical coverage and did not include other institutional populations, such as prisons; the strength of the national level conclusions about the learning disabled population is limited by this. However, sensitivity analysis showed that the figures for overall national prevalence of autism were relatively insensitive to any inaccuracies caused by these limitations. This study does however include people in communal care establishments and people with learning disabilities, two non-mutually exclusive populations which were not covered by the APMS 2007.

People with learning disabilities are a key group to study because they could not take part in the APMS 2007 and have been found to have an increased risk of autism. This is important because in order to improve the lives of people with autism, there is a need to be able to estimate the number of people with this condition.

The original intention of this study was to carry out interviews in three geographical areas with differing demographic profiles. In combination these three areas are a reasonable match for the national profile however it proved difficult to achieve the intended number of interviews in Lambeth and Sheffield. This resulted in a final sample which over represented patients of South Asian ethnicity. Although there is no known link between Autism and ethnicity there is equally no evidence that the reverse is true.

Key facts

- The overall prevalence of autism, combining data from the APMS 2007[12] and learning disability study, was 1.1 per cent (95 per cent confidence interval 0.3 per cent to 1.9 per cent).
    - The prevalence of autism was higher in men (2.0 per cent) than women (0.3 per cent).
- In the learning disability study it was found that the prevalence of autism increased with greater severity of learning disability/lower verbal IQ.
- Among adults with learning disabilities living in private households whose learning disability was sufficiently severe that they could not have taken part in the APMS 2007[12], the prevalence of autism was 35.4 per cent (95 per cent confidence interval 24.7 per cent to 46.2 per cent). Among adults with mild or severe learning disabilities living in communal care establishments, the prevalence of autism was 31.0 per cent (95 per cent confidence interval 23.9 per cent to 38.0 per cent).
    - Sex differences were less marked in adults with learning disabilities compared with the rest of the general population (APMS 2007[12]).

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[1] Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J. Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007. England: The NHS Information Centre for health and social care, 2009.

- The estimated prevalence of autism changed very little when the data were re-analysed to take into account that the prevalence of autism might be higher or lower in other settings, such as prisons or defence establishments. Using assumptions based on different scenarios to take these into account, the overall prevalence of autism was estimated at between 1.1 per cent and 1.2 per cent.

This study has demonstrated that autism is common among people with a learning disability, whether they live in communal care establishments or in private households. This fact is important for service planning and provision. Taking account of the higher rate of autism present among people with learning disability means that our best estimate of the overall prevalence of autism in England is 1.1 per cent. This compares with a previous estimate of 1.0 per cent in the APMS (2007).

Notes

1. The prevalence of autism in this report is presented as percentages to one decimal place, which is equivalent to reporting rates per thousand.

2. The following conventions have been used in tables:
   - no observations (zero value)

3. Row or column percentages may not add exactly to 100 per cent due to rounding.

4. A percentage may be quoted in the text for a single category that combines two or more of the percentages shown in a table. The percentage for a single category may, because of rounding, differ from the sum of the percentages in the table.

5. In general, missing values have been omitted from the tables and analyses. Missing values occur for a number of reasons, including refusal or inability to answer a particular question.

6. The term 'significant' refers to statistical significance. Unless otherwise stated, any reported differences have been found to be statistically significant at the 5 per cent level (i.e. $p < 0.05$).

1. Introduction

1.1. Autism

Autism, including childhood autism and Asperger syndrome, is a neurodevelopmental disorder. Childhood autism and Asperger syndrome were first described in the 1940s[2-4] and now fall within the concept of a broader spectrum of autism[5-6]. Since the 1960s, there appears to have been a steady increase in the number of children with autism[7-11], believed to be a result of improved diagnostic methods, widening of diagnostic criteria, less stigmatisation of the condition and increased awareness from health professionals and families [8].

1.2. Background and existing evidence

In March 2010, the then Government published a new national strategy for autism and guidance for the condition[1], with the view to improving the quality of services provided to adults with autism in England. Such improvements can only be achieved if the number of people with recognised and unrecognised autism in the general population is quantified.

The most recent population-based Adult Psychiatric Morbidity Survey (APMS 2007) set out to determine the prevalence of autism among adults living in private households in England[12]. The prevalence of autism had never previously been studied in the general population. The survey involved 7,403 adults living in private households in England. Adults were interviewed with between two and four validated autism questionnaires: the AQ-20 (A 20-item version of the Autism-Spectrum Quotient or AQ[13]), the Autism Diagnostic Observations Schedule Module 4 (ADOS-4)[14], the Diagnostic Interview for Social and Communication Disorders (DISCO)[15] and the Autism Diagnostic Interview Revised (ADI-R)[16] together with a clinical consensus judgement procedure. The case definition of autism was based on an ADOS-4 score of 10 or greater and was validated against 56 DISCO and ADI-R assessments along with a consensus exercise involving six clinicians experienced in assessing adults with possible autism[17]. Results from the APMS 2007 revealed an overall prevalence of 1.0 per cent (95 per cent CI 0.3 per cent to 1.7 per cent) for autism in adults[12,18].

There were two limitations to the APMS 2007[12] in relation to the measurement of autism. First, the prevalence of 1.0 per cent for autism was based on adults who were living in private households. It is likely that autism is more prevalent in some populations that were not sampled in the household survey. For example, people who live in communal care establishments, such as residential homes and nursing homes, and those in other communal establishments, such as prisons, have been found to have a higher prevalence of autism[19,20]. Secondly, people with learning disabilities (defined by a significant intellectual impairment with onset before adulthood and deficits in skills needed for daily functioning[21-23]) could not take part in the APMS 2007 because the consent forms, questionnaires and assessments were designed for people with full decision-making capacity. This group has an increased risk of autism; current evidence suggests that the prevalence of autism in adults with learning disabilities is between 7 per cent and 20 per cent[24,25], perhaps higher still among those in residential homes[26]. Therefore the published APMS 2007 estimated prevalence of autism that covered adults in private households was likely to be an underestimate for the population as a whole. It is important to know about any variations in this population because it will substantially impact on service requirements for people with learning disabilities. It may also have an impact on the estimate of prevalence of autism for the total population.

1.3. Aims and objectives of the study

The aim of the current study was to extend the existing prevalence estimate of autism in adults to include adults with learning disabilities.

The objectives of the current study were:

i. To identify a representative group of adults with learning disabilities (in terms of age, sex, and place of residence) who were either: (a) living in private households but not able to participate in the APMS 2007[12] due to learning disability; or (b) living in communal care establishments and thus not included in the APMS 2007 sample.

ii. To interview the adults with learning disabilities living in *private households* who would not have been able to participate in the APMS 2007[12] with the validated clinical assessment ADOS-1[14], to determine the prevalence of autism in this population.

iii. To interview the adults with learning disabilities living in *communal care establishments* with the validated clinical assessment ADOS-1 or ADOS-4[14], to determine the prevalence of autism in this population.

iv. To interview a sub-sample of adults with learning disabilities with the clinical assessments, DISCO[15] and ADI-R[16], to calibrate the ADOS-1[14].

v. To combine the estimated prevalence rates of autism in adults with learning disabilities who live in private households and who live in communal care establishments with the prevalence of autism in adults without learning disabilities living in private households (from the APMS 2007[12]) and communal care establishments (extrapolated) to derive an overall prevalence estimate for autism in adults.

vi. To perform sensitivity analyses of the combined prevalence estimate to take into account adults without learning disability who live in communal care establishments.

2. Study design and methods

2.1. Study participants

Participants for this study were sampled from selected regional learning disability case registers in England living in both private households and communal care establishments. Three learning disability registers located in Leicestershire, Lambeth, and Sheffield, were used as the sampling frames (populations from which the samples were drawn). The adult prevalence of learning disabilities using the registers at the three sites was within the expected range (4.9, 4.3, and 5.4 per thousand of the population of Leicestershire, Lambeth and Sheffield respectively[30]); these registers have been used extensively for research[27-29]. Potential participants were sampled in June 2010 (Leicestershire), November 2010 (Lambeth) and January 2011 (Sheffield). Data collection took place between August 2010 and April 2011.

Inclusion Criteria

(i)   All adults (aged 18+ years) who lived in private households (e.g. independently, with family, in supported living accommodation) who would not have been able to participate in a survey interview owing to communication difficulties/lack of capacity to decide whether to participate

(ii)   All adults (aged 18+ years) with learning disabilities who lived in communal care establishments (e.g. residential homes, nursing homes)

Exclusion Criteria

(i)   Participants who lacked capacity and whose carers could not speak English (since all assessments were validated in the English language only)

(ii)   More able participants (i.e. eligible for the ADOS-4) in communal care establishments who could not understand or speak English (since all assessments were validated in the English language only)

(iii)   Participants who were in communal care establishments in Leicestershire and Sheffield with fewer than four residents with learning disabilities, and participants in communal care establishments in Lambeth with fewer than three residents with learning disabilities (owing to an insufficient number of establishments with four or more residents in the Lambeth borough) – see **Section 2.1.2** for more details.

A sample of 500 from the three areas in Leicestershire, Lambeth, and Sheffield was chosen for this study. From these set samples, three-fifths of the set sample (300 participants) was chosen from Leicestershire and one fifth each from Lambeth and Sheffield (100 participants each). A larger sample was selected from Leicestershire due to the higher expected response rate and resource implications (research interviewers were all based in Leicestershire).

2.1.1. Sampling from private households

A random sample of participants from private households was selected, stratified by age, sex and type of residence. In addition, at the request of the Lambeth local authority lead, adults who were sampled but who had profound and multiple learning disabilities were not invited to take part in this study (4 people from private households and 13 from communal care establishments).

Adults from private households were only eligible for the study if they could not have taken part in the APMS 2007[12]. Interviewers initially made this judgement over the telephone and again when visiting the potential participant in their own home (if they had not already been excluded following the initial telephone conversation). Participants were excluded if they were judged to be sufficiently able to have taken part in the APMS 2007.

2.1.2. Sampling from communal care establishments

For Leicestershire and Sheffield, the study adopted a two stage sampling design for communal care establishments. The first stage involved randomly selecting establishments with four or more residents, with selection probabilities proportional to the number of eligible residents. The second stage involved randomly selecting 4 participants from each of the chosen communal care establishments stratified by sex and age. For Lambeth, which had fewer communal care establishments, all establishments with 3 or more residents were chosen and all residents were sampled.

This strategy aimed to reduce the burden on establishment managers and allowed sufficient time to obtain the necessary permission for the research team to carry out the interviews.

2.2. Questionnaires and topic coverage

Table 2A: Questionnaires and assessments used in the study

Name of Assessment/ Questionnaire	Target Individuals	Target Number N* (per cent)		Completed Assessments N* (per cent)	
Autism Diagnostic Observations Schedule (ADOS)[14]	All participants	**500**	**(100)**	**290**	**(100)**
Module 1				239	(82)
Module 4				37	(13)
Not assessable				14	(5)
Vineland II caregiver rating form[31]	All participants	500	(100)	278	(96)
Modified APMS	All participants	500	(100)	290	(100)
Diagnostic Interview for Social and Communication Disorders (DISCO)[15]	Random 60 participants who score high (n=30) and low (n=30) in the ADOS[14].	60	(12)	58	(20)
Autism Diagnostic Interview-Revised (ADI-R)[16]	Random 60 participants who score high (n=30) and low (n=30) in the ADOS[14].	60	(12)	58	(20)

* N = Number

Table 2A shows a summary of questionnaires and assessment measures used. At first interview, all participants were assessed with the ADOS-1 or ADOS-4[14]. The ADOS-1 is designed for individuals who do not consistently use phrase speech and was applicable for the majority of adults who took part in this study. The ADOS-4 is designed for verbally fluent adults and was sometimes appropriate for those in communal care establishments (adults in private households were not assessed with the ADOS-4 as they would have been sufficiently able to take part in the APMS 2007[12]). A threshold score of 12+ in the ADOS-1 and 10+ in the ADOS-4 was use to define an autism case.

Carers were also asked to complete the Vineland II caregiver rating form[31] to give a measure of the severity of the participant's learning disability and a semi-structured questionnaire comprising key questions from the APMS 2007[12] and some additional questions relevant to this client group (see supporting appendices for a copy of the questionnaire and show cards).

A random sample of 30 carers of individuals who scored high in the ADOS-1 (≥7) [14] and a random sample of 30 carers of individuals who scored low in the ADOS-1 (<7) were invited to take part in an interview with two clinical assessments for autism, the DISCO[15] and ADI-R[16], to test the accuracy of the ADOS-1 in identifying autism cases.

2.3. Fieldwork procedures

2.3.1. Interviewers

Fieldwork was carried out between August 2010 and April 2011 by research interviewers at the University of Leicester. Interviews comprised a structured assessment with ADOS-1 or ADOS-4[14], the Vineland Adaptive Behaviour Scales (Vineland II) caregiver rating form[31] and a modified version of the APMS 2007 questionnaire[12].

Interviews with primary caregivers for the DISCO[15] and ADI-R[16] validation study were carried out by a senior research psychologist who had also conducted the DISCO and ADI-R interviews for the APMS 2007[12].

2.3.2. Making contact

Participants, carers or managers were sent a letter of invitation, a care information sheet, a 'participant easy read' information sheet and consent form, and a copy of the Vineland II caregiver rating form[31]. Potential participants in Lambeth and Sheffield were also sent an invitation card (see supporting appendices for relevant fieldwork documents)

Participants in Leicestershire were telephoned by the research team unless they contacted the research team in receipt of the advance letter to say that they did not wish to participate in the study. Carers and participants in Lambeth and Sheffield contacted the research team if they wished to take part in the study.

2.4. Survey response

2.4.1. Response for first interview

290 interviews were carried out with participants and their carers; 246 adults from Leicestershire, 34 adults from Lambeth and 10 adults from Sheffield.

Table 2B: Response rate for first interviews with adults living in private households and communal care establishments

	Learning disability study		APMS 2007	
Private households	N*	(per cent)	N*	(per cent)
Leicestershire				
Eligible individuals approached	223	(100)	-	
Interviews	78	(35)	-	
All sites				
Eligible individuals approached	410	(100)	13,171	(100)
Interviews	83	(20)	7,461*	(57)
Communal care establishments				
Leicestershire				
Eligible establishments approached	65	(100)	-	
Participating establishments	58	(89)	-	
Eligible individuals approached from participating establishments	221	(100)	-	
Interviews	168	(76)	-	
All sites				
Eligible establishments approached	118	(100)	-	
Participating establishments	75	(64)	-	
Eligible individuals approached from participating establishments	300	(100)	-	
Interviews	207	(69)	-	

* 58 interviews were proxy interviews (reasons for proxy were not systematically recorded), and 129 interviews were with participants aged 16 and 17 years and were excluded from the autism study. Hence N=7274 is quoted elsewhere in this report.
N = Number.
Data source: Tables 1a and 1b from the supporting reference data tables.

Table 2B shows the response rates for first interviews in private households and communal care establishments.

As expected, response rates were much higher in Leicestershire under the opt-out procedure (see ethical approval section in supporting data quality and methodology document) than for Lambeth and Sheffield.

Response rates were higher in communal care establishments. Very few family carers of adults living in private households in Lambeth and Sheffield responded, which highlights the difficulties in adopting opt-in procedures for prevalence studies. In Leicestershire, we found that many family carers had a lifetime of caring behind them, were elderly or weary and simply did not have the additional energy to take part in a research study. They had also been overwhelmed by calls about the television switchover to digital, which was being offered free of charge to people with learning

disabilities during the study time period. In addition, we found that we could not contact a significant proportion (15 per cent) of individuals.

The characteristics of participants compared with the learning disability registers are shown in the supporting data quality and methodology document. In Leicestershire, the age, sex and ethnicity profile of adults who took part in the study was similar to those on the Leicestershire Learning Disability Register. In Lambeth, the age profile was similar, but more women were interviewed than expected (65 per cent vs. 44 per cent expected) (see **Table 9b** of the supporting reference data tables). Numbers were too small in Sheffield to report. **Table 2B** includes 14 participants for whom an interview was completed, but who were classified as not assessable on the ADOS-1. These individuals were excluded from the data analysis.

2.4.2. Response for second interview

60 carers were approached to take part in a second interview with the DISCO[15] and ADI-R[16] to validate the ADOS-1 assessments[14] used for the prevalence estimate (the ADOS-4 assessment was validated as part of the APMS 2007[12,17]).

Table 2C: Response rate for second interviews with DISCO and ADI-R to validate ADOS-1 assessments and response rates for APMS 2007 [12] validation of ADOS-4 assessments

	Learning disability study		APMS 2007	
All sites	**N***	**(per cent)**	**N***	**(per cent)**
Set sample of adults	**60**	**(100)**	**60**	**(100)**
No contact	2	(3)	4	(7)
Total interviews carried out	58	(97)	56	(93)

* N = Number
Data source: Table 1c from the supporting reference data tables

A total of 58 carers were contactable and agreed to take part (**Table 2C**). More than half (53 per cent) of interviews were carried out with parents (N=21; 36 per cent) or other relatives (N=10; 17 per cent). The remaining interviews (N=27; 47 per cent) were carried out with paid carers (see **Table 1d** of the supporting reference data tables).

2.5. Estimating autism prevalence among adults aged 18 years and over

2.5.1. Calculation of combined prevalence estimates

Overall prevalence estimates for autism were calculated by combining results from the APMS 2007 [12] with results from the learning disability study of adults in private households and communal care establishments. People aged 16 and 17 years from the APMS 2007 were excluded prior to combining the estimates.

Figure 2A: Calculation of combined autism prevalence estimate
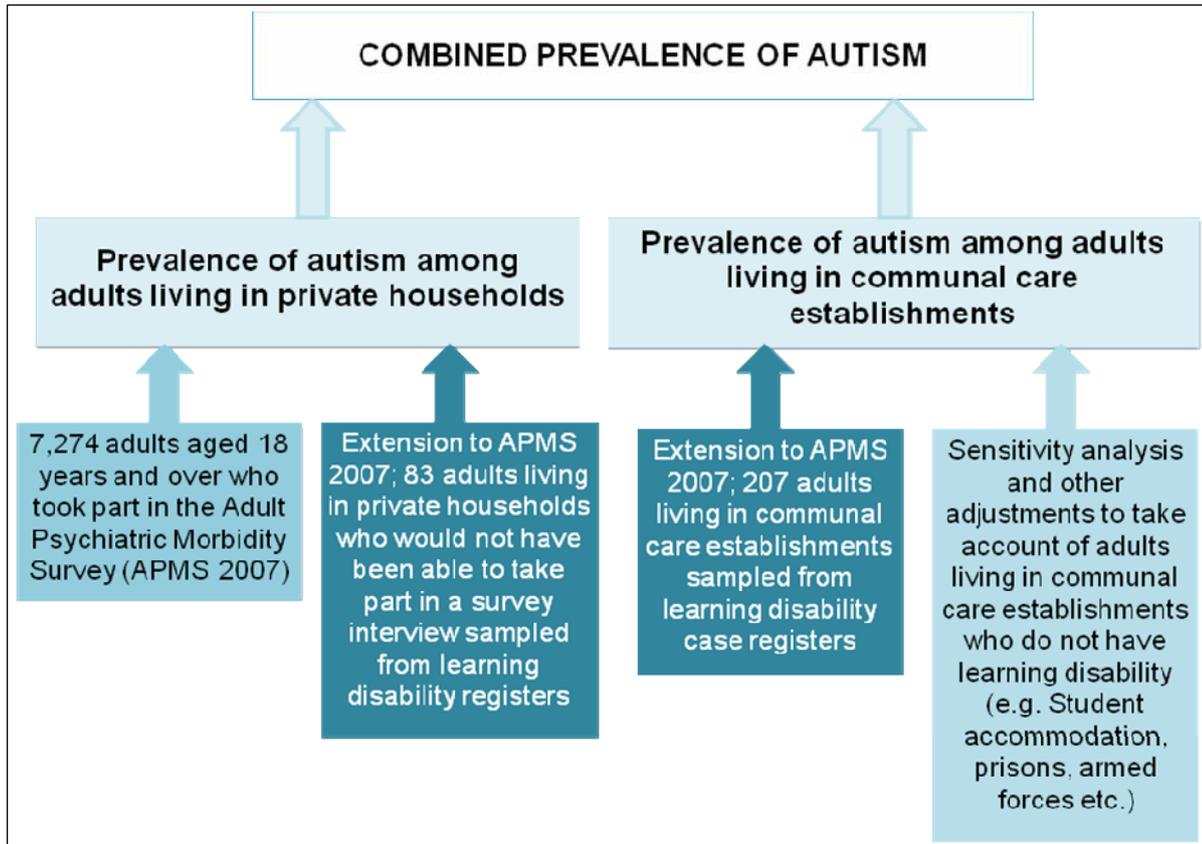
The first stage of the data analysis was to estimate prevalence of autism in those with learning disability, from the learning disability sample. Next, this sample was combined with the assessments of autism from the APMS 2007 [12], to estimate the overall prevalence of autism in the entire population aged 18 years and over (**Figure 2A**). Please refer to the supporting data quality and methodology document for more details.

2.5.2. Sensitivity analysis

In order to estimate the overall prevalence of autism in adults aged 18 years or over, it was necessary to combine data from different sources to build a picture of the population by age, sex, type of residence, and learning disability. This calculation involved a number of assumptions. Source data included the most recent census data available (2001). Since then, a significant proportion of people have moved out of long-stay hospitals and into community settings in line with policy directives. Sources also included information on the prevalence of learning disability from the case registers, giving an incomplete picture nationally. Since no observations were made of autism prevalence in the majority of the population in communal establishments who were not on the learning disabilities case registers, it was necessary to assume autism prevalence for this group.

In order to explore the effect of our assumptions on the final results, we carried out a sensitivity analysis. This involved looking at the effect of the overall prevalence of autism if the prevalence were different in three key areas: (i) among adults with learning disabilities nationally; (ii) among adults living in communal care establishments; (iii) among adults living in other communal establishments, such as defence, prison or educational establishments. We re-calculated the prevalence rate, using plausible upper and lower limits for the prevalence in these different settings to see how this affected the overall prevalence of autism.

Please refer to the supporting data quality and methodology document for more information on the sensitivity analysis.

3. Results

3.1. Prevalence of autism among all adults aged 18 years and over

The overall prevalence of autism, combining the APMS 2007[12] and the learning disability study, using a threshold score of 12 or more on the ADOS-1 and 10 or more on the ADOS-4 to indicate a positive case, was 1.1 per cent (95 per cent confidence interval 0.3 per cent to 1.9 per cent) (**Table 3B**). This represents approximately 450,000 adult cases of autism nationally.

Calculation of overall prevalence involved assumptions about the overall prevalence of learning disability, and the proportion of people resident in communal care establishments, defence, prison and educational establishments, and their corresponding autism prevalence. The sensitivity analysis showed that varying these assumptions did not affect the results substantially.

The prevalence of autism among adults living in private households with learning disabilities sufficient to have excluded them from the APMS 2007[12] was 35.4 per cent (95 per cent confidence interval 24.7 per cent to 46.2 per cent). Among adults with learning disabilities living in communal care establishments, autism prevalence was 31.0 per cent (95 per cent confidence interval 23.9 per cent to 38.0 per cent). A total of 89 cases were identified in the learning disability samples (**Table 3B**).

3.2. Autism in private households and communal care establishments

One of the criteria for exclusion from private households was where participants would have been able to take part in the APMS 2007[12]. We would therefore expect to observe a difference in autism prevalence between adults living in private households and communal care establishments, as people with severe and profound learning disabilities (by implication more prevalent in the private household sample) have been found to have a greater prevalence of autism[25].

Table 3A: Severity of learning disability* among adults with learning disabilities living in private households and communal care establishments included in the sample

Learning disability severity*	Private households N (per cent)	Communal care establishments N (per cent)
Total	**77[†] (100)**	**187[†] (100)**
Borderline/Mild	9 (12)	38 (20)
Moderate	9 (12)	25 (13)
Severe	23 (30)	35 (19)
Profound	36 (47)	89 (48)

* measured using the Vineland II caregiver rating form[31]

[†] excludes 2 people with missing severity data in private households and 10 people in communal care establishments; 14 people could not be assessed with the ADOS-1 (all had profound learning disabilities).

Data source: Table 1e from the supporting reference data tables

Table 3A shows learning disability severity by type of accommodation. As expected, a smaller proportion of adults assessed in private households had mild learning disabilities, as people living in private households were excluded if they could have taken part in the APMS 2007[12]. The majority of adults (77 per cent in private households and 66 per cent in communal care establishments) had severe or profound learning disabilities.

Table 3B: Prevalence of autism (ADOS-1 12+, ADOS-4 10+) in Leicestershire and in the entire sample in private households/communal care establishments

	Number of participants	Prevalence per cent
Adults with learning disabilities* in Leicestershire (N=237)		
Private households	74	36.5
Communal care establishments	163	30.1
Adults with learning disabilities* all sites (N=276[†])		
Private households	79	35.4
Communal care establishment	197	31.0
Adults in England in private households (N=7274)		
All		1.0
All adults (N=7550[‡])		
All		1.1[‡]

* Private households: learning disability sufficient to exclude from the APMS 2007[12]

  Communal care establishments: all on case register

[†] This total excludes 14 individuals who could not be assessed with the ADOS-1.

[‡] Reweighted estimate to represent the English population age 18 and over by age, sex and residence. Adults resident in communal care establishments with no learning disabilities are assumed to have prevalence of autism identical to adults without learning disabilities in private households.

Data source: Table 2 from the supporting reference data tables.

Table 3B shows the prevalence of autism among adults with learning disability living in private households and communal care establishments. As expected, the rate was higher among adults in private households because they had more severe learning disabilities.

3.3. Autism by age, sex and site in private households and communal care establishments

In the combined prevalence estimate, the rate of autism among men (2.0 per cent) was higher than among women (0.3 per cent), the difference being statistically significant (p<0.001). However, this difference was not as marked among men and women with learning disabilities.

Figure 3A: Prevalence of autism (ADOS-1 12+, ADOS-4 10+) by sex and type of residence (private household/communal care establishment)
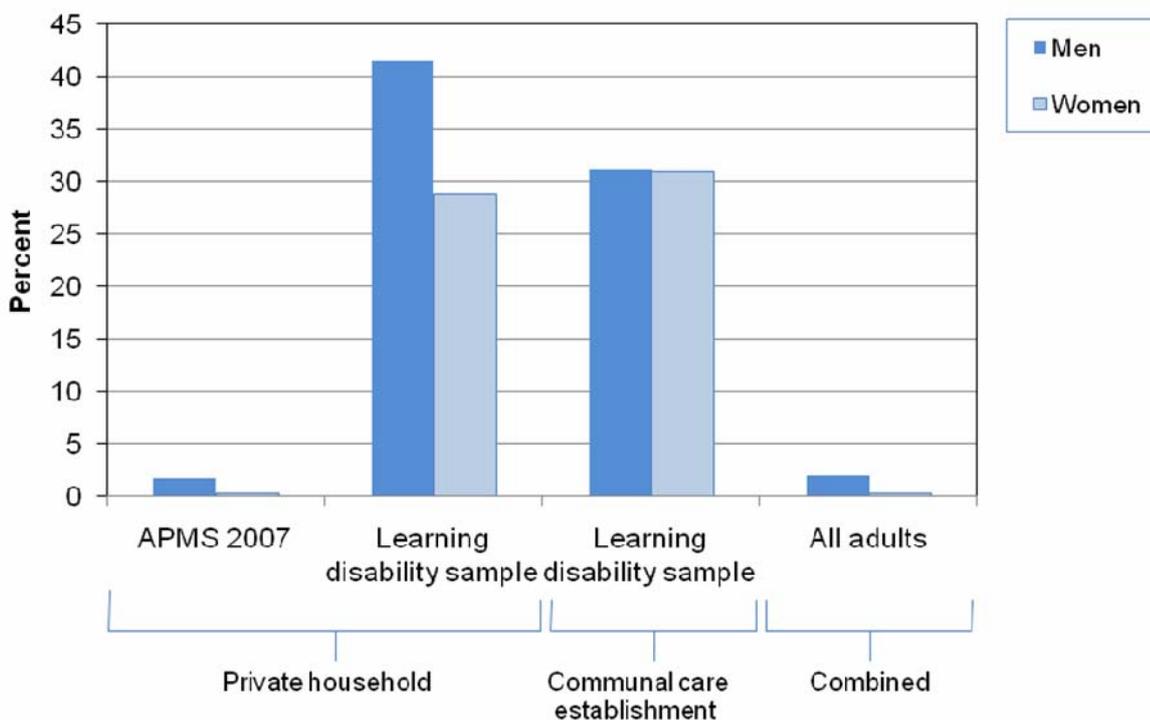
Data source: Table 2 from the supporting reference data tables.

In contrast to the APMS 2007[12], the prevalence of autism in men with learning disabilities did not appear to be so markedly greater than for women in private households (28.9 per cent vs. 41.5 per cent for women and men respectively) and communal care establishments (30.9 per cent vs. 31.1 per cent respectively) (**Figure 3A**).

The prevalence of autism was somewhat higher in men with learning disability who were resident in private households (41.5 per cent compared with 31.1 per cent among those with learning disability in communal establishments). It is worth emphasising that a significant proportion of adults with mild learning disabilities in private households were excluded from this study because they were sufficiently able to take part in the APMS 2007[12]. No significant differences in autism prevalence were seen between age groups but the sample sizes were too small for these comparisons to be statistically robust.

Figure 3B: Prevalence of autism (ADOS-1 12+, ADOS-4 10+) by age and type of residence (private household/communal care establishment)
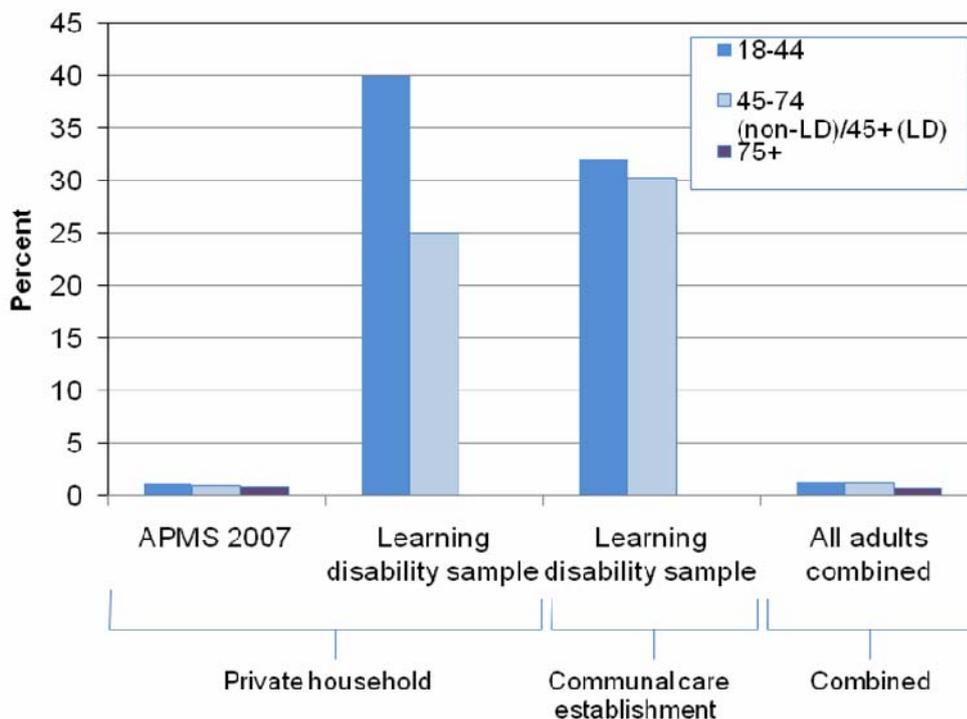
Data source: Table 3 from the supporting reference data tables.

The prevalence of autism reported from the APMS 2007[12] was presented in wide age bands in order to address the small number of positive cases in the sample. For consistency and comparisons, ages have been grouped in the same way. Due to the presence of small numbers of assessed participants aged 75 years and over in the learning disability sample (n=4), these were combined with those aged 45-74 years (**Figure 3B**).

3.4. Autism by other characteristics

3.4.1. Ethnicity

The majority of adults interviewed for this study were of white ethnic origin. As numbers were small in the other ethnic categories, prevalence is only reported for those of White and South Asian origin.

Figure 3C: Prevalence of autism (ADOS-1 12+, ADOS-4 10+) among adults (combined sample) and among adults with learning disabilities, by ethnicity
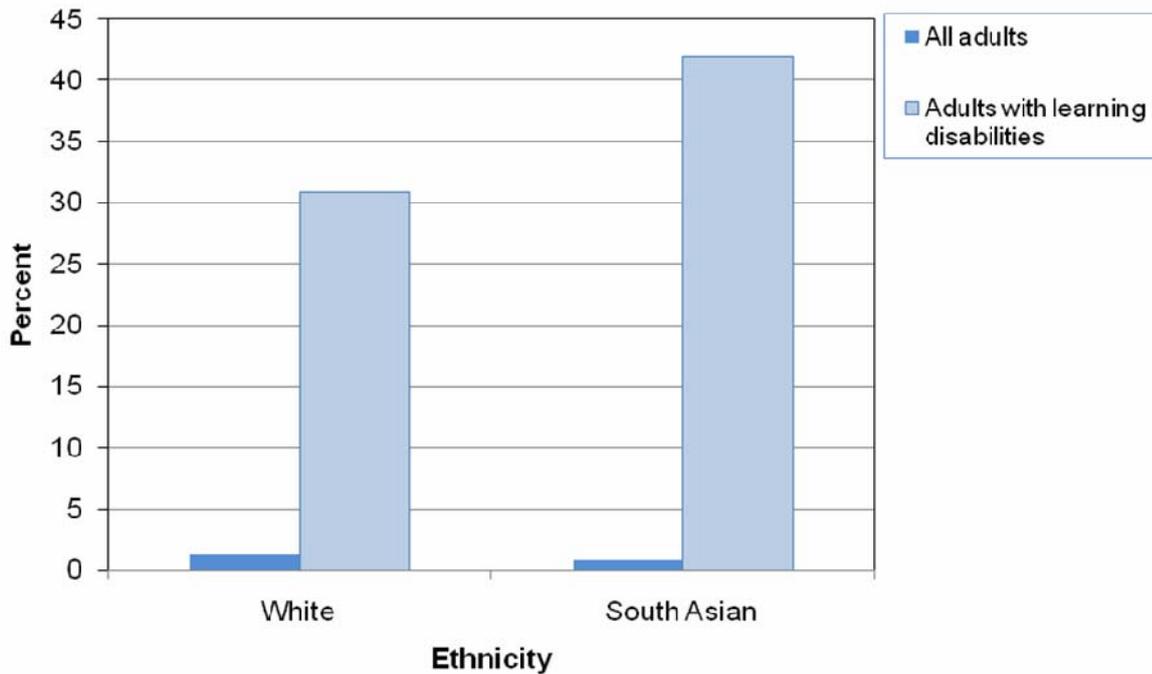
Data source: Table 4a from the supporting reference data tables.

Figure 3C shows the prevalence of autism by ethnic origin for the learning disability sample and the combined general population sample. Overall autism prevalence was 1.2 per cent in Whites and 0.8 per cent in those of South Asian origin, with no statistically significant difference in prevalence by ethnic origin.

3.4.2. Predicted verbal IQ and severity of learning disability

Predicted verbal IQ was collected in the APMS 2007[12] and was combined with severity of learning disability for the current study in order to assess any differences in autism prevalence.

Figure 3D: Prevalence of autism (ADOS-1 12+, ADOS-4 10+) among men and women (combined sample) by predicted verbal IQ/learning disability severity.
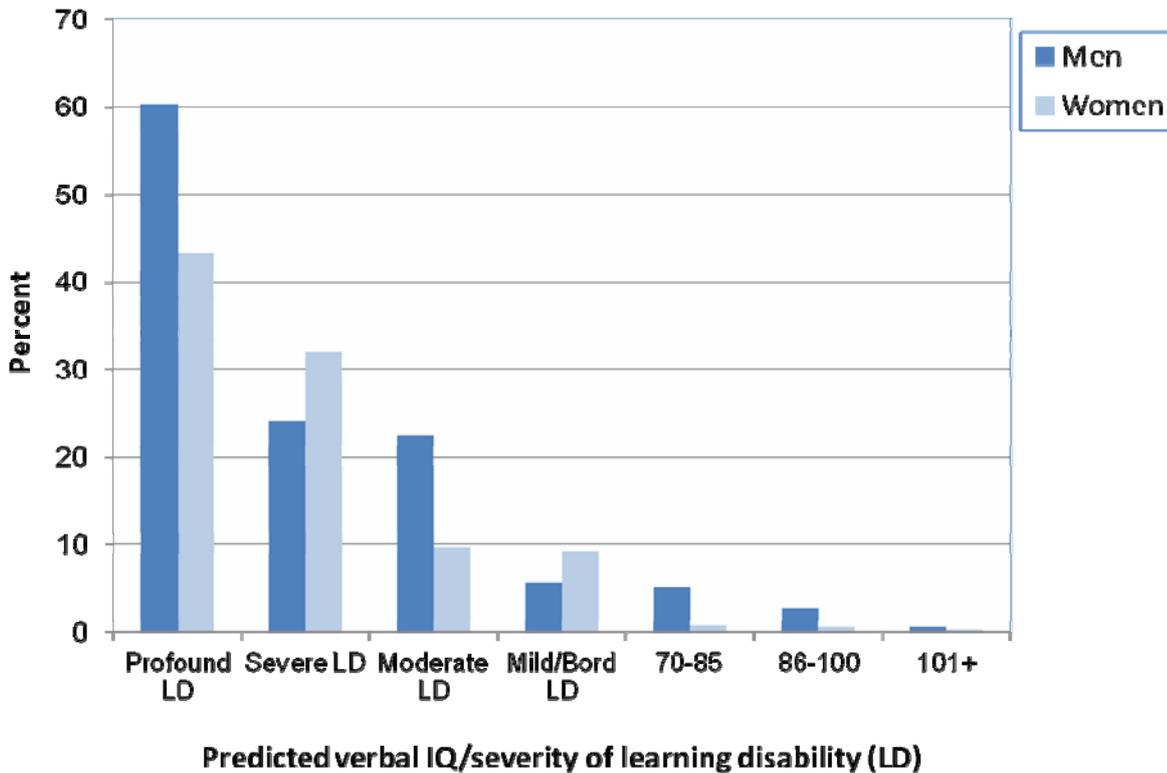
Bord LD = Borderline LD

Data source: Table 4b from the supporting reference data tables.

Figure 3D shows the prevalence of autism by sex and severity of learning disability/predicted verbal IQ from the combined sample. There is a clear gradient in autism prevalence, with highest prevalence among those with the most severe intellectual ability.

3.5. Sensitivity analyses

The sensitivity analysis involved recalculating the prevalence of autism, taking into account plausible extreme upper and lower limits for this prevalence in settings that were not studied such as prisons and student accommodation, to see whether this affected the overall prevalence of autism (see **Section 2.5.2)**. The choice of extreme upper and lower limits was based on the available literature, but was to some extent arbitrary. This is particularly relevant for the prison population, given the lack of evidence on autism prevalence in this setting. The supporting data quality and methodology document provides more information on the process of plausible limit selection.

Using the lower limits, the overall prevalence of autism was estimated at 1.1 per cent. Using the higher limits, the prevalence of autism was estimated at 1.2 per cent (see **Table 8b** in the supporting reference data tables). This suggests that uncertainty in the overall estimate attributable to the assumptions made in the calculation was minor compared to uncertainty owing to sampling variation in the two studies, indicated by the width of the confidence intervals (see glossary in supporting appendices). More details of the sensitivity analysis are provided in the supporting data quality and methodology document.

3.6. Validation study

Of the 58 people taking part in the validation study, a total of 18 positive autism cases were identified using both the DISCO[15] and ADI-R[16] (agreement was 100 per cent between the two interviews).

Figure 3E: Comparison of DISCO/ADI-R interviews and ADOS-1 assessments
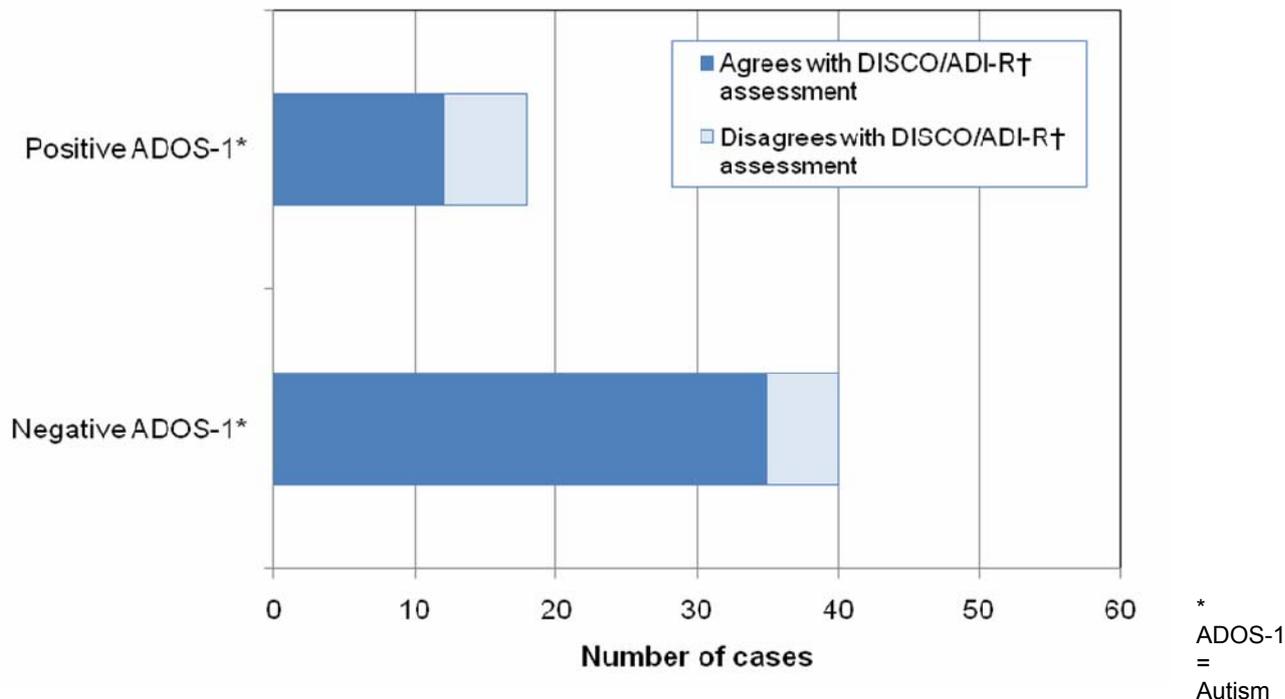
* ADOS-1 = Autism Diagnostic Observations Schedule (module 1)[14]. Positive cases were identified using an ADOS-1 threshold score ≥12.
† Autism diagnoses were determined using the Diagnostic Interview for Social and Communication Disorders (DISCO)[15] and Autism Diagnostic Interview – Revised (ADI-R)[16]

Data source: Table 5 from supporting reference data tables.

Figure 3E shows how the ADOS-1[14] compared with the identified positive autism cases. Twelve of the eighteen positive autism cases had a threshold score of 12 or more in the ADOS-1. In other words, the *sensitivity* of the ADOS-1 for detecting autism in this study was found to be 67 per cent. Similarly, 35 of the 40 negative cases for autism (as measured using the DISCO/ADI-R) had a score of 11 or below in the ADOS-1. In other words, the *specificity* of the ADOS-1 for detecting autism was 88 per cent. In total, 47 of 58 individuals were correctly identified as having/not having autism using the ADOS-1, giving 81 per cent accuracy.   This is comparable to the APMS 2007 validation study of the ADOS-4 where 49 of 56 (88 per cent) were correctly identified as having/not having autism using the ADOS-4 threshold of 10 or more[17]. However, sensitivity was much higher in the latter study (100 per cent), which suggests that the ADOS may not be as accurate in the learning disability population.

4. Discussion

In the APMS 2007[12], the overall prevalence of autism in adults was 1.0 per cent (95 per cent confidence interval 0.3 per cent to 1.7 per cent). By extending the survey to include adults with learning disabilities in private households who could not have taken part in the original survey and adults with learning disabilities in communal care establishments, the prevalence estimate increased to 1.1 per cent (95 per cent confidence interval 0.3 per cent to 1.9 per cent).

The prevalence of autism was calculated among adults living in private households and among adults with learning disabilities in communal care establishments. Adults living in communal care establishments who did not have learning disabilities and adults living in other communal establishments were not included in this study. However, a sensitivity analysis, exploring the effect on the overall prevalence of autism allowing for higher and lower prevalence in these settings revealed very little change in the overall estimate.

Combined prevalence rates of autism were higher in men than women, a result that is consistent with the APMS 2007[12]; however, differences between the sexes were less apparent when the sample was limited to adults with learning disabilities in both private households and communal care establishments. No association in the prevalence of autism with age was found in people with learning disabilities, which is also consistent with the APMS 2007. However, the sample size within each age group was too small to draw robust statistical conclusions relating to age differences.

We found a steady increase in the prevalence of autism as a person's level of intellectual functioning decreased, which is in line with previous learning disability studies[24, 25] and the general population[12]. We also found that some adults' learning disabilities were so profound that they could not be assessed for autism. Given that an autism diagnosis can have little bearing on the support that these individuals receive it is arguable whether such a diagnosis is beneficial.

The population from which the learning disability sample was drawn is known to have a higher proportion of ethnic minorities than in England as a whole. On limiting the study to the white population only, the prevalence estimate did not change significantly (1.2 per cent; 95 per cent confidence interval 0.0 per cent to 2.1 per cent).

5. Conclusion

This study has demonstrated that autism is common among people with a learning disability, whether they live in communal care establishments or in private households. This fact is important for service planning and provision. Taking account of the higher rate of autism present among people with learning disability means that our best estimate of the overall prevalence of autism in England is 1.1 per cent. In other words, just over one in 100 adults in the population have autism. This revised rate replaces the previous estimate of 1.0 per cent.

6. References

1. Department of Health. Fulfilling and rewarding lives: the strategy for adults with autism in England. London: Department of Health, 2010

2. Asperger H. Die 'Autistischen Psychopathen' im Kindesalter. *Archiv fur Psychiatrie und Nervenkrankheiten* 1944;117:76-136

3. Frith U. *Autism and Asperger Syndrome*. Cambridge: Cambridge University Press, 1991.

4. Kanner L. Autistic Disturbances of Affective Contact. *Nervous Child* 1943;2:217-50.

5. Gillberg C, Grufman M, Persson E, Themner U. Psychiatric disorders in mildly and severely mentally retarded urban children and adolescents: epidemiological aspects. *British Journal of Psychiatry* 1986;149:68-74.

6. Wing L, Gould J. Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Developmental Disorders* 1979;9:11-29.

7. Baird G, Simonoff E, Pickles A, Chandler S, Loucas T, Meldrum D, Charman T. Prevalence of disorders of the autism spectrum in a population cohort of children in the South Thames: the special needs and autism project (SNAP). *Lancet* 2006;368:210-15.

8. Baron-Cohen S, Scott FJ, Allison C, Wiilliams J, Bolton P, Matthews FE, Brayne C. Prevalence of autism-spectrum conditions: UK school-based population study *British Journal of Psychiatry* 2009;194:500-09.

9. Filipek PA, Accardo PJ, Baranek GT, Cook EH Jr, Dawson G, Gordon B, Gravel JS, Johnson CP, Kallen RJ, Levy SE, Minshew NJ, Ozonoff S, Prizant BM, Rapin I, Rogers SJ, Stone WL, Teplin S, Tuchman RF, Volkmar FR. The screening and diagnosis of autistic spectrum disorders. *Journal of Autism and Developmental Disorders* 1999;29:439-84.

10. Fombonne E. The epidemiology of autism: a review. *Psychological Medicine* 1999;29:76-86.

11. National Audit Office. Supporting people with autism through adulthood. London: NAO, 2009.

12. Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J. Autism Spectrum Disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007. England: The NHS Information Centre for health and social care, 2009.

13. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders* 2001;31:5-17.

14. Lord C, Risi S, Lambrecht L, Cook EH Jr, Leventhal BL, DiLavore PC, Pickles A, Rutter M. The autism diagnostic observations schedule – generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism & Developmental Disorders* 2002;30:205-23.

15. Wing L, Leekam SR, Libby SJ, Gould J, Larcombe M. The diagnostic interview for social and communication disorders: Background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry* 2002;43:307-25.

16. Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview-Revised: a revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders* 1994;24:659-85.

17. Brugha TS, McManus S, Smith J, Scott FJ, Meltzer H, Purdon S, Berney T, Tantam D, Robinson J, Radley J, Bankart J. Validating two survey methods for identifying cases of Autism Spectrum Disorder among adults in the community [In Press]. *Psychological Medicine* 2012.

18. Brugha TS, McManus S, Bankart J, Scott F, Purdon S, Smith J, Bebbington P, Jenkins R, Meltzer H. Epidemiology of Autism Spectrum Disorders in Adults in the Community in England. *Archives of General Psychiatry* 2011;68:459-65.

19. Anckarsater H, Nilsson T, Saury JM, Rastam M, Gillberg C. Autism spectrum disorders in institutionalized subjects *Nordic Journal of Psychiatry* 2008;62:160-67.

20. Cashin A, Newman C. Autism in the criminal justice detention system: A review of the literature. *Journal of Forensic Nursing* 2009;5:70-75.

21. Department of Health. *Valuing People. A new strategy for Learning Disability for the 21st century. White Paper.* London: HMSO, 2001.

22. American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (4th ed).* Washington, DC: APA, 1994.

23. World Health Organisation [WHO]. *The ICD-10 classification of mental and behavioural disorders.* Geneva: WHO, 1992.

24. Bhaumik S, Tyrer F, McGrother C, Ganghadaran SK. Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research* 2008;52:986-95.

25. Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *British Journal of Psychiatry* 2007;190:27-35.

26. Emerson E, Baines S. The estimated prevalence of autism among adults with learning disabilities in England: Improving Health and Lives.: Learning Disabilities Observatory, 2010.

27. Roeleveld N, Zielhuis, G.A., Gabreels, F. The prevalence of mental retardation: a critical review of recent literature. *Developmental Medicine & Child Neurology* 1997;39:125-32.

28. Institute of Public Care. Estimating the prevalence of severe learning disability in adults (working paper). Oxford: Institute of Public Care via Projecting Adult Needs and Service Information (PANSI), 2009.

29. Parrott R, Emerson E, Hatton C, Wolstenholme J. Future demand for residential provision for people with learning disabilities. . Manchester: Hester Adrian Research Centre, University of Manchester, 1997.

30. National Statistics. Mid-year population statistics 2010. Durham: NOMIS, 2010.

31. Sparrow SS, Cicchetti DV, Balla DA. Vineland Adaptive Behavior Scales: Second Edition (Vineland II), Survey Interview Form/Caregiver Rating Form. Livonia, MN: Pearson Assessments, 2005.