



Estimating the prevalence of autism spectrum conditions in adults:

**Extending the 2007 Adult Psychiatric
Morbidity Survey**

User Guide

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SECTION I: INTRODUCTION

1. Background

The data files contain data on adults (aged 18+) with learning disabilities collected for the report *Estimating the prevalence of autism spectrum conditions in adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. Data files for the separate 2007 Adult Psychiatric Morbidity Survey (APMS 2007) can be found at the following link:

<http://www.esds.ac.uk/findingData/snDescription.asp?sn=6379>

The main aim of the survey was to extend the prevalence estimate of autism among adults aged 18 years or over from the APMS 2007 to include adults with learning disabilities aged 18 years and over living in private households or communal care establishments. The specific objectives of the study were:

- To identify a representative group of adults with learning disabilities who were either: (a) living in private households but not able to participate in the APMS 2007 due to learning disability; or (b) living in communal care establishments and thus not covered in the APMS 2007 sample.
- To interview the adults with learning disabilities living in private households who would not have been able to take part in the APMS 2007 with two clinical assessment for autism (depending on ability level): module 1 or module 4 of the Autism Diagnostic Interview Schedule (ADOS).
- To interview carers of a sub-sample of adults with learning disabilities with two validated clinical assessments to calibrate module 1 of the ADOS.
- To combine the acquired 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) to derive an overall prevalence estimate for autism among adults.
- To perform sensitivity analyses of the combined prevalence estimate to take into account adults without learning disability who live in communal care establishments.

Fieldwork was carried out in Leicestershire, Lambeth and Sheffield between August 2010 and April 2011.

Interviews and clinical assessments were carried out by interviewers at the University of Leicester. A sub-sample of carers of respondents for the first interview were invited to take part in a second interview to validate the clinical assessment used to identify autism. These interviews were carried out by a senior research

psychologist at the University of Leicester who had also conducted validation interviews for the APMS 2007.

2. Sample Design

Response

Interviews with people with learning disabilities

The sample was designed to be representative of the population of adults with learning disabilities living in private households and in communal care establishments in England. Adults were selected from three learning disability registers covering the local authorities of Leicester city, Leicestershire, Rutland, Lambeth and Sheffield.

The primary sampling units for adults living in private households were the individual participants and the sample was stratified by age, sex and type of residence. The primary sampling units for adults living in communal care establishments were the communal care establishments. The sample was similarly stratified by type of residence, and within establishment, by age and sex. Within each establishment adults were selected with selection probabilities proportional to the number of eligible residents. 20% of carers/adults living in private households agreed to take part and 45% of adults living in communal care establishments. In total, 290 adults with learning disabilities and their carers were interviewed and 276 adults were assessable with the clinical assessment for autism that we used.

Interviews with carers of people with learning disabilities

60 carers of adults with learning disabilities were approached to take part in a second interview. Criteria for selection was based on a random sample of 30 carers of adults who scored low (<7) in module 1 of the ADOS and 30 carers of adults who scored high (≥ 7). Interviews were conducted with 58 (97%) of these carers. Data from these interviews were only used to validate the autism diagnosis and are not archived separately.

Data collection

Survey Method

The interviews with people with learning disabilities took approximately 90 minutes to complete. The interviews with carers took between 90 minutes and 3 hours.

At the end of the first interview verbal permission was sought for the interviewer to contact the carer of the respondent to be contacted for a second interview: 84% agreed.

3. Using the data

The data comprise one file, which contains details of all participants with learning disabilities who could be assessed with the Autism Diagnostic Observation Schedule (ADOS). There were an additional 14 participants who could not be assessed with the ADOS because they had extremely profound learning disabilities. These individuals were not included in the analyses.

ASCLDarch.sav	290 records	Contains data on all individuals who were assessed with module 1 or module 4 of the Autism Diagnostic Observation Schedule. It contains demographic information, ADOS module, ADOS score and a Y/N indicator variable for autism. 7 variables have been archived.
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Variables on the file

The data file contains demographic information from the modified APMS questionnaire and information obtained from the assessment tool used for autism. Variables are listed in Section II ('**List of variables**'). Not all data collected are archived to retain respondent anonymity.

4. Main survey report

Further information about the study into autism among adults with learning disabilities can be found in the main study report:

Brugha T, Cooper SA, McManus S, Purdon S, Smith J, Scott FJ, Spiers N, Tyrer F (2012). *Estimating the prevalence of autism spectrum conditions in adults: Extending the 2007 Adult Psychiatric Morbidity Survey*. The NHS Information Centre.

The main report can be downloaded for free from the NHS Information Centre website:

<http://www.ic.nhs.uk/pubs/autism11>

Hard copies of the report are available from:

Freya Tyrer
New Academic Unit
Leicester General Hospital
Gwendolen Road
Leicester LE4 4PW

Further information on the Adult Psychiatric Morbidity Survey 2007 can be found in:

McManus S, Meltzer H, Brugha T, Bebbington P, Jenkins R (eds). *Adult Psychiatric Morbidity in England 2007: results of a household survey*. The NHS Information Centre.

This report can be downloaded for free from the Information Centre website:

<http://www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys/adult-psychiatric-morbidity-in-england-2007-results-of-a-household-survey>

Further information on autism among adults who took part in the Adult Psychiatric Morbidity Survey 2007 can be found in:

Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J (2009). *Autism spectrum disorders in adults living in households throughout England. Report from the Adult Psychiatric Morbidity Survey 2007*. The NHS Information Centre.

This report can be downloaded for free from the NHS Information Centre website:

<http://www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys/autism-spectrum-disorders-in-adults-living-in-households-throughout-england--report-from-the-adult-psychiatric-morbidity-survey-2007>

SECTION II: LIST OF VARIABLES

1. Introduction

This section introduces the data set for the autism and learning disability study and is important for those wishing to analyse the data. Section III (***) outlines how the questions were asked in the study and how any derived variables were defined.

The source of each variable is described in the final column of each table with initials/abbreviations as follows:

Modified APMS	Modified questionnaire, based on the Adult Psychiatric Morbidity Survey 2007
Assessment	Assessment for autism using the Autism Diagnostic Observation Schedule (carried out by clinically trained interviewers)
Derived	A variable derived from other variables

Classification

Individual

Variable	Description	Source
IDNO	ID number of individual	Derived
ACCOMTYPE	Type of accommodation (private household / communal care establishment)	Derived
SEX	Sex of individual	Modified APMS
AGEGRP	Age group (18-44 / 45+)	Derived

Autism spectrum condition

Autism Spectrum Condition

Variable	Description	Source
ADOSMOD	Module of ADOS	Assessment
ADOSSCORE	ADOS score	Assessment
ADOSAUT	Autism case (Y / N)	Derived

SECTION III: DERIVED VARIABLE SPECIFICATION

Classification

Individual

Variable	Description	Source
IDNO	ID number of individual	Derived
ACCOMTYPE	Type of accommodation (private household / communal care establishment)	Derived
AGEGRP	Age group (18-44 / 45+)	Derived

Accommodation type

This variable was derived according to the address of the participant when sampled.

ACCOMTYPE: (D) Accommodation type

- 0 Private household (any address that could have been sampled for the Adult Psychiatric Morbidity Survey 2007, including independent homes, family homes and some supported living accommodation – including unregistered group homes)
- 1 Communal care establishment (any address that could not have been sampled for the Adult Psychiatric Morbidity Survey 2007, including hospital accommodation, hostels, registered residential homes, nursing homes and some supported living accommodation – where previously a residential home)
- 7 Not archived (to preserve anonymity among adults with a “not assessable” rating in module 1 of the ADOS)

SPSS Syntax

```
*ACCOMTYPE  
DO IF (ADOSAUT=-99).  
RECODE ACCOMTYPE (0 thru 1=-7).  
END IF.
```

Age group

AGEGRP: (D) Age group

- 1 18-44
- 2 45 +
- 7 Not archived (to preserve anonymity among adults in the private household sample and those with a “not assessable” rating in module 1 of the ADOS)

SPSS Syntax

```
*AGEGRP  
RECODE age(18 thru 44=1)(45 thru 110=2) into agegrp.  
EXE.
```



```
DO IF (ACCOMTYPE = 0).  
RECODE AGEGRP (1 thru 2=-7).  
END IF.  
EXECUTE.
```

```
DO IF (adosaut = -99).  
RECODE AGEGRP (1 thru 2=-7).  
END IF.  
EXECUTE.
```

Autism spectrum condition

Autism

ADOSAUT: (D) Autism case (Y/N)

1	Yes
0	No
-99	Not assessable

This variable was derived by data analysis. An autism case was defined as a score of 10 or more on module 4 of the ADOS, with the proviso that a communication total score of at least 2 (i.e. autism spectrum cut off) and a reciprocal social interaction score of at least 4 (i.e. autism spectrum cut off) were met. Similarly, an autism case was defined as a score of 12 or more on module 1 of the ADOS, with the proviso that a communication score of at least 2 (i.e. autism spectrum cut off) and a reciprocal social interaction score of at least 4 (i.e. autism spectrum cut off) were met. 14 individuals were not assessable with module 1 of the ADOS and were coded as -99.

SECTION IV: CODING AND EDITING INSTRUCTIONS

1. Instructions

Coding

The answers given by participants/carers and relevant to this archive file were coded by the interviewer in a pre-specified coding frame during a face-to-face interview.

DO NOT delete cases

Please note that you should never delete a case unless you have been instructed to do so by a member of the research team.

2. Demographic information

Sex and exact age

Exact age on the date of the assessment was derived from date of birth. Female sex was recoded as 0 and has been coded as -7 for adults who were not assessable in module 1 of the ADOS (to preserve confidentiality).

Question 1 on Modified APMS questionnaire

ASK CARERS AND PARTICIPANTS (IF POSSIBLE)

INTERVIEWER: IF PARTICIPANT IS IN A RESIDENTIAL HOME, ONLY INCLUDE DETAILS OF THE PARTICIPANT AND KEY WORKER.

A1. Details of all household members/residents

<u>PNo</u>	<u>R</u>	<u>Sex</u>	<u>Birth</u>	<u>MarStat</u>
Person no.	Relationship to participant*	Sex	Date of birth*	Marital status (if aged >16 only)
Circle	Off Use	M F	dd / mm / yyyy	Circle
01	Subject	1 2		1 Single, that is never married 2 Married and living with husband/wife 3 Married and separated from husband/wife 4 Divorced

					5	Widowed
					6	In a legally-recognised civil partnership and separated from civil partner
					7	Formally a civil partner; the civil partnership is now legally dissolved
					8	A surviving civil partner; his/her partner having since died
					98	Don't know
					99	Refused to answer