



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
is England's central, authoritative source
of health and social care information.

Acting as a 'hub' for high quality, national,
comparative data, we deliver information for local
decision makers, to improve the quality and
efficiency of care.

www.ic.nhs.uk

Authors: ¹Brugha Traolach, ²McManus Sally, ¹Meltzer Howard, ²Purdon Susan, ³Scott Fiona, ³Baron-Cohen Simon, ³Wheelwright Sally, ¹Smith Jane, ¹Bankart John

¹Department of Health Sciences, University of Leicester, ²National Centre for Social Research (NatCen), London, ³Autism 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

This is an independent report funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department of Health.

Contents

Contents	3
Summary	4
Background	5
Methods	6
Project design	6
Measures	8
Modification of survey tool:	9
Selection and derivation of a short self-report ASD questionnaire suitable for use in large scale adult surveys	9
Survey phases one and two: AQ20 and ADOS fieldwork	11
Sample design	12
Phase two diagnostic measures	13
Training and supervision of phase one and phase two interviewers	14
Survey phase three: DISCO and ADI-R fieldwork	14
Data analysis I: Examination of the agreement between the DISCO and ADOS assessments	16
Data analysis II: Examination of the use of self-report questions to predict ADOS assessments according to ADOS diagnostic threshold	16
Discussion	17
Appendices	18
APPENDIX A The AQ20 items and impact questions	18
APPENDIX B Bibliography	22

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).

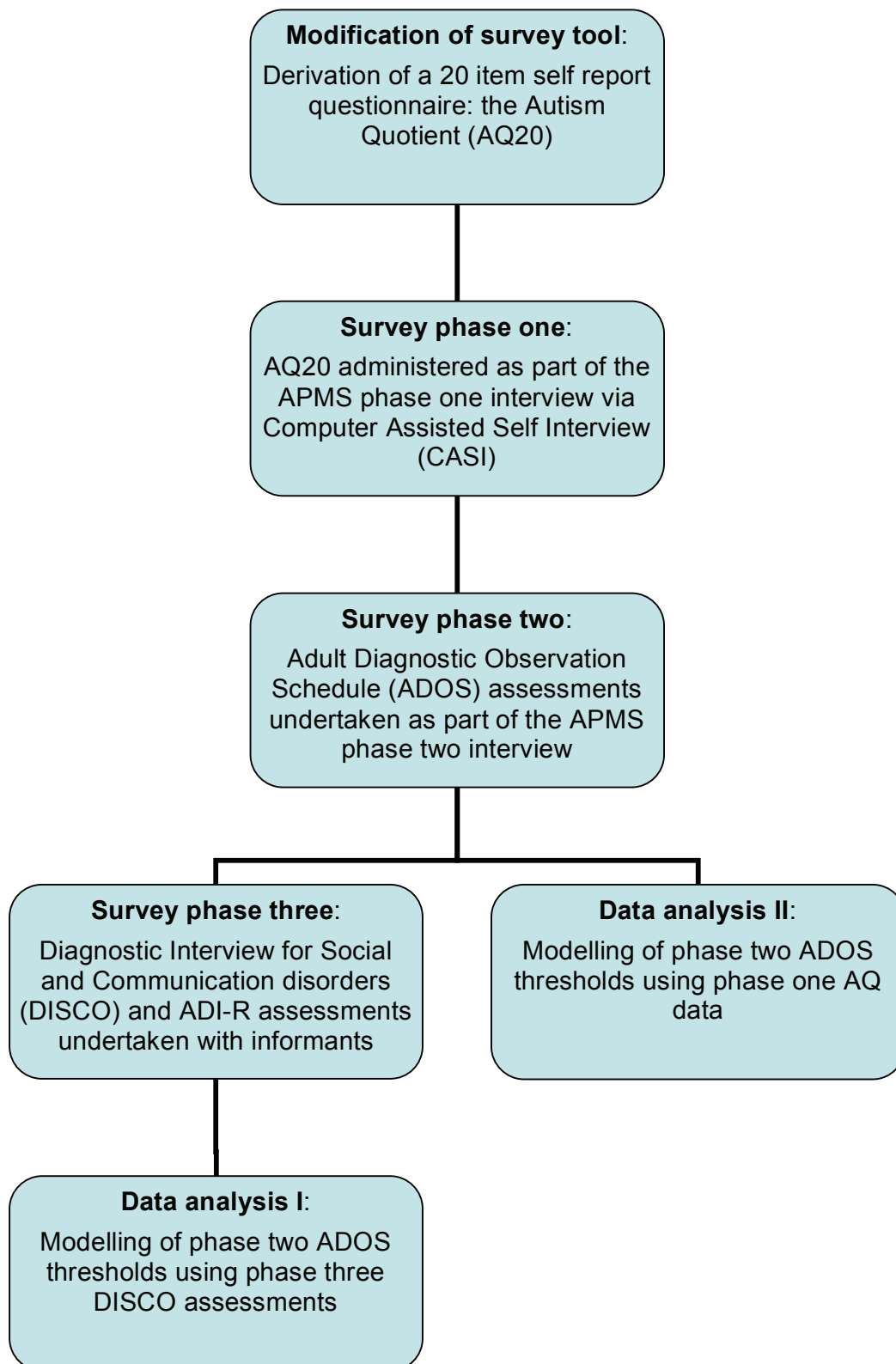
Survey phase one: these questions were included in the first phase of the general population, psychiatric morbidity survey (APMS 2007), which used stratified random sampling (see Section 1.5).

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

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

^a 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)

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 includes 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 (CASI).

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 ≥ 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.

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.

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/en/statug.hlp/surveyfreq_sect2.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 |

ASsound

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 |

ASsocsit

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

AStalk

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

ASfriend

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

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

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 of 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/remembers 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 DVCnsc >=2 AND DVTotal >=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 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 DVImisc >=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

APPENDIX B Bibliography

- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*. American Psychiatric Association: Washington, DC.
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D. & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet* **368**(9531):210-215.
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J. & Clubley, E. (2001). The autism-spectrum quotient (AQ): evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *J Autism Dev. Disord.* **31**(1):5-17.
- Brugha, T.S. & Nienhuis, F.J. World Health Organization Division of Mental Health, (Ed.) (1998) SCAN-SF. A Survey Form of the Present State Examination and SCAN: Supplementary schedule for lay interviewers. p.13 Geneva: World Health Organization.
- Collins D (2003) 'Pretesting survey instruments: An overview of cognitive methods' *Quality of Life Research 12* Kluwer Academic Publishers.
- nQuery Advisor® Release 2.0. Elashoff, J. (1997) Boston, MA: Statistical Solutions.
- Frith, U. (1991). *Autism and Asperger Syndrome*. Cambridge University Press: Cambridge.
- Green, H., McGinnity, A., Meltzer, H., Ford, T. & Goodman, R. (2005) *Mental Health of Children and Young People in Great Britain, 2004*. Hampshire: Palgrave MacMillan.
- Howlin, P., Goode, S., Hutton, J. & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry* **45**(2):212-229.
- Kessler, R.C., Adler, L., Ames, M., Demler, O., Faraone, S., Hiripi, E., Howes, M.J., Jin, R., Secnik, K., Spencer, T., Ustun, T.B. & Walters, E.E. (2005). The World Health Organization Adult ADHD Self-Report Scale (ASRS): a short screening scale for use in the general population. *Psychological Medicine* **35**(2):245-256.
- Knapp, M., Romeo, R. & Beecham, J. (2007) *Economic consequences of autism in the UK*. London: Mental Health Foundation and Autism Speaks.
- Leekam, S.R., Libby, S.J., Wing, L., Gould, J. & Taylor, C. (2002). The Diagnostic Interview for Social and Communication Disorders: algorithms for ICD-10 childhood autism and Wing and Gould autistic spectrum disorder. *J Child Psychol. Psychiatry* **43**(3):327-342.
- Lewis, G., Pelosi, A.J., Araya, R. & Dunn, G. (1992). Measuring psychiatric disorder in the community: a standardized assessment for use by lay interviewers. *Psychological Medicine* **22**:465-486.
- Lord, C., Rutter, M., DiLavore, P.C. & Risi, S. (2002a). *Autism Diagnostic Observation Schedule. ADOS Manual*. Western Psychological Services: Los Angeles.

- Lord,C., Rutter,M. & Le Couteur,A. (2002b). The autism diagnostic observation schedule-generic: a standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders* **30**:205-223.
- Lord,C., Rutter,M. & Le Couteur,A. (1994). 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* **24**:659-685.
- McManus,S., Meltzer,H., Brugha,T., Bebbington,P. & Jenkins,R. McManus,S., Meltzer,H., Brugha,T., Bebbington,P. and Jenkins,R., (Eds.) (2009) Adult Psychiatric Morbidity in England, 2007. Results of a household survey. p.273 London: The NHS Information Centre for health and social care.
- Morgan,J.F., Reid,F. & Lacey,J.H. (1999). The SCOFF questionnaire: assessment of a new screening tool for eating disorders. *BMJ Clinical Research Ed.* **319**(7223):1467-1468.
- Ritvo,R.A., Ritvo,E.R., Guthrie,D., Yuwiler,A., Ritvo,M.J. & Weisbender,L. (2008). A scale to assist the diagnosis of autism and Asperger's disorder in adults (RAADS): a pilot study. *J Autism Dev.Disord.* **38**(2):213-223.
- Williams,J.B., Gibbon,M., First,M.B., Spitzer,R.L., Davies,M., Borus,J., Howes,M.J., Kane,J., Pope,H.G.J. & Rounsaville,B. (1992). The Structured Clinical Interview for DSM-III-R (SCID). II. Multisite test-retest reliability. *Archives of General Psychiatry* **49**(8):630-636.
- Wing,J.K., Babor,T., Brugha,T., Burke,J., Cooper,J.E., Giel,R., Jablensky,A., Regier,D. & Sartorius,N. (1990). SCAN. Schedules for Clinical Assessment in Neuropsychiatry. *Archives of General Psychiatry* **47**(6):589-593.
- Wing,L. (1997). The autistic spectrum. *Lancet* **350**(9093):1761-1766.
- Wing,L., Leekam,S.R., Libby,S.J., Gould,J. & Larcombe,M. (2002). The Diagnostic Interview for Social and Communication Disorders: background, inter-rater reliability and clinical use. *Journal of Child Psychology and Psychiatry* **43**(3):307-325.
- World Health Organization (1993). *The ICD-10 Classification of Mental and Behavioural Disorders: Diagnostic Criteria for Research*. WHO: Geneva.

This document may be requested in large print or other formats.

For further information:

www.ic.nhs.uk

0845 300 6016

enquiries@ic.nhs.uk

Copyright © 2009 The Health and Social Care Information Centre, All rights reserved.

This work remains the sole and exclusive property of the Health and Social Care Information Centre and may only be reproduced where there is explicit reference to the ownership of the Health and Social Care Information Centre.

This work may be re-used by NHS and government organisations without permission.

This work is subject to the Re-Use of Public Sector Information Regulations and permission for commercial use must be obtained from the copyright holder.