



Survey of General Practitioners in England on the subject of autism

**Report prepared for
The National Audit Office**



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1 Summary of Findings

The average number of children (under the age of 18) seen by respondents in a typical six month period is 507:

- Of those, the average number of children who do not have a formal diagnosis of Autistic Spectrum Disorder (ASD) but whose symptoms indicate they may have ASD was 13;
- Of these 13, 50% have symptoms which indicate 'high-functioning' autism or Asperger's Syndrome.

The average number of adults (age 18-64) seen by respondents in a typical six month period is 1,722:

- Of those, the average number of adults who do not have a formal diagnosis of ASD but whose symptoms indicate they may have ASD was 24;
- Of these 24, 52% of these have symptoms which indicate 'high-functioning' autism or Asperger's Syndrome.

The average number of older people (age 65+) seen by respondents in a typical six month period is 934

- Of those the average number of older people who do not have a formal diagnosis of ASD but whose symptoms indicate they may have ASD was 5.

In terms of referral of patients who had undiagnosed ASD:

- Children with undiagnosed 'low-functioning' autism are generally referred to Child and Adolescent Mental Health Services (51%) or Paediatric Services (50%);
- Children with undiagnosed 'high-functioning' autism or Asperger's Syndrome are generally referred to Child and Adolescent Mental Health Services (54%);
- Adults with undiagnosed 'low-functioning' autism are generally referred to Adult Mental Health Services (54%);
- Adults with undiagnosed 'high-functioning' autism or Asperger's Syndrome are also generally referred to Adult Mental Health Services (64%);
- Older people with undiagnosed 'high-functioning' autism or Asperger's Syndrome are mainly referred to Older People's Mental Health Services (73%).

The majority of respondents (80%) don't keep a register of patients diagnosed with autism. Among the GPs who do keep a register, patients diagnosed with 'low-functioning' autism account for, on average, 4% of caseload, and those diagnosed with 'high-functioning' autism or Asperger's Syndrome account for, on average, 5% of caseload.

Seven out of ten GPs (71%) do not provide specific ongoing support, monitoring or condition management for patients diagnosed with autism.

Most respondents said in either type of autism diagnosis they were not very confident that patients are receiving appropriate and adequate care

- 'Low-functioning' autism - 54% of respondents selected 'not very confident'
- 'High-functioning' autism or Asperger's Syndrome - 52% of respondents selected 'not very confident'

Four out of five GPs (80%) indicate that they require additional guidance and training to identify and manage patients with ASD more effectively.

2 Introduction

The National Audit Office is currently conducting a study looking at the area of autism and the extent to which existing services meet the needs of adults with Autistic Spectrum Disorder (ASD), focusing particularly on the transition from adolescence and the subsequent provision of health, social care, education and employment support to adults across the whole autistic spectrum.

As part of this study the NAO has surveyed General Practitioners to understand their views regarding patient numbers, referral of ASD patients, the support they offer ASD patients and their level of confidence in the fact that patients are receiving appropriate and adequate care.

3 Research Objectives and Methodology

The specific objectives of the Doctors.net.uk study on behalf of the NAO were:

- To investigate the number of patients, within different age groups, who are presenting to General Practitioners with symptoms of Autistic Spectrum Disorder (ASD) but who do not yet have a formal diagnosis of ASD;
- To understand to where GPs currently refer patients whose symptoms indicate that they have ASD;
- To look at the ongoing support, monitoring and condition management provided for patients diagnosed with ASD;
- To determine how confident GPs are that patients in their area with ASD are receiving appropriate and adequate care;
- To understand the extent to which GPs feel they require additional guidance and training to identify and manage patients with ASD more effectively.

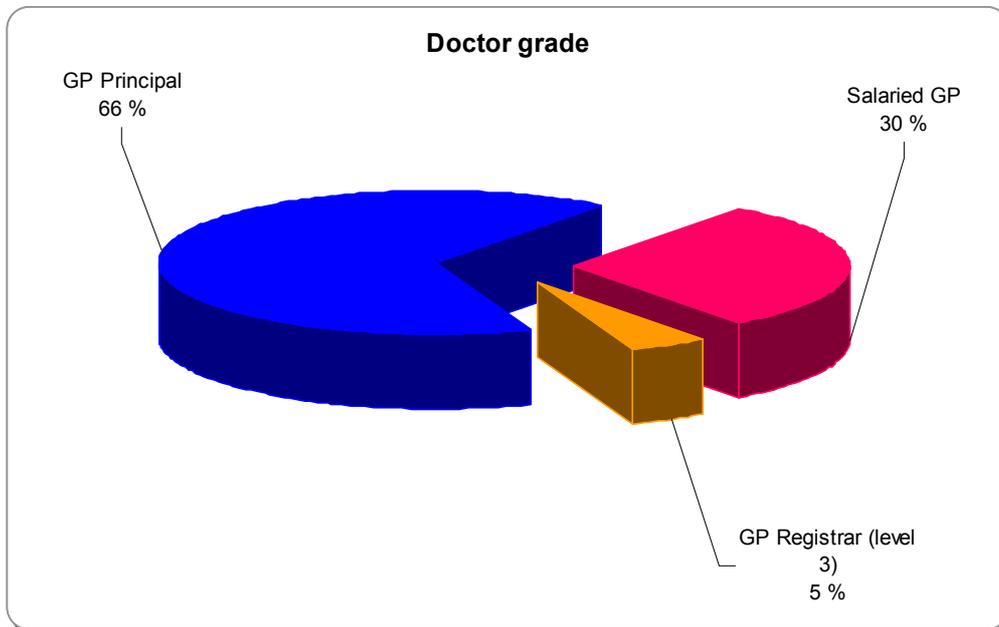
The questionnaire used to collect these data is included in the appendix of this report.

The survey was conducted using an on-line quantitative research methodology with doctors who are members of Doctors.net.uk and registered as practicing in England. All members of Doctors.net.uk are GMC-registered medical practitioners who access the Doctors.net.uk website through a unique user name and password. All those who took part stated that they were currently practicing as doctors in England.

Doctors.net.uk has been contracted to conduct the fieldwork, collect all responses, analyse the information and prepare this report as a summary of the research findings.

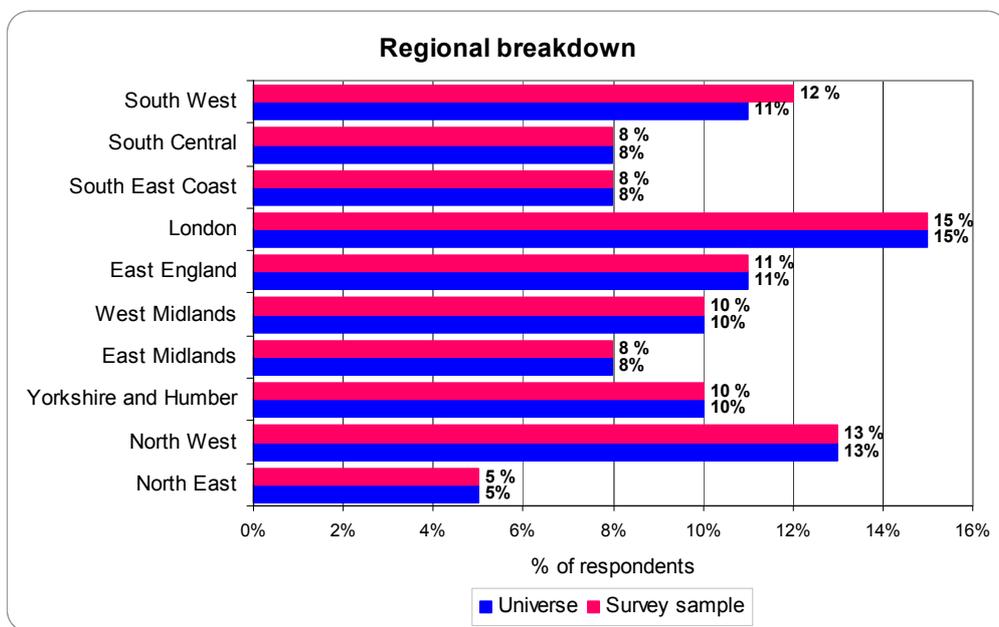
3.1 Sample Demographics

Figure 1 : Grade of doctors in survey



Two thirds of respondents (66%) were GP principle grade with salaried GPs being the second largest group (30%). GP Registrars below level 3 and GP locums were excluded from the survey.

Figure 2 : Sample by Strategic Health Authority¹



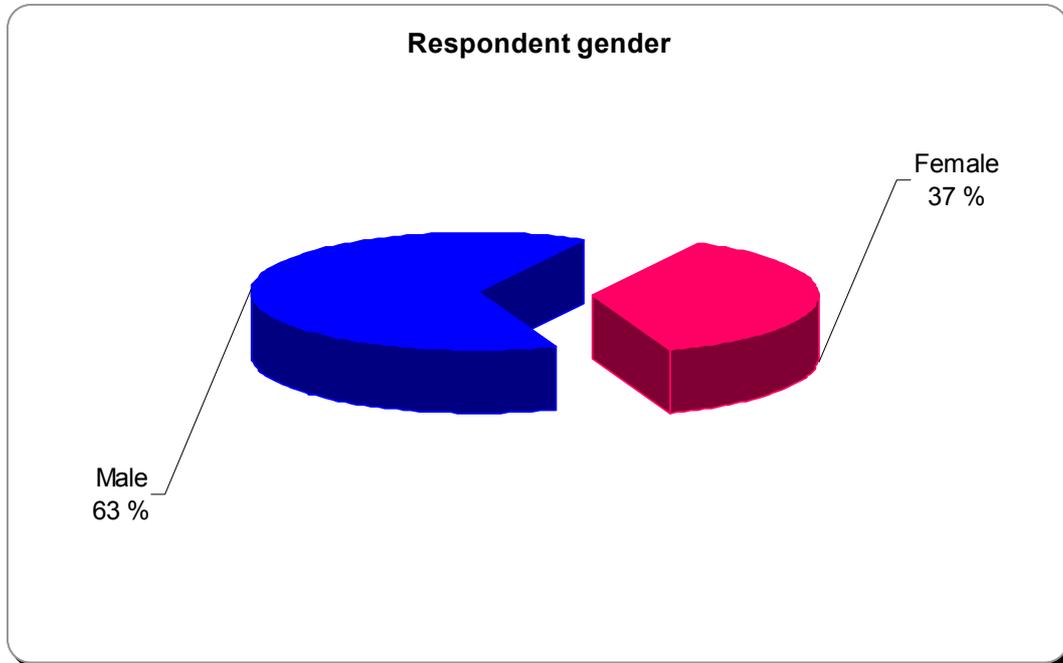
¹ Universe numbers based on NHS Information Centre data from 30 September 2007.

<http://www.ic.nhs.uk/statistics-and-data-collections/workforce/nhs-staff-numbers/nhs-staff-1997--2007-overview>. Last accessed 10th October 2008.

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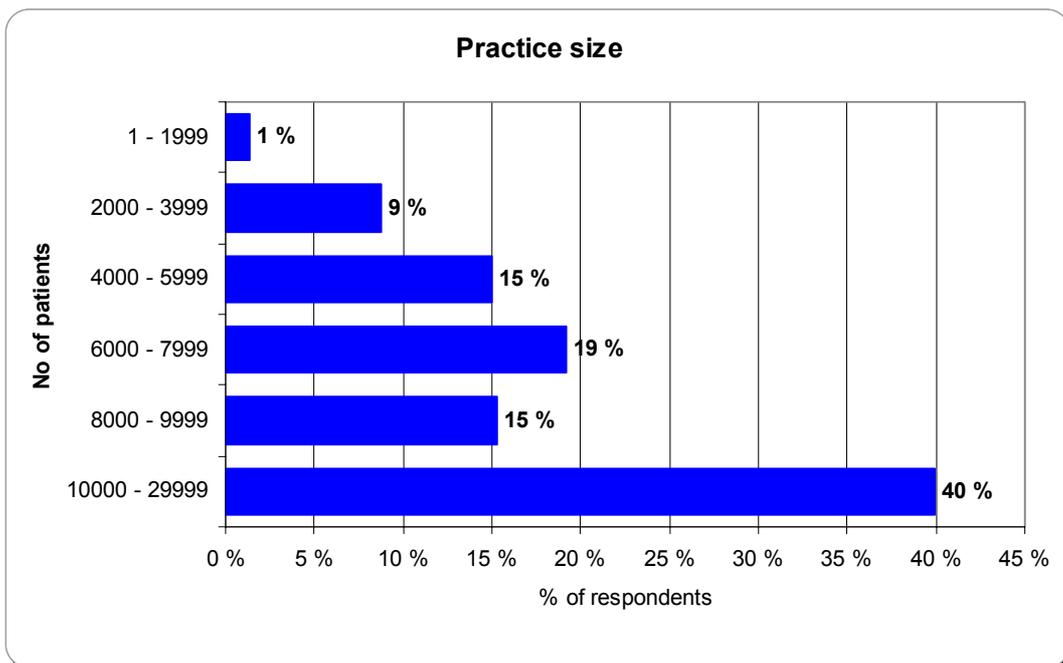
The breakdown of the survey sample by Strategic Health Authority (SHA) closely reflects the breakdown of GPs across England. The London SHA is the largest area represented in the survey (15%), the North East SHA has the smallest proportion of the sample (5%).

Figure 3 : Split of respondent gender



Just under two thirds (63%) of respondents in the survey were male, just over a third (37%) female.

Figure 4 : Practice size of respondents

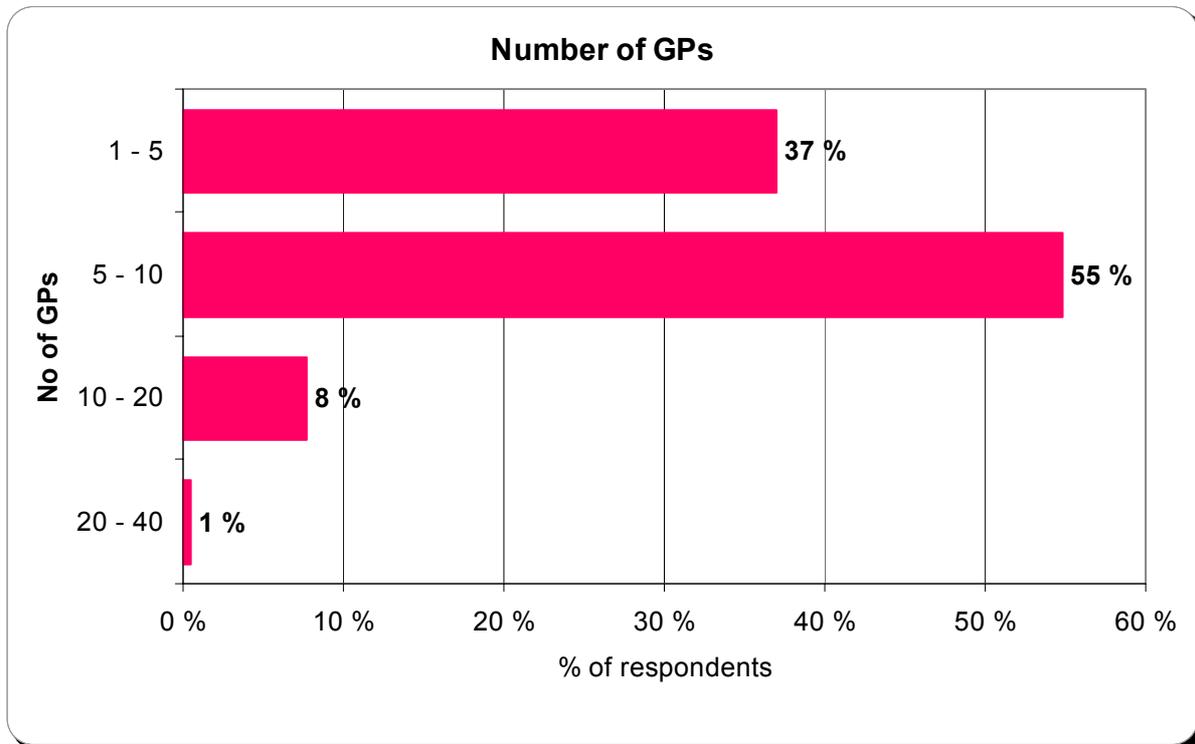




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The majority of respondents (40%) came from practice size of 10,000 patients and above. The maximum practice size represented is 33,000 with an average practice size of 8,826 patients.

Figure 5 : Number of GPs in practice



Most respondents were in practices containing five to ten GPs. The average number of GPs in the practices represented was 5.7. The maximum number of GPs in a practice was 28.

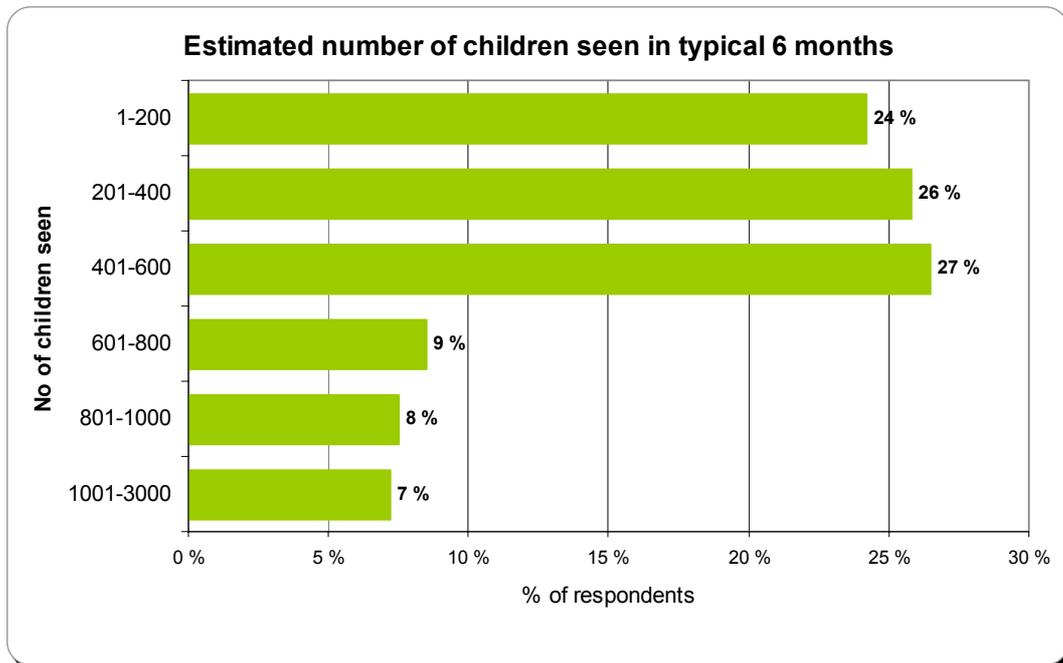
4 Survey Findings

4.1 Population

Respondents were asked about their patient population and the proportion of patients that they feel may have an Autistic Spectrum Disorder (ASD) but who do not yet have a formal diagnosis of ASD.

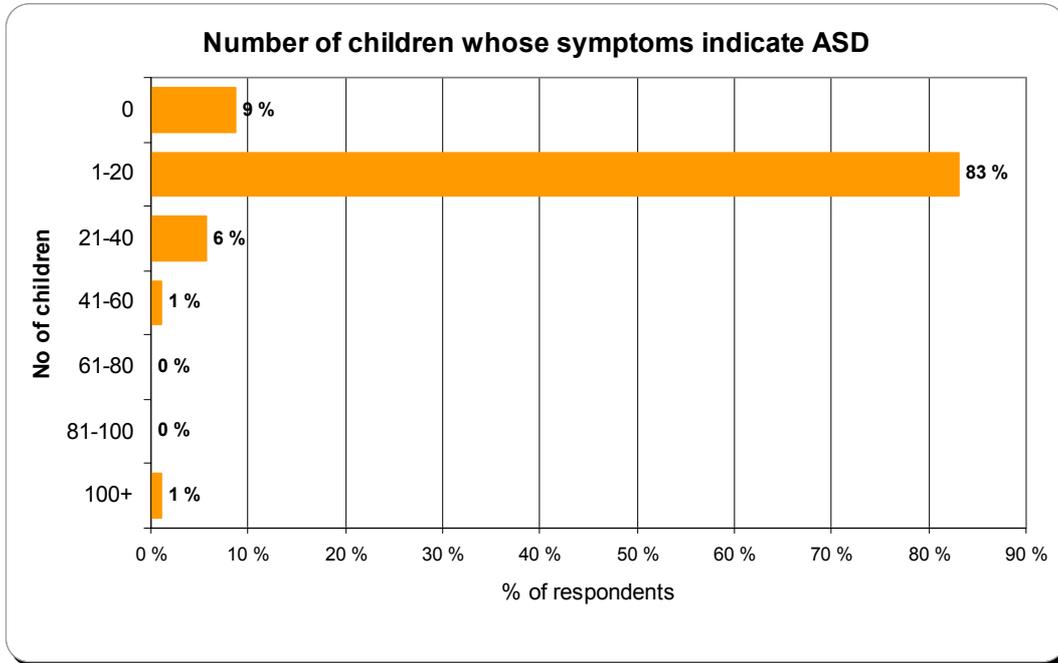
4.1.1 Children (under age 18)

Figure 6 : Number of children seen as patients in a typical six month period



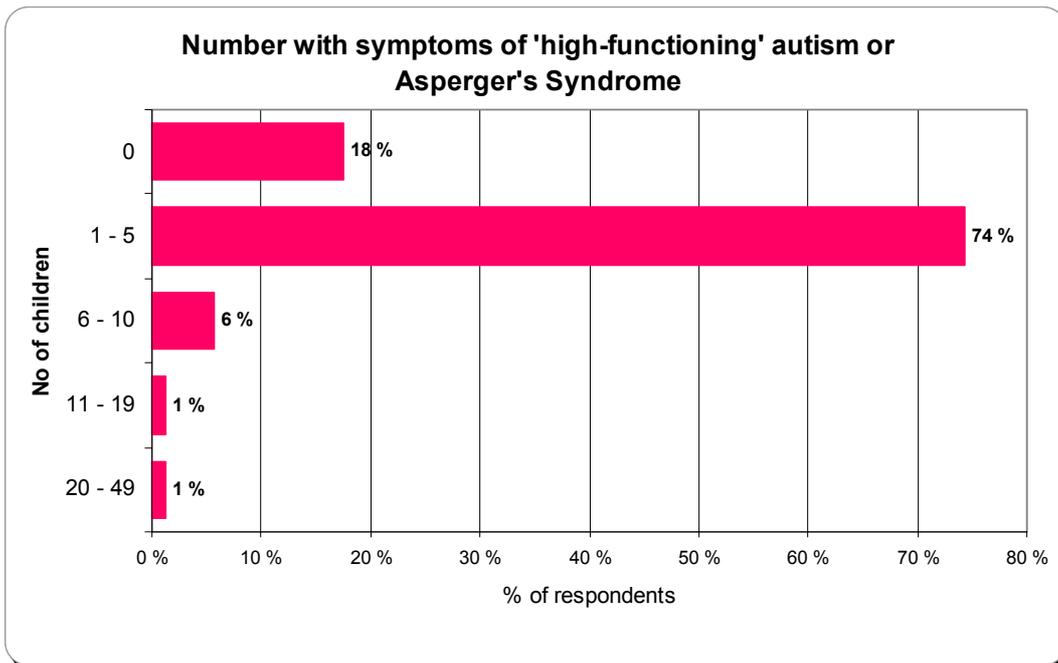
The majority of respondents (27%) estimate that they see from 400 to 600 children (below the age of 18 years) in a typical six month period. The average number across the sample was 507 such patients.

Figure 7 : Number of children whose symptoms indicate they may have ASD but who do not yet have a diagnosis of ASD



Most respondents (83%) reported that they estimate seeing from one to twenty patients in a six-month period who do not have a formal diagnosis of ASD but whose symptoms indicate that they may have ASD. The average number of patients falling into this category was thirteen per respondent.

Figure 8 : Number of children who have symptoms which indicate a diagnosis of 'high-functioning' autism or Asperger's Syndrome



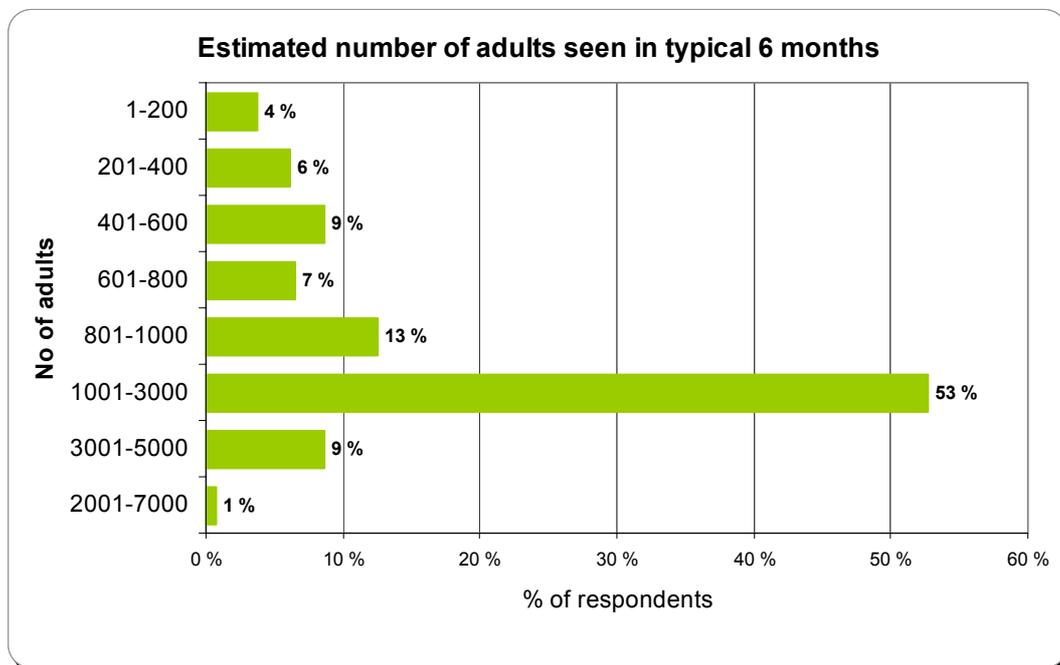
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Three-quarters of GPs (74%) estimate that from one to five of their patients who do not have a formal diagnosis of ASD, but who may have ASD, have symptoms which indicate a diagnosis of 'high-functioning' autism or Asperger's Syndrome. On average respondents reported that they have two such patients which would fit into this category.

On average, across the whole sample, half of the patients in the child category with potential ASD have symptoms which suggest 'high-functioning' autism or Asperger's Syndrome. The number of patients with potential ASD who have symptoms which suggest 'high-functioning' autism or Asperger's Syndrome represents 1.1% of all patients under the age of 18 that a GP sees in a typical six-month period.

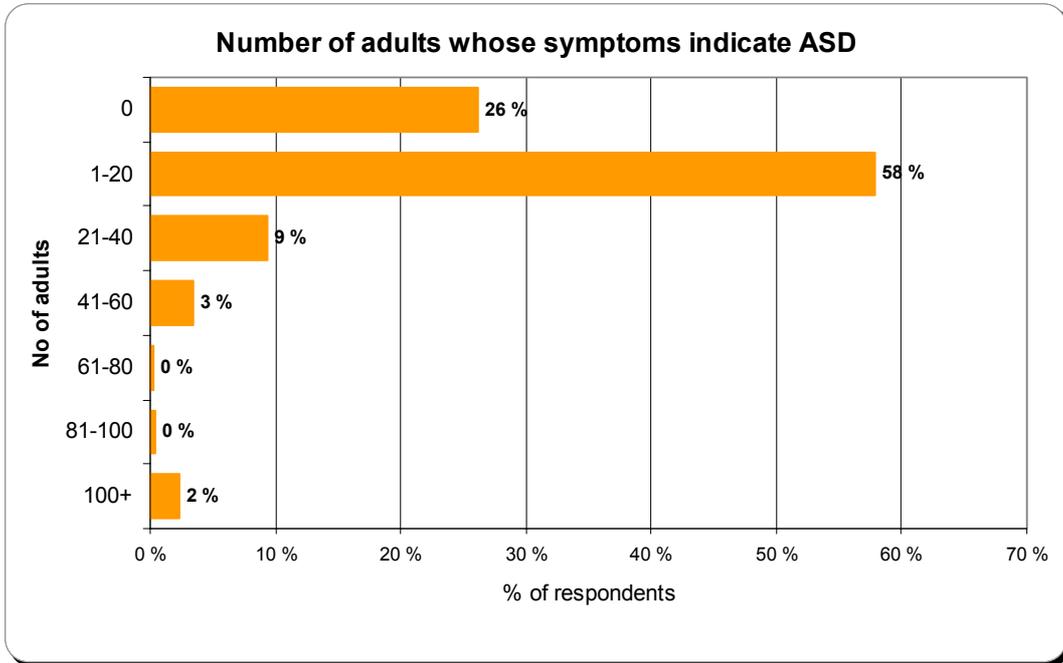
4.1.2 Adults (aged 18 – 64)

Figure 9 : Number of adults seen as patients in a typical six month period



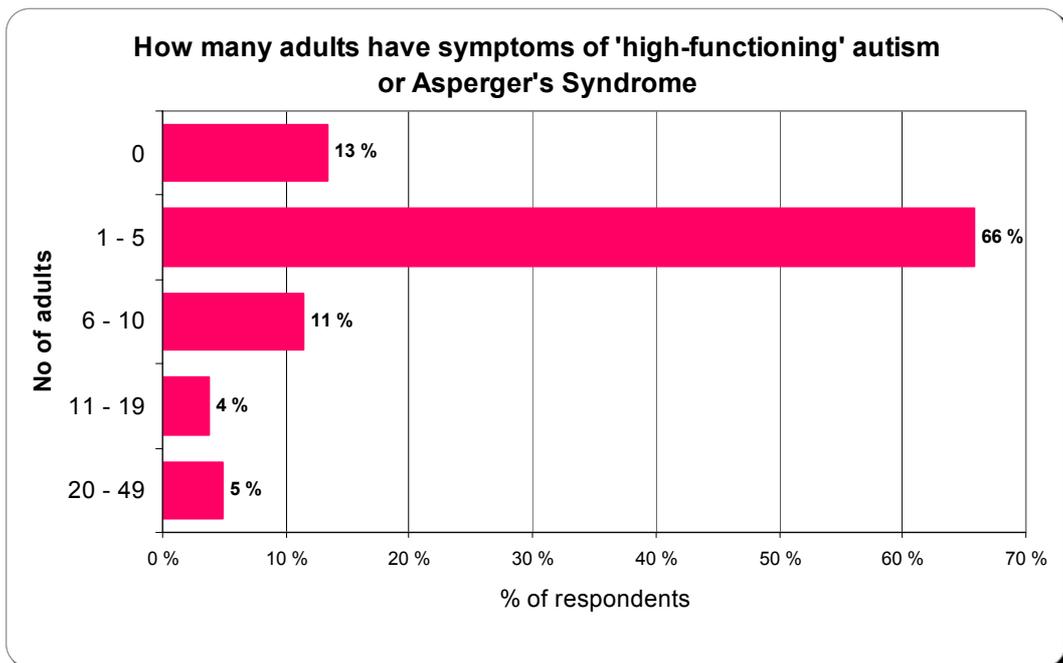
The majority of respondents (53%) see from 1000 to 3000 adult patients in a typical six-month period. The average number of adult patients seen across the sample was 1,722.

Figure 10 : Number of adults whose symptoms indicate they may have ASD but who do not yet have a diagnosis of ASD



Just over a quarter (26%) of respondents estimated that they did not have any patients who fall into the category of not yet having a diagnosis of ASD but whose symptoms indicated that they may have ASD. Three in five GPs (58%) estimated that they have from one to twenty patients who fall into this category. The average number of such patients, across the sample was 24.

Figure 11 : Number of adults who have symptoms which indicate a diagnosis of 'high-functioning' autism or Asperger's Syndrome



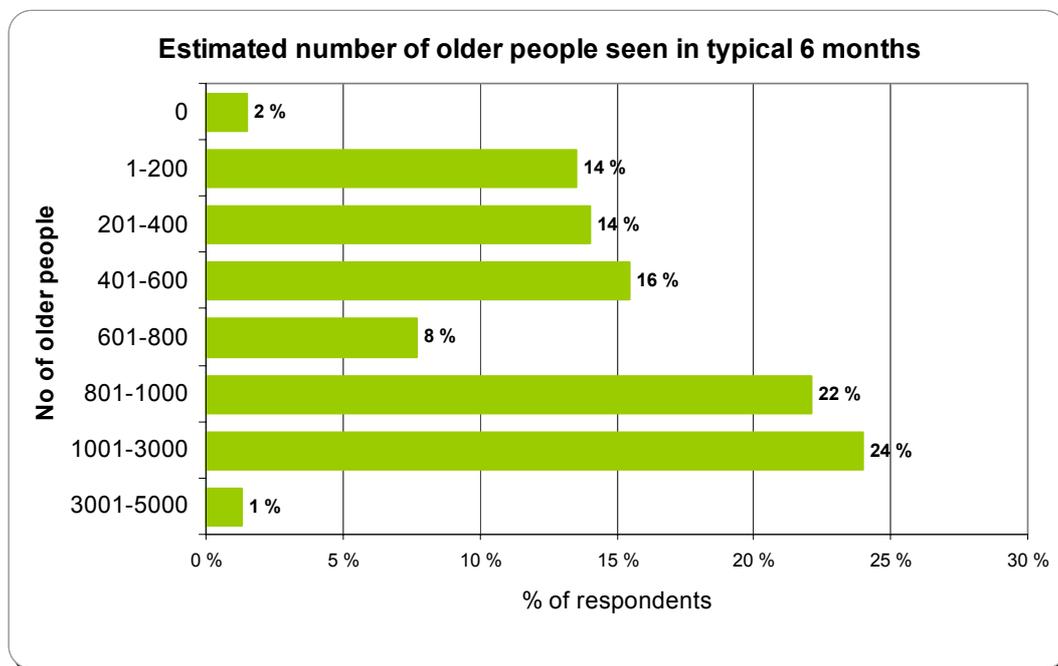
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Most GPs estimate that from one to five of their adult patients who do not yet have a diagnosis of ASD (but whose symptoms indicate that they may have ASD) would be in the group whose symptoms indicate they have 'high functioning' autism or Asperger's Syndrome. On average number GPs estimate that they see five such patients in a typical six-month period.

Over the whole sample the 'high-functioning' autism or Asperger's Syndrome group represents on average 52% of all adult patients who may have ASD, but do not yet have a formal diagnosis, and 0.8% of all patients.

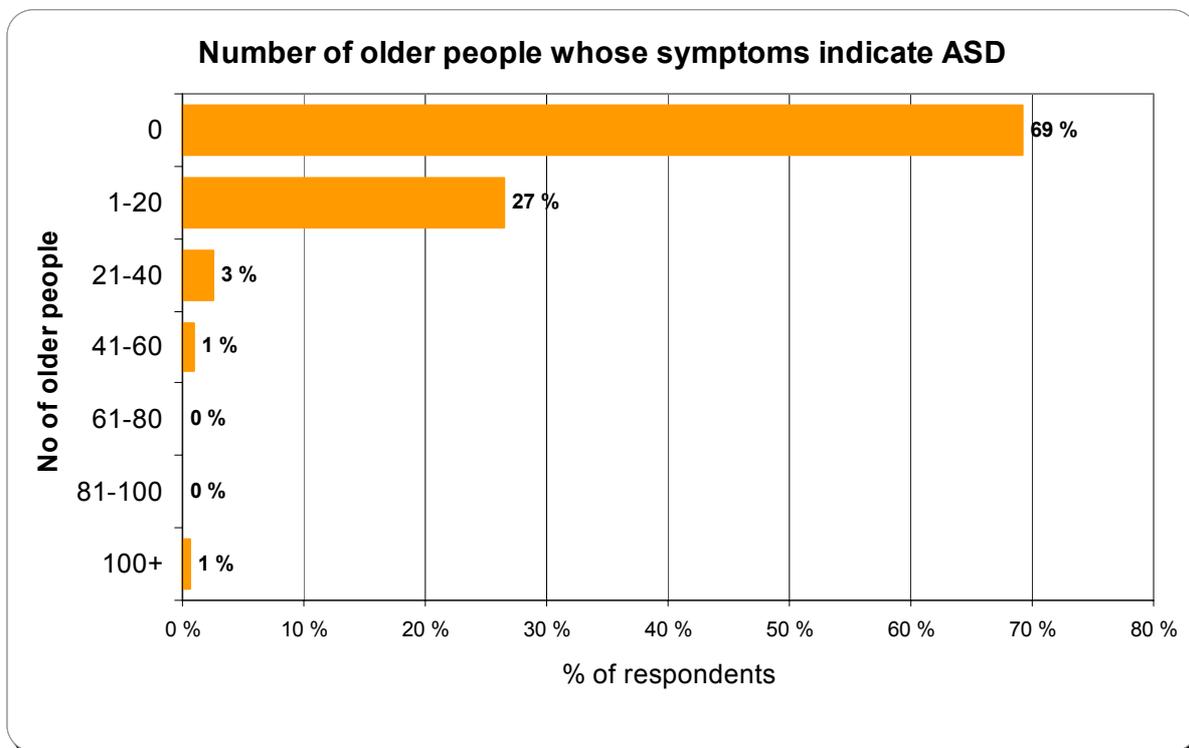
4.1.3 Older People (aged 65+)

Figure 12 : Number of older people seen as patients in a typical six month period



Most respondents (46%) see between 800 and 3000 older people as patients in a typical 6 month period. The average number of patients seen in this category is 934.

Figure 13 : Number of older people whose symptoms indicate they may have ASD but who do not yet have a diagnosis of ASD



Most respondents (69%) estimated that they did not have any patients in the category of not yet having a diagnosis of ASD but whose symptoms indicated that they may have ASD. On average number GPs estimate that they see five such patients in a typical six-month period.

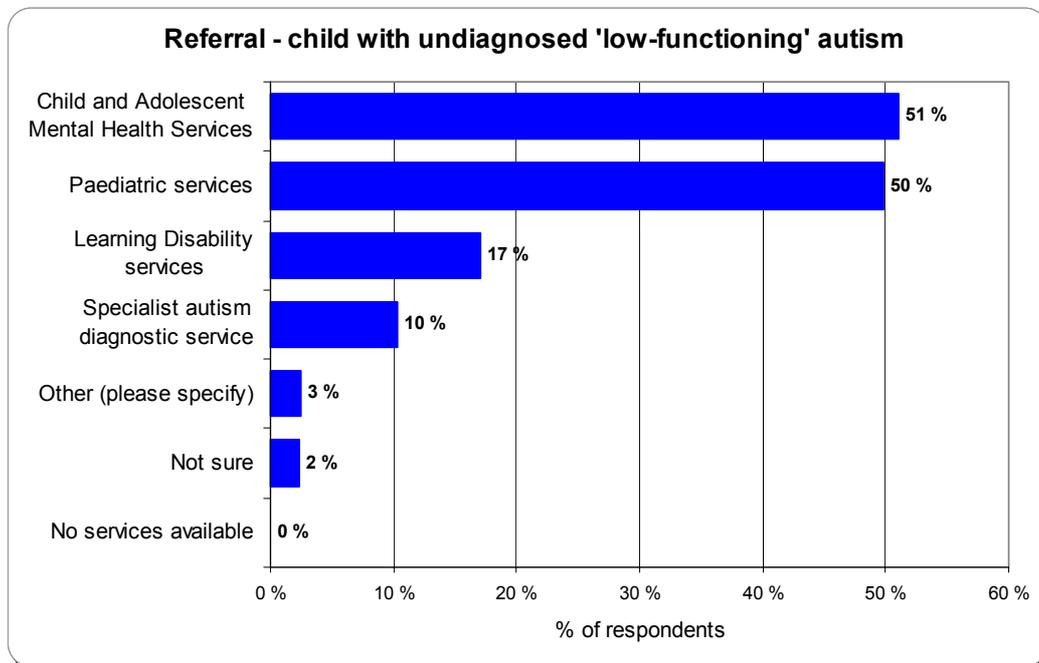
4.2 Referral

Respondents were asked to where they would refer those patients presenting with undiagnosed 'low-functioning' autism versus those presenting with undiagnosed 'high-functioning' autism or Asperger's Syndrome. These questions were asked for the three age-related categories of patients:

- Children – aged under 18 years
- Adults – aged 18 - 64 years
- Older people – aged 65 years or more

4.2.1 Referral of children

Figure 14 : Referral options for children with undiagnosed 'low-functioning' autism

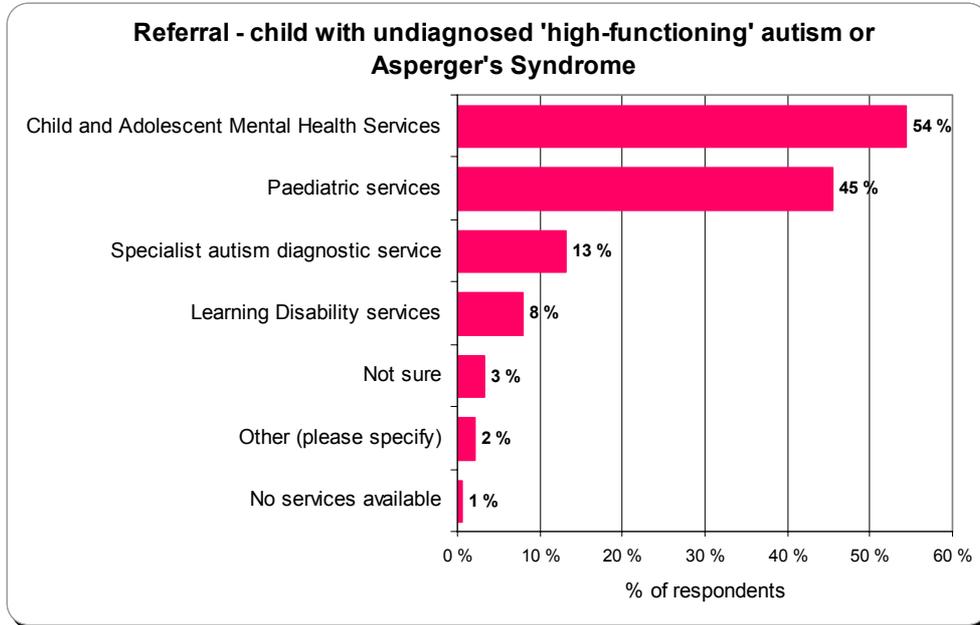


The majority of respondents (51%) would refer this type of patient to the Child and Adolescent Metal Health service. Paediatric Services were also chosen as a place to refer such patients by half (50%) of respondents.

Overall 10% of respondents would refer to a specialist autism service. This varies regionally, in the London SHA 17% of GPs said they would refer to this type of service whereas in the South West SHA this drops to 3% of GPs.

3% of respondents selected 'other' service. In the majority of cases respondents specified community paediatricians as their referral option.

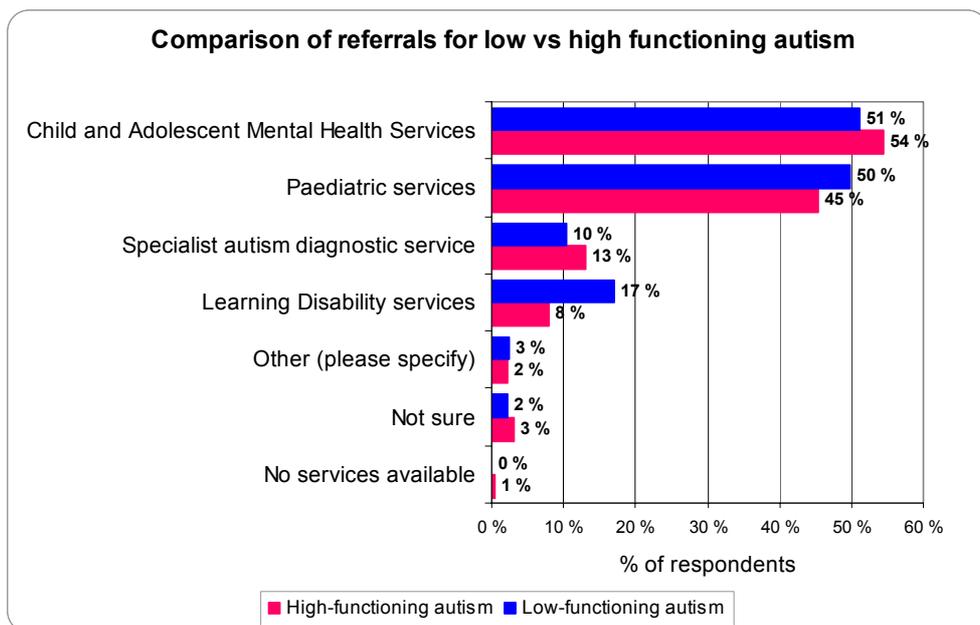
Figure 15 : Referral options for children with undiagnosed 'high-functioning' autism or Asperger's syndrome



In the case of undiagnosed 'high-functioning' autism or Asperger's syndrome respondents were more likely to refer to the Child and Adolescent Mental Health services (54%) and slightly less likely to refer to Paediatric Services (45%).

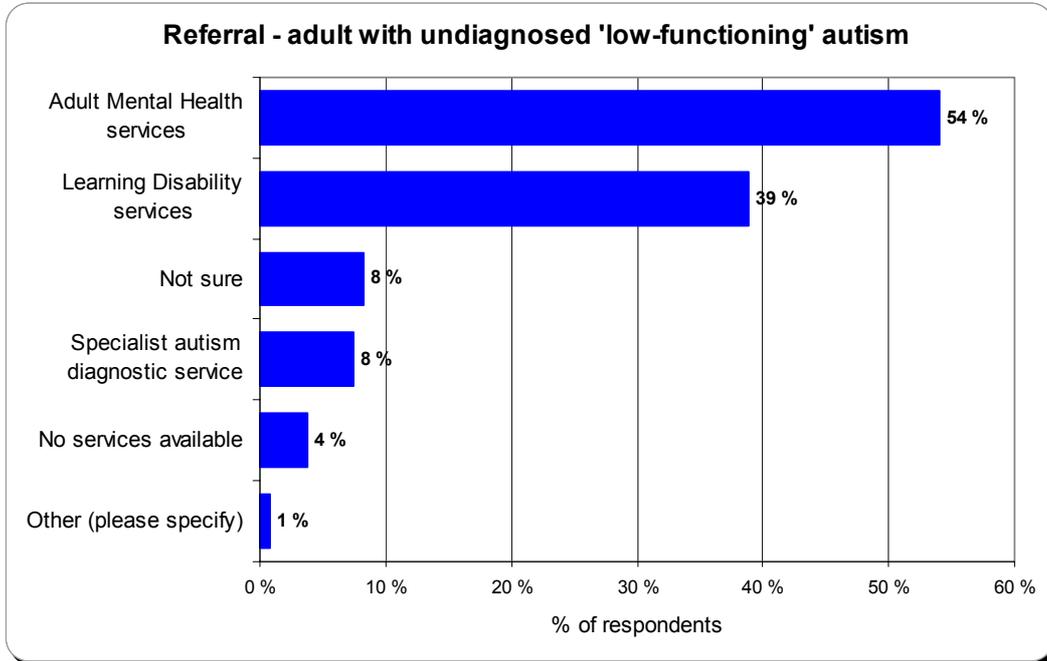
Again the choice of specialist autism diagnostic services was selected most often in the London SHA (20%) and least often in the South West SHA (6%).

Figure 16 : Comparison of referral choices in children with 'low-functioning' autism versus 'high-functioning' autism or Asperger's Syndrome



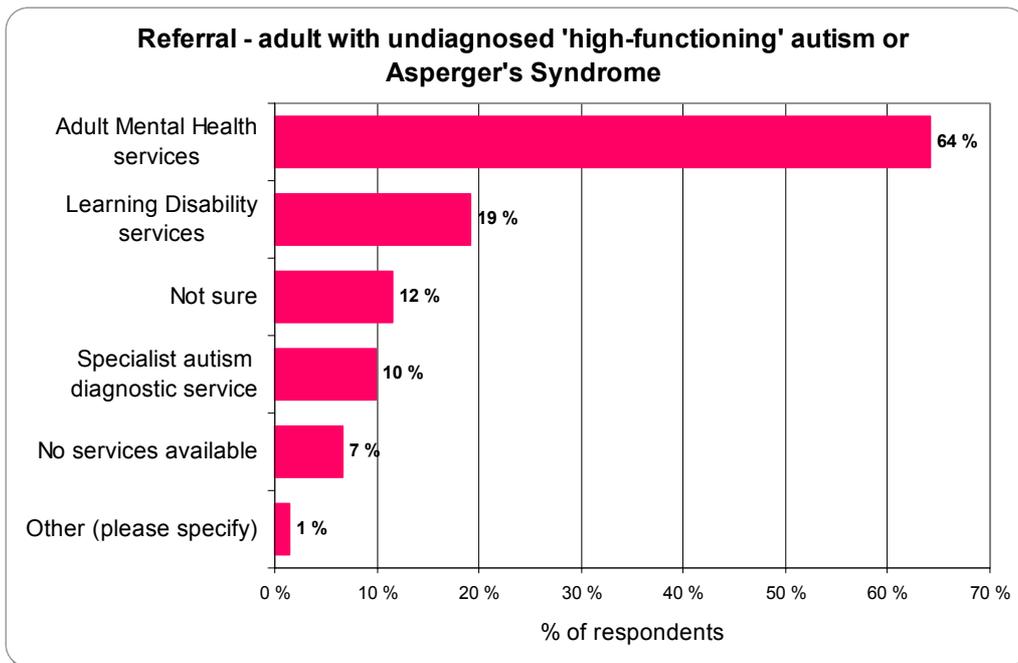
4.2.2 Referral of adults

Figure 17 : Referral options for adult patients with undiagnosed 'low-functioning' autism



Adult Mental Health Services was the option selected by most (54%) respondents as the route of referral for adult patients with undiagnosed 'low-functioning' autism.

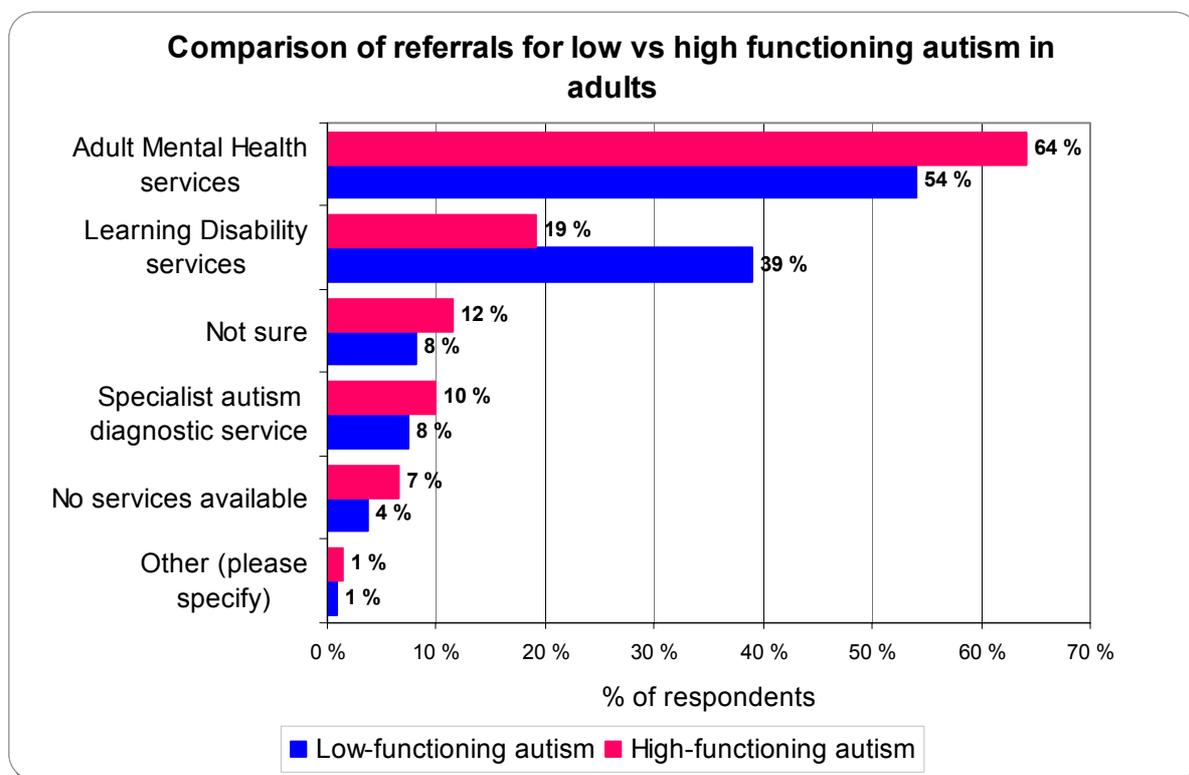
Figure 18 : Referral options for adult patients with undiagnosed 'high-functioning' autism or Asperger's syndrome



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Most respondents (64%) also said they would refer 'high-functioning' autism or Asperger's Syndrome patients to Adult Mental Health Services.

Figure 19 : Comparison of referral choices in adults with 'low-functioning' autism versus 'high-functioning' autism or Asperger's Syndrome



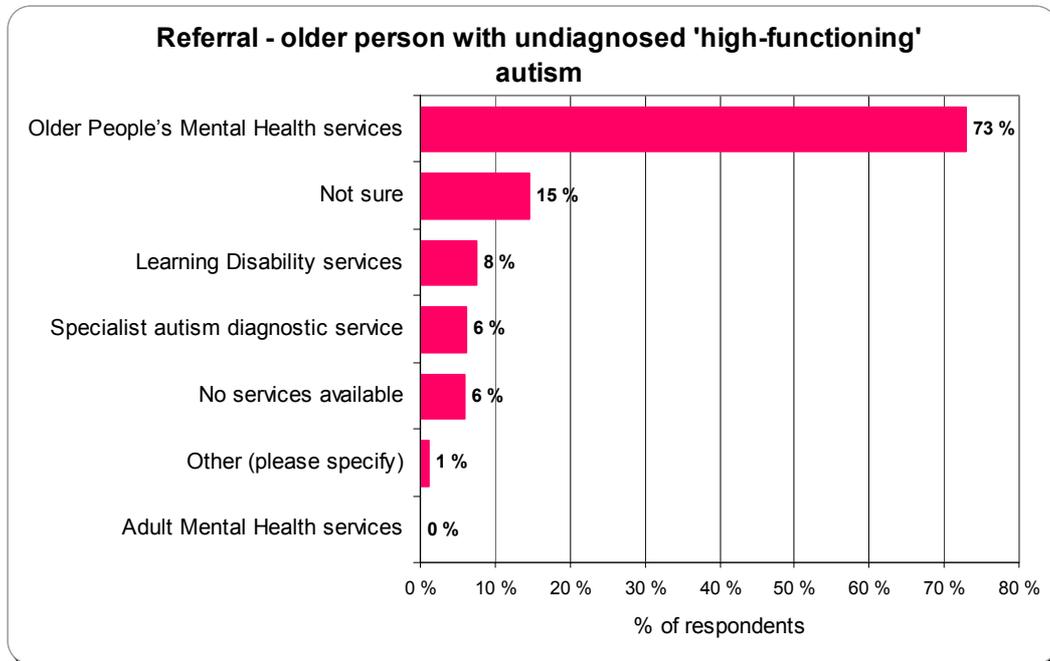
The level of uncertainty regarding where to refer adult patients is higher than when this question was asked for children.

Table 1 : Percentage of respondents who selected 'Not Sure' as their response to where to refer the following patient types

	Children	Adults
'Low-functioning' autism	2%	8%
'High-functioning' autism/Asperger's Syndrome	3%	12%

4.2.3 Referral of older people

Figure 20 : Referral options for older patients with undiagnosed 'high-functioning' autism or Asperger's syndrome



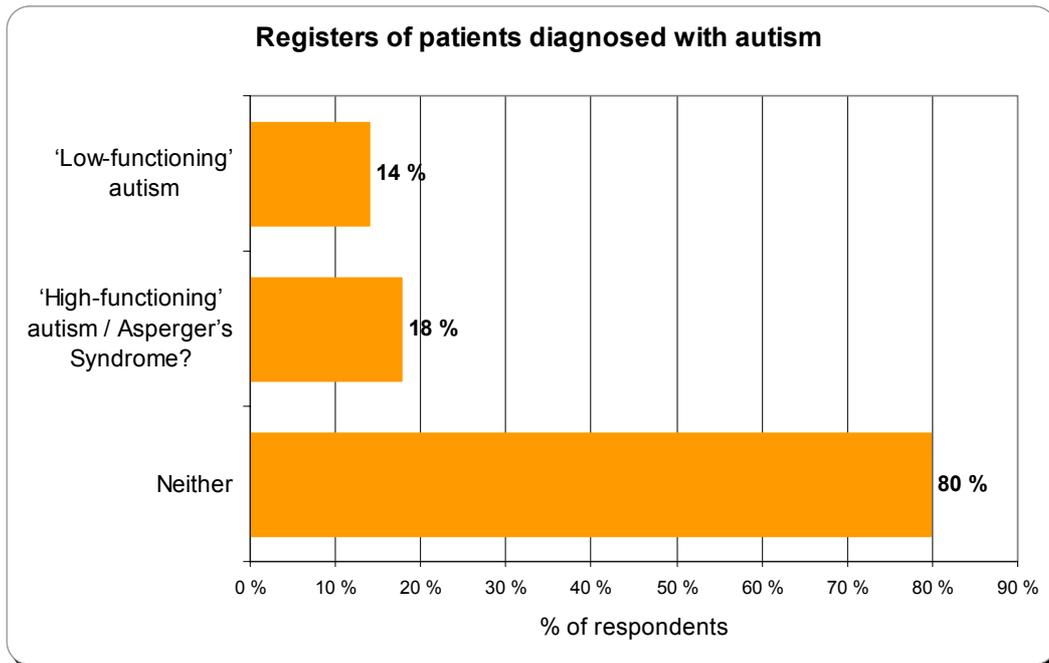
One in six GPs (15%) are not sure to where they would refer older patients with undiagnosed 'high-functioning' ASD, the region with the highest level of uncertainty in this area was the South West SHA where 20% of respondents selected 'not sure'. However the majority of respondents (73%) said that they would refer older people with undiagnosed 'high-functioning' autism or Asperger's Syndrome to Older People's Mental Health services.

4.3 Registers and caseload

Respondents were asked about registers they keep of patients diagnosed with autism and the proportion of their caseload that this group of patients represents.

4.3.1 Registers of patients diagnosed with autism

Figure 21 : Proportion of respondents who keep a register of patients diagnosed with autism

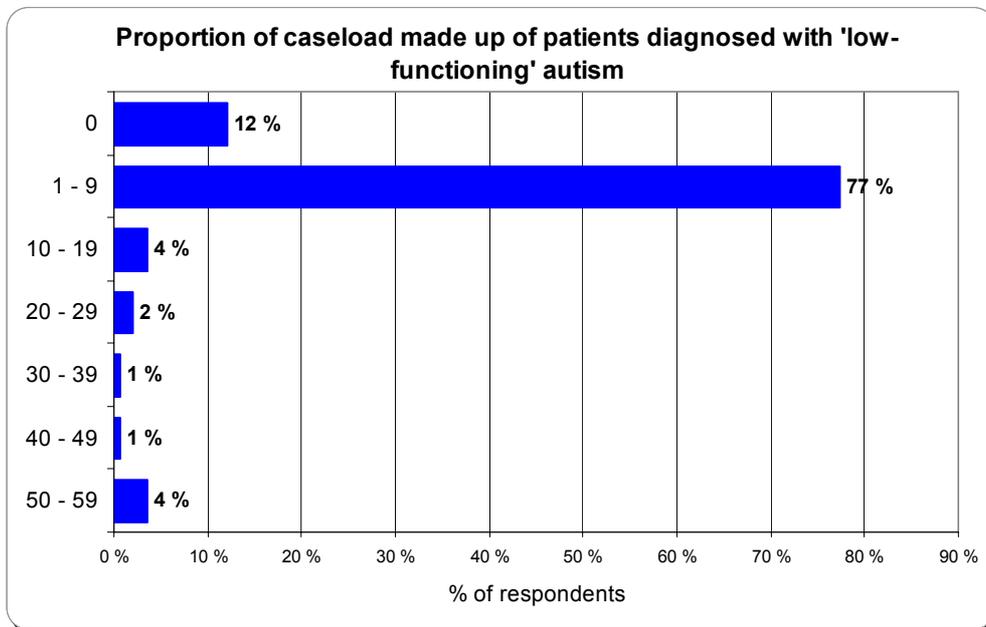


One in six GPs (18%) of respondents keep a register of patients diagnosed with 'high-functioning' autism/Asperger's Syndrome compared with one in seven (14%) who keep a register of patients diagnosed with 'low-functioning' autism.

Overall the majority of respondents (80%) do not keep a register of patients diagnosed with autism.

4.3.2 Proportion of caseload

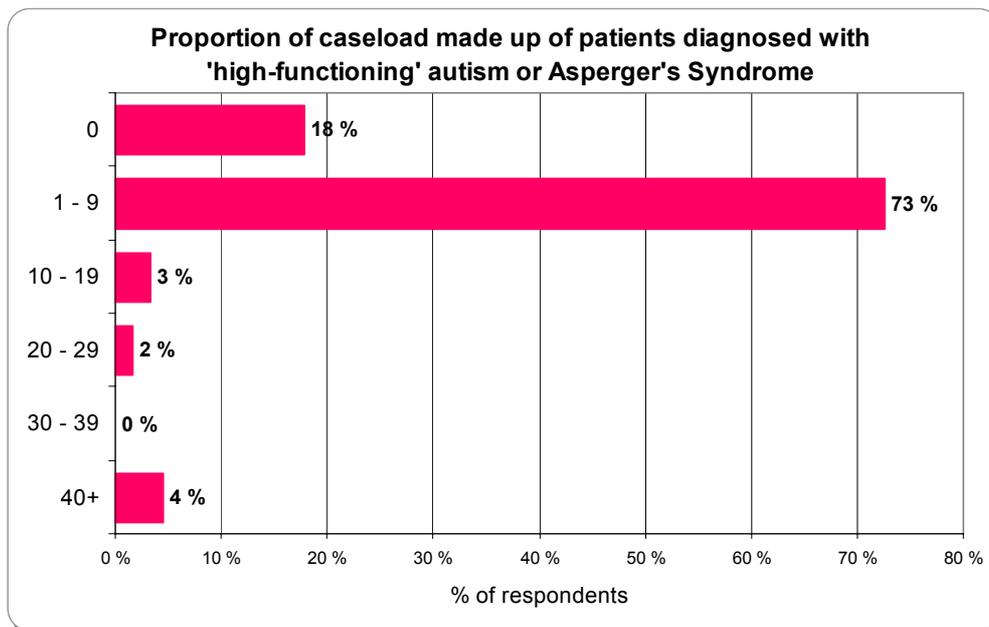
Figure 22 : Proportion of respondent’s caseload made up of patients diagnosed with ‘low-functioning’ autism



Base : Respondents who keep a register of patients diagnosed with 'low-functioning' autism. (n=141)

Of those GPs who keep a register of patients diagnosed with 'low-functioning' autism, most (77%) said that this took up between 1% and 9% of their caseload. Overall the average proportion of GP caseload was 4%.

Figure 23 : Proportion of respondent’s caseload made up of patients diagnosed with ‘high-functioning’ autism or Asperger’s Syndrome



Base : Respondents who keep a register of patients diagnosed with 'high-functioning' autism/Asperger’s Syndrome. (n=179)

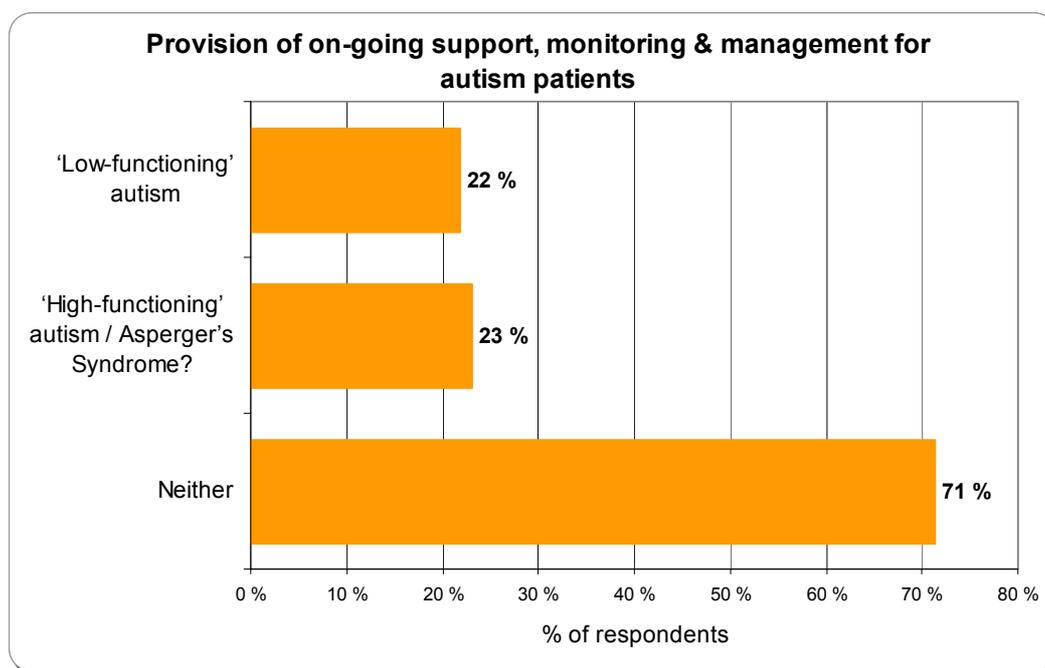
Again the proportion of respondents workload accounted for by patients diagnosed with 'high-functioning' autism or Asperger's Syndrome was generally in 1% to 9% bracket. The average proportion of GP caseload for this group was 5%.

4.4 Support and Care

GPs were asked about the support they provide to patients diagnosed with autism and about their level of confidence that patients receive appropriate and adequate care.

4.4.1 Support, monitoring and condition management

Figure 24 : Proportion of respondents who provide on-going support, monitoring or condition management for patients diagnosed with autism

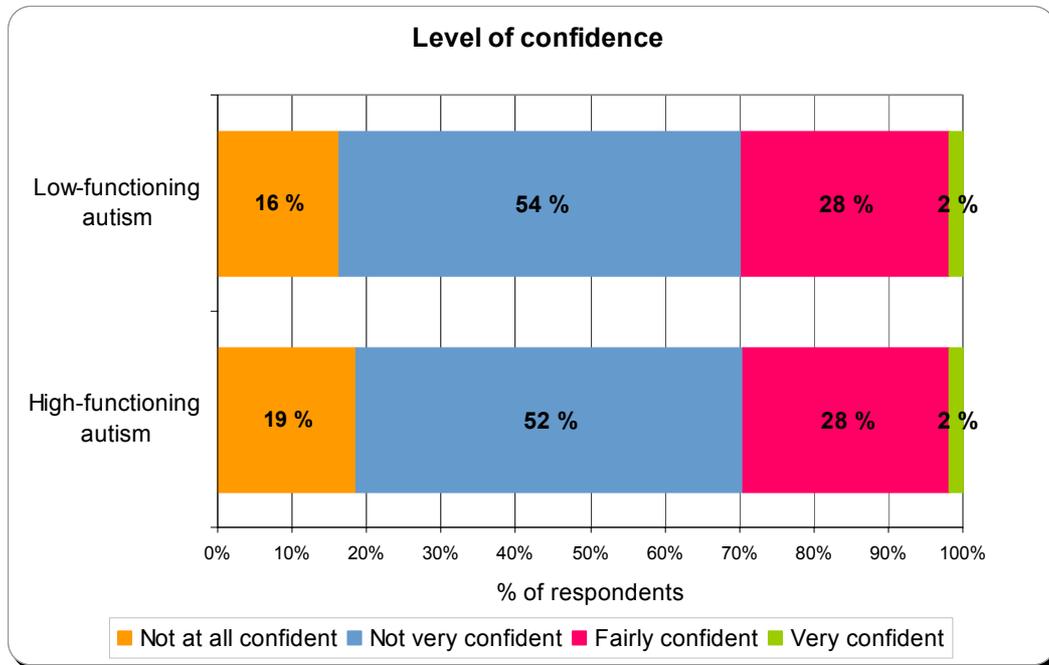


Just over a fifth of patients (22%) state that they do provide ongoing support, monitoring and condition management for patients diagnosed with 'low-functioning' autism. A similar proportion (23%) states that they provide such facilities for patients diagnosed with 'high-functioning' autism or Asperger's Syndrome.

Where GPs state they do provide ongoing support, monitoring and condition management for patients diagnosed with autism the most common method of support specified was through annual or general reviews of the patient.

4.4.2 Confidence that patients with autism are receiving appropriate and adequate care

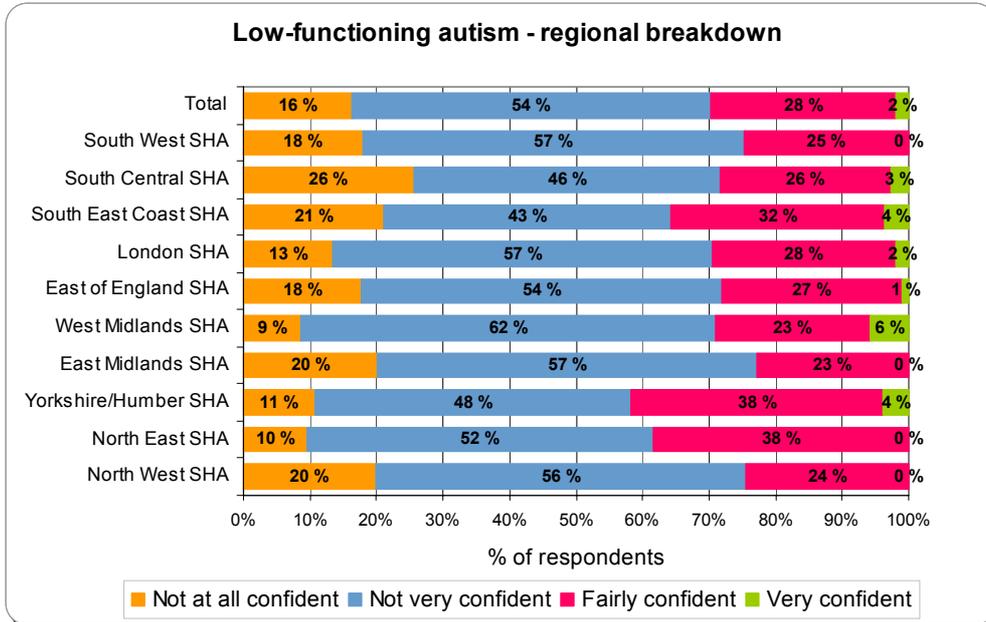
Figure 25 : Level of confidence respondents have that patients with an autism diagnosis are receiving appropriate and adequate care



The overall feeling for both 'low-functioning autism' and 'high-functioning' autism/Asperger's syndrome is that respondents are not very confident (54% and 52% respectively) that patients are receiving appropriate and adequate care for their needs.

A further cohort (16% and 19% respectively) said they were not at all confident that patients are receiving appropriate and adequate care for their needs. Overall 30% of GPs said they were confident or very confident that patients in both of these groups are receiving appropriate and adequate care for their needs.

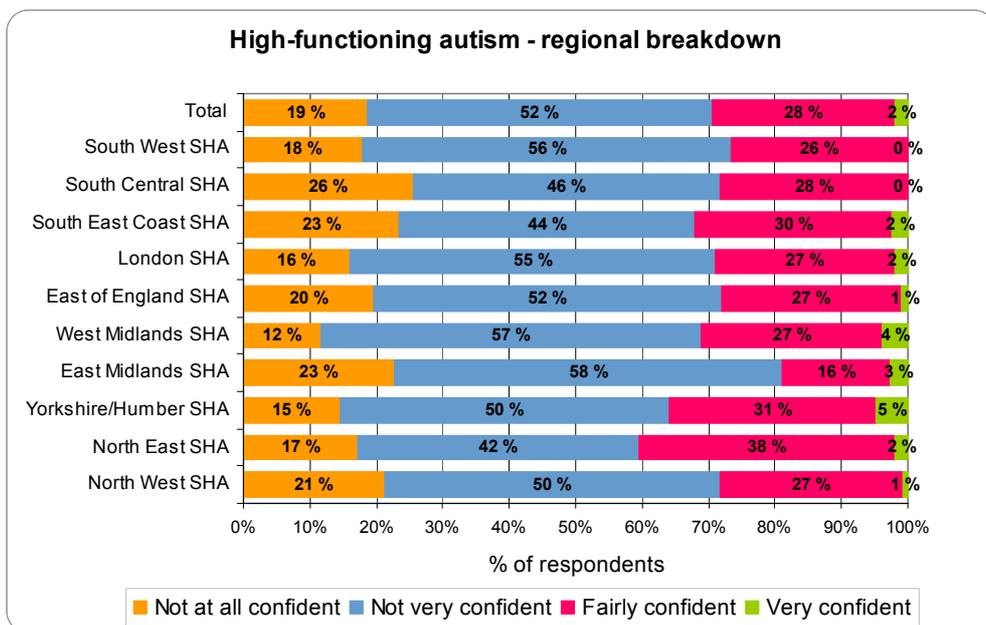
Figure 26 : Regional breakdown of confidence in the care of 'low-functioning' autism patients



In terms of 'low-functioning autism', more than a quarter of GPs practicing in the South Central SHA (26%) indicate that they are not at all confident that patients are receiving appropriate and adequate care for their needs.

The Yorkshire and Humber region GPs are the most confident that patients are receiving appropriate and adequate care for their needs with 38% saying they were fairly confident and a further 4% saying they were very confident.

Figure 27 : Regional breakdown of confidence in the care of 'high-functioning' autism patients



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In terms of 'high-functioning' autism/Asperger's Syndrome, the East Midlands SHA has the highest proportion of respondents saying that they are not very confident that patients are receiving appropriate and adequate care for their needs and a further 23% saying they are not at all confident that patients are receiving appropriate and adequate care for their needs.

4.5 Guidance

Finally respondents were asked whether they felt they required additional guidance and training to identify and manage patients with Autism Spectrum Disorder more effectively.

Figure 28 : Respondents feeling regarding the requirement for additional guidance and training to identify and manage patients with Autistic Spectrum Disorder



Four out of five GPs (80%) indicate that 'yes' they do feel they need additional guidance and training to identify and manage patients with Autism Spectrum Disorder more effectively.

A wide range of ideas regarding what guidance and training GPs require were suggested. Examples are

- Training courses – on-line, workshops etc
- Diagnostic tools and guidelines
- Information regarding what services are available locally
- Guidelines regarding appropriate referral to these services

5 Appendix

Introduction Doctors.net.uk invites you to participate in a survey commissioned by the National Audit Office regarding your referral of patients with autism. Please read the following text, which explains the intent of this research: • The identity of respondents is confidential: no details of respondents are passed to any third party • Results are aggregated to provide an overall picture of attitudes to the areas being discussed • Respondents have the right to withdraw from the interview at any time during the interview process and to withhold information as they see fit The National Audit Office (NAO) is independent of Government and reports to Parliament (the Committee of Public Accounts) on the use of public funds. Your participation in this survey will contribute to an NAO report on the economy and effectiveness with which the Department of Health, the NHS and Local Authorities are delivering services to patients in England. The survey will take about 5 minutes to complete and all members completing the survey will receive 1,000 eSR points. All results will be anonymised in accordance with Doctors.net.uk's zero-tolerance privacy policy and the Market Research Society Code of Practice.

Are you willing to proceed with this survey?

- Yes
- No

Demographic Questions

Are you

- A Hospital Doctor
- A GP
- Other

Are you

- GP Principal
- Salaried GP
- GP Registrar (level 3)
- GP Registrar (level 1 or 2) (close)
- GP locum (close)
- Other (close)

Where are you currently practicing?

- Wales (close)
- Scotland (close)
- Northern Ireland (close)
- North West SHA
- North East SHA
- Yorkshire/Humber SHA
- East Midlands SHA
- West Midlands SHA
- East of England SHA
- London SHA
- South East Coast SHA
- South/ Central SHA
- South West SHA



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- Not practicing in the UK (14) (close)
- Retired (15) (close)
- Don't know (16) (close)

Please select your PCT

Survey Questions

How many children aged under 18 would you estimate you see as patients in a typical 6-month period?

Of these children (aged under 18) that you see in a typical six-month period, approximately how many do not yet have a formal diagnosis of Autistic Spectrum Disorder (ASD), but whose symptoms indicate that they may have ASD?

Please write in the number

Of these how many have symptoms indicating a diagnosis of 'high-functioning' autism or Asperger's syndrome?

Please write in the number

How many adults (aged 18-64) would you estimate you see as patients in a typical 6-month period?

Of these adults (aged 18-64) that you see in a typical six-month period, approximately how many do not yet have a formal diagnosis of Autistic Spectrum Disorder (ASD), but whose symptoms indicate that they may have ASD?

Please write in the number

Of these, how many have symptoms indicating a diagnosis of 'high-functioning' autism or Asperger's syndrome?

Please write in the number

How many older people (aged 65 and over) would you estimate you see as patients in a typical 6-month period?

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Of these older people (aged 65 and over) that you see in a typical six-month period, approximately how many do not yet have a formal diagnosis of Autistic Spectrum Disorder (ASD), but whose symptoms indicate that they may have ASD?

Please write in the number

--

If you suspected that a child (aged under 18) presenting to you had undiagnosed 'low-functioning' autism (i.e. I.Q. <70), where would you refer them to?

Please tick all that apply

- Specialist autism diagnostic service (1)
- Paediatric services (2)
- Child and Adolescent Mental Health Services (3)
- Adult Mental Health services (4)
- Older People's Mental Health services (5)
- Learning Disability services (6)
- Other (please specify) (7) _____
- Not sure (8)
- No services available (9)

If you suspected that a child (aged under 18) presenting to you had undiagnosed 'high-functioning' autism or Asperger's Syndrome, where would you refer them to?

Please tick all that apply

- Specialist autism diagnostic service (1)
- Paediatric services (2)
- Child and Adolescent Mental Health Services (3)
- Adult Mental Health services (4)
- Older People's Mental Health services (5)
- Learning Disability services (6)
- Other (please specify) (7) _____
- Not sure (8)
- No services available (9)

If you suspected that an adult (aged 18-65) presenting to you had undiagnosed 'low-functioning' autism (i.e. I.Q. <70), where would you refer them to?

Please tick all that apply

- Specialist autism diagnostic service (1)
- Paediatric services (2)
- Child and Adolescent Mental Health Services (3)
- Adult Mental Health services (4)
- Older People's Mental Health services (5)
- Learning Disability services (6)
- Other (please specify) (7) _____

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- Not sure (8)
- No services available (9)

If you suspected that an adult (aged 18-65) presenting to you had undiagnosed 'high-functioning' autism or Asperger's Syndrome, where would you refer them to?

Please tick all that apply

- Specialist autism diagnostic service (1)
- Paediatric services (2)
- Child and Adolescent Mental Health Services (3)
- Adult Mental Health services (4)
- Older People's Mental Health services (5)
- Learning Disability services (6)
- Other (please specify) (7) _____
- Not sure (8)
- No services available (9)

If you suspected that an older person (aged 65 and over) presenting to you had undiagnosed 'high-functioning' autism or Asperger's Syndrome, where would you refer them to?

Please tick all that apply

- Specialist autism diagnostic service (1)
- Paediatric services (2)
- Child and Adolescent Mental Health Services (3)
- Adult Mental Health services (4)
- Older People's Mental Health services (5)
- Learning Disability services (6)
- Other (please specify) (7) _____
- Not sure (8)
- No services available (9)

Do you keep a register of your patients diagnosed with

- 'Low-functioning' autism (1)
- 'High-functioning' autism / Asperger's Syndrome? (2)
- Neither (3)

What proportion of your overall caseload is made up of patients diagnosed with 'Low-functioning' autism?

Please write in the percentage

What proportion of your overall caseload is made up of patients diagnosed with 'High-functioning' autism / Asperger's Syndrome?

Please write in the percentage

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Do you provide any ongoing support, monitoring or condition management for patients diagnosed with:

- 'Low-functioning' autism (1)
- 'High-functioning' autism / Asperger's Syndrome? (2)
- Neither (3)

Please explain what ongoing support, monitoring or condition management for patients diagnosed with 'Low-functioning' autism?

Please explain fully

Please explain what ongoing support, monitoring or condition management for patients diagnosed with 'High-functioning' autism / Asperger's Syndrome?

Please explain fully

On a scale of 1-4, where 1 is 'not at all confident' and 4 is 'very confident', how confident are you that people in your locality with 'low-functioning' autism are receiving appropriate and adequate care for their needs?

- 1 = Not at all confident (1)
- 2 = Not very confident (2)
- 3 = Fairly confident (3)
- 4 = Very confident (4)

Please explain your response:

On a scale of 1-4, where 1 is 'not at all confident' and 4 is 'very confident', how confident are you that people in your locality with 'high-functioning' autism or Asperger's syndrome are receiving appropriate and adequate care for their needs?

- 1 = Not at all confident (1)
- 2 = Not very confident (2)
- 3 = Fairly confident (3)

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4 = Very confident (4)

Please explain your response:

Do you feel you require additional guidance and training to identify and manage patients with Autism Spectrum Disorder more effectively?

- Yes (1)
- No (2)

Please explain what additional guidance and training you require to help you identify and manage patients with Autism Spectrum Disorder more effectively?

Please explain fully

Demographic Questions

Please select your gender:

- Male (1)
- Female (2)

How many patients are registered with your practice?

How many GPs work in your practice?

Are you

- A GPwSI in Mental Health
- A GPwSI in Child and Adolescent Mental Health (CAMH)
- Neither of these