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ScHARR:

• brings together a wide range of health related skills including inter alia: health economics, operational research, management sciences, epidemiology, medical statistics, and information science. There are also clinical skills in general practice and primary care, rehabilitation and public health.
• provides a flexible undergraduate degree in Health and Human Sciences offering a comprehensive starting-point for working in health and allied areas in the 21st century.
• conducts applied and methodological health services research, consultancy and teaching programmes for health services staff. It has a diversity of skills and experience and close contacts with the Department of Health and NHS health authorities and trusts make it a natural partner of the NHS.
• houses the Sheffield Unit of the Trent Institute for Health Services Research which is linked to units at the Universities of Leicester and Nottingham.
• supports statutory health bodies overseas and has partnership arrangements with the far east, and, through its European Office, with other leading universities and institutions in Europe.

Professor Ron Akehurst, Dean of the School of Health & Related Research
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EXECUTIVE SUMMARY:

- Only 46% of respondents had received a diagnosis of Asperger syndrome.
- The average age of respondents in this study was thirty years of age. 93% of respondents indicated that their ethnicity was ‘white British’.
- 46% of respondents said that they felt they were poor at talking to other people. 64% said that they were weak at reading, and 71% at responding, to other people’s feelings.
- 53% indicated difficulties with concentration, and 88% with unexpected changes to routines.
- Two thirds of respondents lived at home with their parents. Over 60% indicated that living independently was still a problem for them. 66% said that they would be able to live more independently if they had more help.
- Half of respondents said that they needed more help with their day to day activities. 15% were doing nothing during the day.
- Three quarters of respondents found it difficult to meet people, and over half said they would like to have more friends.
- 81% said that they had been told that they were spending too much time on an interest.
- 90% of respondents indicated that they had been bullied at some point during their lives. Bullying was still a problem for 30% of respondents. 13% of the sample said sexual or financial exploitation was still a problem for them.
- 83% of respondents said that they became angry or violent easily.
- 50% of respondents said that they had felt suicidal at some point.
- Just under two thirds of people indicated that they had psychiatric difficulties, of which anxiety, depression and suicidal thoughts were the most common.
- Three quarters of respondents ended education between the ages of 15 and 19.
- Only 10% had a transition plan.
- Three quarters of respondents felt that if they had problems with money they would not be able to receive help from an agency.
- 61% of respondents said that they had never received a statement of special educational need.
AIMS AND OBJECTIVES

More and more people with autistic spectrum disorders (including Asperger syndrome and High Functioning Autism) are now being identified, with health and social care professionals increasingly having to work with a whole range of clients/patients who have these conditions and who present with a range of different abilities and difficulties. There is a demand that these people should have their needs met through effective targeting of resources and through intervention, where it is required and is called for. However, in many respects such processes and strategies are complicated by the fact that the needs, wants and desires of people with Asperger syndrome and High Functioning Autism (also referred to as AS and HFA, respectively) remain largely unknown, outside of a recognition on the parts of policy makers and researchers that they are complex and protean. This is despite HFA and AS possibly being the most prevalent forms of autistic spectrum disorders (Holland et al 2000).

Understanding the needs of people with Asperger syndrome/High Functioning Autism is therefore a crucial first step in constructing cost effective and useful services for them. This study seeks, by examining the needs of people aged 13 and above living with AS/HFA living in Sheffield, to help build an empirical foundation upon which services can be constructed and the requirements of people living with AS addressed. To do this, the study brings together what has been learnt about the needs of people with Asperger syndrome in general by reviewing the current literature.

The reason for choosing age 13 as a cut-off point for this study is that adolescents 13 and above may have developed the autonomy of knowing what their needs are, which younger children may have not. For example, young people aged 13 can go to their GPs to ask for contraceptive pills in order to prevent unwanted pregnancy.

More generally, the issue of autonomy and self-awareness is important for the entire sample. A person has to be aware of themselves as a person to know what they need, which many people with autism are not able to do. For example, people with autism may not recognize that they are injured. However, there are two points to note here. Firstly, people with AS/HFA are precisely those people with ASD who are self-aware. Secondly, the carer perspective was considered throughout this study (for example if individuals with AS/HFA didn’t want to, or couldn’t, fill in their assessment for whatever reason, then their carer did).
on the needs of people with AS, and complimenting this through an investigation of the health and social care needs of adolescents and adults with AS/HFA in Sheffield in particular.

METHODS
Previous studies of AS prevalence have derived their estimates from child samples. By utilizing children researchers can reduce the costs (in time and money) associated with population sampling. Disadvantages of focusing on children with diagnoses, however, include the risk of overlooking individuals who do not have a diagnosis of Asperger syndrome, and who probably comprise the majority of people with the condition.

In this study we sought to address these weaknesses by examining the needs of adults and adolescents with and without a diagnosis of Asperger syndrome. To recruit adolescents we wrote to all headmasters in Sheffield asking them to draw the study to the attention of school educational needs coordinators, and the pupils for whom they were responsible. Because of ethical considerations we could not use school records or obtain information from the local education authority. We sent letters to every general practice in Sheffield, to all neurologists, paediatricians and community paediatricians, and psychiatrists, inviting them to bring the study to the attention of any of their patients who had, or whom they suspected of having, Asperger syndrome or High-Functioning Autism.

Similar methods have been used in previous studies. These methods, however, are not necessarily suitable for the recruitment of adults and school leavers as adults and older adolescents are not ‘captive populations’ in the same way children are. While school children with Asperger syndrome are regularly identified by diagnostic services, adults and school leavers may have little to no personal contact with any institution let alone one offering diagnostic services, and so attempting to recruit adults through institutions alone may not be the most productive strategy. In order to recruit adults and older adolescents (both with and without clinical diagnoses of Asperger syndrome) we employed a number of additional methods in addition to those that are traditionally employed in the recruitment of people with AS. We designed posters to invite people to contact us if they thought that they, or someone they knew, had the features described (for example, difficulty making friends), or if they had a clinical diagnosis of Asperger syndrome. We placed these posters in supermarkets, shops, cinemas, post offices, libraries, pubs, workplaces, student noticeboards, employment assistance agencies and GP practices throughout the city. We wrote articles for the local Sheffield Star and
Sheffield Telegraph (the local newspapers with the highest circulation in Sheffield), and gave an interview on Radio Sheffield about the study; this interview was subsequently hosted on the main BBC news web-site. We recruited respondents through the Sheffield Asperger’s Parents Action Group (SAPAG). We placed information about the project to the Sheffield ‘Prospects’ office (the employment agency for people with autism in Sheffield) and sent information about the study to social workers, care workers and disability workers throughout Sheffield.

215 respondents came forward. We immediately excluded 64 of these either because they lived outside of Sheffield or because they had a diagnosis of autism and an IQ below 70. We sent the remaining 151, 62 of whom had a clinical diagnosis of AS, copies of the Autism Quotient (AQ), an autism screening instrument developed by Baron-Cohen et al designed to locate an individual’s places on the autistic spectrum. The AQ is a 50 item questionnaire. Baron-Cohen et al suggest that 26 is a valid cut-off point for distinguishing likely autistic behaviour from non-autistic.

120 copies of the AQ were returned.

We asked respondents to allow a trained researcher to complete an Autism Diagnostic Interview-Revised (ADI-R) with their parents. The ADI-R is the principle tool used by clinicians and researchers when checking for the presence of autism. It is a standardised, validated and reliable developmental history interview. The researcher received training in administration and assessment from the ADI-R training unit at the University of Cambridge. His ADI-R codings were assessed a member of the training team at the University of Cambridge and he achieved 90% inter-rater reliability. The ADI-R interviewer was blind to respondents’ AQ scores. The ADI-R is normally combined with an observational scale such as the ADOS in research on children, but no observational scale has been validated in adults and so this was omitted. 22 respondents allowed us to do ADI-R interviews with their parents.

One respondent was excluded based on IQ (<70) and two where the ADI-R indicated a negative result and there was no clinical diagnosis. After all screening phases were completed, we included all respondents who scored 26 or above on the AQ and/or who had a diagnosis of Asperger syndrome and/or who passed the ADI-R and who had an IQ >70. We excluded respondents who indicated that they had a diagnosis of autistic disorder and who did not agree to do an IQ assessment, and respondents who did not pass the threshold score on the ADI-R and who did not have a clinical diagnosis. Based on these inclusion criteria 109 respondents were included as having Asperger syndrome. 25 respondents were women, 83 men. No respondent older than 65 came
forward. 61 had been previously diagnosed as having Asperger syndrome, 53 of them men and 8 of them women. The male to female ratio in the previously diagnosed group was 6.6:1 and in the not previously diagnosed group was 1.8:1.

Data were analysed using STATA. The North Sheffield Local Research Ethics Committee granted the project ethical approval and all respondents gave written informed consent.
Respondent’s geographical profile Figures 1 and 2 show the geographical breakdown, by postal district, of our respondents’ geographical locations in Sheffield. It can be seen that the highest concentration of respondents, both for individuals with and without a diagnosis, is in S8.
Figure 1. Distribution of individuals in Sheffield with a diagnosis of Asperger syndrome, mapped by postal district.
Figure 2. Distribution of individuals in Sheffield without a diagnosis of Asperger syndrome, but who were included in the needs survey, mapped by postal district. It can be seen that the average concentration per postal district is 1-3.
Structure

• The seven sections that follow contain the findings of this needs study in relation to the domains of development, health, education, social situation and services. The prevalence of AS in our sample is also discussed. Section seven is a discussion of the study’s findings.

• The appendixes contain overviews of Asperger syndrome and the philosophy/methodology that was used in this study. They also contain a review of the previous research that has been completed on the needs of people who have AS/HFA.
CHAPTER 1: DEVELOPMENT AND SKILLS

This chapter contains an overview of findings made in relation to respondents’ skills and developmental abilities.

1.1. Population summary data

93% of the respondents indicated that they were ‘White British’, 5% that they were ‘Black Caribbean’ and 1% that they were white other. 76% of respondents were men, and just under one quarter women. Broken down by diagnosis, 37% of respondents without a diagnosis were women, compared to 10% of respondents with one. The modal age was 30-34 (see Figures 3, Table 1). The average age was 30.

The sample is composed of data from 78 individuals. Not all participants answered every question. The number of people who did answer a particular question are highlighted in footnotes. The percentage figure contained within the text is therefore a percentage of the figure located in the footnote. So for example if the text indicates that 50% of respondents like going to the cinema, and refers to a foot note saying “n=20”, then 20 people answered the relevant question, of whom 10, or 50% said they liked to go to the cinema. n=65 n=62 n=61
Figure 3. Age of respondents.

Table 1. Breakdown of respondents by age

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number</th>
<th>Percent of overall sample</th>
<th>Percent of people who indicated their age</th>
<th>Cumulative Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Valid</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13-14</td>
<td>7</td>
<td>9.0</td>
<td>11.5</td>
<td>13.1</td>
</tr>
<tr>
<td>15-19</td>
<td>11</td>
<td>14.1</td>
<td>18.0</td>
<td>31.1</td>
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<tr>
<td>20-24</td>
<td>6</td>
<td>7.7</td>
<td>9.8</td>
<td>41.0</td>
</tr>
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<td>25-29</td>
<td>3</td>
<td>3.8</td>
<td>4.9</td>
<td>45.9</td>
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<td>30-34</td>
<td>14</td>
<td>17.9</td>
<td>23.0</td>
<td>68.9</td>
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<td>35-39</td>
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<td>10.3</td>
<td>13.1</td>
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<td>3.3</td>
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<tr>
<td>45+</td>
<td>9</td>
<td>11.5</td>
<td>14.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Total</td>
<td>61</td>
<td>78.2</td>
<td>100.0</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>9</td>
<td></td>
<td>21.8</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>77</td>
<td>100.0</td>
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1.2. Diagnosis

75% of respondents said that they had problems with their psychological development.  

51% of respondents indicated that they had Asperger syndrome. 46% had received a medical diagnosis of Asperger syndrome (that is, 92% of the respondents who indicated that they had AS). All of the people who said that they had autism indicated that their condition had been diagnostically confirmed. 11% of respondents said that they had another condition on the Autistic Spectrum. 6% said that they had Semantic Pragmatic Disorder, 10% AD/HD and 25% some other condition such as depression, dyspraxia or general learning disability. 33% of respondents with a clinical diagnosis of Asperger syndrome had one or more of these other conditions as well. Overall, the developmental condition of 71% of respondents had been confirmed by a professional, with 60% of respondents indicating that their condition had been well understood by the person making the diagnosis.

\[n=76\]

\[n=78\]

\[n=69\]

\[n=36\]
1.2.1. Age of diagnosis

When asked when their condition was first diagnosed, 60% of the total number of people with Asperger syndrome in our sample (all of those people included in the Needs Survey) were diagnosed before the age of 20 (see Figure 4). The peak age of diagnosis was between 11 and 14, where 23% of people were diagnosed. The diagnostic rate then declined until the early 30s where 21% of individuals were diagnosed. After this the rate then again declined. Most of the individuals above 45 were undiagnosed. The implications for late diagnosis are discussed on page 70.

![Figure 4. Age of diagnosis-Asperger syndrome.](image-url)
1.3. Language and communication

1.3.1. Understanding others

36% of respondents said that they had difficulties understanding other, though 64% felt their understanding was good. 61% of people indicated that that understanding had sometimes been a problem at some point in their lives.

53% of respondents asked for professional support in relation to their understanding difficulties. Of these 84% indicated that they were happy with the support they received. However this support was resource intensive. 45% of the people who sought help for understanding difficulties were assisted by two or more professionals.

There was a strong current of anxiety present in the accounts of respondents who said that they had difficulties talking to other people:

Sometimes I don't understand what other people mean or intend to do. I don't always say the right thing at the right time. I get anxious and loud.

I don't always hear what people say, my ears stop listening or there's a lot of noise or I don't really understand what they're talking about. I just smile at them and hope they don't notice.

Sometimes get words mixed up when I am anxious. Sometimes lose my train of thought when I am anxious. Sometimes slow to understand what people say to me, especially when unexpected question e.g. at job interviews, slow to respond.

Because I have lived independently for so long I've learned how to look like I manage and how to look like I understand what people are saying. I have a good memory so I remember what to say next time someone says something.

n=78
n=59
n=60
n=34
Faced with something new that I haven't foreseen I go blank because I don't know how you're supposed to respond.

1.3.2. Ability at talking to other people
A more even pattern emerged in relation to how capable respondents felt they were with talking to other people, with 53% saying they were good or very good at this, and 46% saying they were poor or very poor at this task. 81% indicated that they had experienced, at some point in their lives, difficulties talking to other people, and only 3.2% said they were fine now at this task. The majority, 60%, said talking to people was at least sometimes a problem. 43% of people had asked for help at some point in their life in relation to this problem. 54%, were not currently receiving professional support for talking to other people.

Some of the difficulties respondents themselves noted were:

I mumble when I speak and I often have to repeat myself several times to be understood.

I have a good vocabulary, but I very often have problems using words and sometimes I repeat myself or stammer.

When I go into conversation I carry on speaking without letting the other person speak. When I do want to talk, I must say everything then even if it is not an appropriate time.

\[n=78\]
\[n=36\]
\[n=27\]
\[n=55\]
1.3.3. Reading

73% of people indicated that they were good or very good at reading and understanding textual material. At the same time, reading sometimes or regularly posed a challenge for 50% of people. 52% of respondents had asked for support in relation to their reading difficulties, of which just under three quarters were happy with the support they received. Over half of individuals were receiving some form of support for their reading difficulties at the time of the survey. Reading non-factual material seemed to pose difficulties for several respondents.

When I read fiction it is a case of either not working out what is going on or a case of "a route map", e.g. he goes to B goes to C etc, it is better if it is a mathematical puzzle rather than getting to know the characters etc.

Fluency is a problem for e.g. in reading out loud. Big effort in reading means I avoid fiction. I prefer factual books or magazines where it is divided into short portions.

1.3.4. Handwriting

Finally, handwriting was a problem for about half of the respondents. 55 people indicated that handwriting had been difficult for them at some point during their lives, with 67% of these indicating that handwriting was sometimes or still a problem. 16 people had asked for help in relation to their handwriting, of which 11 expressed satisfaction with the help they received. The majority, 78%, were not currently receiving support for handwriting difficulties.

"n=78"
n=60
n=40
n=48
n=36
1.4. Motor skills

1.4.1. Balance

65% of people indicated that their balance was either good or very good. Of the people who said that their balance had ever been a problem, 72% specified that they still sometimes or regularly had a problem with balancing. 13 people had asked for support in relation to balancing difficulties, of whom 8 were satisfied with the support they received.

1.4.2. Catching

53% of people indicated that their catching ability was good or very good, with 47% saying that this ability was either poor or very poor. 48 people indicated that catching had been a problem at some point in their lives, 67% of whom indicated that catching was either still or sometimes a problem. The majority of people, though, 81%, had not asked for support in relation to any difficulties they may have had with catching.

1.4.3. Jigsaws and maps

62% of respondents indicated they were competent or highly competent with manipulating maps and jigsaws, though 32% indicated that they had some problems with this. Of the people who indicated that doing jigsaws had ever been a problem, 75% indicated that this was sometimes or still a problem. Only 8 people had asked for support in relation to this ability, of whom 4 were satisfied with the support.

1.4.4. Motor skill correlations

Motor skill deficits were interlinked. For example, 67% of people respondents who felt they were very good with jigsaws and maps also felt that they were good or very good at balancing. In contrast, 80% of respondents who felt they were very poor at jigsaws and maps also felt that they were poor or not very good with balance (p<.001). A similar relationship was noted between catching and balance (p<.009).
1.5. Feelings

1.5.1. Reading other people’s feelings

34% of people said that they were good or very good at reading other people’s feelings. In contrast 64% of respondents felt that they were not very good or poor at this ability. 78% of respondents indicated that difficulties reading other people’s feelings had been a problem for them at some point in their lives, with 91% of these people indicating that it was sometimes or still a problem. 24% of the respondents who indicated that they had difficulties reading other people’s feelings asked for support for these problems, though 60% said no one was currently helping them.

1.5.2. Responding to other people’s feelings

71% of respondents said that they were not very good or were poor at responding to other people’s feelings without them having to ask for a response. 90% said that this was sometimes or still a problem (see Figure 5). Difficulties here were correlated with reading feelings. For example, 78% of respondents who said they had difficulty reading other people’s feelings also said they had trouble responding to them (p<.001). 37% of people had asked for support in relation to understanding people’s feelings. 84% of respondents indicated high or good levels of satisfaction with the support they received on this matter.
Figure 5. Has responding to other people's feelings ever been a problem?

1.5.3. Showing feelings

61% of respondents indicated that they had problems showing their feelings to other people. 67% had never asked for support in relation to these difficulties.
1.6. Planning and time management

59% of people indicated that they were not very good or poor with executive functioning skill such as planning or time management. Of the people who indicated that executive functioning skills had ever been a problem, 83% indicated that this was still regularly or sometimes a problem (see Figure 6). 36% had asked for support in relation to this, of whom 68% indicated good or high levels of satisfaction. Of the people who received support, the majority, 40%, had multiple (two or more) sources of professional backing.

Figure 4. Is time management ever a problem for you?

n=78
n=34
n=27
n=25
n=18
1.7. Memory

The number of people who indicated they had a good memory was evenly split (50%/50%) with those who felt they had a not very good or poor memory. 81% of respondents though indicated that memory difficulties were still sometimes or regularly a problem. 13 people received support for their memory difficulties, 11 of whom expressed satisfaction with the support received. 62% of people who responded though said they did not receive support from anybody for their difficulties.

1.8. Interests

81% of people specified that they had been told at some point that they were spending too much time on an interest, though only 15% had asked for support in relation to this, indicating that spending time on an interest wasn’t seen as being problematic for respondents most of the time.

1.9. Concentrating and switching tasks

1.9.1. Concentration

47% of respondents said that they were good or very good at concentrating on one task without becoming distracted, with 53% saying that they were not very good or poor at this. 64% of respondents indicated that concentration had been a problem at some point in their lives, with the most common answer (42%) being that this was still a problem. The majority of people had not asked for support here.

1.9.2. Switching tasks

63% of respondents indicated that they were poor or not very good at switching tasks. 69% of people indicated that switching tasks had been a problem for them at some point in their lives, with 61% saying that it was still or sometimes a problem.
though 75% of these respondents indicated that no professional was currently providing them with support.

1.9.3. Coping with unexpected changes

88% of people indicated that they had difficulties coping with unexpected changes. 34% of people had asked for support in relation to this. 22 people indicated that they had subsequently received some form of support, and 65% of people expressed satisfaction with this. 35% of people said that they were not currently receiving support from any professionals for these difficulties. 11% were receiving support from one they classified as ‘Other’, and 8% of people were receiving support from two or more professionals.
2.1. Living Situation

66% of respondents lived at home with their parents, with the next most common answer being that the respondent lived in some other place, usually with a partner or child (Figure 7). Broken down by age, 92% of respondents below the age of thirty lived at home with parents or family. Above thirty, the living situation of respondents became more heterogeneous, though there was still a concentrated number of people living at home with parents/family (Table 2).

Figure 7. Place where currently lives.
60% of respondents answered that they were not very good or poor at living independently. 66% indicated they would be able to live more independently if they had help. Of the areas where people indicated that they needed more help, 28%

n=72
n=51

<table>
<thead>
<tr>
<th>Age of respondents</th>
<th>Where do you currently live?</th>
<th>Group</th>
<th>At home with parents/ family</th>
<th>but someone monitoring the situation</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-7</td>
<td>13-14 % within Age of respondents</td>
<td>0</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>15-19</td>
<td>17.9%</td>
<td>0</td>
<td>10</td>
<td>0</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>20-24</td>
<td>25.6%</td>
<td>0</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>25-29</td>
<td>15.4%</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>30-34</td>
<td>5.1%</td>
<td>1</td>
<td>8</td>
<td>1</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>35-39</td>
<td>20.5%</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>40-44</td>
<td>5.1%</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>45+</td>
<td>2.6%</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>100.0%</td>
<td>1</td>
<td>39</td>
<td>12</td>
<td>55</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Table 2. Where respondents live broken down by age.
indicated they needed help with finding their way around town, 39% with public transport, 44% with getting to places on time, 47% with cooking, 53% with managing money, 46% with being to look after the house, 42% with getting things ready, 25% with personal hygiene, 58% with throwing things away and 39% with washing clothes.

61% of respondents indicated that living independently was still currently a problem for them. Difficulties in living independently were closely correlated with difficulties coping with unexpected changes (p<.001) with 65% of respondents who had difficulties coping with unexpected change also had difficulties with living independently. Overall, 61% of participants indicated that no professional was currently providing them with support for this.

2.2. Occupational activities
21% of respondents were in paid work during the day. All of the people who were in paid work were over the age of 20, and the numbers here increased with respondents’ age. Of the entire sample, 5% were in paid work with support, 40% in education with support, 3% in voluntary work, 5% in voluntary work with support and 11% in day care. 14% said they were doing nothing (including 4 of the 14 respondents aged between 30 and 34) and 21% said that they were doing something else. 50% indicated that they needed more help with their day to day activities.

Skills which participants identified as areas they needed help with were: getting around (14%), using public transport (20%), social skills (40%), interview skills (33%), getting things ready (27%), being on time (27%), and 9% needed some help with something else.

Difficulties which respondents noted themselves noted:

- Understanding organizational environment.

n=64
• Needing help dealing with desire to impose order on a world that was too flexible.
• Low confidence, and feelings of inadequacy.
• Lack of relevant skills.
• Panic attacks when out alone.
• Difficulty talking to unknown people/ people of own age.
• Obsessive compulsive behavioural problems.

2.3. Shopping
43% of respondents indicated that they needed some help with shopping. 24% noted that they needed specific help getting to the shops, 21% with navigating public transport and 33% with money skills. 11% said they needed help with some other aspect of shopping.
Of those people who indicated a need for help with regards to their shopping, only 31% said that they had received any extra support for this.

Reasons why participants indicated help was needed here:
• Not knowing what to buy.
• Money difficulties (not knowing how to budget)
• Lack of skills and an inability to cope
• Difficulties understanding non-verbal communication
• Feelings of vulnerability when out shopping

2.4. Interacting with other people
74% of respondents indicated that they find it difficult to make friends with other people, and 76% found it difficult to meet people. 70% indicated that they sometimes or very often felt put down by other people. 56% said they wanted to have more social activity.
One respondent noted:

I am stuck in a rut and seem to just go around in circles and never get any further forward in life. I can have difficulty with conversation and making

"n=71"
"n=78"
"n=77"
friends, meeting people, though I enjoy chatting to people who share my particular interests. Everything had always seemed to go wrong in my schooling, relationships and employment and I would just like to get on in life and have a proper friend that I can trust.

2.5. Getting on with others

2.5.1 Getting on with people of own age
82% of respondents indicated that they had difficulties getting on with people of their own age (see Figure 8), with these difficulties persisting into adulthood. 46% of people had sought support for this. The majority of people, 51%, said no one was currently helping them with this difficulty, though 16% of those who were receiving help required the assistance of two or more professionals or carers to support their needs. Difficulties getting on with others were closely correlated with difficulties responding to (p<.002), and reading (p<.001), other people’s feelings.

![](image)

**Figure 8. Do you have difficulties getting on with people of own age?**

"n=77"  
n=65  
n=51
2.5.2. Getting on with people in different situations

66% indicated that they had difficulties getting on with people in different situations. These difficulties persisted into adulthood, with 40% of people indicating that they had difficulties even when they were above the age of 20. 78% of people said that this was sometimes or still regularly a problem for them. 35% had asked for help in relation to this. 66% of people expressed feelings of positive satisfaction with the help they received. Currently the majority of people, 56%, were not receiving professional help for this. However of those who were, 21% were getting help from two or more professionals.

2.6. Feeling left out of things

47% indicated that they very often or all the time felt left out of things. 50% of respondents indicated that they sometimes or often felt lonely, though 48% indicated that they rarely or never did. 49% of respondents indicated that they felt that other people rarely or never understood them.

2.7. Thinking about the past

64% of respondents indicated that they sometimes or very often kept the past alive by thinking about it. 40% of people indicated that they thought about the past on a regular basis. 58% of people indicated that this was because they had been treated badly in the past, 36% because they wanted to change feelings, 45% because they wanted to make the past right, 39% because they felt sorry about a way they had reacted. 36% of people said that they could not stop thinking about the past if they wanted to, in contrast to 15% who said that they could. 28% indicated that they thought about the past because it was a time when they were happy.
2.8. Experiences of loss

72% of respondents indicated that they had lost someone close to them. The most common answer was that respondents sometimes missed that person. 49% of respondents indicated that they had moved away from a place that was close to them, and 49% that they had lost an object close to them. 61% indicated that they sometimes or very often missed this object.

2.9. Relationships

71% of respondents were not in a relationship, though 68% said that they would like to be in one. More people said that they never or rarely felt sexually frustrated (40%) than did those who indicated that they did (23%). However, more people without a diagnosis (28%) felt sexually frustrated than did people with (13%), though it also has to be taken into account that people without a diagnosis were generally older. When it came to who respondents talked about their difficulties with, 21% said they could talk to their partners, 72% to their family members, 18% to close friends, 18% to care workers, and 27% to someone else.

2.10. Spaces frequented

36% of people said they go to the pub, 46% to the cinema, 5% to clubs, 24% to museums, 45% to libraries, 5% to community centres, 14% to none of these and 28% to some other place. It’s important to note here that the two most common answers given, the cinema and library, are spaces where social interaction is normally kept to a formal minimum with others in relation to the performance of designated roles.
2.11. Bullying 90% of respondents indicated that they had been bullied (see Figure 9). 60% had asked for support in relation to this problem. 41% indicated that they had received some support for bullying. Bullying was still a problem for a substantial 29% of respondents.

Figure 9. Have you ever been bullied?

n=78
n=69
n=69
n=65
2.12. Sexual or financial exploitation

69% of respondents said that they had never been exploited, though a substantial minority, 31%, said that they had. 36% of respondents who answered the question said that they had asked for support in relation to being exploited. Two thirds of people who answered the question said that they had not received support in relation to this matter. 10 people, or 13% of the overall sample, said exploitation was still a problem for them. 9 of these also said bullying was also still a problem (p<.001).

2.13. Family problems

37% of respondents indicated that they had experienced family problems. These figures were higher for people without a diagnosis (47%) compared to individuals with one (25%). 51% of respondents indicated that they had asked for help in relation to family problems and 57% indicated that they had received support for family difficulties. 68% indicated that family problems were still happening.

2.14. Work problems

64% of respondents indicated that that had a problem at work that had affected their personal life at some point. Bullying was by far the main problem observed here. It’s also important to note here that many respondents equated work with school for this question. 47% of people had asked for help in relation to this. 43% of people indicated that they had received help for work related difficulties and 47% of people indicated that work related difficulties were still happening.

\( n=74 \)
\( n=25 \)
\( n=24 \)
\( n=27 \)
\( n=43 \)
\( n=53 \)
\( n=41 \)
\( n=76 \)
\( n=44 \)
\( n=45 \)
3: HEALTH

3.1. Anger and Violence

83% of respondents said that they became angry or violent easily. Anger was correlated with difficulty reading other people’s feelings. 69% of respondents who indicated that they were not very good or poor at reading other people’s feelings also said that they became angry easily; in contrast 61% of people who said they were good at reading other people’s feelings also said that they didn’t become angry easily (p<.027). Anger here was also linked to difficulty coping with unexpected changes. For example, 87% of respondents who indicated that they became angry also said they had difficulty adjusting to changing circumstances and routines (p<.020). With regards to how this anger typically manifested itself, 65% of respondents indicated that they shouted and screamed when they became angry, 55% said that they became abusive, 31% threatening, 35% indicated that they would break things, 38% that they would hit or hurt things and 14% that they would become violent in some other way. 43% of people had sought help for this behaviour, of whom 64% were happy with the support they received. Currently 45% of people indicated that no professional was helping them with this problem.

n=76
n=77
n=63
n=28
n=42
3.2. Suicidal thoughts

50% of respondents indicated that they had thought about suicide at some point (Figure 10). 60% of people without a diagnosis, compared to 40% of individuals with one, had thought about suicide. 34% of people had told another person about their suicidal thoughts, 11% had tried committing suicide but had not needed hospital treatment and 10% had tried and needed to go to a hospital. People without a diagnosis were more likely to attempt to commit suicide. 71% of people who answered the question had received professional support for their suicidal thoughts and actions 100. 67% were happy with this support 101. At the time of the survey, 50% of people who answered the question were not receiving support here 102.

Figure 10. Have you ever thought about suicide?

100 n=39
101 n=28
102 n=31
3.3. Drug and alcohol consumption

90% of respondents indicated that they had not used street drugs, and 85% of respondents indicated that they had never had problems with alcohol (see Figures 11 and 12).

![Figure 11: Have you ever had problems with alcohol?](image1)

![Figure 12: Have you ever used illicit drugs?](image2)

n=77
3.4. Eyesight

35% of people indicated that their eyesight was poor\(^{104}\). 78% of people indicated that they had asked for support in relation to their eyesight\(^{105}\). 95% of people indicated that they were satisfied with the support they received in this regard\(^{106}\). 81% of respondents were being treated by an optician.

3.5. Hearing difficulties

78% of respondents indicated that they did not have hearing difficulties\(^{107}\). 48% of people who answered the question indicated that they had asked for support in relation to hearing\(^{108}\). 9 out of 12 people indicated that they were happy with the support they received for their hearing difficulties. Most people (14 out of 18) were currently not receiving any support from professional for this difficulty.

3.6. Sensitivity

51% of respondents indicated that they did not have a problem with their senses, though 47% said that they did\(^{109}\). 86%\(^{110}\) indicated that they had not asked for support in relation to sensitivity. The ratio of people who were satisfied with the support they received compared to those who were dissatisfied was 3 to 1.

3.7. Body image

51% of respondents indicated that they had had a problem with their body image at some point\(^{111}\). 40% of people had asked for support in relation to this. 82% of people who answered the question indicated that they still had problems with their body image\(^{112}\). The figures for individuals who still had a problem with their body image were slightly higher for individuals without a diagnosis (46%) compared to those people who had one (36%).

\(^{104}\) n=76  
\(^{105}\) n=28  
\(^{106}\) n=23  
\(^{107}\) n=76  
\(^{108}\) n=25  
\(^{109}\) n=78  
\(^{110}\) n=42  
\(^{111}\) n=77  
\(^{112}\) n=39
3.8. Involuntary movements

63% of people indicated that they did not suffer from sudden involuntary movements. **70% of people indicated that they had not asked for support in relation to this matter.** Of the eight people who answered the question, seven indicated that they were satisfied or highly satisfied with the help they received for involuntary movements.

3.9. Genetic disorder

78% of people indicated that they did not have a genetic disorder. Of the people who answered the question positively, 52% had asked for support with this matter. 7 out of 11 people were happy with the support they received here. Currently half of the respondents said that no professional was helping them with this.

3.10. Neurological problems

76% of respondents indicated that they did not have neurological problems. 81% had asked for support in relation to their problems, of whom an equivalent number (7 and 6 respectively) were satisfied and dissatisfied. The majority of people indicated that no professional was currently providing them with help on this matter.

3.11. Psychiatric difficulties

61% of people indicated that they had some form of psychiatric difficulty. 53% indicated that they suffered from anxiety, 45% from depression, 17% from suicidal thoughts, 26% from panic attacks, 3% from schizophrenia, 8% from psychosis, 17% from an obsessive-compulsive disorder, and 16% from some other condition. 83% had asked for support in relation to their psychiatric difficulties. 79% indicated that they were happy with this support. The most common answer in relation to the question of who supports psychiatric difficulties was ‘three of more’, which was
given by 26%. There was a higher incidence of psychiatric disorders amongst people without a diagnosis.
4: EDUCATION

4.1. Being labelled as gifted

69% of respondents indicated that they had never been labelled as gifted. However, a sizeable minority (25%) had been. Of those who had been labelled as gifted, 76% indicated that they were satisfied or very satisfied with the description. Twice as many people without a diagnosis were labelled as gifted as those with one.

4.2. Education levels

4.2.1. Primary education

100% of respondents indicated that they had passed through primary education. 77% of respondents had attended a mainstream school. The rest of the sample was evenly split between those who attended a special needs school exclusively, and those who attended a special needs unit in a mainstream school. 69% indicated that they were satisfied with primary education. 64% had not received any extra professional support when they were in primary education. 59% though indicated that they were happy with this support when it was given.

100% of respondents had also attended secondary education. 69% of respondents attended a mainstream educational facility. 60% indicated that they were happy with their secondary education. However, dissatisfaction was higher amongst people without a diagnosis (45%) compared to individuals with one (32%). 41% of people indicated that they had received some form of professional support in secondary school. 67% were happy with this support.

\[\text{n}=78\]
\[\text{n}=19\]
\[\text{n}=77\]
\[\text{n}=77\]
\[\text{n}=77\]
\[\text{n}=75\]
\[\text{n}=75\]
\[\text{n}=75\]
\[\text{n}=32\]
57% of respondents indicated that they had attended a college of further education. 70% went to a mainstream college. 86% were satisfied with their college education. 68% indicated that they had not received any professional support at college. 11 people indicated that they were happy with the support they received in college, compared with 3 who were dissatisfied.

Only 18% of respondents indicated that they had gone to university. 10 out of 13 people were happy with their university experience. Only 1 person out of 14 indicated that they had received help at university.

4.3. Transition plan

75% of respondents ended education between 15 and 19. Only 10% of respondents indicated that they had a transition plan. 52% of respondents were not currently in education.

4.4. Topics education covered

Of the entire sample of 78 people, 46% said their education covered home economics, 37% personal care, 35% relationships, 54% sex, 30% social interaction and 18% said none of these. 37% said some other form of help not noted here was needed.
5: SERVICES

5.1. Contact with social services 50% of respondents had some contact with social services (Figure 13). 52% indicated that they had received some services after this contact. More people with a diagnosis received support from social services after contact than those without. 75% of respondents indicated some degree of positive satisfaction with the services they received.

Figure 13. Contact with social services.

\(^{138} n=78
\(^{139} n=57\)
5.3. Contact with health services

82% of respondents indicated that they had some contact with health services at some point. 78% of people said that they had received some service after this contact. 62% of people were satisfied or highly satisfied with the support they received.

93% of respondents indicated that they would be able to receive help if they had a problem with their health. 51% said that they had taken medication for a psychological problem at some point, of whom 17% were rarely or never told what this medication would do for them. 45% said that they were not informed of potential side effects. 34% of respondents sometimes suffered side effects from their medication. Overall, 76% indicated feelings of positive satisfaction in relation to taking medicine.

5.4. Benefits

60% of respondents were receiving state benefits. 24% indicated that their carer was receiving state benefits. 30% of respondents with a diagnosis said that their carer received state benefits, compared to 10% of respondents without a diagnosis (although it has to be borne in mind here the general differences in age between respondents with and without a diagnosis). There was strong correlation (p<.001) between contact with social services and receiving benefits. For example, 67% of respondents who had contact with social services also received state benefits, in contrast 77% of respondents who had not been in contact with social services were not claiming benefits. 74% though said that if they had problems with money they would not be able to receive help from an agency.

n=75
n=67
n=53
n=71
n=73
n=40
n=40
n=38
n=77
n=63
n=38
n=39
5.5. Statement of special education

61% indicated that they had never had a statement of special educational need\(^\text{152}\). 72% of people were happy with this statement once they received it\(^\text{153}\) (Figure 14).

\[\text{Figure 14. Satisfaction with statement.}\]

\(^\text{152}\)\hspace{1em}n=77

\(^\text{153}\)\hspace{1em}n=27
6. Prevalence of Asperger syndrome in this community sample

We calculated a prevalence rate of Asperger syndrome of 2.4/10,000 with the highest rates in the youngest boys. We used a Poisson regression on detected prevalence year by year, with an offset for the population, to estimate the true prevalence. This also provided confidence intervals for the estimates, based on odds ratios. Figure 2 shows the detected 5 year prevalences and the best fitting curve for the estimated true prevalence against year. There is no significant fall by year in girls and women, but there is a significant decrement in the estimated prevalence of boys and men by year of 0.93 (95% confidence intervals, 0.91 to 0.95) or 7% (95% confidence intervals, 5% to 9%) for each year of age. The fall was a steady, log linear one, with no points of inflection that might correspond to changes in selection e.g. after leaving school.

There was a comparable decrement in the estimated true prevalence of AS in the previously undiagnosed males, although because of the smaller numbers involved in this did not reach significance.

The overall prevalence rate that we found, 2.4 per 10,000, is below the prevalence rate of 9.5 per 10000 suggested by some recent estimates. However, we also found that rates fell with chronological age, and the mean prevalence in our youngest two age groups, of 13 and 14 year olds, was 0.8 per 1000, but other studies have not attempted to estimate prevalence in adult populations and calculate a mean overall prevalence based on adult and adolescent figures.

We wondered whether the decline in apparent prevalence may have been due to the increased likelihood of being diagnosed in the last decade, but a fall, although not such a large one, was also seen in the prevalence of Asperger syndrome when only the participants who had no diagnosis previous to the study were considered.

The numbers in the cells are small, and there are many other possible explanations of this apparent fall, including increased mortality, increased institutionalization and therefore inaccessibility to a community based survey, or decreased willingness to participate in a survey of this kind. We had some evidence of the latter in that some of the women who participated in the early phases of the study were unwilling to be interviewed because they had met new partners whom they did not want to tell of their condition. It may also have be that older people with Asperger syndrome who are not too severely affected, are not cognitively impaired, and are able to live in the general population without the need for major support from their parents or societal resources.
will escape detection from a study of this sort. It is likely that this study therefore has not captured everyone with high functioning autism in Sheffield. There was a comparable fall in prevalence in males without a diagnosis, which suggests that treatment for AS, for example institutionalization, is not the explanation for the fall in the total sample.

We are not assuming, however, that the detected prevalence that we found is representative of everyone with AS in Sheffield. For one thing, participants had to consider themselves to have a social problem to come forward. Evidence from ADI-R interviewing indicated that people who self-selected themselves to come forward for this study were those for whom their Asperger syndrome was causing them significant social impairment. This is important because as noted in the introduction to this paper the diagnosis of AS requires that a person is ‘socially impaired’ and so it is possible that many children who are socially impaired are not socially impaired as adults and are therefore not eligible to be diagnosed. It may be that ‘mild cases’ of AS would not fulfil DSM criteria and would not be eligible for inclusion in a prevalence study of this sort.

The results of our needs survey will be discussed in a set of forthcoming papers but indicate that most respondents were experiencing substantial social difficulties at the time that the study was conducted. Respondents without diagnoses and female respondents (who are less likely to be diagnosed) reported themselves to have greater social difficulties than male respondents, or respondents with diagnoses.

Women did not show the same decline in apparent prevalence and we do not know the reason for this although it may suggest that men are likely to have a more ‘developmental’ form of Asperger syndrome. Previous research has demonstrated that girls with Asperger syndrome are more likely to show demonstrable neurological abnormalities than boys. There may be other explanations for this finding, however. It may be that men with Asperger syndrome are expected to go to work and become increasingly visible and often overtly antisocial with age, and so end up institutionalized, perhaps with other diagnoses such as schizophrenia, and so either prevented from having access to a study such as this one or not seeing a study such as this one having relevance to them (because of misdiagnosis). Women may be more likely to live in society with parents, relatives or partners and, because they are in close proximity to people on an everyday basis, may be more likely to be identified as ‘different’. It may also be that AS only becomes ‘overt’ when it is associated with social impairment. So a diagnosis may only be required when role dysfunction becomes critical. In men that may be when they fail to find work on leaving school, but thereafter a parent or a spouse may provide them with protection against role
dysfunction. This is less likely to happen for those women who have children since there is less willingness for either parents or partners to take over the role of child care from a mother.

Despite the fall in prevalence, whether real or apparent, there remained a substantial group of adults with Asperger syndrome, nearly half of whom had not been previously diagnosed. Diagnosis was less likely in older men, and in females.

Limitations in this study include the likelihood that there was a selection bias influencing those participants who came forward and, therefore, that we have underestimated the prevalence of AS. There is also an under-representation of non-white groups in our study, and an uneven geographical distribution of the addresses of our respondents with many more respondents from south rather than north Sheffield.

Despite these limitations, our data do suggest that there is an apparent fall in prevalence of AS with age, consistent with Asperger’s original statement that ‘autistic psychopathy’, as he termed Apserger syndrome, has a “good prognosis”. This finding is perhaps supported by the fact that person older than 65 decided to participate in this study. This needs replication in a large study, but if true, has important clinical implications.

One is that efforts to increase the rate of this spontaneous remission are worthwhile. As we discuss in a forthcoming set of papers, respondents in this study expressed high levels of satisfaction when they received help from health and social services. Unfortunately, in many cases very little help is available for people with Asperger syndrome.

Another implication is that we may need to consider more carefully whether AS is a more variable disorder than is normally thought. Although its basis is neurodevelopmental, it is possible that, like other neurodevelopmental conditions, the functional impairment varies according to social, emotional, or cognitive demand. Childhood is a time of considerable social and emotional demand, and it is possible that the remission of AS in adulthood is partly a consequence of the remission of this social demand. The clinical significance of this would be that, if true, then it could be expected that AS might apparently ‘recur’ at some later stage when there is a surge of further demand.

Finally, we would acknowledge again that while our figures may not be completely representative of the universe of people with AS, they may accurate for those for whom
AS causes significant social impairment. Our figures do make a strong case for having more definitive surveys, both to see if our findings are replicated and because if AS does become less prevalent with age there are important and obvious implications for services and for the science of AS aetiology. Future studies will need not only need to use a door to door method of ascertainment (although even this will miss people with Asperger syndrome who are homeless, in institutions, or living alone and reluctant to answer the door) to assess prevalence (since there is no equivalent in adult life to the school record of pupils with difficulties), but also to have more up to date methods of assessing social impairment which reflected not just objective role performance (e.g. working, living independently, and so on) but also subjective assessment of the quality of social inclusion and participation.
7. Conclusions
We here report the first comprehensive community based study of the health needs of people with Asperger syndrome. Previous studies have been based on less representative samples, such as the several studies of their membership conducted by the National Autistic Society (Barnard et al., 2001).

We found Asperger syndrome to be much less prevalent in our sample than in recent studies of children. There may be several reasons for this, including the remission of autistic spectrum disorder reported by both Kanner and Asperger, but one reason may have been that many people who would have met the criteria for Asperger syndrome had they come forward, chose not to do so.

Results from our sample cannot therefore be unreservedly generalized to everyone with Asperger syndrome although our efforts to sample people with AS who had not been previously diagnosed and our use of a community sample, rather than a clinic one, does mean that our results are more representative than previous studies.

It is possible that people who are only mildly affected by Asperger syndrome were less likely to come forward for inclusion in the study than those who were more severely affected. The diagnostic criteria for Asperger's disorder in DSM-IV TR (APA 2000) (but not Asperger’s syndrome in ICD-10) include the requirement of “clinically significant impairment in social, occupational, or other important areas of functioning”. So if the US criteria are applied, this self-selection bias may have actually helped to reduce the rate of false positives in our sample population.

Almost half of our sample had never received a diagnosis of an autistic spectrum disorder with a much higher proportion of women in the undiagnosed group, confirming as some clinicians have suggested (Attwood, 1998), that women are underdiagnosed. The ratio of women to men in the diagnosed and undiagnosed groups together was 1 to 3, compared to the ratio in the diagnosed group of 6.6 to 1. The undiagnosed were also 10 years older, on average, than the diagnosed suggesting either that the diagnosis is harder to make as a person gets older or, more likely, that the diagnosis of AS in children has become much more common, recently.

We have relied on respondents to evaluate their own needs, needs, although using a questionnaire to ensure that they consider them systematically. We also encouraged respondents to discuss their answers with a carer to overcome the problem that many carers anticipated in the planning stage of the study, which was that, at least according
to carers, people with Asperger syndrome would show a lack of awareness of their own needs and a lack of awareness of what might be done about them.

This lack of awareness means that we have probably under-estimated the true level of need, although our use of subjective measure of need does at least ensure that we have not simply measured professional assessment of health status.

Not surprisingly needs directly related to Asperger syndrome, such as dealing with change, are reported by respondents as being areas where help is needed. Executive function is rarely routinely assessed by clinicians, and yet is one of the commoner reasons that carers and people with Asperger syndrome give in clinical practice for reasons that a person cannot function independently. Executive difficulties, like cooking and self-care, are also routinely assessed in granting benefits in the UK such as Disability Living Allowance. Our findings suggest that executive problems might usefully be assessed more fully as part of the routine assessment of people with Asperger syndrome or high functioning autism.

The use of methylphenidate and other stimulants in adulthood may overcome some of these executive problems, and where medication is helpful, it can be hoped that the proportion of met to unmet need will rapidly increase. This will depend, however, on the willingness of general psychiatrists to accept that executive problems in people with Asperger syndrome are their province and for more to be willing to prescribe these drugs on the named patient basis that is required, at least in the UK.

Many of our participants had problems with psychiatric disorder. Even if mental health services in Sheffield cannot directly address the problems of living with Asperger syndrome, and the previous argument suggests that these services can do more than they realized, these generalist services are needed by the substantial number of people with Asperger syndrome who have these additional problems.

Almost two thirds of participants without, and two fifths with, a diagnosis had thought about suicide. Over 10% of people without, and about 6% of people with, a diagnosis had attempted suicide. This is an indication of the high distress that Asperger syndrome causes, and a further indication that mental health services do need to be address the needs of at least some people with Asperger syndrome. The percentage of respondents with body shape problems is also very high.

The lowest ratios of met to unmet need in the group who asks for help apply to violence, anger, and the often related need of being exploited by others. These needs
for help are also considerable sources of burden—to others in the case of anger and violence, and to carers and also to the self in the case of exploitation. The violence can be severe enough to lead to assault or a more serious offence. It is therefore worrying that so little seems to be available to meet this need, at least amongst our respondents.

Some needs may spontaneously reduce with age. This is true especially of executive and of motor problems. Both may be disorders associated with networks involving the frontal lobes of the brain, and may therefore benefit from the maturation of the frontal lobes that continues until the end of adolescence.

In terms of respondents’ social needs, only 21% of them over the age of 18 were in paid work without support. A further 6% were in paid work with support. These percentages figures were the same—though not statistically significant—for both respondents with and without clinical diagnoses. 50% of respondents under 16 received additional support in primary school. 72% of respondents under 16 received additional support in secondary school. We would suggest that mainstream schools need to be more aware of Asperger syndrome/High Functioning Autism, with at least one member of staff in each school being designated as a person that individuals with AS/HFA can go to if they are experiencing difficulties. Also need to take a more active role in helping young people with AS in Sheffield make the transition from school to post-school life. More help also needs to be provided to people with Asperger syndrome while they are in school, for example with one to one tuition.

Quality of life or at least satisfaction for our respondents improves in some respects in later adolescence: there was more satisfaction with college or University than school. Quality of life may however drop again, later, since the proportion of people who did nothing all day increased with age.

The quality of life of people with Asperger syndrome may be adversely affected by other people’s reactions. 90% of our respondents considered that they had been bullied. This may have been linked to the choice of places to spend the day: the most common of these were libraries, where talking is prohibited; the cinema, where talking is prohibited and one cannot be seen; and the pub, where there is a continuous supply of alcohol which can be used for self-medication for anxiety. Other places often frequented by young people such as clubs were rarely visited by our respondents. This may partly have been because of a reluctance to use public transport, and amounts to a degree of social exclusion that may reduce learning social skills and may also increase the feelings of being rejected or marginalized to which many people with Asperger syndrome are prone.
Though people with Asperger syndrome have many needs as our survey shows, when help is offered it is usually highly valued. Our survey therefore supports the commonly held view that people with Asperger syndrome have very many unmet social needs, and also provides some indirect support for the common assumption that these needs are for help in areas that are especially relevant to wellbeing (we shall consider this more in our second paper). Contrary to preconception, however, is the fact that many professionals have found ways to meet these needs, and that when help is offered, it is highly valued by people with Asperger syndrome.

Getting a diagnosis continues to the goal of many carers or people with Asperger syndrome. Having a diagnosis may be the key to services, and this may be one reason that so many people with AS value it is valued, but this present survey suggests that diagnosis is also important in helping people to make use of interventions and that it may also have offer some protection against bullying, perhaps because an eccentric is less likely to be bullied if their eccentricity is known to be the consequence of a medical problem.
<table>
<thead>
<tr>
<th>Question</th>
<th>Percentage of respondents for whom this is at least sometimes a problem</th>
<th>Percentage of respondents who asked for support</th>
<th>% of respondents satisfied with the support received</th>
<th>What health professionals currently provide help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has reading other people’s feelings ever been a problem for you?</td>
<td>91%</td>
<td>30%</td>
<td>73%</td>
<td>None 60% Speech therapist 7% Teacher 7% Other 16% Two more professionals 11%</td>
</tr>
<tr>
<td>Have you ever been bullied?</td>
<td>90%</td>
<td>37%</td>
<td>83%</td>
<td>None 50% Speech therapist 9% Teacher 7% Other 11% Two or more professionals 23%</td>
</tr>
<tr>
<td>Has responding to other people’s feelings ever been a problem for you?</td>
<td>90%</td>
<td>60%</td>
<td>40%</td>
<td>NA</td>
</tr>
<tr>
<td>QUESTION</td>
<td>Percentage of respondents for whom this is at least sometimes a problem</td>
<td>Percentage of respondents who asked for support</td>
<td>Satisfaction with support received</td>
<td>What health professionals currently provide help</td>
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<tr>
<td>Has switching tasks ever been a problem for you?</td>
<td>89%</td>
<td>17%</td>
<td>64%</td>
<td>None 75% Teacher 9% Social worker 3% Other 8%</td>
</tr>
<tr>
<td>Do you have difficulties coping with unexpected changes?</td>
<td>88%</td>
<td>34%</td>
<td>77%</td>
<td>None 56% Psychiatrist 2% Teacher 6% Social worker 6% Other 18% Two or more professionals 12%</td>
</tr>
<tr>
<td>Have you ever found yourself getting angry or violent easily?</td>
<td>83%</td>
<td>42%</td>
<td>62%</td>
<td>Psychiatrist 10% Psychologist 7% Therapist 4% None 45% Two or more professionals 26%</td>
</tr>
<tr>
<td>QUESTION</td>
<td>Percentage of respondents for whom this is at least sometimes a problem</td>
<td>Percentage of respondents who asked for support</td>
<td>Satisfaction with support received</td>
<td>What health professionals currently provide help</td>
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</tr>
<tr>
<td>Has planning ever been a problem for you?</td>
<td>82%</td>
<td>36%</td>
<td>68%</td>
<td>None 63% Other 14% Teacher 4% Social worker 4% Two or more professionals 14%</td>
</tr>
<tr>
<td>Has getting on with people in different situations ever been a problem for you?</td>
<td>81%</td>
<td>42%</td>
<td>66%</td>
<td>None 56% GP 2% Psychiatrist 2% Teacher 4% Social worker 2% Other 11% Two or more professionals 22%</td>
</tr>
<tr>
<td>Has anyone ever told you that you were spending too much time on an interest?</td>
<td>81%</td>
<td>15%</td>
<td>98%</td>
<td>None 74% Teacher 5% Social worker 5% Two or more professionals 14%</td>
</tr>
<tr>
<td>QUESTION</td>
<td>Percentage of respondents for whom this is at least sometimes a problem</td>
<td>Percentage of respondents who asked for support</td>
<td>Satisfaction with support received</td>
<td>What health professionals currently provide help</td>
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<tr>
<td>Has doing jigsaws or maps ever been a problem for you?</td>
<td>79%</td>
<td>22%</td>
<td>44%</td>
<td>None 82% Teacher 4% Two or more professionals 13%</td>
</tr>
<tr>
<td>Has balancing ever been a problem for you?</td>
<td>75%</td>
<td>34%</td>
<td>66%</td>
<td>None 82% Teacher 4% Other 11% Three or more professionals 4%</td>
</tr>
<tr>
<td>Do you have any psychiatric difficulties?</td>
<td>62%</td>
<td>83%</td>
<td>68%</td>
<td>GP 12% Psychiatrist 12% Counsellor 12% Two or more professionals 36%</td>
</tr>
<tr>
<td>Do you have difficulties showing your feelings?</td>
<td>61%</td>
<td>33%</td>
<td>68%</td>
<td>None 60% Teacher 5% Other 10% Two or more of the above 16% Speech therapist 14%</td>
</tr>
<tr>
<td>Question</td>
<td>Percentage of respondents for whom this is at least sometimes a problem</td>
<td>Percentage of respondents who asked for support</td>
<td>Satisfaction with support received</td>
<td>What health professionals currently provide help</td>
</tr>
<tr>
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<td>------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Have you ever thought about suicide?                 | 50%                                                                    | 72%                                             | 52%                               | Psychiatrist 10%  
None 51%  
Psychologist 6%  
Other 6% Two or more professionals 22%                                      |
| Have you ever been told that you are overactive?     | 41%                                                                    | 28%                                             | 66%                               | None 78% Teacher 9% Other 9% Three or more professionals 4%                                                        |
| Do you have any sudden involuntary movements?        | 36%                                                                    | 30%                                             | 88%                               | None 84% Neurologist 4% GP 4% Other 4% Two or more professionals 4%                                                          |
| Do you have any neurological problems?               | 17%                                                                    | 82%                                             | 73%                               | Neurologist 20%  
None 50% Other 10%                                                                                                             |
| Do you have any neurological problems?               | 17%                                                                    | 82%                                             | 73%                               | Neurologist 20%  
None 50% Other 10%                                                                                                             |
APPENDIX 1: ASPERGER SYNDROME

It has been over 50 years since Hans Asperger (1944) first identified a group of children who had what he called 'Autistic Psychopathy', and Leo Kanner described a similar group of children with a condition he referred to as autism. While Kanner’s work, became renowned quite quickly, Asperger’s pioneering studies were not internationally acknowledged until the 1980s. Nevertheless, the terms Asperger syndrome and Asperger’s syndrome (AS) are fast becoming used to describe certain patients who have never been easy to classify but who seem to constitute a recognisable type of autistic individual (Frith 1991).

Characteristics of, and differences between, AS and HFA
The criteria for Asperger Syndrome are similar to those of autism but with additional exclusion criteria, that there is no significant history of cognitive or language delay (ICD-10, World Health Organisation 1994). The common symptoms between AS and autism are considered to be common to all ‘autistic spectrum disorders’ or ‘pervasive developmental disorders’. They are based on the ‘the triad of social impairments’ (Wing & Gould 1979): absence or impairment of reciprocal social interaction, nonverbal communication and inflexible imaginative activity. These features alone though do not constitute AS in the original descriptions of both Kanner (1943) and Asperger (1944). For instance, both of these authors also wrote of poor motor coordination in relation to the conditions they described.

This is an indication of how the concepts of autism and AS have evolved since they were first identified in the 1940s and more has been learned about them. The relationship between Kanner’s autism and Asperger’s syndrome have also become widely debated since the 1970s and 80s. Comparison of Asperger’s writings with Kanner’s by Wing (1991) showed certain profound similarities and also some differences between them. The similarities included such things as the following:
Autism and AS affect males more than females.

Both conditions show the characteristics of social isolation, lack of interests or understanding in the feelings or thoughts of others and egocentricity, for example, treating some people as if they were a piece of furniture.

Both authors described the same problems in the way language is used, including the lack of meaningful language for interpersonal communication (e.g., inventing words or using language in idiosyncratic ways); the reversal of pronouns (e.g., ‘you’ means ‘I’) in the early years; the repetitive questioning; and the peculiar and pedantic speech in some of their children who have verbal abilities.

Difficulties in using and understanding non-verbal aspects of communication were both observed by both authors and these include poor eye contact, monotonous vocal intonation and the lack of expressive gestures.

A repetitive pattern of activities and the lack of flexible pretended play were both noted by both authors, including resistance to changes in environment and collection of peculiar objects.

Fascination with spinning objects and sometimes odd responses to sensory.

The impression of clumsiness in gait and gross motor co-ordination in some of their cases and the dexterity were recorded.

Behaviour problems like aggression were frequently observed in both groups.

And in contrast to the children’s learning difficulties in certain areas such as reading, writing and arithmetical skills, good rote memory and special abilities were also mentioned by both authors.
Further research and clinical study has not supported sociability as a distinguishing characteristic once overall level of functioning is partialled out. Language delay, as a marker of receptive language impairment, may be a more important functional difference, hence its inclusion in the criteria of the International Classification of Disease and the American Psychiatric Association's Diagnostic and Statistical Manual. Asperger does appear to have been describing children who were less severely impaired and more intelligent than those described by Kanner, and global functioning is the criterion which most working professionals and carers use to distinguish autism and Asperger syndrome. One particularly important marker of global function is self-awareness. People with AS/HFA are aware of their differences from others, suffer emotionally as a result of this comparison, and bring this self-awareness to the care that they receive about which they may have strong views. They therefore rarely go along with the child-like role that less able people with autism, and other people with moderate to severe mental handicap, seem to comfortably accept.
Diagnostic criteria

Numerous principles have been put forward to differentiate and to diagnose individuals with AS/HFA. Kanner selected five features from his original descriptions as the diagnostic criteria for ‘early infantile autism’ (Kanner & Eisenberg 1956), while Asperger did not lay down any criteria for his syndrome at all. Nevertheless, there are several sets of specific criteria have been suggested by other authors or groups as central to the identification of AS since Asperger’s original publication (Leekam et al 2000):

1. Tantam’s (1988) five criteria included the wish to be sociable but failure to relate to peers, idiosyncratic but engrossing interests, language used freely but not adjusted to the social context, marked impairment of non-verbal communication, and clumsiness.

2. Szatmari et al.’s (1989) four criteria covered impaired social interaction, impaired non-verbal communication, odd speech and solitariness.

3. Gillberg’s six criteria (Ehlers & Gillberg, 1993) included social impairments, narrow interests, repetitive routines, speech and language peculiarities, nonverbal communication problems, and motor clumsiness.

4. The diagnostic criteria set out by both the international nomenclatures – DSMIV (American Psychiatric Association 2000) and ICD-10 (World Health Organisation 1994) are virtually identical. Howlin (2003) notes that they make reference to:
A. Qualitative impairment in social interaction, as manifested by at least two of the following:
   (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze and gestures to regulate social interaction.
   (2) failure to develop peer relationships appropriate to developmental level.
   (3) lack of spontaneous seeking to share enjoyment or achievements with others.
   (4) lack of social or emotional reciprocity.

B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
   (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
   (2) apparently inflexible adherence to specific, non-functional routines or rituals.
   (3) stereotyped and repetitive mannerisms (e.g., hand or finger flapping or twisting.)
   (4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language.

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia* (p.77).

Among those sets of criteria, the last one is the least like Asperger’s own descriptions. However they are also the most recently formulated, and based on extensive clinical
reviews, and are as such the criteria used in this study. They also apply to HFA once criterion D is excluded (Howlin 2003). We, as such, follow Tantam (2000) in using Asperger syndrome “to refer to all those suffering from the core syndrome, who are not excluded by the criteria given in the ICD-10 definition” (Tantam 2000: 48). The use of the DSM-IV criteria are also relevant given that they also apply to HFA.

Complex features

Current diagnosis of ASD is made by analysing patterns of behaviour present from early childhood; no medical test has been developed to diagnose autistic disorder. However, making the diagnosis in adulthood may be a different case, as it requires the person’s developmental history from infancy and comprehensive information about his/her current behaviour in many areas. Although the core set of diagnostic features (social interaction, communication and imagination and the rigid, repetitive pattern of activities and interests) can assist in the identification of ASD, there are other difficulties in relation to the diagnosis of individual children and adults. For example, the impairments associated with ASDs can be displayed in many different ways. In some cases, some of the behavioural signs are apparent and easy to recognise while some are subtle and hard to identify. The intensity of impairments may also change through the course of development. Furthermore, ASDs can occur together with any level of intelligence ranging from profound disability to above average intelligence. Autism can also co-occur with general learning disabilities, or mental handicap.
Although AS, as defined, is not being associated with generalized learning difficulty (mental handicap) or language impairment in both ICD-10 and DSM-IVTR, in practice this may not be the case. Some argue that a more appropriate term for this group is ‘high-functioning autism (HFA)’, and this has become the preferred term in the US. To add further confusion, parents and service providers increasingly use the term ‘Asperger syndrome’ for any person with an autistic spectrum disorder who is more able, or less severely impaired, than is expected of someone with autism. The judgement of greater ability seems to be strongly influenced by whether or not a person is aware of themselves or their own needs.

Co-morbidity
Other medical conditions or developmental disorders can also be associated with the core syndrome. Tantam (2000) for example notes that AS/HFA is more commonly associated with other developmental problems than would be expected by chance. These associated disorders include dyslexia, dysexecutive syndrome and short term working memory deficits (causing deficits in planning and following instructions), Tourette syndrome (tics and explosive vocalizations), attention deficit/ hyperactivity disorder, developmental dyspraxia (clumsy child syndrome) and dyscalculia (problems in handling numbers). Genetic and chromosomal diseases are also more common in people with Asperger syndrome, as are some conditions such as tuberous sclerosis that affect brain development. In addition a proportion of people with AS/HFA may also lack the ability to empathise with others and may become involved in antisocial conduct and, in rare cases, serious crimes. All of these problems may contribute to the difficulties faced by people with AS/HFA in adolescence and adulthood, and may contribute to the substantially increased risk people with Asperger’s syndrome have of developing depression, anxiety and anxiety-related conditions and psychotic disorders, particular bipolar affective disorder (manic-depressive psychosis). It is generally felt among sufferers, their parents and professionals that the pathway to health and social care for sufferers with AS is difficult and varied. There is growing evidence indicating that the development of a psychological disorder secondary to AS, is affecting the sufferers commonly and more severe than has been thought previously (Tantam 2000).
APPENDIX 2: PHILOSOPHY AND METHODOLOGY

In order to provide a good service for individuals with autistic spectrum disorders, it is important to understand their needs, an understanding that must be based on a detailed knowledge of both people with autism’s disabilities and their views and feelings about their own requirements (Wing 1993). While delineating or becoming aware of the needs of people with AS does not automatically mean that these needs will be met or acted upon, an analytic overview of their needs through a needs assessment could be seen the first phase in health promotion planning, providing the fundamental building block upon which care can be built. However, before this can be done, it is important to explore the concept of need itself.

Needs

Dating from parliamentary amendments in the early 1990s, the evaluation and assessment of need has become a core tenet of the government’s position and policies on people with mental health conditions (Secretary of State For Health 1990, in Evans et al 2000). Institutional stakeholders are being increasingly asked to recognize and delimit the social and health care needs of particular groups in the local population in order to design and/or facilitate suitable interventions and services (Evans 2000 et al).

Defining need

Despite this policy focus, though, very little attention has been given to what needs are and how they are to be evaluated (Wing et al 2001: 7). The simplest and perhaps most elegant delineation of need is the ability of a recipient to benefit from care. The simplicity of this statement, however, belies its deceptiveness. Need is something that can mean many things to many different people. It is “at best a relative concept” whose definition depends as much on the people who are using it, and the reasons why they are doing so (Jezzard 2001: 364). For example in an investigation of the meaning need has amongst health professionals Parry-Jones and Soulsby (2001) found that no central consensus existed over the use or interpretation of the concept of need. In their conceptual overview Wing et al note that rather than being singular notions that are immutable through space and time, needs are protean and can be built around scales, impairments, absences or hindrances, or they can be constructed around management practices and therapeutic intervention (2001: 8). The concept of
need is therefore complex (Evans et al 2001), and each of the various definitions of need has its own practical, taxonomic and epistemological ramifications.

Evans et al (2001) suggest that a fundamental prerequisite that must be addressed before attempting to answer the question ‘what is need?’, is deciding whether or not ‘need’ and its assessment is linked directly to the provision of services. Tackling need in this way by linking it to provision leads, according to Evans et al, to two broad perspectives on need, the pragmatic perspective and the ideological one.

The pragmatic perspective focuses on the ability of a person or a group to benefit from care or from service provision. The focus is on whether individuals can gain from existing resources while at the same time making sure these resources are targeted effectively. The more idealistic perspective concentrates on individuals or groups ability to achieve a state of complete health and social well being, with no allusion being made as to whether these states can be practically fulfilled or not.

These two perspectives both exist within the NHS care framework. For example the NHS & Community Care Act (Secretary of State for Health 1990) defines need as “the requirements of individuals to enable them to achieve, maintain or restore an acceptable level of social independence or quality of life” (Department of Health Social Services Inspectorate 1991). This more idealistic definition however may well identify needs which cannot be met by current service provision and within current resources. Another definition by the NHS Management Executive (1991) sees need as ‘need for care’ or ‘the ability to benefit from services’; this offers the potential to develop a pragmatic action plan based on the initial description of need.

From a commissioner’s point of view, the most suitable delineation of need is this latter approach, where need is predicated upon the ability of a group to gain from care (NHS management Executive 1991, in Steven et al 2001: 65). Defining and assessing the needs of a group from the perspective of institutions can however lead to a number of potential problems. One obvious difficulty with having care staff assess the needs of their own patients is that their judgements may be excessively conservative and constrained by their knowledge of current practice and the treatment resources available (Brewin 2001). While a commissioner orientated focus does not
automatically guarantee that a group’s needs would be overlooked, it would mean that needs would be assessed from the perspective of people who are aware of the limits of their organizational constraints (Carr-Hill 2001: 84). As a result, needs that the assessors think they cannot meet given resource constraints may not be identified.

Asadi-Lari et al (2003) note that the focus of policy makers will more than likely be on eliminating resource inflation and implementing cost containment, rather than attempting to deal with the large number of people who have genuine needs but don’t pose a critical threat to themselves or other people. Need here is based on a view of hazard or danger as interpreted from some objective perspective, rather than trying to attempt to elucidate the needs of people with conditions like AS/HFA on their own terms. An important point to note here, therefore, is that resource distribution and intervention, ostensibly in relation to need, is often done through an assessment of risk rather than need, with those deemed to be in greater danger more likely to receive more resources and more support (Parry-Jones and Soulsby 2001). People with AS/HFA for example, may consequently be less likely to receive help based on their needs than people when compared with individuals who possess more severe autistic conditions because they are perceived to pose less of a threat. However, it seems equally logical that the allocation of resources based on a pragmatic analysis of the needs of a particular group would favor those needs which can more easily be reduced by unit resource, such as those of people with AS/HFA, particularly given that the cost of not addressing these needs now can be extensive over the long term.

**Subjective and Objective Estimates of Need**

Objective and subjective estimates of the ability to benefit from care can also be distinguished. In objective estimates a measure, such as a symptom score, is weighted according to the values, or utilities placed on each system. For example, depression is heavily negatively weighted compared to absent mindedness. As such, in conditions of limited resources, rational cost-benefit analysis will usually conclude that using resources to alleviate negatively weighted symptoms will have more positive effects than they would if used to address symptoms such as absent mindedness because it is assumed that this will lead to a greater improvement in individuals’ quality of life.

Subjective measures rely on a more qualitative approach. They are particularly associated with *carer or client* perspectives and as such have become highly valued.
by the government and professionals. For example, Parry-Jones and Soulsby’s (2001) completed a study looking at how health professionals defined need, and while they did not find an agreement amongst the individuals they interviewed about what need was, they did find a general accord that attempting to understand the perspectives of those individuals being assessed, and their social and cultural context, is of central importance in attempting to define and meet their needs. The perspective of individuals must be explored if the existing priorities constructed by the current care environment are not just repeated and a situation avoided that does not just lead to a conservative underlining of current distributions and concerns (Wing et al 2001, Lockwood and Marshall 2001). However, this does not mean that subjective and objective estimates of need must be odds. The most productive way forward, as we see it, seems to be to understand need as simultaneously both “an objective requirements for physical and mental health and a subjective expression of want and desire” (Brewin 2001: 273).
APPENDIX 3: LITERATURE REVIEW ON THE NEEDS OF PEOPLE WITH AS/HFA

The last ten years has seen increasing interest in autism and AS. A considerable amount of valuable work has been carried out on, for example, the epidemiology of AS (Ehlers & Gillberg 1993) and issues relating to the diagnosis of, and diagnostic issues surrounding, AS/HFA (Leekam et al 2000, Gillberg 1998, Wing 1991). Some previous work has looked at the needs of people with Asperger’s syndrome. Barnard et al’s (2001) research is the most comprehensive study in this regard, and has influenced government policy. Barnard et al carried out research for the National Autistic Society (NAS) with 450 parents of people who had an ASD exploring their children’s needs, situations where carers thought these needs were not being met and where carers felt their children were being failed on an institutional level. Overall, these researchers found that:

“Statutory agencies are failing adults with autism and Asperger Syndrome. The majority of individuals and their families are excluded from the care system. They are either ignored or discriminated against through rigid eligibility criteria, often established through ignorance of autism” (Barnard et al 2001: 7-8).

Difficulties getting their needs met or recognised by health professionals meant that people with an ASD in the NAS study often had had problems with education, with making transitions from institutions such as school to work, with finding a job once those transitions were made, with living independently, and often experienced mental health problems. The importance of recognising, and satisfying, the needs of people with AS were clearly articulated here.

There are a number of points that have to be borne in mind when looking at Barnard et al’s work, though. Firstly, it did not differentiate between AS/HFA and other types of autistic spectrum disorder, and the information given in it was mainly provided by parents and caregivers, with less than 10% of responses being from people with AS/HFA themselves. The design of Barnard et al’s survey also did not allow for detailed data about health needs to be collected. Furthermore, the data collected by
the NAS survey only collated information about adults who had had received a medical diagnosis of an ASD. As a result the health and social care needs of adolescents, and adults who had not received a diagnosis, and who probably comprise the majority of people with AS/HFA, remained largely unexplored here.

The limitations in Barnard et al’s study are not unique. Howlin (1997) notes for example that very little has been written about the needs of people with autism who are more able, though their difficulties in communication and social interaction may continue to persist throughout adulthood.

So then, given the overall lack of research on the needs of people with AS/HFA, what can we say about the studies and findings that have been so far carried out in relation to the needs and abilities of high functioning sufferers? The rest of this chapter will explore this question in relation to five dimensions of need for people with AS/HFA:

- Diagnosis
- Development and skills
- Health and health related services
- Social situation
- Education
- Adult outcomes

1. Diagnosis
Diagnosis is an important step for people with AS/HFA. It can profoundly influence sufferers’ social and personal identities and how others see them (Tantam 2000), and is a crucial factor in determining whether or not people gain access to appropriate services that meet their needs (Barnard et al 2001). It also permits the appropriation of symbolic and material resources by individuals with AS/HFA. These could be resources that people might previously have been prohibited from using, been unaware of, or which they had deemed unnecessary or irrelevant given pre-diagnostic understandings of their condition.
Despite the importance of diagnosis, diagnostic delays are, however, especially common for people with higher functioning autism, particularly compared to people who have more severe autistic spectrum disorders (Barnard et al 2001). These delays can be most profound for people with Asperger’s syndrome, 46% of whom are not diagnosed until they reach 16 (ibid). The information from the U.K. so far suggests that children and adults who are not of white British origin are also under-represented among those who are diagnosed as having AS/HFA (Holland et al. 2000).

Late diagnosis of this kind and on this scale has negative implications. For example, late diagnosis can influence how well young people get on at school, which in turn can influence their subsequent life chances. Barnard et al (2001) found that two thirds of parents whose children had been diagnosed before the age of 5 were happy with the education their children was receiving, compared with only a fifth of parents whose children who had not been diagnosed when they had reached adulthood. A diagnostic delay can also lead to the development of disabling emotional and psychiatric problems that could otherwise be checked or ameliorated through early intervention (Barnard et al 2001). For example, while over 33% of parents in Barnard et al’s 2001 study reported that their child with AS/HFA had some experience of mental health problems, this figure increased to over half for parents who reported that their child had received a diagnosis when they were in their thirties. Unfortunately, clinical experience suggests that people with AS/HFA are sometimes diagnosed incorrectly, and often receive inappropriate and ineffective treatment. The cost of this mistreatment can be great, and not only from a personal perspective. Jarbrink & Knapp (2001) have recently estimated that the life-time costs for living support and day activity alone for one person with an autistic spectrum disorder to be 2.4 million pounds. However, while this cost is great, they note that the cost implications of incorrect diagnosis or insufficient service provision, from a purely economic perspective, have the potential to be substantially greater.
2. Development and skills

People with AS/HFA often have particular difficulties with related to their skills and developmental capabilities

2.1. Speech, reading and writing

One of the key features differentiating AS/HFA from more other autistic spectrum disorders is an absence of a clinically significant language delay. Young people with AS/HFA may even display hyperlexia, the use of words, particularly words that relate to the young person’s idiosyncratic interests, that are beyond the range of what would be considered normal language use for their age. However there is often no sign that the child has developed a corresponding development in comprehension. Words are often used out of context, or contradict what other people would consider to be their normal agreed-upon meaning. Hyperlexia may, in fact, even serve to hide high levels of vulnerability and need if sophisticated language use is understood by others to indicate that the young person is capable and has no obvious learning difficulties. Combined with a normal or above normal IQ (which people with AS/HFA often have), this can contribute to service providers considering young people with AS/HFA to be the responsibility of 'other people', and lead them to target their resources at those considered to be ‘obviously’ impaired by autism (Tantam 2003).

Research on the needs of people with AS/HFA in relation to their reading and writing abilities is sketchy. Tantam (2003) noted that one of his patients could read Tolstoy’s War and Peace with no difficulties, but clinical experience with many other people indicates that sufferers’ often have difficulties in reading, understanding and navigating their way through things like government claims forms and benefit allowances. IQ may play a crucial role in determining outcomes here. Clinical experience also indicate that handwriting dyspraxia is sometimes present amongst people with AS.

2.2. Executive functioning

Individuals often have difficulties in relation to their executive functioning skills. Executive functioning refer to abilities to “control processes (such as planning, flexibility of thought and action, set-shifting, inhibition, and the retention of mental
representations) underlying action, in the broadest sense” (Holland et al 2000: 17). People may have difficulties with coping with unexpected changes, with alterations in their daily routines or with switching attention from one activity to another. However, although executive dysfunction may contribute to the difficulties that people with autistic spectrum disorders often experience in both inhibiting and adolescence actions, as yet little attention has been specifically paid to executive dysfunction in children or adults with AS/HFA or its impacts on their needs (Holland et al 2000).

2.3. Choice
Finally here, individuals may also have trouble with making decisions in the face of competing imperatives. Choice is often associated with increased anxiety for many individuals with AS/HFA. Some people are able to freely make choices, others need to experience them first before they can make a reasoned decision, and others still require considerable support to express their choices. The difficulty with choice appears to relate to individuals’ with AS/HFA particular thinking style – a style that Frith and Happé (1994) argue is characterised by weak central coherence. Frith (1989) developed this phrase to refer to the difficulties for individuals with AS/HFA to integrate local information into global meaning. It refers to the tendency of people with AS/HFA to focus on particular features of their environment at the expense of the overall picture (Holland et al 2000). Practically, it can indicate a relative lack of flexibility, weakness in certain problem-solving skills, and difficulty imagining futures. When faced with multiple outcomes or options, the thinking style of people with AS can generate anxiety and uncertainty.

3. Health and Related Services
Numerous medical problems are more common amongst people with AS (Tantam 2003). These can include “disorders affecting brain development in childhood, such as hydrocephalus, tuberous sclerosis, and neurofibromatosis; congenital perceptual disorders affecting social interaction; and disorders affecting motor control, such as myotonia and myopathy” (ibid: 147). Additionally (Brogan 2001) found from his study that sufferers reported additional medical conditions including dyslexia, dyspraxia, learning disabilities, M.E. or Chronic Fatigue Syndrome, asthma, bowel, bladder and stomach problems. Problems relating to sensation are sometimes found, and some people with AS/HFA show extreme sensitivity to particular sights or
sounds. On occasions sufferers may attempt to forcibly suppress the offending sensations.

3.1. Involuntary movements

Involuntary movement disorders such as epilepsy are common. The onset of epilepsy usually occurs around adolescence or young adulthood (Howlin 2000). The incidence rate of epilepsy amongst sufferers is highest for people who have substantial learning difficulties. Once this group is set aside, “the incidence rate of epilepsy is 18 to 20%, with little distinction between people who have an average IQ and people who have an average learning disability” (Howlin 2000: 73). Gilles de La Tourette’s symptom is also frequent amongst people who have AS (Tantam 2000).

3.2. Mental health problems

Although little mention of mental health needs was made in Asperger’s original account of AS/HFA, it is now widely believed that children and adults with AS are at an increased risk of developing mental health problems, including psychiatric disorders. Whilst the exact prevalence and nature of the problems varies between studies, there is some evidence of increased rates of ADHD (Ghaziuddin et al. 1998).

In adults, the main psychiatric diagnosis are depression and other mood-related disorders. The apparently high rates of depression in particular, but also other mental health problems, may reflect the characteristics of the syndrome itself and its neurobiological aetiology. For example, first degree relatives of individuals with AS seem to be at increased risk of depression (Gillberg 1991). However, the social isolation which many children and adults experience as a result of living with AS/HFA may increase the risk of developing a mood disorder. The continual pressure to fit in and be like others may also take its toll and lead to mental health problems (Howlin 2000). For example several authors with ASD have described the compensatory abilities that they have developed to get along in the world as contravening their natural inclinations and reactions to the confusion of the social world. Coping mechanisms may be called ‘facades’ (Williams 1992), ‘masquerading’ (Carrington and Graham 2001), or simply, ‘pretending to be normal’ (Willey 1999).
As a result of trying to ‘fit in’ and pretending to be normal, however, many adults experience significant levels of anxiety (Attwood 1998).

There may also be critical periods at which co-morbidity is more likely to develop, such as during adolescence, when the development of insight and extra social pressures are particularly likely to affect individuals with AS/HFA. Although the vulnerability to mental health problems, including diagnosable psychiatric illness, appears to be increased amongst people with AS/HFA, the prevalence rate needs to be examined further.

3.3. Health and social services

Where health difficulties do occur people may require access to health and social services to help them resolve their needs. People often, however, find it difficult to access the particular professionals they want to see. 91% of Parson’s (2000) respondents said that they found their GP easy to access whereas only 64% said they found it easy to talk to a paediatrician.

In relation to service provision, Brogan (2001) questioned the service providers of people with an ASD (200 questionnaire sent out, 103 returned). Of these only 7 service providers indicated that they provided a service solely for individuals with autism, and 56 indicated that they provided for people with a range of disabilities.

A total of 47 service providers completed the item of Brogan’s survey about additional specifications for the provision of care services for people with autism. Of these, 28 provided highly planned and structured activities, 37 provided independent living skills training, 38 provided social skills training, 38 reported to manage and reduce challenging behaviours, 36 had close links with family members and 45 had close links with professionals. The low level of provision for people with AS/HFA is clear.
4. Social Situation

People with Asperger’s syndrome often have particular needs in relation to their social situation, for example with their accommodation provision. The majority of adults with AS live at home with their parents or require some kind of support from other people. Tantam (1992) found that 76% of his respondents lived in residential or hospital accommodation, while Jarbrink and Knapp (2001) note that at least 35% of people with HFA will need to live in sheltered care once they have moved out of their family accommodation. Only a maximum of 35% of those who have HFA will be able to live independently of any type of carers in their lifetime (ibid). 70% of the parents in Barnard et al’s study (2001: 6) were of the opinion that their children would be unable to manage an independent life, and that “less than 10% of adults [with AS/HFA] can manage the most basic household tasks such as shopping, preparing meals, laundry, paying bills and managing money without help”. However, while a large proportion of people with AS live at home, 65% of adults with AS living at home in Barnard et al’s did not have a community care assessment. This meant that the burden of care for accommodation provision was often passed onto the parents.

Continual carer support of this type can come at a price, though. For carers who do support a loved one or partner with AS/HFA, the stress can be great. In fact taking continual care of an adult child with AS/HFA in the parental home can have such a profound toll on the lives of carers that it often results in them needing some kind of support of their own. The National Autistic Society (1996) notes that 81% of carers reported that they suffered from stress as a result of caring for someone with ASD.

4.1. Activities

People with AS/HFA can find it difficult to get paid employment, and often require assistance in doing so (Howlin et al 2000). The difficulties individuals with AS/HFA have with empathy (see below), and the use of repetitive, ritualistic gestures and movements may have negative affects on their ability to obtain employment in a service based workplace that is increasingly predicated upon effective discipline of the body and the ability to present oneself as ‘normal’ and lacking ‘impairment’ or ‘disability’. Howlin et al argue though that the benefits of helping people with AS/HFA to obtain work are clear. If a successful effort isn’t made to help people with AS/HFA make the shift from the institutionalised world of school to the workplace...
the effort and money that has been put into the young person’s education until that point has been wasted. The other option to paid work, dependence on state assistance for fifty or sixty years, is an incredibly expensive alternative, particularly when the cost of the mental health problems linked to long term unemployment are factored in (ibid).

4.2. Relationships
One of the key characteristics of the children Kanner and Asperger looked at was a lack of social interaction by young people with ASDs with other individuals, and a difficulty in communicating with others on those occasions when this interaction was sought.

These difficulties may be related to what the research literature refers to as ‘a theory of mind’ deficit on the part of people with AS/HFA (Baron-Cohen et al 1985). A theory of mind refers to the ability to infer mental states in others, and reflect on one’s own mental states. A deficit here indicates a discrepancy in the ability to figure out the emotions, feelings and thoughts of other people. These deficits were initially identified experimentally in children with autism (Baron-Cohen et al. 1985) and the importance of these deficits in terms of limiting the possibility of social interaction is now well established (Leslie and Thaiss 1992, Charman and Baron-Cohen 1992, Perner et al 1989).

The more developmentally disordered a person with autism is, the more severe is their theory of mind deficit. Out of all the people with an autistic spectrum disorder theory of mind deficits may cause the most stress for people with AS/HFA given that their deficit may not be so severe as to make them unaware of the judgments of other people, or to prevent them from thinking that they are somehow different from other people. This may increase the stress of interpersonal interaction.

Some large scale studies have suggested though that, contra to Asperger and Kanner, having friends or a sexual partner is considered by individuals with AS/HFA to be one of their top three needs (Barnard et al. 2000). However, many people with AS/HFA find it difficult to make friends with other people. In a study of 68 people who had AS/HFA Howlin et al (2004) found that over half had no friends at all, and very few had ever had a sexual relationship. Only 26% (18 individuals had interactions with others that involved a contribution in a host of activities (ibid)).
Where individuals with AS/HFA do construct adult friendships, they can be complicated by the deficits associated with the core of the Asperger Syndrome (Slater-Walker and Slater-Walker 2002). The partners of people with AS/HFA can adopt the position of full time carer as well. The emotional costs of these role adoptions can be significant, especially when the relationships go through times of stress which all do at some point (Aston 2001). Periods of upset can be further intensified by the relative cognitive inflexibility of people with AS/HFA, whose thinking tends to be rigid and therefore has difficulties adapting to transitions and periods of change (Attwood 1998).

Some people with AS/HFA for whom the social world seems too difficult to understand seek protection in “a special world of idiosyncratic interests, routines and private preoccupations” (Tantam 2000: 57). These interests are often introverted, obsessional and can dominate the person’s thinking (Attwood 1998). Tantam notes that for individuals who do attempt to deal with the world in this way interactions with others have little appeal. There is little sign of thinking about the future, and a disinclination to take on adult roles and liabilities (Tantam 2000). However, at the same time the needs for service provision for these people becomes arguably even greater given their purposeful unwillingness to take care of themselves and engage with others.

4.3. Emotions
The important place emotions, and difficulties stemming from them, have in mediating the experiences of people with AS/HFA is clear. In Tantam’s (2003: 145) words, most “do not live in their own world so much as live on their own island floating in a sea of humanity. They do have projects and plans for themselves, and they do compare themselves with other people, often painfully”. Feeling different from others, however, is common and can lead to alienation and loneliness. It can for example result in sexual frustration and an disrupt abilities to articulate desire identities through successful social performances.

Where people with AS feel victimised or put down upon by others they may dwell on the experience over an extended period of time until eventually their feelings become
channelled into aggression towards others (Tantam 2000). Intense anger is not common. In fact many people with AS/HFA have strong ethical codes that dissuade them from engaging in violence or harmful practices directed towards others. Anxiety and frustration are more frequently found amongst individuals with AS/HFA. However, Tantam (2003: 158) notes that individuals with AS/HFA can become angry when they feel that their anger is justified, for example if they feel purposely slighted. Aggression towards younger brothers and sisters is a relatively common occurrence, as are displays of anger in institutionalised settings such as schools and workplaces, though the most common place for aggression is the home (ibid). While this level of aggression is for the most part quite rare in people with AS/HFA, where it does occur it can lead to social isolation “because parents are ashamed for friends and family to call at the home and see broken furniture or walls with holes punched in them” (ibid). One contributory factor to aggressive displays may be an empathy deficit of the sort discussed above which can lead to interactional difficulties. There may be a need here for empathy training for people with AS/HFA who have anger problems

4.4. Criminal activity

Behaviours and actions, such as violence spilling over from anger, may be considered problematic in children with AS and result in exclusion from educational and other facilities. In adulthood such behaviours are most often interpreted as criminal offending. A prevalence study by Scragg and Shaw (1994) of the male population of Broadmoor (maximum security) hospital indicated the presence of AS in just over 2% of the sample. This rate is much higher than would be expected.

Based on these finding is safe to assume that there probably people with AS in prison or in other secure facilities, and it is important that their needs are addressed. However, it is important to note that using the limited research findings as evidence of an association between AS and offending, particularly violent offending, is unwarranted (Howlin 1997). A representative study of the quantitative and qualitative nature and extent criminal activity amongst people with AS needs to be on the basis of large and systematic community sample, which so far has not been done.

In fact, it appears that where people with AS do commit crimes these crimes can result from difficulties in understanding social interaction or from obsessional
personal interests. Holland et al (2000) note that the cognitive rigidity of people with AS more typically leads to an obsession with rules and order and the adoption of an authoritative personality that seeks to control and police the behaviour of others. In turn, however, these types of actions can serve to distance the person with AS even further from his or her peers.

4.5. Drug use
Howlin (2000) notes that there is no data on drug or alcohol use amongst individuals with autism. However, based on clinical evidence she notes that many high-functioning individuals with autism seem to make great efforts to avoid drug use of any kind. Rather, as mentioned, they may adopt a law enforcement persona and try and stop other people from taking drugs, whether legal, like alcohol and tobacco, or illicit. Howlin (ibid) and Tantam (2000) both note, however, that given the rigid nature of the cognitive styles and behavioural practices of people with AS/HFA, where drug and alcohol use becomes a regular occurrence it can prove to be an addictive behaviour and hard to change. This may be especially so for sufferers with anxiety and mood disorders. The use of street drugs like heroin is considered rare amongst people with autism, given that acquiring them often takes a lot of successful inter-personal negotiation and street wise ‘common sense’ (Tantam 2000).

5. Education
Young people with AS/HFA often have special needs with regards their educational provision. A statement of Special Educational Need is the key to this. However it can be difficult to acquire this document. People with severe autistic spectrum disorders, who are considered to be low functioning, are much more likely to receive support from learning disability services than individuals considered to be high functioning (Tantam 2003). The literature is ambiguous about the number of people with AS/HFA who possess this statement. Powell (2000) for example argues that 1 in 5 pupils with AS receive a Statement of Special Educational Need in the UK. In contrast Parsons (2000) indicates that 85% of children with AS/HFA have or had a statement of educational needs. Of those who did not have this statement, Parsons found from his sample (n=63) that half were some way through the process of obtaining this statement. The discrepancy between the results of these two studies is so large that it
clearly indicates that further exploration needs to be done on the educational needs of people with AS/HFA.

Where young people with AS/HFA go to school is also an important factor. For example, even those individuals with a low-functioning autistic disorder who have very substantial support are very rarely included in mainstream secondary schools. On the other hand, young people who have a high-functioning ASD are much more likely to be represented in mainstream schooling (Beatson & Prelock 2002). In these institutional settings young people with AS often have special needs in comparison to other young people and present special challenges to teachers and other pupils.

Very few research studies have included an analysis of the difficulties of the social integration of young people with AS/HFA (Attwood 2000). Those that have been conducted suggest that the age of the child is relevant. Younger children in mainstream schools seem to be able to make allowances for the social impairments of a child with AS/HFA (Bosch 2002), particularly if the child with AS/HFA has help in orientating to the mainstream classroom (Harrower & Dunlap 2001). The attitudes of teachers have particular influence during the early primary school years, and teachers with a positive attitude towards children with AS/HFA are often rewarded by a reduction in challenging behavior and more social integration by the pupils with AS/HFA.

As children with AS/HFA become older their parents' confidence in the appropriateness of inclusion often diminishes (Kasari et al 1999). The challenge of primary school is often replaced by the distress of secondary school (Tantam 2000). The difficulties in non-verbal communication and empathy that characterise AS/HFA can be especially deleterious in adolescence and young adulthood, when successful social relationships are the key to almost every achievement (Tantam 1991). They can disrupt social interaction, and often place obstacles in the way of making friendships. If they are not supported in this period, young adolescents with AS/HFA can feel misunderstood and isolated in secondary school, which can lead to a long-term lack of self-esteem (Mishna and Muskat 1998) and depression (Attwood 1998), particularly during early adolescence when self-awareness is increasing.
This distress is often linked to bullying by other pupils, who have a greater influence over the success or failure of inclusion than teachers, as pupils become older (Ochs et al 2001). Bullying is a significant source of anguish for young people in school (Smith & Sharp 1994). One major study in the UK found that almost 10% of 11-18-year-olds were bullied at least 'sometimes' and that 4% were bullied at least 'once a week' (Whitney and Smith 1993). Overall, Whitney and Smith's study found that reports of bullying showed an overall decrease for the 8-16-year-old sub-sample although there was an increase at the beginning of secondary education (usually occurring at 11-12 years). Bullying has both long-and short-term effects.

Although bullying of SEN pupils has been less studied, it is known that communication problems and learning difficulties increase its risk (Whitney et al 1994), suggesting that children with ASD, who may have both of these problems, may be bullied more than other children, although this is unknown. Social rejection by peers of young people with special needs also increases the likelihood of school refusal and therefore the breakdown of education (Myklebust 2002). It has been suggested, but not demonstrated, that bullying may be one of the factors that has impeded mainstreaming of special needs pupils in secondary school (Norwich & Kelly, 2004).

Where victimization of young people with AS/HFA does occur it can lead to long-term unhappiness, depression, conduct disorders and have a negative effect on young people’s confidence (Tantam 2000). These feelings can intensify and complicate the mental health problems that young people with Asperger’s syndrome often experience during adolescence (Ghaziuddin and Weidmer-Mikhail 1998, Tantam 1991). Tantam (2000) notes that the development of psychological disorders amongst young people and adults with AS/HFA are more widespread, and their impact more intense, then has previously been acknowledged in much of the literature.

Tantam argues that in general “what is not changing is that the high functioning adolescent finds that on leaving school, no support is available from pediatric services, from child and adolescent psychiatry, and, because he or she is high functioning, from learning disability services either” (2003: 145).
6. Adult outcomes

Although people with AS/HFA are more able and many make good progress as they grow older, their difficulties in social interaction and communication persist throughout adulthood and the impact of these deficits remains profound (Howlin, 1997). Lack of empathy is one of the most important factors in this older group, too, as it determines the quality of relationships that a person with AS/HFA is able to make with others (e.g., carers/family members, spouses/partners, employers, etc.).

Much of the recent research that has been carried out on people’s experiences of living with AS primarily concentrates on the child and adolescent population, meaning that the experiences and needs of adults are often overlooked. There has been a growing awareness of this problem in recent years. The necessity for research on adults with AS/HFA is clear. Many adults who are affected by the condition either don’t know they have AS/HFA or they don’t have a formal diagnosis of it. Because of this, because they are out of touch with clinicians in the first place, and because they are often skipped over by researchers in the second, there is currently no extensive knowledge base about the health and social care needs of affected adults with high functioning autism, and the impact the condition may have on adult functioning.

Howlin (2000) reviewed what was known about outcomes in adulthood for individuals with HFA or AS. Her paper was based on a meta-analysis of several longitudinal follow up studies. She found that the outcomes for adults with AS/HFA in these studies were heterogeneous over the long term, and the effects AS/HFA had on the everyday lives and functioning of adults was highly variable. Depending on the study being looked at, Howlin discovered that the number of people with Asperger’s syndrome who were working ranged from 5 to 44%, the percentage who lived on their own from 16 to 50%, evaluations of an overall positive transition from childhood to adulthood from 16 to 44% and the incidence of psychiatric disorder from 11 to 67% (Howlin 2000: 73).

Based on her meta-analysis, Howlin found that overall the chances of psychological, emotional and economic decline for individuals with AS/HFA in adolescence or young adulthood was related to IQ levels, and the onset of epilepsy; namely, individuals who had a low IQ were less likely to demonstrate a functional
improvement. In contrast, for individuals with a higher IQ adolescence was as likely to be associated with an improvement in functioning as not (Howlin 2000). However, overall outcomes appear to be ambivalent. Adults with Asperger syndrome were likely to develop mental health problems. Depression was the most prevalent condition found in the studies looked at by Howlin, and was typically connected to anxiety. Bipolar disorders and mania were found in the sample, though Schizophrenic illness showing a much reduced incidence rate compared to the other mental illnesses. While the epidemiological data is comparatively sparse, Howlin argues that the studies point to people with Asperger’s syndrome being at a comparatively greater risk of developing mental health conditions.

In a later follow up paper Howlin et al (2004) completed one of the largest studies of the effect the condition had on the transition from child to adult functioning. This study examined 68 young people who met the conditions for autism as children and had an IQ of at least 50. These individuals were then followed up as adults. Overall, these authors found that their respondents continued to make progress with their condition from when they were children. However most of the individuals involved in this study were reliant on their families to some extent or needed some degree of housing or care. The authors found that only those individuals who had an IQ of at least 70 had a reasonable expectation of being relatively successful. Even then, Howlin et al noted that the repetitive and ceremonial practices often engaged in by people with Asperger’s syndrome could ameliorate the potential benefits of having a normal or above normal IQ. The authors argued that, overall, envisioning outcomes for people with AS/HFA is difficult given the heterogeneous range of dysfunctions linked with the condition. Furthermore the question of geography, the question of where people reside and what kinds of facilities are available or potentially available to them may be more crucial than any other factors at determining overall life possibilities and chances of success. Becoming a relative success as an adult may be predicated just as much on the material and symbolic support the individual with AS/HFA receives as on IQ levels.

Conclusion
Overall, then, from the little research that has been done in this area, it seems that individuals with AS/HFA have specific needs relating to the severity of their
condition, their social identities, the existing service provision, their stage, their developmental abilities, their IQ levels, their position in the lifecourse, and their relationships to other people. Like all people with autism, and like all people living with chronic conditions in general, these needs can be complex or simple. Needs can result from wanting help navigating a way through a benefits claim form, or from a desire to construct an emotionally satisfactory social identity.

However, though people with AS/HFA may require help with actualising their needs, this help is often lacking or remedial. This absence can result from an unwillingness to help people with AS, a prioritisation of existing resources so that they will benefit those with more ‘severe’ conditions. Other people’s perceptions of individuals with AS/HFA can also be a factor. For example Howlin (1997) notes that society’s perceptions of individuals who appear to be only mildly impaired tend to be much less sympathetic than those who appear to be severely so. The demands made on someone who is clearly very ‘disabled’, has little or no speech, and who withdraws from social contact into a life of solitary routine are unlikely to be excessive. However, for someone who appears to be ‘nearly normal’, who has had the benefits of a good education, and who possesses considerable ability, at least in certain areas, expectations are often unrealistically high. If and when the adolescent or adult with autism is unable to meet these expectations they may well be faced with criticism and rejection, which in turn can do little to improve the feelings of failure and low esteem that may often be present (Howlin 2000). As such they may experience considerable emotional troubles being expected to fit in with everyone else but not being sure how, and being castigated for their efforts and failures. People with AS/HFA often therefore need some kind of tangible social and/or emotional support structure, but may be relatively less likely to receive it than people considered to be more handicapped.

Misperceptions about what AS/HFA is and what its effects are may stem in large part from a lack of information about the condition. Brogan (2001) noted poor autism awareness amongst professionals, and also that there was a lack of resources for the assessment and diagnosis of teenagers and adults with ASD.
Without appropriate provision for, and understanding of, their needs, the literature, and clinical experience, indicates that many adults with AS are at a greater risk of becoming socially isolated, dropping out of school or college, being unable to work, suffering mental health problems or experiencing psychological breakdown (Howlin 1997). An increasing amount of research also confirms what practitioners have been reporting for a long time, namely that adults with AS are at significant risk of mental health difficulties (Howlin 1997), particularly affective disorders (Wing 1981) and appear to fit the high risk ‘suicide prone’ category (Wolff and McGuire 1995). While the emotional and personal devastation of such social interruptions, both for individuals with AS/HFA, and their carers, is clear, the economic costs may also be substantial. Lack of support services for people with AS who are experiencing difficulties can lead to police involvement, prison sentences, admission to psychiatric units and trial-and-error drug treatment. Even if AS/HFA is looked at through a model that prioritises allocation of services on a cost benefit analysis, it seems clear that it is more cost effective to deal with the needs of people with AS/HFA prior to personal breakdown than with the consequences afterwards.
How good are you at reading other peoples feelings? * Have you ever found yourself getting angry or violent easily? Crosstabulation

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</tr>
<tr>
<td>No</td>
<td>34</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.180</td>
<td>3</td>
<td>0.027</td>
</tr>
<tr>
<td>9.184</td>
<td>3</td>
<td>0.027</td>
</tr>
<tr>
<td>1.304</td>
<td>1</td>
<td>0.253</td>
</tr>
</tbody>
</table>

Note: A 4 cells (50.0%) have expected count less than 5. The minimum expected count is 1.04.
How good are you at reading other people's feelings? * How good are you at responding to other people's feelings without them having to ask for a response?

**Crosstabulation**

<table>
<thead>
<tr>
<th>How good are you at Responding to others feelings without them having to ask for a response?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>2 0 0 0 0 2</td>
</tr>
<tr>
<td>Good</td>
<td>2 1 2 5 0 3 2</td>
</tr>
<tr>
<td>Not very good</td>
<td>1 1 9 1 0 1 2</td>
</tr>
<tr>
<td>Poor</td>
<td>0 1 1 0 0 1 0</td>
</tr>
<tr>
<td>Total</td>
<td>6 2 0 3 9 1 0 1 5</td>
</tr>
</tbody>
</table>

**Chi-Square Tests**

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>73.399(a)</td>
<td>1</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>59.528</td>
<td>2</td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>25.320 75</td>
<td>1</td>
</tr>
</tbody>
</table>

* 15 cells (75.0%) have expected count less than 5. The minimum expected count is .16.
Do you have any psychiatric difficulties? * Have you ever been bullied?

### Crosstabulation

<table>
<thead>
<tr>
<th></th>
<th>Have you ever been bullied?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have any psychiatric difficulties?</td>
<td>43 25 2</td>
<td>70</td>
</tr>
</tbody>
</table>

### Chi-Square Tests

- **Pearson Chi-Square**: 1.465, df 1, p = 0.214
- **Likelihood Ratio**: 3.227, df 2, p = 0.199
- **Linear-by-Linear Association**: 1.139, df 1, p = 0.286

---

Is bullying still a problem for you? * Do you have any psychiatric difficulties?

### Crosstabulation

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is bullying still a problem for you?</td>
<td>14 25 39</td>
<td>4 20 24</td>
<td>1 1 2</td>
</tr>
</tbody>
</table>

### Chi-Square Tests

- **Pearson Chi-Square**: 3.086, df 1, p = 0.214
- **Likelihood Ratio**: 1.459, df 1, p = 0.214
- **Linear-by-Linear Association**: 1.045, df 1, p = 0.304

---

Note: a 7 cells (77.8%) have expected count less than 5. The minimum expected count is 0.03.

- a 2 cells (33.3%) have expected count less than 5. The minimum expected count is 0.58.
### Crosstabulation

<table>
<thead>
<tr>
<th>Are you receiving any state benefits?</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you ever had any contact with SSD?</td>
<td>31</td>
<td>39</td>
<td>70</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>31</td>
<td>77</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
<th>Exact Sig. (2-sided)</th>
<th>Exact Sig. (1-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>14.877(b)</td>
<td>.000 .000</td>
<td>.000 .000</td>
<td></td>
</tr>
<tr>
<td>Continuity Correction(a)</td>
<td>13.139</td>
<td>.000 .000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>15.628</td>
<td>.000 .000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fisher's Exact Test</td>
<td>15.484</td>
<td>.000 .000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>77</td>
<td>The minimum</td>
<td>.000</td>
<td>.000</td>
</tr>
</tbody>
</table>

Notes:
- (a) Computed only for a 2x2 table
- (b) 0 cells (.0%) have expected count less than 5. The minimum expected count is 15.30.
Have you ever had a Statement of Special Education Need? * Satisfaction with secondary ed Crosstabulation

<table>
<thead>
<tr>
<th>Have you ever had a Statement of Special Education Need? Total</th>
<th>Highly satisfied</th>
<th>Satisfied</th>
<th>Dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>Don't know</td>
<td>18</td>
</tr>
<tr>
<td>Chi-Square Tests</td>
<td>5.929</td>
<td>6.038</td>
<td>3.879</td>
</tr>
<tr>
<td>Pearson Chi-Square</td>
<td>0.038</td>
<td>0.132</td>
<td>0.014</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>2.272</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>73</td>
<td>74</td>
<td></td>
</tr>
</tbody>
</table>

Have you ever had a Statement of Special Education Need? * Did you receive any extra support in secondary education from professionals? Crosstabulation

<table>
<thead>
<tr>
<th>Did you receive any extra support in secondary education from professionals? Total</th>
<th>Yes</th>
<th>No</th>
<th>Don't know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>17</td>
<td>13</td>
</tr>
<tr>
<td>Chi-Square Tests</td>
<td>12.445</td>
<td>13.257</td>
<td>3.879</td>
</tr>
<tr>
<td>Pearson Chi-Square</td>
<td>4</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>0.038</td>
<td>0.132</td>
<td>0.014</td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>74</td>
<td>74</td>
<td>74</td>
</tr>
</tbody>
</table>
Has planning ever been a problem for you? * Do you have difficulties coping with unexpected changes? Crosstabulation

<table>
<thead>
<tr>
<th>Has planning ever been a problem for you? Total</th>
<th>Fine now</th>
<th>Only problem when anxious</th>
<th>Sometimes</th>
<th>Still a problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1, 6</td>
<td>22</td>
<td>21</td>
<td>50</td>
</tr>
<tr>
<td>No</td>
<td>1, 1</td>
<td>1</td>
<td>4, 2</td>
<td>23</td>
</tr>
<tr>
<td>Total</td>
<td>1, 1</td>
<td>1</td>
<td>27, 22</td>
<td>54</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Do you have difficulties coping with unexpected changes?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1, 6</td>
</tr>
<tr>
<td>No</td>
<td>1, 1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pearson Chi-Square</th>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likelihood Ratio</td>
<td>6.349</td>
<td>3</td>
<td>.096</td>
</tr>
<tr>
<td>Linear-by-Linear Association</td>
<td>3.641</td>
<td>3</td>
<td>.303</td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>54</td>
<td>1</td>
<td>.071</td>
</tr>
</tbody>
</table>

A 5 cells (62.5%) have expected count less than 5. The minimum expected count is .15.
Has getting on with people in different situations ever been a problem for you? * Has switching task ever been a problem for you? Crosstabulation

<table>
<thead>
<tr>
<th>Has getting on with people in different situations ever been a problem for you?</th>
<th>Has switching task ever been a problem for you?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fine now</td>
<td>Only problem when anxious</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Count</td>
<td>10 113</td>
<td>0 2013</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>25.526(a)</td>
<td>9</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>14.911</td>
<td>9</td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>3.687</td>
<td>1</td>
</tr>
</tbody>
</table>

12 cells (75.0%) have expected count less than 5. The minimum expected count is .07.
How good are you at getting on with people in different situations? * How good are you at reading other peoples feelings? Crosstabulation

<table>
<thead>
<tr>
<th>How good are you at getting on with people in different situations?</th>
<th>Very good</th>
<th>Good</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>1 2 3 0 6</td>
<td></td>
<td>20</td>
</tr>
<tr>
<td>Not very good</td>
<td>0 14 5 1</td>
<td>16 19</td>
<td>37</td>
</tr>
<tr>
<td>Poor</td>
<td>0 0 2 8 10</td>
<td>0 0 2 9</td>
<td>73</td>
</tr>
</tbody>
</table>

Chi-Square Tests

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>39.997(a)</td>
<td>.000 .000</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>39.446</td>
<td>.000</td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>22.701</td>
<td>.000</td>
</tr>
</tbody>
</table>

How good are you at Responding to others feelings without them having to ask for a response? Crosstabulation

<table>
<thead>
<tr>
<th>How good are you at Responding to others feelings without them having to ask for a response?</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good</td>
<td>0 0 2 0 2</td>
</tr>
<tr>
<td>Not very good</td>
<td>1 1 2 1 17</td>
</tr>
<tr>
<td>Poor</td>
<td>0 0 9 14 8 31</td>
</tr>
<tr>
<td>Total</td>
<td>1 0 9 11 21</td>
</tr>
</tbody>
</table>

Chi-Square Tests

<table>
<thead>
<tr>
<th>Value</th>
<th>df</th>
<th>Asymp. Sig. (2-sided)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pearson Chi-Square</td>
<td>31.353(a)</td>
<td>.002 .000</td>
</tr>
<tr>
<td>Likelihood Ratio</td>
<td>37.865</td>
<td>.001</td>
</tr>
<tr>
<td>Linear-by-Linear Association N of Valid Cases</td>
<td>11.175</td>
<td>.001</td>
</tr>
</tbody>
</table>

a 10 cells (62.5%) have expected count less than 5. The minimum expected count is .16.

a 12 cells (60.0%) have expected count less than 5. The minimum expected count is .05.
9: BIBLIOGRAPHY


NAS(2002): http://w020211.web.dircon.net/family/partners/partnerguide.html#common


