

ASPECT **Consultancy Report**

Executive Summary

A National Report on the Needs of **Adults with Asperger Syndrome**

Compiled by Luke Beardon and Genevieve Edmonds, 2007

Introduction / Background

There is currently a paucity of information regarding the needs of adults with Asperger Syndrome (AS)¹. While there are an increasing number of autobiographical accounts being published, there are few studies looking at the broader population with large numbers of individuals. It is clear that services for adults with AS are few and far between and there are no structures within Local Authorities to provide Asperger specific support as a statutory duty. As a result it is extremely likely that a high proportion of adults with AS who require support are either being supported inappropriately, or not being supported at all. It is intended through the publication of this report to highlight some of the common areas of difficulty faced by people with AS.

This report was compiled specifically to allow individuals with AS to directly contribute towards it. All contributions have been recorded within the report, along with all comments made. If there were potentially litigious comments these have been altered (e.g. names changed). Names of organisations have also been removed. Terminology used by individuals with AS has been left unaltered unless it has been deemed to potentially cause offence.

Aims / Rationale

The original group of people who worked towards getting the consultation process running were a mix of people with AS, a parent, and two 'professionals' working within the field of autism / AS. The overall intention of undertaking the consultation was threefold:

1. to allow individuals with AS to voice their opinion
2. to highlight areas of difficulty for adults with AS
3. to produce a report that could be used by any party to lobby for better services at a local and / or National level

Point one: many people with AS are, by nature, isolated from society. Additionally, many individuals may have little faith in a system that has let them down in the past, and may be reluctant to pursue options for better services on an individual basis. There have been very few 'studies' at a National level with large numbers of adults², and few (if any) that allow large numbers of individuals to individually articulate opinion and experience. While the end result may seem, to some, unwieldy, it was with deliberate intent that individualised comments and opinions are expressed within the report to allow a level of individual expression. As in any diverse population not all opinions are the same; it is felt that the diversity of population should be demonstrated just as much as overarching, similar issues faced.

¹ We have not defined AS in this study; individuals themselves were 'self referred' and are either formally diagnosed with a form of autism, including AS or High Functioning Autism (HFA) or consider themselves to have AS though not formally diagnosed. See results to question 1 for further details.

² By 'large' we mean more than 50 people; by adults we mean aged 16 or over.

Point two: while it has already been inferred that no two individuals' experiences will be the same, there are patterns of similarity in terms of needs not being met. As we intend the report to be used effectively in terms of lobbying we have tried to highlight some of the patterns emerging from the consultation in as an objective manner as possible. We have summaries certain responses to specific questions and have included a final summary including the key issues for ease of use.

Point three: the 'ASPECT team' specifically had an achievable goal - to consult with as many adults with AS as possible and to produce a report that could then be used by individuals and groups as they saw fit. The team itself did not have any intentions to lobby themselves, though it is hoped that with additional funding a more active role may be undertaken. We are aware of other groups who are already lobbying and working hard to spark change, and it is hoped that such individuals and groups will find the report beneficial in their campaigning.

The Team

The steering group consisted of:

Genevieve Edmonds, person with AS
Dean Worton, person with AS
Giles Harvey, person with AS
Andrew Bailey, person with AS
Clare Hughes, NAS Regional Officer
Jane Sochovsky, parent
Luke Beardon, Senior Lecturer in Autism, Sheffield Hallam University

The steering group were responsible for organising the venue and the Aspect Action day attended by 100 individuals. Following this the steering group disbanded and the consultation / data collation / write up phase was taken on by Genevieve Edmonds and Luke Beardon, with invaluable IT support from Andrew Bailey.

Process

Adults with AS were invited to a consultation day event with a program of speakers. Invitations were sent electronically to as many different individuals and groups as we could find. Speakers were adults with AS who outlined their own experiences. Questionnaires were available as a hard paper copy or via the ASPECT website electronically. The questionnaire itself was designed to produce as much information as possible, in order to have as high an impact as possible following publication and dissemination. Tickets for the event were 'first come first served'.

Results

A total of 237 questionnaires were received and recorded. As far as we know this is the largest consultation with adults with AS to date. Figures (percentages in 'results' sections) have been rounded for clarity.

Executive Summary

Section 1 - Diagnosis

Summary of findings:

- ◆ The average age of diagnosis is 29 years of age
- ◆ One fifth of individuals remain undiagnosed
- ◆ 28% of individuals report a diagnosis of something in addition to AS
- ◆ Of those 23% have a diagnosis of dyslexia, 15% a diagnosis of dyspraxia, and 15% ADD / ADHD
- ◆ 64% of individuals reported that the diagnosis was either very or somewhat problematic to obtain
- ◆ There is a clear and major problem for most adults with AS to get a formal diagnosis

Recommendations:

- ◆ Local Authorities designate a specific team to have key responsibilities for diagnosing adults with AS
- ◆ Training in AS and the diagnosis of for *all* clinical professionals involved
- ◆ All GPs to have AS specific training
- ◆ Waiting lists to have a fixed duration
- ◆ Clinicians accept the need to take parental reports into account
- ◆ A diagnosis to be seen as a basic human right for those who seek one, not an obstacle

Pertinent quotation:

"People who have a complex diagnosis should be referred to the top people in this country for assessment and not a local service who might mis-diagnose the Asperger traits as other mental illnesses. The psychological damage of this is far too great to be messed around with. People with Asperger Syndrome have rights - and it is not fair just to expect them to fall in with the rest of the world. AS people have to accept an NT world so why can't an NT world accept people with AS?"

Section 2 - Route to Diagnosis

Summary of findings:

- ◊ 61% of individuals describe the route to diagnosis as either difficult or very difficult
- ◊ Individuals felt in general that medical clinicians including GPs and Mental Health professionals were very poor in their understanding of AS
- ◊ There is a lack of consistency across the country for referral routes and levels of expertise
- ◊ Training for professionals is felt to be very inadequate

Recommendations

- ◊ Clear referral routes for adults
- ◊ Clarity for GPs as to where to refer
- ◊ Consistent practice across all Local Authorities, with poor Authorities recognising and implementing good practice from elsewhere in the country
- ◊ Higher levels of accountability in medical professionals
- ◊ Individuals themselves should never be put into a position where they have to pay to get a private diagnosis

Pertinent quotation:

"GPs need to have awareness training on Asperger Syndrome instead of thinking people with AS are mentally ill and need psychiatric help. Making GPs more aware is the first step to helping people with AS feel more trusting of the NHS."

Section 3 - Post Diagnostic Support / Advice

Summary of findings:

- ◇ 86% of individuals either received no support or not enough support post diagnosis
- ◇ No level of consistency across the country for post diagnostic support
- ◇ Support that does occur is often from voluntary organisations or other people with AS

Recommendations:

- ◇ All Authorities automatically refer individuals for support post diagnosis
- ◇ Levels of support clear and consistent throughout all Local Authorities
- ◇ Support to be carried out by individuals with specific knowledge and experience in the field of AS
- ◇ AS specific counselling to be offered as appropriate

Pertinent quotations:

"I wish my doctor and psychiatrist had a better understanding of my diagnosis. They seem to find it difficult dealing with me and just look like they are gritting their teeth to get through consultations!"

"So much seems to be geared towards parents, family members and carers. What about me? I want to pick up a book and not see the words for everyone except the person with an ASD. There needs to be far more for adults."

"Not enough support for adults with AS; all money put into helping children."

"Having a very high IQ, in many ways makes my problems worse, than having an average or below average IQ."

"Social services say AS is not a 'learning disability' and not 'mental health' - so no support given."

"At the moment I do not fit the criteria for any help as my I.Q. is 85. At times I'm at my wits end and need help & support but; where do I go?"

"People need to get over the idea that the neuro-typical way is 'right' and any other way is 'wrong'. The AS way is just as valid - in fact better in some respect. We should be accepted in our own right and the emphasis should be on educating NTs not to be so discriminatory and to get over the absurd and offensive idea that they are better than anyone else. People with AS don't need to be 'cured' or trained as to how to 'pretend' to be normal - it is the 'normal' people who need to learn that, contrary to what they think, they are not the pinnacle of God's creation and that there is in fact a lot they could learn from Aspies. They need to be taught not to be prejudiced and discriminatory and to accept and accommodate us for who we are."

Section 4 - Clinical Professionals

Summary of Findings:

- ◇ GPs are regarded as both the most helpful (29%) and the least helpful (34%)
- ◇ A third of individuals classed psychiatrists as least helpful in their experiences
- ◇ 7% of individuals did not find any clinical professionals helpful
- ◇ Understanding and awareness is generally very low
- ◇ There is a tendency not to listen to the individual with AS and not to treat them respectfully
- ◇ Clinicians still have a lot to learn about AS

Recommendations:

- ◇ As recommended in Section 1 AS training for all GPs as well as other clinical professionals including psychiatrists and psychologists
- ◇ Better adjustments for individuals with AS
- ◇ A greater propensity to listen to individuals and to take them seriously

Pertinent quotations:

"I think that clinical professionals should work on finding out the causes of their patients' health problems such as depression. I think that there seems to be a lot of emphasis placed on treating the symptoms of their patients' health problems and not enough emphasis on treating the underlying causes."

"Know about it [AS], not just say they've studied it."

"Learn a bit about AS, listen to clients, understand that we aren't dishonest and that we are scared, clarify things if our answers indicates we got the wrong meaning from your question, respect our need to communicate via e-mail/fax/letter and reduce telephone calls/face to face meetings"

"The biggest problem is the dichotomy between learning disability and mental health services. Often all one gets is the latter which is geared toward a "recovery ethos" and does not understand the neurological constraints of autism. There are valuable services for people with learning disabilities which would be appropriate to me that I am simply not allowed to access."

Section 5 - Accommodation

Key findings:

- ◇ 65% of individuals live alone
- ◇ Of those who do not, 51% live with parents and 37% with a spouse or partner
- ◇ 46% receive no support
- ◇ Of the 52% who do receive support 83% is either from a spouse / partner, or family / parents
- ◇ The vast majority of individuals either get no support or support from family or partners. Only a small minority get dedicated support from the Local Authority
- ◇ Very few people felt they were supported in getting accommodation
- ◇ 75% of individuals would prefer to live somewhere other than their current abode

Recommendations:

- ◇ Individuals with AS should have clear routes to gaining accommodation
- ◇ Agencies involved in accommodation issues should receive training in AS
- ◇ The needs of the individual must be taken into account

Pertinent quotations:

"I have tried to get help to get housing and all agencies and professionals refused to help me on the ground that I am an intelligent lady. They therefore think I can do it all my self."

"I have difficulties dealing with most "officials" who set up there own barriers between them and me, who don't really appreciate and understand the problems from my perspective and why I am not like other people in what I need."

"I just want to live with others like me and feel safe"

Section 6 - Benefits

Key findings:

- ◇ 64% of individuals are in receipt of benefits
- ◇ Over a third receive DLA
- ◇ Less than half got any support in applying for and finding out about benefits
- ◇ Most support comes from voluntary organisations or family

Recommendations:

- ◇ Forms need to be made more specific to AS
- ◇ Staff in benefits agencies to receive training in AS

Pertinent quotations:

"DLA forms are very long and complicated and need to be completed fully time and time again."

"DLA form TOO COMPLICATED and TOO LONG. Also it is tailored towards physical problems - it is very difficult to explain mental health and AS problems on that form."

Section 7 - Employment

Key findings:

- ◇ Only 21% of individuals got any support in getting a job
- ◇ For those that did only 19% got any support from generic (non specialist) employment agencies or job centre
- ◇ Only 10% got any support at interview
- ◇ Only 22% had / have any support during employment
- ◇ Over a third of individuals have sensory needs at work

Recommendations:

- ◇ Support to finding work and support at work should be available for all individuals who require it
- ◇ Employers should be encouraged to adapt recruitment techniques to reduce discrimination against individuals with AS - for example written interviews rather than face to face verbal ones
- ◇ Supported employment specific to AS should be provided by Local Authorities rather than relying on charitable organisations, or Local Authorities should support voluntary organisations to cater for all individuals
- ◇ Employers to get better support themselves by Local Authorities and incentives to employ and support individuals with AS

Pertinent quotations:

"I told my boss about the AS at my last annual review (c 1 year ago). He agreed to explain things in more detail for me if needed. This has happened only once in the year. Sadly, since I told him, he has stopped talking to me about promotion."

"I would say that I may well be prone to sensory overloads at work, from many conflicting demands all at once. Also, the need for at least some guidance within the workplace instead of being left very much to fend for myself."

"I need space to be alone at times away from people, sometimes to work and space away from expectations from social situations."

"I would love to get back to work, but all the application forms ask if I have a disability. I NEVER even get interviews now since diagnosis. Before I used to get a job within days, never mind an interview, since I have such a good CV!"

"The bottom line is that many jobs deliberately screen out Asperger's unwittingly. Personality tests ought to be illegal; it is a form of discrimination."

"Employment is key, we spend so much of our time there. I am simply degraded by a system that spits me out. I am massively overqualified but will get no promotion."

Section 8 - University / College

Key findings:

- ◇ Only 27% of individuals at College or University receive any support, and of those nearly a third of it comes from family or friends

Recommendations:

- ◇ Support for students must be provided from the outset, including support to fill in relevant forms
- ◇ Support must be individuals and specific to personal needs, rather than generic
- ◇ Students need encouragement and incentive to declare AS in order to access appropriate support
- ◇ All staff (not just teaching staff) at Colleges and Universities should have training in understanding the needs of individuals with AS

Pertinent quotations:

"I went to university and it was the worse time of my life. I had not expected the change to freak me out so much. I also didn't realise that I could not learn from lectures so avoided lectures and social contact. I did a psychology degree but clearly my issues were not obvious to anyone at the time."

"Once I was diagnosed with Asperger's Syndrome, I had some study skills tuition, as I had difficulty being able to grasp the necessary study skills, and extra time for exams, as I had much difficulty working under pressure. After I had this support, my work became comparable with others and I got better marks than other students who said that I wasn't good enough."

Section 9 - Public Transport

Key findings

- ◊ Major problems include sensory issues, particularly proximity to others and olfactory sensitivity
- ◊ Many individuals found lack of accuracy for arrivals / departures stressful
- ◊ Poor attitudes from other passengers and staff were reported

Recommendations

- ◊ Staff on public transport trained in AS
- ◊ Quiet areas available on all transport and for this to be 'policed'

Section 10 - Social Situations

Key findings:

- ◇ 77% of individuals find social situations either extremely or very stressful
- ◇ Only 1% stated that they did not find social situations stressful at all
- ◇ Only 34% of individuals have had any support in understanding social situations
- ◇ Many individuals felt that with appropriate support quality of life would dramatically improve and mental health issues would reduce

Recommendations:

- ◇ All individuals to have access to AS specific social skills training
- ◇ LAs to develop innovative and suitable ways to support individuals with AS in social situations

Pertinent quotations:

"If I do the social thing I can do it for very short periods of time but this will cost me so much I will have a massive headache and need sleep for about 20 hours."

[In answer to how you could best be supported in social situations]: "If there was a book or lecture series which explained neuro-typical behaviour in an objective, impartial and even critical way. If more was done to make NTs understand and not be discriminatory or think they are better than Aspies; if there was less pressure on Aspies to socialise when they don't necessarily want to."

"I feel that I now understand how Asperger's affects me and I have tried to become better at social situations but I still find it extremely hard to deal with groups of people, I cannot communicate with people I don't know and this makes me feel uncomfortable, I feel like I need someone to explain my situation before I speak as I don't know where to begin."

"NTs need to stop thinking they are better than us. They should accept us for who we are instead of only accepting us if we try to be like them and rejecting us and being mean if we make a mistake or get confused or stressed, or just don't always want to socialise."

Section 11 - Friendships / Relationships

Key findings:

- ◇ Two thirds of individuals have never had any support in understanding friendships or relationships
- ◇ Many individuals felt that better support would have a major positive effect on their lives
- ◇ Additional support to understand social relationships and friendships would dramatically improve many lives

Recommendations:

- ◇ All individuals, children and adults, should be provided with friendship skills training / relationship training when required - and that the training is specific to AS
- ◇ All individuals should have AS specific counselling offered to them

Pertinent quotations:

"I need someone to help me meet new people and for them to understand about my disability - people just think I'm a little bit strange."

"It would be wonderful if a training programme could be developed that was aimed at adolescents/adults which very explicitly explained the "What, Why, How" of social/relationship skills. This programme would be best delivered to a group of AS people, role-played first amongst the group. Subsequently individual trainees would practice the techniques in real life, shadowed by a coach."

"I've noticed that I am particularly prone/vulnerable to being used and manipulated by people taking advantage of me."

Section 12 - Acceptance

Key findings:

- ◇ 83% of individuals felt strongly or very strongly that many of the problems they faced were as a direct result of others not understanding them

Recommendations:

- ◇ Awareness of so-called 'disabilities' should be a part of educational curriculum, and should include awareness of AS
- ◇ More accurate portrayals of adults with AS in the media

Pertinent quotations:

"Western culture and the media are much to blame in setting impossible life goals and showing a diversity of cultural responses none of which are appropriate. I fit in with no class or culture particularly well. I do not want to be stigmatised, pitied, despised or feared because of a label, and I fear that is the trend in ASBO land where AS becomes the new schizophrenia in the grimoire of folk devilry."

"I think there could be more focus on our caring side as we are caring and kind people. There should be more attention to how affectionate we can be and how nice we can be."

"As a public speaker and author on the subject of Asperger's Syndrome, mainly based around my own personal experiences, I strongly believe that the world needs to be taught as much about Asperger's Syndrome by people with the condition, as we experience what it is actually like to live with it. What the world also needs to know is that Asperger's Syndrome is a very individual condition. Every individual with Asperger's Syndrome is different in terms of personality, intelligence, characteristics etc. In this sense, the more public speakers/authors there are on the subject the better. Too often, society tries to encourage people with Asperger's Syndrome to 'appear more normal'. If they don't understand the condition, this can be patronising."

Section 13 - Legal System

Key findings:

- ◇ Two thirds of individuals do not feel adequately protected by the legal system

Recommendations:

- ◇ Legislation should cover AS more specifically
- ◇ Adequate protection should be established within the penal system for adults who are vulnerable as a result of their AS
- ◇ Training should be provided as a statutory process to police and those associated with the penal system

Pertinent quotations:

"The police should be more aware of AS. Also the courts and legal system in general."

"It should be much easier to take legal action against people who discriminate against me or take advantage of me."

"I am often assumed to be behaving suspiciously, but it's just me. At airports I get in trouble for example for not answering questions the right way, and then I get into trouble. I'm only answering the questions literally."

"The legal profession is an area, along with the police and criminal justice system, where Autism and Asperger's Syndrome are still largely poorly understood. People who work in this field need to be aware of how different a person with Asperger's Syndrome may react in situations such as a courtroom or police interview. For instance, certain social signals such as lack of eye contact may often imply guilt, but this may not be the case with a person with Asperger's Syndrome."

Section 14 - Neurotypical (NT) Behaviour

Key findings:

- ◇ 74% of individuals have never had any support in understanding NT behaviour
- ◇ Most who did have some support found it very helpful

Recommendations:

- ◇ All individuals with AS should have access to training courses run specifically to develop an understanding of NT behaviour

Pertinent quotations:

"I have on-going help via e-mail to understand the NT perspective of things that confuse/upset me. It's very beneficial but the problem is that I generally have to reassure myself about the NT behaviour and so cannot relax because NTs need to understand from our perspective too."

"NT's behaviour is often illogical, and unpredictable based on irrational emotion. They demand an empathy of us which is lacking in them. I am not that interested in being supported to understand. I am just happy to work and live alongside them without causing or experiencing friction."

"Frankly, after nearly 50 years of trying to understand NT's lying, manipulating, bending principles, power tripping, money grabbing, status chasing, etc. and seeing the devastating effects all these have both on a personal level and on a global scale, I'm not actually convinced that I want to 'be supported' in understanding these behaviours. How about YOU NTs understanding spectrum folks' behaviour and our principles? I can guarantee you that you'd find them far more conducive to a fairer, more equitable and peaceful world."

Section 15 - Mental Health

Key findings:

- ◇ 68% of individuals have had contact with Mental Health services
- ◇ Of those only 12% found it a positive experience
- ◇ Of those who have had contact with Mental Health services 10% did so as a result of attempted suicide or following suicidal thoughts, 38% for depression, and 12% for anxiety
- ◇ There is still clearly a lack of understanding of AS in MH services as a whole

Recommendations:

- ◇ All MH practitioners should have ongoing and up to date specialist training in AS
- ◇ Services provided must always take AS into account
- ◇ If MH practitioners do not have the expertise to provide a service an appropriate alternative must be made available by the Local Authority

Pertinent quotations:

"When I was in the Psychiatric hospital, I wasn't given any attention. I just sat there all day with no one to talk to. The medication they gave me was not good. My Mum did mention AS to them but they didn't want to know."

"The most negative aspects have been that the professionals I have come into contact with so far have only treated the symptoms but not the underlying causes."

"Not one single mental health worker in 3 years has ever asked my why I thought the things I was saying. If they had they would find out that I thought them to be true because people had told me. They drugged me up to stop me thinking and they decided that I was copying mentally ill people for attention. They have done more harm than good through their lack of knowledge and understanding."

"I was so frightened after just one night as an inpatient that I discharged myself the next day. Psychiatric inpatient services for all types of mental ill-health are severely lacking in monitoring and inspection and patients are very vulnerable to ill-treatment and abuse."

"During my wait to be seen by a professional I twice tried to kill myself. I received no treatment because I did not tell anyone about these attempts. I seemed fine (medically) after a few days and to be honest I didn't care if I had done any permanent damage to myself. I also paid a private therapist during this time because I was so desperate to talk to someone but it was taking up more than half of my weekly benefits and at one point I had to steal food just to eat. I really don't know how desperate you have to be to get to see someone on the NHS."

"These Professionals with degrees, letters after their names need to go back to school you could say and learn about these Neuro Diverse conditions, some don't even believe these conditions exist, they are living in the dark ages, we need to bring them into the future, the here and now, the quicker the better. It should be a compulsory part of their training, and if they have been in their field for many years they need to go back and study."

Section 16: List the services in order of priority for you that you would want the local authority to provide

There were 3 main groups for priority:

Highest priorities	<ul style="list-style-type: none"> ◇ Support in employment ◇ Help in getting appropriate accommodation ◇ Getting social skills training
Second highest priorities	<ul style="list-style-type: none"> ◇ Counselling ◇ Getting a diagnosis ◇ Social groups
Third highest priorities	<ul style="list-style-type: none"> ◇ Single point of contact/drop in centre ◇ Support to access benefits ◇ AS specific MH service ◇ Home help / supported living ◇ AS specialist staff

Section 17: Information

Key findings:

- ◇ Only 27% of individuals noted that information they required was readily available
- ◇ The two main priorities for information were on AS and related issues and what support / services were available locally
- ◇ Information is best produced in the following formats:

Internet / email	48%
Leaflet / book / post	24%
Specific people / talks	21%
Phone	4%
Library	3%

Recommendations:

- ◇ Local Authorities have a specific directory listing all AS specific services available as well as all other services for individuals with AS that adults can access; this should be updated regularly
- ◇ Information should be made available in appropriate formats, taking the above finding into account

Pertinent quotations:

"Customer service shouldn't be about ticking the boxes. It's important that people can access service information to avoid wasting their time investigating services that don't have the capacity to meet their needs."

"I think that it is essential to consult people with AS before publishing the information so that they can tell the publishers whether or not the information has been written in an AS friendly way."

Section 18: Individual comments (a selection):

"Please, please, any NTs out there, learn about the ASD perspective. Don't try to force us to always behave in an NT way- it's exhausting. How would you like it if we forced you to behave like you're autistic all the time?"

"Staff need awareness training in the Asperger's Syndrome. Until knowledge is in place people with AS will be severely disadvantaged and all service providers within the UK will be acting unlawfully."

"We need rights according to our own disability. Autism must become an automatic criteria to disability rights. I have worked extremely hard to build a career, I have a degree and a post graduate qualification, I have 5 yrs post grad experience and I am doing unskilled work, I am worth the same as a person straight off the street with nothing in particular to offer. People with obvious social ability will always get preference with promotion. This must be stopped it is destroying my life and I am helpless without rights."

"I don't like it when people assume that all AS adults behave the same way and if you are not very obviously autistic then you are a 'mild' case. It's not necessarily true. If it makes me want to kill myself at times there is nothing mild about it. Less affected adults suffer just as much and even more because nobody is going to believe you if you don't flap your hands or make funny noises. It's offensive."