



NO 4 - SEPTEMBER 1994

A Newsletter for high functioning people with autism

## EDITORIAL

A big (emphasis on the big) hello to this issue of "Asperger United".

I must offer my most sincere apologies for the delay of this issue. This is due to my last placement breaking down. I am now in a place which is inappropriate. It is a hostel for people with learning difficulties, so once again I am waiting to be moved on to somewhere that has an understanding of Autism/Asperger Syndrome.

However, not to worry, I will continue to write the editorial for the time being.

Recently, I spoke to Mark Bebbington, who runs the newsletter for parents, carers and professionals. Mark told me that some people have said that Asperger United is professional orientated, I agree, but for the time being it will be that way until we start to write articles, so **WHAT DO YOU THINK?** tell me, for better or for worse. The American equivalent, i.e. Our Voice, is run by the autistic, so come on lets show them that we can do just as good, if not better than our American counterparts on the other side of the Atlantic.

Lets show the professionals what we can do, then they can see our good things as well as our problems or difficulties we have. Some of us have difficulty in expressing ourselves, so why not write short sentences, statements or just a list of words of how you feel. I am sure someone could understand it.

Please send all correspondence c/o the N.A.S. (usual address).

Until the next time, take it easy.

I look forward to hearing from you.

**Richard Exley**

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\* As some of you may know Richard has moved to Yorkshire and is unable to continue as Editor of this newsletter.

On behalf of all 'Asperger United' readers we would like to thank Richard for all his hard work as Editor of the magazine over the past 18 months and wish him well for the future.

**Mark Bebbington**

**Pam Yates**

\* Front cover design Graeme Richard Lawson

## **ASPERGER SYNDROME DAY CONFERENCE**

**Chris White**

**2nd February 1994**

I am privileged to have been able to attend the first ever 'Asperger Syndrome Day' which was organised and run by the National Autistic Society (N.A.S. for short). The day was attended by around 40 people including myself, although this did not include the people from the N.A.S who helped run the conference to make sure that all ran smoothly, and the conference itself was held at the King's Fund Centre in Camden Town, which is a relatively new building. I arrived at 10am after registering with the conference administrator, Breege Byrne (who I think is Scandinavian). I sat down for a cup of tea with other people who had already arrived early until it was time to start.

### **Asperger Syndrome: An Overview**

After a small delay in proceedings, the conference started at 11am, instead of 10.45am (this delay ran right through the day). The first topic of the conference was in fact Asperger Syndrome. The term itself was first used by a foreigner (I think German), named Asperger, who had recognised that in a small group of people there were minor problems, although they appeared almost perfectly normal outwardly during 1944 to 1945. He decided to term this small group after his name, hence Asperger Syndrome. Unfortunately, due to the time that he first mentioned Asperger Syndrome (i.e. during the war), the term was widely ignored and shunned by the experts and it was not until the 1980's that the term Asperger Syndrome first started to be recognised officially and used widely by the professionals. The main problems the Asperger Syndrome individual are faced with are the following:

1. Communication and understanding - when you have to do so rapidly or too many things in one go.
2. Social misunderstanding - being vulnerable to teasing.
3. Obsessional traits - problems with unpredicted change in routine for example.
4. Concentration, deciding and choosing, to a certain extent emotional control, lack of confidence, stress and anxiety.

The above outlined are the main problems; other problems include understanding how other people feel or what they mean and communication problems, including speech problems early on in life, and sometimes finding difficulty in answering certain questions.



We then paused for refreshments for about 15 minutes.

### **Welfare Benefits**

This section discussed the type of benefits that were available to people with Asperger Syndrome, which are as follows:

1. Severe Disablement Allowance (SDA)
2. Income Support (IS)
3. Disability Living Allowance (DLA)
4. Disability Working Allowance (DWA)
5. Therapeutic Earnings
6. Housing Benefit
7. Council Tax Benefit/Exemption/Reduction/Discounts
8. Social Fund

All of the above can be obtained by Asperger Syndrome individuals in the appropriate circumstances, but all have conditions which must be adhered to. If an application is refused, you can turn to the local Citizens Advice Bureaux (CAB), who can help or the NAS if needed.

I found that this section made me more aware of the benefits on offer and it was one of the most helpful sessions.

### **Relaxation Techniques**

After having an hour long lunch break of sandwiches and fruit, we resumed at 14.00 hrs on the subject of relaxation techniques.

This is really about these points:

1. Overcoming stress/fear
2. Sleeping
3. Relaxing muscles and associated ideas.

Relaxation becomes necessary when we start experiencing stress or anxiety, both of which causes tension within the body and it manifests itself much more quickly in the Aspergers Syndrome individual. The ways of dealing with the stress/anxiety are as follows:

1. Take exercise
2. Try to stop anxious thoughts
3. Sometimes smells can be useful for relaxing stress (Aromatherapy)
4. Think about relaxing thoughts
5. Music can play a very important part in relieving stress/anxiety.

This was one of the most interesting sessions of the conference.

## **Employment**

After the final 15 minute refreshments break, we began the last session of the conference, employment. Out of 40 people at the conference, only five had jobs, and three of these were happy in their jobs. The problems for the Asperger Syndrome individual in obtaining employment are as follows:

1. People do not leave you alone
2. General acceptance/understanding in the work environment
3. Being susceptible to teasing or slowness
4. Trying to fit in/coping with change
5. Not good enough qualifications
6. Getting nervous about being wrong
7. People never respond to application letters.

Some instances of help that have been offered by some employers are:

1. Sympathetic boss'
2. Having a support team
3. Having a job club
4. Help from the church
5. Other outside support.

Sources of help are:

1. Go to the Job Centre
2. Visit the DEA (Disability Employment Advisor)
3. Pathway - they have strong links with MENCAP
4. Special agencies
5. NAS Shaw Trust
6. Work experience, college, YTS, MENCAP.

To decide what to go for, list strengths, skills, interests, areas of interest and weakness (not liking people who you work with). Be realistic and optimistic.

To get a job you first have to have an interview. Remember: Practice makes perfect. Some techniques in interviews are as follows:

1. Take help if possible (like a mock interview)
2. What are your strengths
3. Make sure you know about the job and the firm
4. How do your strengths fit in with the company needs
5. Take some notes along
6. Listen to questions - ask for clarification if necessary
7. Predict questions about pay/yourself/why no job before

8. Have questions to ask, write them down.

Explain to employers - be honest. To prepare:

1. Have a good CV
2. Get what qualifications you can like NVQ's
3. Training courses appropriate to your interest

After the discussion on employment had finished, there were general questions asked about the conference, and after this, the conference finished at 16.30.

As a general summary, I would like to say that I thoroughly enjoyed the conference, it was enjoyable and informative and I very much hope to attend a similar such conference in the future. I would like to express my sincere thanks to Breege Byrne, Patricia Howlin, Pam Yates, Thuy Burrows, Richard Exley and Mark Bebbington. I have now made contact with Jan Snook who works for the NAS in Bristol, and I hope to make contact with her again soon as we chatted at some length during lunch at the conference. Once again, thank you all very much for such a good day.

**Chris White.**

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### **HANDY TIPS: CLUBS AND ASSOCIATIONS**

A very useful way of meeting new people is through clubs and associations based round a shared interest. There are hundreds of such organisations around the country to choose from. For some hobbies, such as chess, there will probably be a club in most towns. With more unusual interests there may be a national association that will organise occasional events where members can meet one another.

Even if there is a topic that you are only half interested in, it may still be worth finding out what associations exist around it. Often a casual interest in a particular subject can grow as you investigate it further.

In order to find out more about local clubs and associations, a good place to start is your local library. Most have an information desk with a librarian there who will be happy to tell you if there are any organisations based around your particular interests in the area. Libraries usually also have some kind of notice board on which local organisations will advertise their activities.

In order to find out more about national associations, you can consult the Voluntary Agencies Directory. There are over 2,000 entries in the current edition. Some of the organisations listed are charities and campaigning groups etc., but there are also many special interest associations; everything from the Historical Model Railway Society to Subterranea Britannica (a group for people interested in underground tunnels and buildings), to the Postal History Society. The book has a useful classified index so that you can quickly look up a particular subject, e.g. transport, and see a list of related organisations whose details are held in the publication. The directory is published by the National Council for Voluntary Organisations, but hopefully any good library should have a copy in their reference section.



## **ASPERGER SYNDROME - THE WAY FORWARD**

### **Matthew Robinson**

My name is Matthew Robinson. I am 17 years old and the reason I am writing to you is because I feel there is a need to express the problems I constantly face day to day which I now understand can be related to having a degree of Asperger Syndrome.

To a stranger at first glance whether it be a person I walk past along a street, or somebody who has a reason for entering my home, for example a friend of my mother's, looking at me you would be seeing a perfectly normal looking teenager therefore why would the person have any reason to expect that I would be suffering from lack of the necessary social skills and general social interaction for copying day to day and which I know are essential for any social activity, e.g. going out with friends to see a movie, going to a party or practically any conversation I find myself engaged in with another person or persons. The answer as I believe is not only would the other person or persons think I would, they wouldn't even begin to think. The person would communicate with me in the same fashion they would to any other person, depending on the situation and what is involved. Therefore, if the person thought nothing strange or wrong about me when starting a conversation, why do they think negatively about me or base judgement on me after departing from me and effectively ending the social interaction. In other words, how did I handle myself badly in terms of the way I behaved and communicated, and why is it that the same person, being a teacher at school or a member of the family could have many other successful conversations with other people who know exactly how to behave and communicate, and I, for some reason which I am beginning to understand, cannot behave appropriately and effectively for the purpose of the social interaction. As I look around in my own home, and in the outside world, I come across many people. In my own home, I live with my brother and mother and at the weekend, my mother's boyfriend.

These are people I consider to be part of me and my mother and brother are the two closest people to me. I view them as being successful and happy go lucky people. My brother attends a private secondary school - he has many friends, is studying nine GCSE's and will inevitably end up with excellent results. He has an active social life. He is sixteen.

My mother is also like my brother in many ways. The point, however, I would like to make is that both my mother and brother's ability to interact and behave appropriately to many situations they might encounter throughout the day seems to come completely naturally to both of them.

I believe that my life, up to now, and my development and continued development as an individual have both been heavily effected by the problems I understand can be related to Asperger Syndrome. Being socially skilled is vital for a successful and productive life. It seems that the majority of people in the first few years of starting school seem to



develop this skill. How many 17 year olds find it difficult to physically walk past a stranger along a street, feel extremely anxious in doing so having their mind completely bombarded with thoughts and feelings concerning what does the other person think of me, how should I walk past them - do I look at them or not, perhaps I will try to avoid walking past them altogether. What shall I do? How many 17 year olds find the experience of getting on the tube like a living nightmare? The ability to decide whether to sit down or not - if I sit down will someone stare at me and do I therefore stare back - what does the person imply by staring at me? If I touched a stranger by accident, would the person think I was coming on to them@? Why ARE people staring at me? Do I look disfigured or extremely ugly? How shall I behave? When I have discussed the difficulties I faced with this situation with my mother, her response is, "I don't know what you find so difficult about this situation. All you do is get on the tube, sit down, and get off at your stop. It's hardly difficult - you are not even speaking to anyone."

A person who, in my opinion, is part of the majority of say, for example, the population of England could be described as 'socially skilled.' Confronting people is a daily task which seems to come naturally to them and with relative ease. The situation of walking into a room whilst there are guests eating lunch, and you upon just arriving, proceed to walk into the room and make your presence felt is an encounter which most people find easy as pie but I find nerve wracking. A socially skilled person will often ask the question, as has been asked of me in the past, "What is difficult about this situation?" and after having handled myself badly, for example avoiding the situation altogether by going up to my bedroom because I was feeling extremely anxious and nervous fear the person will remark, "Nobody thinks negatively about you, you are creating false images inside you head. Nobody thinks anything about you - you think people are staring at you when they are not." These are just some of the responses I have received from people like my brother and mother after what I have considered to be failed social situations. The positive comment the persons usually says is, "All you do is walk in, say hello smile and sit down." What the socially skilled person seems to forget is that although you are carrying out what they consider to be a relatively easy task, you don't know how other guests will respond to you. You don't know what atmosphere you are entering and how to behave accordingly. A guest might decide to start a conversation and the other guests might all turn around and looked at you and listen to what you have to say. A guest might ask you a question like, "Where do you go to school? Are there more boys than girls?" If there is a person sitting at the table who you have not seen they might want to get up and give you a hug ..... so already, even though logically all you are doing is entering a room, sitting down and eating a meal, there are many areas of social interaction like body language, touch, posture, eye contact, answering questions, tone of voice etc., with which I find problems with, which the socially skilled person fails to acknowledge or understand, that this is where I have problems, or states that there is nothing wrong with me.

I would like to speak briefly about my life and the problems I have faced through out attending both Primary and Secondary schools which I recently left in June 1993, and which I am sure suffering from Asperger Syndrome and the problems I face bear a strong

relationship to each other. I attended a small Jewish primary school where I was one of twelve pupils who joined the school when it opened in 1981. I cannot remember a lot about the general working day but I remember that I was continually teased and made fun of and suffered from a total lack of self confidence and anxiety particularly when communicating with other pupils. I was an average student in the class, made few friends and I thought as I left the school aged eleven, that I would be going onto a proper school, a better school and was though anxious, looking forward to what I thought would be a whole new beginning. Indeed it was. What was going to do was to join a secondary school J.F.S. (Jewish Free School), with 1,500 students and six years of fucking isolation, loneliness, fear anxiety, unhappiness and ultimately depression. If I was unaware of the struggles I had faced at Akiva Primary School, was I to be stunned at what was in store for me at J.F.S.

I don't wish to speak too much about the unhappy experience I faced at J.F.S., but the problems with relation to Asperger Syndrome hit me on a wider scale. I didn't participate much in class, was teased, called names and generally disliked and taken advantage. I felt different. Indeed, I still do. I was always described as an extremely sensitive person and that was the impression I was supposed to conveyed and the reason why people were being nasty to me. I think if I look back on those school days the fact that I had trouble communicating and behaving appropriately especially having eye contact is the reason why people treated me in this fashion.

At seven years old, when my father passed away, I was, as I understand from my mother, struggling to get over his death, sent to see a psychotherapist. This was only the beginning of a ten year period seeing two psychotherapists and having therapy.

I went to the Tavistock Clinic in Belsize Park, North West London, originally for the purpose I have described, but eventually it was psychotherapy which was viewed as the key source in helping me with my problems. After having therapy for ten years, I feel that it was not really the right approach. Sitting on a chair and telling your therapist whatever comes in your mind, then having the therapist analyze and understand it does not seem to be constructive help for a person who has problems like mine, as I first understood at sixteen years of age with social skills. I am not saying that psychotherapy has not relevance or positive influence and has not helped me in any way. What I am purely saying is that if I had been aware at a much younger age that it was Asperger Syndrome - lack of social skills, I might have been able to receive more practical help and be in a better position now. I have also seen a behaviour therapist for ten months who has managed to help me in such areas as assertive behaviour and social interaction. I currently attend a residential boarding school, Alderwasley Hall in Derbyshire and live with other students who have speech and language difficulties and also suffer from a lack of social skills. The school set-up enables me to receive more help both academically and socially. I would like to have a girlfriend and an active social life and be able to experience the same joys and happiness, which as I look around, most other teenagers are experiencing. I would like not to feel myself struggling with many situations, some of which I have described in my letter.



I believe that, depending on the progress I make with social skills, both my life and my development as an individual could see substantial improvement.

Being a teenager can prove to be harrowingly difficult at times. In my opinion, teenagers and adults suffering from the problems I have suffer a much greater price.

If the majority of our society are socially skilled people, then surely it is those people who, rather than verbally abusing us, by seeing people like me displaying weakness in the ability to communicate, should show understanding and be sympathetic by acknowledging our problems. They should try and understand the effects their behaviour has upon the Asperger sufferer and try helping us rather than attacking and damaging any confidence we have. What I would like to see is some sort of campaign to make; a) people aware of Asperger Syndrome - what it is; b) the effect aggressive behaviour and verbal abuse have upon the Asperger sufferer; c) how people feel with lack of social skills amongst other things.

I think the above could be achieved by giving talks in schools and other institutions. People suffering from the problems I have described need not be treated with extremely irrational behaviour. We are human beings and we deserve to be treated with respect and understanding and not with cruelty and aggression.

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## CONTACTS/PEN PALS

In order to ensure the privacy of contributors to Asperger United full addresses will not be printed. If you would like to reply to any of the letters or requests for contacts please write to the N.A.S and we will pass your letter on to the appropriate person.

Dear Asperger United

As I have Asperger's Syndrome and am desperate to meet new people I thought it a good idea to write about it. Although I may be wrong I feel that Asperger's Syndrome is not catered for by the NHS as it is not a physical illness, mental illness or mental handicap although if somebody with Asperger's Syndrome becomes suicidal they would be treated as mentally ill. At the moment I live in a private home for the mentally handicapped. I spend my time dreaming of being a five year old again (I am 26) arriving at a beautiful home with other Asperger's children and some kind nurses. Do such places exist today? They were not in existence 21 years ago.

**Tim Beaumont**

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Neville Taylor  
Gloucestershire

Neville is 27 and has a wide range of interests including nature, walking, electronics and a variety of sports. He would like to hear from other people with Aspergers Syndrome.

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Anna Cohen  
Hertfordshire

Hi everyone, my name is Anna. I gave our magazine, it's name "Asperger United".

A couple of months ago I turned twenty and although I was diagnosed two years ago, I haven't met many people around my own age who have Asperger Syndrome or any other very mild form of autism, and I would appreciate it if anyone in their late teens or twenties could get in touch with me by writing to me.

I am one of the most highly functioning autistic people you could meet.

I have a wide circle of friends, enjoy art, going to disco's, night clubs, bars, cinemas and theatres, and I enjoy cooking too, and I'm on a catering course at the moment. I also like travelling and have travelled around most of Europe and I've seen a lot of America. A month ago I went to visit a friend in Scotland for a week. If anybody out there would like to meet me or be pen pals please write.

Thank you

**Anna Cohen**

## LETTERS

Neville Taylor  
Gloucestershire

14th April 1994

Dear Mark

I am writing with regards to your recent letter which I was so pleased to receive.

While thinking about the National Autistic Society, I have just thought of some important suggestions for you to consider.

I do feel that there is a great need to establish a Group Holiday Organisation for people who suffer with Asperger's Syndrome. I wonder if there is a possibility to arrange trips abroad as well as to the English mainland.

I feel that this could be a very easy method for people of similar characteristics aged 18+ to meet and make new friends. Meeting people face to face is the easiest way to make friends.

I do hope that you will find my suggestions useful for the future.

I shall be looking forward to hearing from you to find out your opinions.

Yours sincerely

Neville Taylor