

**NEWSLETTER FOR PEOPLE WITH ASPERGER
SYNDROME**

NO. 2 - August 1993

EDITORIAL

Hi and welcome to the second issue of the Newsletter. I would like to thank everyone who has decided to order the Newsletter.

Please keep the articles coming for future issues. I would also like to remind everyone, we still have no title and there is a Parker Pen to be won, so come on get those thinking caps on.

Finally, enjoy reading and I shall write again soon.

Your friend and editor

Richard Exley

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PROFESSIONAL SECTION

ADVICE ON FINDING A JOB... AND HOW TO KEEP IT

Patricia Howlin, Pamela Yates, May 1993

HOW TO GO ABOUT LOOKING FOR A JOB

Finding a job is one of the biggest problems you'll face after leaving school or college, especially if you've already been unemployed for some time. **THIS DOES NOT MEAN THAT YOU'RE A FAILURE!** In these times of recession even many very skilled and intelligent people find themselves out of work and any one with even a mild disability is at a disadvantage. If you want to be successful here are ten useful hints:

1) Register as Disabled !

This may not sound terribly attractive but has the enormous advantage of allowing access to the Disablement Resettlement Officer who may be an important source of help. A diagnostic label will be needed from the consultant involved in treatment. This does not necessarily have to stress the autism itself; it might, for example, focus on your communication problems instead. Although there is a government ruling that big companies should employ at least 3% of people with disabilities in their workforce not all of them comply with this. However, some large firms have a very positive policy of employing people with disabilities and if you are registered as disabled you are likely to increase your chances of employment in such companies.

2) Contact the DRO through the local Job Centre for advice about finding jobs; also try the local Special Careers Officer.

When discussing job opportunities with them it's important to take your own interests and skills into account and to concentrate on jobs that will make use of these.

3) Enlist the help of specialist employment agencies -

e.g: Status Employment, Croydon. Tel: 081 681 3178
Excel Recruitment, Hornsey. Tel: 081 347 8756
MENCAP Pathway Services (if available locally), or,
PACT, your local Placing, Assessment and Counselling Team
(Get the address from the Job Centre).

4) Contact specialist training organisations -

e.g: Accord, Brixton. Tel: 071 274 2299
OUTSET (North and SE London) Tel: 081 692 7141
Shaw Trust Tel: 0372 728287

5) **Find out as much as possible about job opportunities -**

Information is available from the Education, Training and Employment Advisor, MENCAP, 115 Golden Lane, EC1Y 0TJ in their "London Wide Directory of Opportunities in Employment for People with Learning Difficulties" (other directories also available). Explore voluntary work with charitable organisations. Ask your DRO about local Sheltered Employment schemes.

6) **Find out about special education courses/pre-vocational training -**

Information available from: ACCESS Tel: 071 486 5811 Ext. 6275
MENCAP Directories on further education and adult education. Local adult education classes.

7) **Find out about what local TEC'S, Enterprise schemes etc. can offer -**

Also explore YTS and employment training schemes (ET's) run by the Training Council (used to be known as Manpower Services Commission).

8) **Find out about special financial support -**

Contact local branches of The Shaw Trust. Enlist help of local social services for advice about benefits. Contact local CMHT (Community Mental Handicap Team) for advice and support.

9) **Get out and meet other people -**

Job clubs; sports centres; adult education centres, etc. If you can't get paid work try the voluntary agencies instead, or contact local homes, hostels or hospitals for people who are elderly, sick or disabled. You'll be working for a good cause and it will help in your applications for "proper" jobs.

10) **Find out about further education courses and adult education classes -**

Get list from the library of Adult Education Classes (day and evening) in your area. Contact local MENCAP offices for advice about specially designed courses in further and adult education for people with special needs. Most adult education colleges have a particular contact person who will be able to help. In London the address for information is:

115 Golden Lane, EC1Y 0TJ. Tel: 071 454 0454

APPLYING FOR A JOB

Find a friend or family member with a word processor and printer and get them to help you type out your Curriculum Vitae (CV). This should give a straightforward account of your training and education to date and should stress your SKILLS as far as possible. You may need to alter your CV a bit according to the sort of job you are applying for, to make sure it's relevant which is why it's best to keep it on computer. Do not try to cover up gaps in your employment history with "white lies" of any kind;

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you'll only get found out in the end and that will be embarrassing, to say the least. Be honest about why you've not got a job at present but don't feel obliged to go into this in great detail; instead make sure you make the company aware of how your skills will be of advantage to them.

Do not be tempted to apply for jobs at too high a level. You may think you are quite capable of holding a managerial post or want only to work for a particular airline, for example, but no-one ever starts at the top. You will need experience and training first and it is much better to take a post that allows you to learn basic skills, than to search for the "perfect" job. This may mean accepting a rather low level of job initially, but if you succeed at that, and manage to stay in the same job for a couple of years, then it will be much easier to find a more demanding post later.

GOING FOR AN INTERVIEW

Don't just expect to turn up on the day and find that everything goes smoothly; you'll have to do a lot of homework first.

Firstly, find out all you can about what the job involves, by talking to someone in the company if you can or reading up about them if you can't. This will enable you to sound knowledgeable and interested at the interview and to make a strong case for how your particular areas of skill can be useful for the company.

Secondly, practice your interviewing techniques with a member of the family or a friend, going over pretend questions and answers until you feel comfortable with them. Making a video or audio recordings is an even better way of correcting your mistakes.

Thirdly, make sure you know where you have to go for the interview and how long it will take to get there. A trial journey the day before may be well worthwhile.

Finally, make sure that you are spotlessly clean and smartly dressed. It won't matter how well qualified you are if you look a mess!

KEEPING A JOB

Once in a job it can be difficult to understand all the rules that other people seem to cope with, without even being told. Even using the telephone can be a problem; coping with change in routine can be especially difficult. Making sure that reports and work sheets are properly written up or that records are kept accurately and neatly, especially if there is no-one there to nag you all the time, is also often difficult. Planning projects

in advance; taking the initiative in developing new projects or working co-operatively, on a team basis with others, can all present difficulties.

In particular, not keeping to deadlines, failing to finish work on time, or to get in on time in the morning are all common causes of people losing their jobs; as of course are outbursts of temper or rudeness.

Not paying enough attention to personal hygiene or standards of dress is also a good way of quickly offending people. Invading people's sense of personal space, by using their things, standing too close, listening to their conversations, asking questions all the time or talking about your own special interests are all likely to make you unpopular, even if your work skills are good.

SOME SIMPLE GUIDELINES TO HELP AVOID SUCH PROBLEMS

Never be afraid to ask for help. There are ways of improving social skills; of increasing work performance; of controlling feelings of anger or frustration and professional advice can be very valuable.

Be honest about your problems. Explain to people that you have a communication problem (they probably won't understand the term "Autism") and that you have difficulties understanding rules, and particularly social situations without help. If you think it might be helpful, the National Autistic Society, or other professionals who know a lot about autism, would be able to provide your employer with a brief pamphlet explaining about the types of problems that people with autism or Asperger Syndrome tend to experience at work.

Tell them to let you know AS SOON AS YOU HAVE DONE SOMETHING THEY DON'T LIKE.

Explain that you will need to ask for help or guidance more often than other people and don't be afraid to ask for such help as soon as you need it - waiting around only makes problems worse. If it helps, it may be worth checking what you are expected to do each day with your manager and then making a written list of all the tasks that need to be done. You can then tick these off as you finish them and this will help avoid the need to bother people too often throughout the day.

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If you do need to ask for help, try to do this when other people aren't already in the middle of a conversation or finishing off a complicated task. Keep requests brief and concise and don't hang over people when you go to see them.

Try to develop other ways of helping yourself; keeping lists of important things to be done; keeping a diary; planning in advance; reorganising your daily timetable in a more effective way can help to solve problems before they get out of hand. If talking on the telephone is something you find difficult practise with friends or family outside office hours.

Learn to recognise your own feelings so that you can ask for help, or avoid unpleasant situations, as soon as you start to feel frustrated or confused. If you don't take avoiding action straight away things will just get worse.

Learn to relax when things get difficult - there are lots of successful distraction techniques to be learned but you'll need some specialist advice first.

Make sure you shave and bathe every day if possible, and wash your hair frequently. Change shirts and socks and underclothes DAILY; make sure the rest are washed or cleaned regularly. Have a good look in the mirror to make sure zips are fastened, buttons done up and shirts tucked in etc. If you have not been working for some time you may well have got into the habit of going to bed and getting up late so you will need to make sure that you reorganise your routine in order to have enough time for all these things each morning.

DON'T TALK ABOUT YOUR SPECIAL INTERESTS IN THE OFFICE OR SHOP, keep that for when you are not working and even so remember that other people may not be as fascinated by such things as you are. Just because people are too polite to tell you to go away does not mean they are really interested. When in doubt, keep quiet!

Don't borrow people's desks, pens, telephones etc. without asking, and even then keep such requests to a minimum. Don't let other people borrow your things too often either.

Just because staff in the office (especially if you are a man and they are female) are kind to you doesn't mean they want a close friendship. Asking people for a date, or expecting them to spend a lot of time with you out of work, simply because they are polite will only lead to trouble. Keep your distance until you really get to know them well, and this can take many months. You can, however, still be friendly to them, greeting them in the morning, smiling when you see them and responding when they speak to you. It is particularly important to treat your managers with respect. So, for example, it's better to address them as Mr or Mrs or Ms until they suggest you use their Christian names.

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Finally, although making friends is important, never let people persuade you into doing things that you know are silly, dangerous or illegal, or will get you into trouble in some way, just because it will please them. Stand up for yourself and your principles and don't be afraid to say "No" firmly if necessary.

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'GOOD NEWS SECTION'

How I obtained my job and about my job with British Rail - 6.8.1993

David R Harris

I applied to join BR approximately in the winter of 1990/91. I was put on a waiting list, and had an interview at Reading in the Spring of 1991, for a clerical Officers Job which was vacant. A couple of weeks after my job interview I heard that I was unsuccessful.

I virtually immediately re-applied to join BR, during my lengthy unemployment period. In June or July 1992, I had another interview with Sue Dalglish (Recruitment Officer) and then the Station Manager for the Slough Area, David Bird. With the help of my "Green Card", (the 'Green Card' is issued to people who are registered disabled under the Disabled Persons (Employment) Act 1944) I had learnt, that I had got my job, working in the Telephone Enquiry Bureaux (TEB) at Slough.

I started on August 29th 1992, on my Induction Week at Western Tower, Reading. During my Induction Week, we were being looked after by Neil Thomas (Recruitment Manager), Sue Dalglish and Dorothy Farr (Recruitment Assistant). We covered all sorts of things such as First Aid, Fire, Employment, Health and Safety, and general knowledge about BR. On the last day, Friday, we had a buffet lunch, with most of Network SouthEast, Thames and Chiltern Managers and this is where I met my new Station Manager, Peter Robins. After the buffet lunch, and after all the managers had gone, we then met Andy Whitaker, the Financial Controller for T & C, where he handed out our "Induction Certificates", after he went, we then met our then T & C Divisional Director, Dick Fearn.

After the Bank Holiday weekend, I reported to Slough Station, just before 9.00am on Tuesday September 1st 1992 where for an hour or two, I spoke to Mrs Steve Callan (Passenger Services Manager). After I spoke to Steve, I then went into the Telephone Enquiry Bureaux, where I met my temporary supervisor Pam Chang. (Pam was only a temporary supervisor in the TEB because she was pregnant at that time, and she found it difficult to carry money in the booking office where she normally works). Around midday, I met my main Supervisor Chris Taylor. I had about 3-4 weeks of training, where I already knew about train timetables, and route knowledge, etc, but I then had to learn about the complicated fare structure. Although the TEB at Slough is the smallest (3-6 people) it is the most efficient. We deal with all kinds of travel enquiries, such as Slough and Maidenhead to Paddington/London, and enquiries such as Watford to up North and to tiny unknown stations in Britain. The TEB at Slough is open from 07.00 - 19.30 hours, most days.

Since February 1st 1993, I have mainly been working in the Information Office, where I meet the customers face to face and help the customers with their enquiries. I work on my own in the Info Office but in the past, we have had Work Experience people learning as well. As well as looking after my customers in the Info Office (of which some are regulars), I also have to bleed portable ticket machines.

Thames & Chiltern are very good to their staff by publishing a Quarterly Magazine called "T & C" Link, and during July, a few members of staff had a guided tour around Wembley Stadium, which was interesting. Afterwards we had a video about T & C and then a buffet meal. It was there I met for my second time our present Divisional Director "Mr Roger McDonald".

During the past two years the Division has been taking delivery of the "Class 165 Network Turbos", and more recently the "Class 166 Network Expresses", replacing 30 year old DMU's. The 165's and 166's are the most modern trains in Network SouthEast, and they have all sorts of new things which includes a Public Address System, and for the first time ever "Dot Matrix-Route Indicators".

And finally Thames & Chiltern is expanding all the time. Below is the major stations of which T & C serve:

- a) CHILTERN: Marylebone, Amersham, Aylesbury, Wembley Stadium, South Ruislip, Denham, Gerrards Cross, Beaconsfield, High Wycombe, Princes Risborough, Bicester North, Banbury, Leamington Spa and Birmingham Snow Hill.
- b) THAMES: Paddington, Ealing Broadway, Hayes & Harlington, Southall, Slough, Windsor & Eton Central, Maidenhead, Bourne End, Marlow, Twyford, Henley, Newbury, Bedwyn, Basingstoke, Reading, Wokingham, Guildford, Gatwick, Didcot, Oxford, Bicester Town, Banbury, Leamington Spa, Stratford-Upon-Avon, Hereford, Gt Malvern, Birmingham New Street, and Worcester Shrub Hill, and Forgate Street Stations.

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HANDY TIPS SECTION

THERAPEUTIC EARNINGS

Thuy Burrows - NAS Advice Worker

The Benefits Agency (DSS) **can** allow a person with Asperger Syndrome to work for a salary of up to £42.00 per week and still keep their disability benefit (sickness benefit; invalidity benefit; severe disablement allowance). This is called therapeutic earnings.

I am using the word "can" because the decision to allow or not to allow is at the discretion of the Benefits Agency. Permission from the Benefits Agency should **always** be sought in writing before starting work.

In order to get permission you will need to persuade the Benefits Agency that:

- 1) - You will not earn more than £42.00 per week.
- 2) - Your work will be beneficial to you. The Benefits Agency must see your work as a "therapy".
- 3) - You work under medical supervision
OR
You have a non-medical "good cause" for wanting work, ie you have acted on the basis of medical advice.

Individuals with Asperger Syndrome could argue for example that:

- 1) - Working will help build up their confidence and self-esteem.
- 2) - It enables social contacts and breaks isolation.
- 3) - It develops communication skills.

People with the condition should seek backing from someone medically trained and who knows of Asperger Syndrome. It is also important to explain to the Benefits Agency what Asperger Syndrome is, and what are the difficulties faced by sufferers.

- * If you are working less than 16 hours a week you can get:
invalidity, sickness benefit or severe disablement allowance and therapeutic earnings.
- * If you are working 16 hours or more a week you have a choice:
You can either: 1) get invalidity, sickness or severe disablement allowance and therapeutic earnings

- or
- 2) get disability working allowance. Contact our Advice Line 081-451 1114 or your local Citizens Advice Bureau if you need further information.

What is the catch?

Because you have been working, after a period of time The Adjudication Officer (AO) could decide that you are no longer incapable of work and will expect you to "sign on". The AO could argue that you could take a part-time ordinary job on a consistent and reliable basis. The AO might also allow therapeutic earnings for a trial period and at the end of the period ask your employer how you are getting on. If your employer gives a glowing sympathetic report, this could give a false impression. Honesty will be the most useful way of reporting and employers should be warned beforehand of this.

Remember that the Benefits Agency (DSS) can refuse permission but if you disagree with their decision you should appeal.

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LETTERS

383 Innsworth Lane
Churchdown
Gloucester GL3 1HA

Tel: Churchdown 856093

25 May 1993

Dear Richard

Thank you very much for the first issue of the magazine specifically for people with Asperger Syndrome.

I would be grateful if you would include the following article in the next issue:

My name is Paul Lowe. I am 25 and am the eldest of a family of 6 boys and 2 girls and was diagnosed as having Asperger Syndrome last year following concentration lapses at work.

I attended St Mary's Roman Catholic Primary School, Churchdown and St. Peter's Roman Catholic Comprehensive School, Gloucester, and have been a Catholic all my life. I achieved 3 'O' Level Passes in Maths, French and German, 'AO' (between 'O' and 'A' Level) French and German and took GCSE English Language at College where I gained a Grade D with a 2 in the Oral. At primary school I was good at mental arithmetic, spelling, punctuation, grammar and factual writing, including history, geography and nature, and singing, for which I was in the school choir. I developed a phenomenal mind for figures and dates (eg, 24 January 1968, Wednesday). Socially, I enjoyed outings, went out with and visited people outside school hours, had a 'childhood sweetheart', and invited people to my birthday parties, but in school I was a loner, was often regarded as being clumsy and picked on from the age of ten onwards. I became slow at reading and couldn't tie my shoe laces until I was nearly 9. In my final year at junior school I had to write two long stories and as a result of my poor reading my stories were not very imaginative.

At secondary school, things improved socially. Though I was still teased a lot, I made a few friends after my first term, some of whom I still see now. My best subjects, as shown earlier, were Maths and Languages and people often pestered me to find out what day of the week they were born on. Next best was music, and I also enjoyed Drama for which I was involved in four Christmas productions/plays. Though not a very keen reader, I enjoyed some of the set texts I studied for English, including 'Kes - A Kestrel For A Knave' by Barry Hines, J B Priestley's 'An Inspector Calls' and Shakespeare's 'The Merchant of Venice', the first two of which had people in whom

you could sympathise with. There were, again, girls who I admired there, some of whom found their own dates by the age of 16.

Towards the end of my secondary school I went on a couple of religious retreats. From those experiences I began to feel that I could make friends easier going to church activities on my own than with someone I was already friends with. In the third year I enjoyed the school's French Exchange trip to St Brienc, Brittany. This was my first ever trip abroad and the two days before I left were chaotic in our family. We went to see the Pope in Conventry and on the way home were waiting on the coach for two hours for someone who was missing. The weather was hot and stuffy. I began to worry a little, having to be at school for 4.30am the following day. When I did get home I had about 8 hours sleep and woke up at 4.00am. I rushed so much that I'd forgotten to say goodbye to my parents! Nevertheless, the family I stayed with were very pleasant. There were the parents, four girls, two boys, plus three cats, three dogs and two birds! I visited a few places with the school including Mont St Michel, St Malo, a satellite telecommunications centre at Pleumeur Bodou and the local beaches. We had a few social evenings (English and French students) and one of the funny highlights of the trip was people letting off bangers ('petards' in French).

My urge for having a steady date and more friends got stronger after that and perhaps one of my embarrassing things I did was stare at or just sit near people I didn't go around with during breaktimes, when I was at a social evening when most of my regular friends weren't there. My biggest disappointment was probably obtaining a 'U' for English 'O' Level when I retook it in November 1985. I expected a 'C' or at least a grade!

Since leaving school I have worked in a number of different clerical environments and have gained RSA passes in Typing (Stage 1 and part Stage 2), Computer Literacy Stage 1 (Word Processing, Spreadsheets, Databases) and 3 out of the 6 modules in the first year of a BTEC National Diploma in Computer Studies. My first job was as a part-time temporary Clerical Assistant on a Community Programme Archives Project at the College of St Paul and St Mary, Cheltenham. The environment was quiet and sheltered and the staff were very friendly. The work included Typing and preparing lists of historical documents of the College. I found myself a girlfriend there whom I went out with for four years. She suffered from epilepsy but was very pleasant. We went on day trips together to places like Longleat Safari Park, Cirencester, Worcester, Ironbridge Gorge and Stratford-upon-Avon and to the theatre and cinema sometimes. Things petered out from the point where she had to go to Exeter on Employment Training and towards the end of May 1991 I phoned her to see if she wanted to come to Oxford with me. She declined, and after nearly 4 months of not having seen her, I took it that the relationship was over. My second main job from September 1988 to February 1989 was as a Temporary Coding Clerk for the Universities' Central council on Admissions. This included coding 'A' Level and equivalent results manually, by board, subject, grade, year of sitting and time of year of sitting. There were two of us initially doing the job and as we were going so quickly, the staff gave us some course

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codes to input on the computer. Again, the staff were friendly. We took it in turns to buy buns for tea breaks and Helen, the girl I was doing the coding with, gave me some tips on writing English essays for GCSE.

In my next job at the Home Office, things were quite different. It was more varied and more pressurised. When I was delivering things, I occasionally misplaced things. Balancing transport figures at the end of each month was a step-by-step task - I received the information in bits and pieces and was frequently interrupted, so I didn't know where I was. I was easily offended by criticism for mistakes I didn't think I'd made. I was caught out once or twice doing photocopying - if there was more than one copy needed, the number was written on the front and those times it was on the back in the corner.

Two of the things I enjoyed and coped better with were answering the telephone and obtaining computer printouts of people's timekeeping. I liked it when the switchboard was busy and was confident with the computer, but even there one or two mistakes were detected.

Following this I worked on the Government's Sheltered Placement employed by an organisation called the Shaw Trust at Gloucester Land Registry. Intended for registered disabled people, the host company (eg, the Land Registry) pays according to an employee's output (eg 65% was mine) and the sponsoring company (eg, Shaw Trust) pays the rest. I was doing mainly filing, extracting, sorting and checking documents by county or code and in numerical (occasionally alphabetical) order. I enjoyed it there, but after so long, had several concentration lapses, probably because the job was getting monotonous. While I was there, I also encountered the most disturbing experiences of my life outside work; a mentally-ill girlfriend and brother (the relationship with the girl lasted only 3 weeks), a cousin's death and a fire at home. Anthony (my brother) has been mentally-ill for the last 17 months and has recently moved into a home designed specifically for people with his problem and other similar conditions. Despite the problems, I joined the Shaw Trust Supporters' Club, enjoyed the Trust's 10th anniversary Concert at the Barbican Centre, London, last year and went on holiday with the Trust (21 employees, 4 Trust officers) to Majorca last September. I hope to continue on the Sheltered Placement Scheme in the future and still support the Shaw Trust by receiving their magazine every 3 months and doing a sponsored walk once a year. I've booked another holiday with them to Rhodes this year.

Outside work, I enjoy singing, for which I am a member of Churchdown Choral Society and (unfortunately not for much longer) Gloucester Opera, and sing in our church choir sometimes. I also enjoy walking (I am a member of Gloucester Ramblers' Association), other church activities (organising things for young people, helping with the handicapped, going on weeks/weekends away for young adults, lay reading and

singing the psalms), watching football (I am a Manchester United supporter), and quizzes and listening to pop music/light opera and occasionally go to the theatre.

I am currently on Training For Work at Bridge Training Resources, Quedgeley, Gloucester, hoping to obtain my RSA Stage II Computer Literacy exam. This again is a very sheltered environment, but the tasks are more interesting than those at the Land Registry.

My problems at the moment are mainly around the home, where I have often shouted back at my parents. Often I still lack firmness with people like Anthony and have over-defended him. When I was assessed last year, some of my reactions to questions about the workplace were rather immature but my outstanding mathematical ability showed.

I would like to hear from anyone in their 20's who is good at Maths and Computing and who has similar outside work interests to mine.

Yours sincerely

Paul Lowe

ANNOUNCEMENTS

One Day Conference for People with Asperger Syndrome, London 1994

(exact date to be finalised)

The National Autistic Society is planning to hold a one day Conference in London specifically for people who have Asperger Syndrome. In order to make sure that the event covers the subjects that are of most interest and importance to these people we would like you to write down your ideas on the subject on the form below and return it to us at the NAS.

Mark Bebbington
NAS ADVICE WORKER

Name (optional)

I would like to hear the following subjects discussed at the proposed day
Conference for people with Asperger Syndrome/autism.

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Please return this slip to Mark Bebbington at The National Autistic Society.