

NEWSLETTER FOR PEOPLE WITH ASPERGER SYNDROME

NO. 1 - MAY 1993

EDITORIAL

Welcome to the first edition of this Newsletter for those like me who suffer from Asperger Syndrome.

I would firstly like to say thank you to those who decided to buy this publication as it is only with your support that we are able to produce it and thus establish a way of communicating with each other in a way that is hopefully helpful as well as interesting!

At the moment the Newsletter has no title and we are looking for suitable suggestions. If you have any, please send them to me care of the National Autistic Society (Family Service Department). There will be a prize of a smart Parker Pen for the winner.

For those who care to contribute to the Newsletter, interesting articles about you, your life, your work, your interests, or any suggestions would be welcome. These too should be sent to me care of the National Autistic Society (Family Services Department).

Your friend and Editor

RICHARD EXLEY

22 January 1993

How I got to Frank House

I first heard of Frank House through Issue 4 of the Asperger Syndrome Support Network. At the particular time there was three vacancies. As soon as I saw the advertisement I knew that Frank House was for me. I must have looked at the advertisement for 10 minutes and soon realising I had the most difficult task on my hands. The task being how would I get to Frank House?

A short while later my mother and I discussed it. We both had ideas and one by one we looked at each idea. After a while the list became shorter, this was due to the elimination process. We eventually came down to one idea; ie that Bradford Council (my local council) should pay. We both realised this wasn't going to be easy. We then drew up another list of who to approach. The question now was does Richard want to pursue his education. Unfortunately this made the problem harder as there was another group. While my mum wrote names for the education, I wrote names or people involved with the social services. We decided that I will contact and work on the social services, my mother will work with the education.

While all this was going on I was living with foster parents. I was mistreated, I didn't get fed, my bed was a mattress on the floor with a blanket to cover me up and finally I couldn't get in the house as she used to work at night. I had to stand in the yard waiting for her to let me in. Sometimes it was gone midnight when it was raining etc, so when I went to bed it wasn't for long because I was up early for school. I started at half past eight every morning. Throughout this time I played truant from school and as I didn't get fed, I used to starve - sometimes I wouldn't return so I'd sleep rough in doorways etc. This was no life for anyone let alone me. I told the police, my social worker and I got accused of lying. I wasn't lying, I needed proof.

When I went home to see my mum and family she would spoil me, but it was no good we used to argue and in my temper I would smash windows with my fist or stones. A couple of times the police were involved. This made things worse. If I hadn't had enough of the police.

I was trying to tell my social worker I wanted a residential placement and all she did was shut the door on me (metaphorically that is), she would say "you won't see your friends you will have no responsibilities", etc. I just said "maybe or maybe not".

A couple of weeks later I tried again but I changed my tactics slightly. I remember sitting opposite her in a cafe and she kept putting the cup near her mouth, it almost seemed like a one sided conversation. While I was eating my cheesecake I had a list

of all the good points and I left the bad points for my social worker to say, but she couldn't succeed because everything she said I had an answer to, eg you will miss your friends; I would but I would make new friends.

My mum mentioned funding for Frank House and we worked it out that what Bradford Council pay for me and what they would pay for a year at Frank House is no different. Back at the social services my social worker suggested that my mum should pay for it. I felt like telling my social worker to "get lost", but I did say "if my mum paid for me how do you think the rest of the family would react?" She replied "I never thought of that". I felt humiliated, I felt like hitting her, but that would have been no good. She then apologised.

When I went home my mum decided that we should have an update. We both agreed this was not easy but we also decided that we should stick with it and keep going right until the end despite the chances were slim.

I eventually decided that this is no good. I should talk to her boss, the team leader. I deliberately went to see him when it was her day off. At first I was beginning to feel my thoughts was unnecessary. After a while he started to try and put me off but I just stuck to my guns and use the same tactics that I used previously. I began to feel humiliated.

I was now becoming desperate for some one to support me, and help me to get advice. I tried at school but the people weren't bothered they just thought it as a step backwards. It wasn't it was a step forwards. Well a step to the side, the forward as a future and the side being where it was.

My mum was going well, she'd got success to an extent but not as far as she had anticipated, meanwhile I was getting nowhere.

Back at school I couldn't concentrate, I just had thoughts how can I convince you that this place is right for me. The social worker says "we've your interests at heart" but then they say "no, this is wrong, it is a stupid idea", is that contradiction or what.

I had an opportunity to meet the head of Special Needs for Bradford Council. I accepted as I knew my mum was going to be there. But to my amazement, my social worker, team leader, deputy head from school was there also. The meeting was fine except they all, except my mum, kept using the same excuse to put me off - the excuse being money - there isn't enough of it. Poor excuse I felt, if you want to put me off you'll have to try better than that. I felt ignored or I didn't exist and if I did I was a piece of dust on the table or a piece of paper with details under a paperweight. This was due to the nature of him instead of Richard, eg what does he want instead of what does Richard want. Most people including myself wrote notes. It seemed that everybody put pen to paper to write down excuses to put me off, so this made me feel

more confused, one moment in the meeting, next moment trying to think of reasons to put them off. I couldn't cope. I had to start breathing heavily to think straight. My social worker suggested compromise, I felt like saying "forget compromise, more reason". This was no time for compromise - it was one thing only getting to Frank House with no ifs or buts. After the meeting everyone asked how was the meeting? It was bees around a honeypot or somebody leaving court with journalists all around you. I felt squashed, I couldn't breathe. All I said was "fine" and left it at that. My mum and I discussed it in more depth over a cup of coffee. The only conclusion we came up with was that we'd did our best.

For a couple of months things were quiet until October 1991 when Frank House opened and my mum sent off for an application form. She soon filled it in waiting in anticipation and apprehension, would they accept me. She eventually received a letter confirming the place. But as she received the letter my social worker got some information on Frank House including an application form. The question now was why the change of mind? I asked but I got no reply. One evening I showed my mum and we laughed at the response of the social services as we'd already been there a long time ago. With my perserverance and determination I found the answer on the doorstep. It was my local vicar, he'd put a word in.

Now they had agreed to a place there still loomed the big question of funding. Who is to pay? There was bickering and arguing like school children in the yard "it isn't my department it's theirs" and little reason. I couldn't care less I just thought just get the pens out and sign the document.

Eventually on the 6th May 1992 it was goodbye to the North and a hello to the South - yes I was moving down at last I was flabbergasted, and all this trouble for something like this - God only knows what they're like for other things, not that I'm bothered I am just glad this is all over.

I would just like to say thanks again mum for everything.

USEFUL INFORMATION - THE DISABILITY WORKING

ALLOWANCE

Most people with disabilities, including those with autism/Asperger Syndrome have skills that, with the right kind of support, could enable them to get a job. Unfortunately though such people are frequently only able to get low paid work. However, there is now a new welfare benefit, the Disability Working Allowance, designed to help them by 'topping up' their earnings.

In order to qualify for the Disability Working Allowance you need to be:

- 1) Aged 16 or over.
- 2) Working for 16 hours a week or more in a paid job. If it is a temporary job it must be expected to last for 5 weeks or more.
- 3) You must have a disability such as autism/Asperger Syndrome which makes it difficult for you to get a job.
- 4) You need to be already getting one of the following benefits:
 - Disability Living Allowance
 - Attendance Allowance
 - Mobility Allowanceor one of the following in the last 8 weeks:
 - Invalidity Benefit
 - Severe Disablement Allowance
 - Income Support with any Disability Premium
 - Housing Benefit with any Disability Premium
 - Council Tax Benefit with any Disability Premium

Note: If you are awarded the Disability Working Allowance and have previously been receiving Housing Benefit or Council Tax Benefit you will need to re-apply for them. It may also affect the amount you receive of these benefits. This is also true for the National Health Service benefits such as free prescriptions.

Additionally it is important to remember that the amount of money paid to people under the Disability Working Allowance will vary depending on their individual circumstances, eg, how much savings they have, if any, and how much they are earning. Not everyone is better off claiming the benefit. If you want to find out if this is the case for you, you should contact your local Citizens Advice Bureau and ask them to check for you.

You can also get further information by contacting the Benefit Enquiry Line for people with disabilities on 0800 882 200. You will not be charged for this call.

For further information on other welfare benefits that you maybe entitled to send a stamped, addressed envelope to the National Autistic Society Family Services Department for a copy of our leaflet 'Once You are Sixteen'.

Mark Bebbington
NAS ADVICE WORKER

STOP PRESS

Interkids, a support group in Enfield, North London for parents of children with communication disorders, including autism and Asperger Syndrome, need someone to help them keep their accounts. If there are any readers of this Newsletter who are good at maths, and live within easy travelling distance of Enfield, and would like to help the group, contact Denise Brownlow on 081-363 9433.

WHAT DOES IT MEAN TO HAVE ASPERGER SYNDROME OR MILD AUTISM?

HERE ARE SOME ANSWERS TO THE QUESTIONS THAT PEOPLE OFTEN ASK:

IS THERE A DIFFERENCE BETWEEN AUTISM AND ASPERGER SYNDROME?

In most ways the 2 conditions are much the same and both involve communication, social problems and rigid patterns of interests or behaviour. People with Asperger Syndrome however do not usually have the severe learning or communication problems that are often associated with autism - though they may be more clumsy. Often the term Asperger Syndrome is used to describe people with autism who are relatively mildly affected and the term is more or less interchangeable in this article.

WHAT CAUSES AUTISM OR ASPERGER SYNDROME?

No one is really sure, but the problems usually develop very early in life, and may be caused by difficulties that occur before birth. Although the exact causes are still not known, it is thought that something goes wrong in the way in which the brain develops. This does not mean that parts of the brain are necessarily damaged or that there are "bits missing" but it seems that something is interfering with the very complex way in which the different parts of the brain come to interact.

HOW MANY PEOPLE HAVE AUTISM OR ASPERGER SYNDROME?

Probably more than you think! The exact number is hard to calculate but some estimates suggest that 2 or 3 people in a thousand may be affected. There are about 7 million people living in London so how many do you think might have autism? For some reason there are many more men who suffer from autism than there are women (the ratio is around 4 to 1).

ARE PEOPLE WITH AUTISM OF NORMAL INTELLIGENCE?

Some autistic people do have problems in many different areas of their development so that they may have learning difficulties as well as their special autistic problems. However, a significant number are at least of normal intelligence and some are particularly gifted in skills such as memory, music, mathematics or computing. This is the group that is often referred to as having 'Asperger Syndrome'.

WHAT PROBLEMS DO CHILDREN WITH AUTISM OR ASPERGER SYNDROME SHOW?

Although general intelligence may be normal or well above average children with these problems usually show difficulties in the following areas:

- (1) From an early age there are problems in understanding what people say or in recognising what they mean by their gestures or facial expression. Autistic children tend to be delayed in learning to talk and when they do, their speech is often very repetitive, so that they will copy what other people say rather than making up their own phrases for things. Some people have particular problems learning how to use words such as 'I or you', or 'her or she' properly. Conversation is usually very difficult so it is often easier to talk about special interests, or to ask people the same questions over and over again rather than to think up new topics to talk about. Often, too, there are problems in using non-verbal skills, and making eye contact with other people is often especially difficult.
- (2) Understanding how other people think or feel can also be a major problem. It can be very hard to understand why people are bored or angry with you, or to understand when something is upsetting them.
Often other children take advantage of this and when the child with Asperger Syndrome tries to be friendly they will deliberately make them do silly things or may tease or bully them very badly.
Some children with autism also dislike being held or touched and they can feel very uncomfortable if people come too close to them or if they are in a large crowd.
- (3) Understanding how other children play is also a problem. Often, dolls or cars, or the other games that children enjoy, do not have much attraction or meaning. The rules of pretend games, or sports like football can be impossible to understand. It's often much easier to avoid being with other people and to spend the time reading about or collecting things that interest you; lining up objects, or keeping them in a special place or in a special order is often very important. Doing the same things over and over again can be very reassuring and it can be most upsetting if other people try to stop this.

DO PEOPLE WITH AUTISM OR ASPERGER SYNDROME GROW OUT OF IT?

With the love and help of their families, together with the right sort of education and support from sympathetic teachers, people with Asperger Syndrome can make very good progress. Many manage to get to college where they tend to do best in subjects such as computing, mathematics, science or music. However some problems do remain, especially when it comes to social relationships.

WHAT SORTS OF SOCIAL PROBLEMS DO ADULTS WITH AUTISM OR ASPERGER SYNDROME HAVE?

Although most people no longer have to put up with the teasing and bullying that made them so miserable when they were children it can still be very difficult to make friends

(and especially to find a sympathetic girlfriend) and sometimes life can feel very isolated and lonely.

It is often very difficult to know how other people are feeling or to understand their point of view, and this can lead people to accuse you of being unsympathetic or unfriendly. Understanding when people are being sarcastic, or if they are joking or using metaphors instead of saying exactly what they mean, can give rise to problems too.

It is also often difficult for other people to understand how the person with autism feels and this can lead to anger or frustration.

Sometimes the person with autism may offend other people without meaning to: perhaps by being rather too friendly; by asking personal questions or making remarks that others consider to be impolite; even staring, sitting or standing too close to someone whom you do not know well can give offence.

Often people with autism may find it difficult to appreciate the effects of their behaviours on others but it is important to remember that outbursts of temper, rudeness or irritability (even if you are in the right!) are unlikely to win you friends. Talking aloud to yourself; pulling faces or making odd noises or movements are also to be avoided in public.

Finally, many autistic people find it difficult to be assertive when they really do need to stand up for themselves and this can sometimes result in their being exploited by unscrupulous individuals.

WHAT CAN I DO TO HELP AVOID SUCH PROBLEMS

Some simple guidelines:

Never be afraid to ask for help. There are ways of improving social skills; of increasing work performance; of controlling feelings or 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 terms 'autism' or 'Asperger Syndrome') and that you have difficulties understanding rules, and particularly social situations without help.

Tell people 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.

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.

Try to develop 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.

FINALLY, AND MOST IMPORTANTLY:

Don't dwell on your problems. Tell yourself you have done amazingly well to have got this far and just concentrate on ways of getting even further. Don't mope about not having a girlfriend. Concentrate on developing as wide a range of interests and acquaintances as you can. Local Sports Centres; adult education classes; voluntary organisations can all offer a wide range of different activities; they'll help you BE a more interesting person and help you meet more people too.

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