

ASPERGER UNITED

A Newsletter for high functioning people with autism

NO 3 - DECEMBER 1993

Asperger United is produced jointly by Richard Exley (Editor), Pam Yates from The Maudsley Hospitals Home Based Team for Autistic Individuals and Mark Bebbington from the National Autistic Society. Contributions for the Newsletter should be sent to Richard c/o The NAS, 276 Willesden Lane, London NW2 5RB.

EDITORIAL

Hello and welcome to the third issue of our magazine. Since the last issue we have got a title - courtesy of Anna Cohen - ie 'ASPERGER UNITED' so well done to Anna. However, the number of entrants was very measly - I only received two.

So please, please pull those fingers out and tell me your experiences, your interests, your ambitions, etc, etc.

We have a new competition for you - yes another. This time get those pencils and can you draw? We need a Logo, so come on get drawing.

I thought it would be a good idea to tell you what the next issue is to be about to give you ideas what to write about - it is about communication and relationships.

Finally, as you are aware it is coming up to Christmas so I wish all of you a Merry Christmas and a Happy New Year.

Your friend

Richard Exley

A HOME OF YOUR OWN

Christine Hatfield
Social Worker

One of the biggest steps that anyone has to take is moving away from their parents when they get to adulthood. It is difficult enough for everyone but for someone who has Asperger Syndrome it is much more difficult and he or she will need a lot of extra help at this time. I have worked with four people who have Asperger Syndrome and they all started off by moving into staffed accommodation to begin with. We are lucky in High Wycombe, that the Health Authority set up a staffed house of bedsitting rooms, together with a housing association. Two people moved into this house from home and the staff helped them to learn how to look after themselves by teaching shopping, budgeting, cooking, washing and cleaning. After a year to 18 months, one man has moved out into his own home and the other man is looking for a place at present.

Finding a place of your own can be very difficult. It probably helps if you have a Social Worker or a community support worker to help you. Some councils or Housing Associations are sympathetic, especially if you can get letters of support from your doctor and Social Worker.

If you are not working, and have little savings, the council will pay Housing Benefit. Our local council will pay quite a high level of housing benefit for people with special needs, as much as £83 per week. This means that privately rented houses and flats can be looked for, which give more possibilities. If you are lucky enough to be employed, you may be more restricted financially as you cannot claim Housing Benefit.

The amount of help and support you can get when living on your own will vary from area to area. Since the Community Care Act came in last April, anyone requesting help from Social Services has the right to an assessment. After the assessment, how much help they can offer will depend on what priority they can give you.

The other two people I work with had considerable difficulties, so were funded by the Social Services to go to live in special staffed housing run by the MIDCAS Autistic Society in Gloucestershire. After 2-3 years they have just moved into an unstaffed

house in the same area but are still supported by the same staff. They have taken longer to learn all the skills of looking after themselves and will probably always need quite a lot of support. It was quite difficult for them to obtain funding from Social Services for this and if anyone is asking for this now, it is even more difficult. If you are in this situation it is often helpful to tell your County or Borough Counsellor about your situation and write to your member of Parliament, as they can make sure the situation has been fully examined.

Having found your own place to live, the most important thing is to feel good about your progress and to let people know when things are getting difficult. There are a lot of people around, who want you to be as independent as possible and are willing to help you achieve it.

LEARNING INDEPENDENCE

Mark Fleisher

Hi, my name is Marc, I'm 26 years old, and I live and run, on my own to a large extent in my own rented accommodation. I have confidence in my ability to be independent, and of my ability to make appointments and decisions for myself to make the most out of my life. I also feel a great sense of satisfaction to have these skills. However, I am also labelled with 'Asperger Syndrome' a complexing and sometimes frightening disorder which can hamper social communication and independent development, and indeed at one time I hardly did anything by myself, relying upon my parents totally. Having made the transformation between the two extremes, I will now describe some ways in which this can be brought about, and what helped me as well as generalising rules for others.

Reaching almost total independence is not something which can be achieved overnight, or even in a few weeks or months. Like the tennis player who's ultimate goal is to win Wimbledon and become a star, one must first, slowly and painfully at times, work their way up the rankings, from County and club level, to Regional and National events, and finally to International stardom. Likewise, independence also requires time, effort and sometimes the sheer willpower to have a go. Considering some of the main aspects of being independent, one might consider:

(1) **Shopping**

Shopping skills are needed so that we can obtain the food and drink we need to survive. This requires an understanding of money (see (3)).

(2) **Cooking**

Once we have the food, we need to know how to prepare and eat it properly. We need to have an idea of the right sort of food to buy, and how to store it.

(3) **Finance**

An understanding of money is not only important in the short term, so that one can just spend it, but also in the longer term that one builds up an idea of how to budget, how much they should be spending in relation to money available, which items have priority, and the amount needed for other items like bills (which have to be paid).

(4) **Reading & Writing**

Many people take these basic skills for granted, but for some, including autistic people (I refer autism to the general population with that condition, Asperger Syndrome to the more able end of the range) reading and writing can be difficult, yet it should be learnt, even a little would help, because all of (1), (2) and (3) will be difficult without these skills, eg not being able to read a cookery book for instructions, or how much a bill is worth, or a shopping list, will make tasks harder.

(5) **Clothes/Washing**

The ability to wash clothes regularly will be required for independence, how to use machines, how to iron or dry clothes, etc. Also how to clean the house generally.

(6) **Social Contacts**

How will the individual cope socially with uncertainties, or if exposed to unknown social situations. Will they be able to make appointments and have enough confidence to get trying when things go wrong.

It is only when we have learnt these skills and more, to a fairly high level of efficiency that we can start thinking about the final step, moving away to your own house, where support can be minimised, and confidence in ones own ability intensifies.

But how can one set about an incredibly difficult task. How can we make this transformation. The housebound autistic person, perhaps not even able to eat without help, let alone buy food may seem as far away for an individual running his own house as a club tennis player seems against a world champion. Could it be that only a few autistic individuals are destined to improve markedly and become successes in significant ways. Is there some magic ingredient that only a few people have. Are

many autistic people destined never to perform or exceed a certain level of ability simply because they learn or talk more slowly than others, or because someone else said so. Not in my opinion! In my view every one autistic person on the planet can be helped to some degree. There are no limits to what can be achieved, no more than any unaffected person. Given the resources, the staff, the patience, the understanding, and most of all the belief, the skies the limit. I was lucky enough to have all these at my disposal. And one of my goals today in life is to show other people what you can achieve, despite your condition, if you put your mind to it.

Let us go back to our 'tennis player' comparison. What does the club player need to reach a world class player. Well, clearly he needs resources, without a tennis court, he can't improve! Not to mention balls, racquets, and what have you..... second, he needs a trainer (a coach) who can guide him in the right direction, pointing out faults, hinting suggestions on how to improve. Third, he will require enough (as many as possible) to play against to gain the experience. Fourth, he should know what to eat, how much exercise to get, how to prepare and organise his time and money (he must have a minimum amount of this). Fifth, he should have the belief, the desire to conquer the opposition, of not to quit when the going gets tough. The more effort he puts in, the more results he sees.

Learning independence can be thought of in a similar vein. Except that the resources have become homes, (cooking facilities, washrooms, bedrooms, cleaning equipment, etc, all included) for autistic people, the trainers are now members of staff and the ultimate goal is becoming as independent as possible, and perhaps living in ones own house. A great achievement for anyone, but even more so for the autistic individual, who has to live with his condition. I am often asked what it is like to be autistic, arguably described in a very broad sense by a 'social and communication problem'. Some autistic people can't walk, talk or even move much, others can do almost anything, some act strangely or seem unexplainable unpredictable, others act almost normally, such that you couldn't tell the difference of the condition being present. There are so many different variety and severities of autism that (like the common cold) there is simply no single answer. One way of thinking of what it might be like is to imagine that you are visiting a foreign country on your own, knowing nothing of the language. You could certainly see everything around you, but how much sense would social contact mean. Everyday sayings such as 'it's on the house' or 'I owe you one' in this language might not mean anything to you. You might think there's something on the roof! Like the autistic individual you have an inability to recognise small figures of speech.

What about my individual circumstances! As a child I went through the familiar problems of autism, bullies, teasing, virtually no friends and isolation at school. People would tell me how stupid I was, and then laugh at me for looking vulnerable. They would threaten me with stares, sticks and their fists! My mum and dad and sister (two and a half years older than me) were unaware of my autism. I was not diagnosed until much later (about 12). When I was 11 my sister was killed in a car crash. All the family had to cope with the grief. Later we adopted another sister and a few years ago my mum developed cancer and died, and my gran also died. Until I was about 21 I had also always lived with my parents, but with my mum becoming ill and I growing up, the need for me to improve my independence was noted. You should have seen me then! I stayed in my room most of the time, nervy and hyperactive, suffering from years of bullying and teasing which had evaporated all my confidence. I couldn't even dress myself properly, and relied on my parents for everything.

My first real chance to improve independence came about 4 years ago when I had the chance to move in to a special home with four other people with learning difficulties plus members of staff working on a rota to assist them. Whereas my parents had done things for me, the staff here challenged my lack of confidence and ability for independence. They believed I could do more. I found this transition difficult at first. Dealing with new surroundings, coping with strange people and uncertainties, it often seemed too much. I used to run away sometimes, back to my mothers home and safety. But was this the answer? If our tennis player has a weakness in one of his shots (say his backhand) and he backs away from the problem, playing only on his forehand, he will forever be severely restricted in his game plans and capabilities. If, on the other hand he makes a serious effort to improve his backhand, even though this seems a lot harder in the short term, in the longer term he will benefit greatly and have a far more reaching and able game. Likewise, when learning independence, in order to solve or overcome a problem or difficulty, one must understand and face what they are trying to overcome.

Slowly, my confidence increased. I stopped running back home when difficulties arose. Through the support of the West Wycombe staff, I gradually learnt about shopping, finance, washing and organising my time, many of the things I have described already as being necessary for independence. Of course there were difficulties, but the staff were there to help me, not to do the task for me, but to provide helpful tips on how I could do them better. The more I did, the more confident I became. Finally one day I sat up and told myself 'Wow! I never believed I could do all this on my own. I am almost fully independent. I feel so confident I reckon I could run my own house with minimal support'. About two years later my dream came true! Take a look at me now. Apart from one or two visits a week from a good Social Worker and rehab. officer, I

am virtually completely independent in my own rented accommodation, making my own decisions on housekeeping and lifestyle. I can shop, budget, deal with finance, cook, and organise my time. I also have the ability to be flexible and assess situations, as well as making or even changing appointments in my diary. Most of all, I feel the sense of satisfaction of having learnt independence to the highest degree (running one's own home) and the knowledge that one day, when I'm older, I can sit down and say 'I had what it takes' to become independent.

Some of my other achievements are:

- (a) playing table tennis in the league. Last season was one of the best in my division, winning over 80% of my matches.
- (b) providing speeches for public events, including the National Autistic Society AGM, and planning to do one for the International Conference on Autism next April in Sunderland.
- (c) Wrote articles and had them published in a local magazine.
- (d) achieved many good exam passes including 'O' Level Physics (grade A), Grade 1 CSE English Language and English Literature, and 'A' Level mathematics and statistics (Grade B). Just starting a university course at Brunel University in Uxbridge in mathematics.
- (e) helped GCSE pupils with their maths in a maths workshop, aiding the teacher.
- (f) Playing tennis, and coaching mentally handicapped people in the game.
- (g) Running my own rented accommodation with minimum support.

Advice to Followers

- (1) New jobs or skills towards independence should be learnt at a reasonable rate. For example, if someone is learning how to use money, they should learn that in one step, more advanced aspects such as budgeting should be done later. Learn one job at a time and learn it properly, but equally don't be too slow, get a sensible time period to achieve a set amount.
- (2) The larger goals can only be achieved when we know the basics. Living on your own is the final ultimate achievement of independence, like Wimbledon is the final goal of a would be tennis star. We require money for resources, enough people - staff - for training the affected ones, understanding what the autism or affliction means in terms of the difficulties of learning and the ability of these staff to keep going when things are tough.

- (3) There is no short cut to the top. It has to come, in the end from the individual, the belief that he can get better, the determination to face difficulties as they arise. One must distinguish between expecting too much too soon, and not pushing far enough. Continued support throughout this period is vital, for every new skill that is learnt brings us a step closer to that ultimate goal, yet if that support waivers, is cut back, or does not believe in the individual, things will only step back.
- (4) For me, vital messages and connections can be made through the telephone which is very important now that I live on my own. I have TV and Radio also to keep a track on the outside world. My visits from my Social Worker and rehab officer is important too, since this gives me the opportunity to sort out harder problems (such as complex financial ones) and then the opportunity to make important remarks about how I live my life and whether I should change anything.
- (5) The underlying fact is that there must be the belief in the autistic's ability, both himself and from his parents and care staff personnel. A tennis coach on his own can never make a champion. All the staff in the world can't make someone run their own house. Not unless, deep inside the mind of the affected person, amongst all the thoughts of self doubt and fear, there is a tiny part which thinks 'I can!' Then, and only then can the trainer (who also must believe) and the learner work together, slowly but surely, higher and higher up the achievements list until the summit is reached!

WHAT MAKES PEOPLE WITH ASPERGER SYNDROME DIFFERENT

Thomas Walker

I would like in this article to describe in general terms, as I see it, the essential differences between the autistic/Asperger person (hereinafter referred to as AA) and the normal person (hereinafter referred to as NP). NP interact with other people on two levels or in two different dimensions of thought namely, the factual objective level and the emotional subjective level. AA can only interact on the factual objective level and even this is done in a fragmented and piecemeal way. This is not to say that the AA does not experience emotions or feelings but that he is unable to use them in a meaningful way in his interaction with others. Thus the AA is not dead to his emotions and feelings in the way, for instance that the psychopath, is but rather that he cannot refine and encode his own and other people's emotions in a way that has a mutuality of meaning between himself and others. This lack of emotional meaningfulness is the direct cause of the AA's fear when he experiences his own and other people's emotions and feelings. Everyone experiences fear when they do not know what is happening or going on around them, particularly when they see that other people seemingly do understand what is happening. It is like a one legged man trying to compete in a footrace with a two legged man and when also that one leg is weaker than a normal leg. The weakness that I refer to is the fact that AA people possess only fragmented perceptions in both their hearing and vision. They lack the necessary innate and instinctive fusing factor which enables NP to join together that which they factually hear and see into a meaningful wholeness of sense. The AA has to labour long and hard to try and fuse together and make sense of that which he factually hears and sees and sometimes he is unable to make sense and establish any meaning at all.

I have to admit to a certain degree of exasperation when people refer to the Asperger person as one who is suffering from a mild form of autism. In saying this I am not in any way downgrading or failing to perceive the devastating problems of that form of autism described by Leo Kanner as childhood or infantile autism. This form of autism is very terrible; many cannot speak and many are mentally retarded and live in perpetual fear. The Asperger person who often possesses good and fluent speech and is not mentally retarded, nevertheless still possesses the essential core deficits of autism. This is to say that the Asperger person cannot:

- (1) socialise
- (2) obtain any fulfilment of his basic emotional desires
- (3) express his sexuality and marry and have a family
- (4) obtain work and as a consequence is condemned to a life of poverty, and
- (5) the Asperger suffers from his awareness of his situation relative to the NP. This can produce a very high degree of anxiety and depression which can lead to chronic depression over a period of many years which happened in my case. Thankfully I have now overcome my depression due in major part to having been diagnosed as having Asperger Syndrome which enabled me to better understand the cause of my depression.

Can anyone suffering from the things I have mentioned above ever be described as suffering from a MILD anything. There is nothing mild about Asperger Syndrome. Anyone who has it has these core deficits and in consequence has a devastating affliction for life for which there is no cure.

The Asperger has, vis a vis the outside world, the appearance of a normal healthy person (except for a stiffness or rigidity in walking and a lack of balance and clumsiness). His defects and deficits are mostly hidden and sometimes not even his family appreciate properly what is wrong. Many demands are placed upon him with which he cannot comply and he suffers accordingly. He often suffers in silence because he finds it so difficult to explain what is wrong. He is often wrongly maligned when (1) he does not understand correctly what people are saying; (2) he does not recognise people properly and for example passes them without speaking, and (3) when he becomes frightened when emotions are involved.

At best the only way he can communicate is through his factual intellect. He only has one string to his bow. This is why he appears pedantic, literalistic, repetitive and obsessive. He cannot communicate emotionally hence his tantrums, frustration and anger. Human beings have developed into very emotional creatures and they use their emotions all the time to communicate with each other; thus shutting out the autistic. This is one of the main reasons why the autistic is at such a disadvantage all his life. The best way for an AA to communicate is through the written word. This is why I was so pleased that the team at the Maudsley Hospital had proposed to set up a Newsletter written by and for autistic people. In this way the medical experts can become more aware of the experiences of the autistic person and obtain a greater understanding of autism. But also the autistic will be able to see what other autistic people have gone through and obtain the courage and fellow feeling to enable them to

enhance their own lives and deal better with their adversities. I have obtained great encouragement through reading about other autistic people and this has helped me through difficult times. If therefore it is at all possible for them to do so, it would be marvellous if autistic people would use the Newsletter to tell others about themselves and pass on their experiences. I will write about some of my own experiences at a later date.

MY MUSIC

Lionel Elton

After being suspended and then sacked from my job at the Royal Bank of Scotland, I have taken up my music again. Although I have to practise I found great joy in doing chamber music. The piece I played was Mozart's clarinet trio for piano, clarinet and viola, and now I am learning the piano quartet, also by Mozart.

I play both the viola and piano, although I play the viola more than I do the piano.

Practising is quite stressful and after it is done, I find great joy playing my music and know it is better from the last time I last played it.

In September I hope to play in an orchestra at one of the evening classes in Westminster and maybe who knows, they might give concerts.

LETTERS

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Dear Richard Exley

I'm 37 years old and I'm autistic and I live by myself because my mum has just recently died. I've got a book of poems out called "Taking The Load Off My Mind". This poetry book is about 170 pages long and it's had a mention in Mark Bebbington's Newsletter and from what I can gather it'll get a mention in Communication too. People can get a copy of this book by sending £6.50 to The Child Development Research Unit, Nottingham University, Nottingham NG7 2RD.

I would also like it if someone out there could write and record a song about autism. As songs need to be written about this subject. If people want to contact me about this my address and phone number is above. I might not be able to phone you back though because there's a block on the line so I can't call out long distance. Although you can phone in from any distance even abroad. This block only affects outgoing long distance calls. I can't afford to run up huge phone bills now my mums not here to pay off the bills. Also I'd be pleased if any nice lasses can get in touch with me too. As I have not much social life what with being autistic. Anyway once again I hope that song for autism will soon be written and recorded. Hopefully it'll be done by someone reading this. I've asked for a song about autism in Mark Bebbington's Newsletter with no luck. Hopefully I'll have more luck with your magazine. I can't do this because I'm no good at matching words with tunes for some reason. This is why I write poems. Also I don't have a recording deal. Anyway I think that's about all. So bye bye for now.

Yours hopefully

David C Miedzianik

Say....Med-Gen-Nik

HANDY TIPS: HOUSING BENEFIT

Mark Bebbington

If you are on a low income and have savings of less than £16,000 you may be eligible for financial help from your local authority in paying your rent. The rules for claiming Housing Benefit are complex so you may need help in making your claim, but as with any other kind of welfare benefit, if you think you might be entitled to it, it is better to make an application than risk losing out.

Forms can be obtained from either your local authority's Housing Department or a Citizens Advice Bureau (CAB). Alternatively if you are making a claim for Income Support you should automatically receive forms for both Housing Benefit and Council Tax Benefit. These can then be completed and returned to the Benefits Agency who will then send them to your Housing Department.

Further help in making an application for Housing Benefit can be obtained from either your local CAB or Housing Aid Centre if there is one in your area.
