



No8 - SEPTEMBER 1995

Asperger United is a self-help group run by and for people with Asperger Syndrome. Its aim is to put people with the condition in touch with one another and to provide them with information so that they can lead more independent lives.

The Asperger United Newsletter is produced by an editorial group consisting of the two current Editors; David Wright & Ian Reynolds; Pam Yates from The Maudsley Hospital's Home Based Team For Autistic Individuals and Mark Bebbington from The National Autistic Society.

INDEPENDENT DAVE

by
David Wright

I have recently moved into my own flat after living in supported accommodation for some time. There are many troubles to this existence, rough with smooth must be taken. Loneliness is a disadvantage, we all think we are wonderful, not necessarily true. Buying your own food, changing in the sense of being alone. To be honest to achieve this in less than two years is quite an achievement and not easy for anyone in this day and age let alone a person with Asperger Syndrome. Problems of independent living can be solved if one uses positive thinking. Try to tackle your problems head on, think strong, believe in yourself. Criticism is not something I like but I find it useful, it helps me to turn to good books to beat the devil within.

To gain an ideal existence is not possible but we can all try. Feel good about yourself do not abuse yourself who needs these things, be determined to turn bad into good. Having a council flat may sound as if you are onto a good thing, well you still pay rent and its a responsibility which I accept.

Here I am saying quite simply love yourself. If you do not, who will? Self esteem is important. The mountain, can be climbed, you can do it. This is not necessarily a religious statement but nothing is wrong with faith in yourself, it is what life is about.

Be on top of life do not let life get you. Independence is a way forward make sure its your way forward. Reference book 'Staying OK', Amy and Thomas Harris.

DAVE RAVE WRIGHT

LIVING INDEPENDENTLY

by
Ian Reynolds

I rent a flat in Essex. I got it through a landlord you can rent or buy a flat or house, rents can vary but if you try you can get a mortgage from a building society and pay off some years until it is paid off. You can have an Endowment Policy at a fixed rate for so many years. Before getting a mortgage however you need to be in a stable job earning enough to cover the mortgage payments. The flat I am in is very nice and I like it very much and it is what I always wanted to do. I am now 34 years of age and pleased I have done it, the flat was not furnished but it is now carpeted, I have a cooker and most things you might have as basic. When I moved into the flat it was yellow and pink, it is now painted white with white wallpaper. I am enjoying my independence and the responsibility it brings.

OUT & ABOUT WITH IAN REYNOLDS

Shows in the West End I have seen. I got in to see the Nat King Cole Story at the Garrick Theatre near Leicester Square. I sat in the Upper Circle. It was the first night which is press night and I was lucky to get tickets. I paid £7.50 restricted view but I could see and it was a one man show with a small band. Clark Peters played the part of Nat King Cole. Very nice songs worth a visit. It's a musical. Some nice shows on at the moment to see and concerts at Wembley Stadium. Ring Wembley box office to see when and whats on at the Stadium. At Wembley Arena Conference Centre there are shows all year round, shows on most nights. Been to see the Horse Derby at Epsom and Oaks at Epsom, the side I went was free on the downs where a market was set up for 3 days. Racing on Derby day only. Queens Stand ticket holders. Men top hat and tails and bow ties, Ladies dress and hat. Royal Ascot Heath Enclosure for royal meetings used only one pound. I always go for the cheap seats and do things very cheaply. I like going out mostly in London. I am going for a job in the Midland Bank near where I live. I went for their assessment on Monday morning at 9am, left 11 o'clock then I got the train to South London, Denmark Hill for a group meeting, then I went to Earls Court to see the Royal Military Tattoo, that night the Queen was in the Royal Box. 29 soldiers came into the arena in cars and each one of them had got the Victory Cross for bravery in the second world war, it was a sight to see. I have been to Colchester to see David Moat. It was good but Colchester in Essex is a bit way out but the meeting with David and Pam was good. It lasted about 45 minutes then I made my way back home, I got a lift there and back. In the meantime I have been to see the musical 'Fame' at the Cambridge Theatre in London. I went on press night. It cost me £10, I sat in the Upper Circle, it is now a sell out. Most musicals I hope to go on press night if I can get tickets. Finally I saw the tennis at Wimbledon on the 2nd Thursday, I went to court number 2, on the Friday I went again and saw tennis on court number 1 and on Saturday I was standing at court number 1. I saw the mens doubles final and the mixed doubles final.

Please keep yours letters coming in to let us know about you!

LETTERS/CONTACTS/PEN PALS

Thank you to Paul Lowe, Peter Myers, Nick Priechenfried and everyone else who has sent letters to Asperger United. Unfortunately due to limited space we cannot print all the letters we receive but please do keep sending them in, along with anything else such as drawings, jokes, etc, which you think other readers might enjoy.

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Please note - 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.

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As you know, my name is Tim Loder.

I have a form of autism and when I was born 36 years ago, many of you will know that those with my condition were regarded as hopeless cases. I am living proof that this is not true. Surely, in any civilised society the answer to disability is helping people to overcome their difficulties and not killing them as happens in abortion. In fact, I do not regard myself as disabled.

Thankfully, I was helped enormously by my parents who spent many hours teaching me to speak and to read and write. Despite my Christian family, I was brought up that abortion was acceptable, and is often meant for the best but during my adult life I have become more and more Christian - particularly as a result of passionately thinking about my right to life and the rights to life of those who have any form of disabling condition by principle.

Today I have my own garden maintenance business. Many of my clients have been with me for years and I have my own accountant who works out my tax and other relevant matters.

I acknowledge that women are much more independent nowadays, but so far as abortion is concerned I do not believe that they have a right to choose because of my right to life.

I am interested in trains and politics and I believe in a constitutional right to life. Enoch Powell always states that although we have no written constitution in this country, we nonetheless have a constitution which is based on our case law which was originally formed from Christian teaching.

I enjoy travelling and do quite a lot during my holidays. My mother was German and I go to Germany to visit the family and I am learning to speak German. I also enjoy visiting Italy to see a German relative who lives there, and I go to Scotland quite often to visit Scottish relatives.

I work - and I enjoy my work. I travel and I enjoy my life. So who is anybody to claim that my life is not worth living. So, let me end by saying that I hope you will join me in fighting for the right to life of everybody.

TIM LODER

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Dear Asperger United

Hello, my name is John Beavan, I am twenty-seven years of age. My interests are walking, going to the cinema, watching sport on T.V., listening to music and going on trips if possible. I am looking forward to hearing from anyone with Asperger's who is interested in becoming a pen friend in the near future.

**JOHN BEAVAN
DORSET**

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Hi everyone

I am 20 and a young man who would like to hear from other people with Asperger Syndrome, I enjoy quite a bit of sport and generally having a good time, and I am interested in getting to know someone like myself, anywhere in the country.

**RICHARD LITTLEWOOD
NOTTINGHAM**

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I am 36 years old and mildly autistic, and live in North West London. I would like to meet other autistic persons who share my interests; art, music, going to exhibitions, museums and concerts. I also like walking and I have no problem in communicating.

Any one interested in shared activities or in forming a small group, please contact me on 0171 435 1075.

**DAVID BRAUNSBURG
LONDON NW3**

Reply to article entitled 'Self Advocacy With a Purpose'

(Asperger United, issue 7, June 1995)

I agree with David Shamash that a new group could be started for people with Asperger Syndrome by the National Autistic Society and that we could perhaps meet more regularly than at the conference once a year. I like the idea of having discussions as well as lectures or talks and the idea of setting up a committee.

However, in the interests of those having to travel long distances, perhaps meetings could be held for 4 hours once every 2 or 3 months, with an hour's break for lunch midway through and coffee breaks midway through the morning and afternoon. May I also suggest that some meetings are held during the week and some at weekends, so that those of us who are working can attend as well as those who are not working, and that people do not have to attend every meeting.

Whilst writing, since I wrote my last article in January, I have been on a work experience placement at Tesco's in Quedgeley, with the support of a job coach based at the Employment Training Units and Gloucestershire Group Homes in Nailsworth for people with autism/Asperger Syndrome, the organisation which I described in that article. I have been working in the dairy produce section at Tesco's doing shelf-filling, sorting stock in the dairy produce chiller, bringing stock in on delivery (or as soon as possible afterwards), doing various types of reductions on goods and disposing of non-consumable items and non-saleable items.

My job coach visits me on average once a fortnight. I have been in touch with my Disability Employment Advisor (DEA) at Gloucestershire Job Centre and am hoping to start full employment at Tesco's on the Sheltered Placement Scheme as soon as any suitable vacancies occur.

I would like to hear from anyone with similar interests to mine (namely singing, amateur dramatics, long-distance walks, watching football, cycling and listening to pop music) or who is working in the clerical or shop work fields. In proper employment or on work experience placements. Perhaps the meetings mentioned above could be the ideal place to meet. May I suggest that names and addresses of those attending are taken at each meeting so that people can keep in touch with each other in between times.

Paul Lowe
Churchdown, Gloucester

Thank you to Paul, and David Shamash in Asperger United No.7, for raising the subject of self-advocacy groups for people with Asperger Syndrome. Whilst The National Autistic Society appreciates the possible benefits of such schemes it simply does not have the resources to set them up at present and this situation is unlikely to change in the foreseeable future. However, we are committed to continuing our involvement in Asperger United and running our annual conference for people with Asperger Syndrome.

Mark Bebbington
National Autistic Society Advice Worker

Learning to cope with the world in a philosophical way

By Marc Segar

Being the victim of nature's game
I forfeit the shield and carry the blame
By trying to cope I play the fool
Within a world of hard and cool
They mock, they tease, they make me cry
They do not seem to tell me why
No-one offers to explain
The rules of this confusing game.

My name is Marc Segar. If you are a keen fanatic in the world of autism and special needs you may have heard my name before. This is because I used to be a text book case of an Asperger Syndrome sufferer and I have since made considerable progress. I am now 21 years old and I am doing a BSc in Biochemistry. In my spare time I am a volunteer and a workshopper for Kith and Kids, a support group for families with children or adults who have special needs.

I also take a keen interest in philosophical ideas and concepts. But getting straight to the point, I have now learnt to socialise in a way that seems so natural, no-one would believe I'd ever been autistic. I can fit in with a crowd, recognise a tease when I see one, be one of the lads, take full responsibility for others, I can even get into relationships. I believe that, despite all the world's wit, sarcasm and cynicism, everyone has the right to these apparently simple things which so many take for granted.

For most of my childhood and teen years, I was in special needs education. For me, this was a very sheltered environment. It was not until afterwards, when I went into sixth form, that I was really first exposed to the world. For the first few long and frustrating years, nothing seemed to make much sense. I was just being constantly teased and told to get lost for reasons I couldn't even begin to understand. My second year at university has been much easier, perhaps because at last I understand the people around me.

I have approached the problem of social interaction in a highly analytical and philosophical way. I believe that all you need is an analytical and open mind and to become obsessively interested in social interaction. As far back as I can remember, I have been on some kind of quest for the meaning of life. For the last few years I have had a very open mind and accepted that any theory could be truth, even though I have favoured some above others. The theories I feel I have found most useful are those of Desmond Morris. I feel that the patterns of social interaction I observe around me are consistent with natural selection and survival of the fittest, or in this case, maybe survival of the best adapted. I seem to spend more than half of my thinking energy on working out why people have evolved to behave in the way they do and how it would benefit them in surviving and passing on their genes.

When it comes to natural selection, one must remember that ideals, innocence, justice and the phrase "meant to be" go straight out the window.

When I'm not thinking about the Desmond Morris theory, I'm often trying to think of ways to strive for perfection, an ideal which I know one can never fully achieve. Then again, I feel one of my worst social imperfections is that I simply won't stop going into deep analytical conversation with my closest friends. However, being aware of this, I now stop myself before it goes beyond the limit.

It would probably give encouragement if I were to state that the more one is able to get ones self accepted by peer groups, the more opportunities for learning one will be exposed to. The more one learns, the easier it becomes to be accepted by peer groups.

Recently, I have become aware of some of the concepts concerning Zen and Buddhism. As the Buddhist philosophy tells, each must find their own route to enlightenment. I believe that each Asperger sufferer should be encouraged, with the aid of plenty of discussion, to find their own route to achieving social acceptance. It is up to the individual whether or not this has to be connected with the seeking enlightenment and perfection.

MARC SEGAR

Supported Living

by Keith Toogood

My name is Keith. For reasons of confidentiality, I will call my client David. My role is to support David, to help him live independently. David has Asperger Syndrome. I am employed by West Berkshire Housing Consortium, a charitable organisation established to give help to a wide variety of people who have support needs. There are two 'arms' to the organisation; Residential and In-House. The Residential 'arm' provides support to the residents living in the 35+ residential homes that we run and the In-House 'arm' provides support to those people who live independently, or at home with their family. I would like to tell you a little of what my work with In-House involves.

Firstly, a bit about David and myself. He is 31 years old, single and has been living independently for about five years. I'm over 40, married and have been working with David for just over one year.

What does it mean to provide support for David? Well that depends on his specific needs at any one time. Like everyone, these can vary, it depends on the situation and this means that the most important part of my role is to be flexible in the support that I provide. All of us, as we develop, learn to do things for ourselves and we enjoy being able to make decisions for ourselves. The ability to make choices is what living independently is all about. Therefore, the last thing that David or anybody wants is to have their level of independence reduced. However, David has Asperger syndrome, so you know that there are things that he needs help with. But, there are many things that he can do, and his achievements are not lessened by having someone to help with the tricky bits.

That's the theory; what does that mean in practice? On the practical side, it means, for example, helping with moving house. David has recently moved into a new place. This meant going to the local authorities to make sure that David was receiving his Housing and Council Tax benefits. Moving home means going out and buying things. It also means choosing colour schemes for the different walls - this is nearly finished and next we will buy the wallpaper and paint and then start to decorate. Living independently means that **you** decide what things you would like for **your** home. This is great fun, but is not always straight forward. My main role when out buying things with David was to give advice and to help keep track of the money, moving home is not cheap. I also helped by dealing with the utility services, the electric, the gas and the telephone companies. Your own telephone is, perhaps, the most symbolic piece of equipment when you live independently.

I also help with the boring things, like cleaning, washing etc. David has standards which he likes to achieve within his place my task is to provide the additional help to aid in reaching these goals. Like most of us, David enjoys having money to spend, so shopping is (mostly) a pretty good time. I say mostly, because all of us would like to have loads of money to spend on things that we fancy, but very few of us are that lucky. So, you know how frustrating it can be when you are told, 'no, you cannot afford it' -a real turn off!

David, like many of you, likes to go out and meet people, family, friends and would-be friends. Like very many families these days, David's relatives do not live in the same town as him. This means that family get-togethers are more likely to take place around birthdays, Christmas time and other holidays. Being a support means helping to make sure these get-togethers happen. One of the things that David and I do, when we go out, is to visit various pubs, some local and others in the surrounding areas. We also go swimming, walking and playing golf. Then, on the less energetic side, we listen to music, watch television or play board games.

So far, I have outlined some of the practical, physical help given to David. But, like everyone, we all need someone to talk to, or to complain to about things. Being a friendly ear is an important part of being a support worker.

What is it like supporting David? David is no different to most of you. He is an intelligent person who has difficulties in handling social situations. This can be very frustrating and being frustrated means that you often get angry, so this can then be a very hard time for both of us. However, like most of us, the anger quickly evaporates and then we can both be at ease with each other.

What is it like being supported and living independently? You will have to ask David that. But, I do not think it is an easy thing to have someone coming into and then going out of your place, so, David, my old mate, I think, on the whole, you do darn well! Living independently is hard work and there are no quick solutions to the problems that being in the community brings. However, even with all its difficulties, being able to make your choice about the things that effect you is much better than having them made for you.

KEITH TOOGOOD
WEST BERKSHIRE HOUSING CONSORTIUM

NOTICES

AUTISM ON THE INTERNET

Damon Matthew Wise, a man with Asperger Syndrome, is planning in conjunction with the Irish Society for Autism to set up a Bulletin Board System (a library of information, pictures and working groups to be accessed by E Mail and Modem) for people with autism, their friends, families and interested parties.

Anyone wishing to find out more about Autinet can do so by contacting Matthew at the following address;

4 Lisin
Tullyglass
Shannon
Co. Clare
Ireland

Tel/Fax (061) 472 812

E.Mail: Wise@iol.ie (Subject : Autinet)

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CAN YOU HELP?

Are you currently unemployed but looking for work?

Would you be willing to give some time to tell us about your experience?

We are carrying out some research that aims eventually to make it easier for people with Asperger's Syndrome to get a job. If you would be willing to help please call Lynn Mawhood on 0181 725 5604

HANDY HINTS

Living Independently - Welfare Benefits

Listed below are some of the welfare benefits that you maybe able to claim in order to help you live independently.

Due to limited space we cannot go into too much detail on the subject here. However, the information is based on a handout which was produced by Tui Burrows for the day course for people with Asperger Syndrome held at the Kings Fund Centre, London in April of this year. If any one would like a copy of this handout please send us a self-addressed, stamped envelope.

Remember that if you need assistance applying for welfare benefits your local Citizens Advice Bureau (CAB) or Welfare Rights Agency should be able to help you. Alternatively The National Autistic Society Advice Service maybe able to assist you. Their direct Advice Line number is 0181 830 0999 and is normally available weekdays, 9.30am - 4pm.

NAME OF BENEFIT	WHEN YOU CAN CLAIM	CONDITIONS
Income Support (IS)	Normally from 18, but people with Asperger Syndrome maybe able to claim from 16	<p>If you have no income or it is low.</p> <p>You must not work for over 16 hours a week.</p> <p>You cannot claim IS if your capital is over £8,000</p>
Severe Disablement Allowance (SDA)	From 16	<p>That you have been continuously incapable of work for 19 days.</p> <p>You must not be working (unless it is therapeutic earnings)</p>
Disability Living Allowance (DLA)	<p>Care Component from 3 months</p> <p>Mobility Component from 5 years</p>	<p>You need to fulfil a number of criteria. eg. you need help with;</p> <ul style="list-style-type: none"> - cooking - personal care - getting around
Disability Working Allowance (DWA)	From 16	<p>You must be working over 16 hours a week but earning a low wage.</p> <p>Prior to starting work you must have been receiving one of a range of welfare benefits</p> <p>You must have a disability which puts you at a disadvantage in getting a job.</p> <p>Your capital must be under £16,000</p>

Therapeutic Earnings This allows you to keep your Income Support <u>and</u> earn up to £44 a week	From 16	You must not earn more than £44 a week. The work must be beneficial to you ie. 'Therapeutic'. The work must not be more than 16 hours a week. You must be working under medical supervision or have acted on medical advice in getting a job.
Incapacity Benefit (IB)	From 16	You must have worked and received sufficient relevant national insurance contributions. You must be incapable of work for at least 4 days.
Social Fund (you can get a grant or loan to set up home, eg. to buy essential items like a bed or a cooker; to help with removal expenses; to connect gas or electricity. If you are destitute you may be able to get a crisis loan of about £30.	From 16	For the Social Fund Grant & Budgeting Loan you must be on Income Support.

Housing Benefit	From 16	<p>You must be on a low income</p> <p>Your savings should not be over £16,000</p> <p>You are responsible for paying rent.</p>
Council Tax - Benefit/ Exemption/Reduction/ Discount	From 18	<p>Too many to list here. You will need help from a local advice centre.</p>