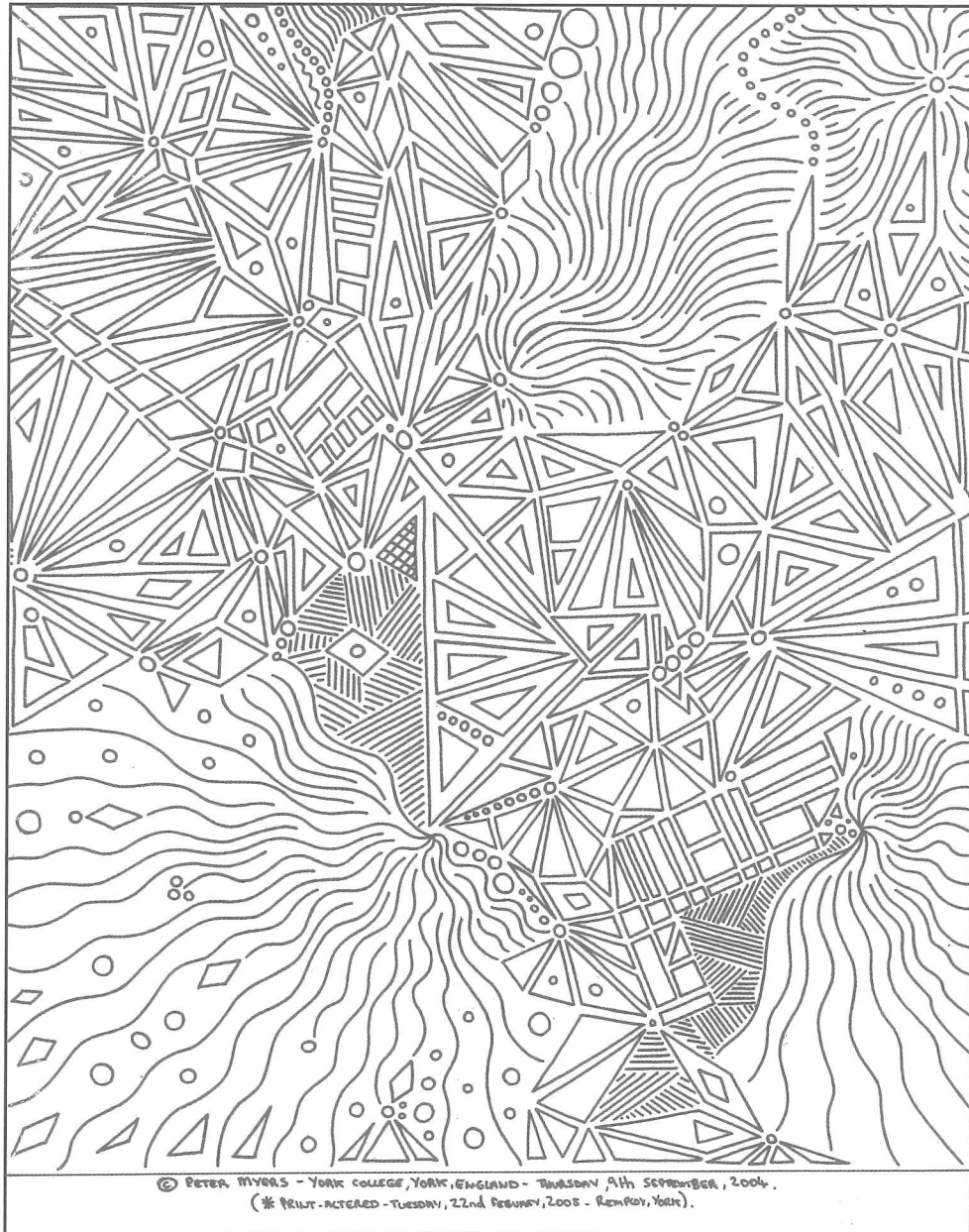


Produced by and for people with Asperger syndrome

Asperger *united*

Edition **43** July 2005





Asperger United is a self-help newsletter run by and for people with Asperger syndrome. The newsletter aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Asperger United is free to people in the UK with a diagnosis of Asperger syndrome. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs.

Editor John Joyce

Additional support The National Autistic Society's Publications Department

Please send all correspondence and subscription requests to:

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Subscribing to *Asperger United*

Tel: 020 7903 3541
Fax: 020 7903 3767
Email: asp.utd@nas.org.uk

All we need is your name and address and we will add you to the mailing list – free of charge to people with a diagnosis!

Thank you to George Cox who kindly produced the illustrations included in the Pen Pal Network section. Thank you to Graeme Lawson for producing the *AU* logo.

Please note that the views expressed in Asperger United are not necessarily those of the editor, The National Autistic Society or those involved in the publication of the newsletter.

Contributions for the next issue should reach us by 1 September 05

Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of The National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds and the current editor, John Joyce.

Pamela Yates provided support and advice to the editors until the publication was handed over to The National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most 'appropriate name' for the publication. This was suggested by Anna Cohen.



Dear Readers

Welcome to the July edition of *Asperger United*. Hope all is well and that you are all happy and enjoying your lives. Since writing my last editorial I have spent a holiday in Europe (more of that later on - see back page) and I had the great pleasure of attending the First Holy Communion of a nephew, who is also my godson.

I have now retired and I'm having to adjust both financially and socially. So far so good. I shall be continuing my Open University Spanish course so that should keep me busy.

Due to the large number of contributions we are now being sent, we have decided to increase *AU* by four pages. So please keep

those contributions coming in. We would particularly welcome artwork for our covers. Thank you for the high standard of material and long may this continue.

Thank you to Peter Myers for kindly allowing us to use one of his designs for our front cover. Peter's book, *An exact mind: an artist with Asperger syndrome* is available from NAS publications priced £15.99 plus £3.95 postage & packing. To order please call NAS publications on 020 7033 9237.

Have a wonderful summer, keep safe and well.

Best wishes - **John Joyce**

The cure for Asperger syndrome.

If a magical cure was available for AS how effective would it be?

People with AS have average or above average IQ. Would it cure us of that?

People with AS are very original and are naturals at improvisation. Would it cure us of that?

People with AS make the most creative and dedicated artist, musicians, engineers. Would it cure us of that?

People with AS go through life in a different and some times more interesting way. Would it cure us of that?

People with AS or autism are very happy in their own little world. Would it cure us of that?

It is alleged that talented inventors such as Albert Einstein, Thomas Edison or the talented painter Michael Angelo have AS. Would it cure the world of people like them?

Or would it only have to cure society of being prejudiced against people who do nothing wrong but who do things a little differently or unconventionally.

John D

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My life with Asperger syndrome and horses by Genevieve Edmonds

For as long as I can remember I have always felt a natural empathy with non-human species; not aliens I hasten to add! This empathy is with the animal species equus – ie the horse. When I look back through photos spanning the 23 years of my life I can find many photos of me with horses and other animals appearing to be in natural harmony. I am never happier than when hacking out in the country side, cantering across a field or just being around horses. In fact, a lot of the time I wonder if I actually relate better to horses than I can to people! The language of the horse is something I actually seem to innately understand. It is a complex language, which relies on visual associations. It can be learnt through theory and by tapping deliberately into the psychology of the horse. Some years ago I began to consolidate what I felt I innately experienced around horses by reading material on the psychology of horses. It dawned on me that it already was quite natural to me and that a lot of it I found I subconsciously already understood.

Around this time last year, I was diagnosed with Asperger syndrome. This did not come as a shock to me as I suspected that I had it for about a year before and years earlier suspected there was

something ‘different’ about me. However, I had no name for what it was or even any idea that I could be on the autistic spectrum. This was something I had only ever associated with the people I had got to know on voluntary befriending schemes and social groups that I helped out with at organisations such as Mencap and Barnardos. These individuals had severe learning difficulties and didn’t relate or only related in very challenging ways to other people. Little did I imagine that I could have more in common with my autistic cousins than neurotypicals! Although, I must admit that I always enjoyed the company of these ‘challenging’ individuals but never knew why until now!

I also began to reflect recently as to why I also always felt so happy in the company of animals and most notably with horses. Whilst engaging in research on autism and Asperger syndrome I stumbled across the work of Temple Grandin, and realized that I knew exactly where she was coming from. I would dearly love to meet Temple someday as I fully agree and respect her theories and views on the humane and successful handling of certain animals by viewing things from their point of view. In her article ‘*Thinking the way animals do*’, Temple explains a number of

points which identify the links between the behaviour and outlook of horses and autistic individuals.

I have learnt through my own observation and experiences now that I am aware of my own autism, that those who handle horses and other animals in a wholly neurotypical way tend to achieve less of a bond and fewer trusting relationships with them. The two horses in the picture are called Gracie and Dan. I spend a lot of time around them both talking to them, caring for them and of course, horse riding!! They belong to Vicky, a psychologist who specialises in learning disability and autistic spectrum. Vicky appears herself to be certainly on the autistic spectrum. She shares a similar approach to the horses as I do. This approach has often been called ‘natural horsemanship’ which considers the good of the horse over human desires. This approach is championed by famous horse personalities such as US based, Monty Roberts and UK based Kelly Marks.

In his book ‘*Horse sense for people*’, Monty Roberts describes his observations of traits that autistic individuals and horses have in common. Such things are: fear of loud and unusual sounds; thriving on routine; distress at eye

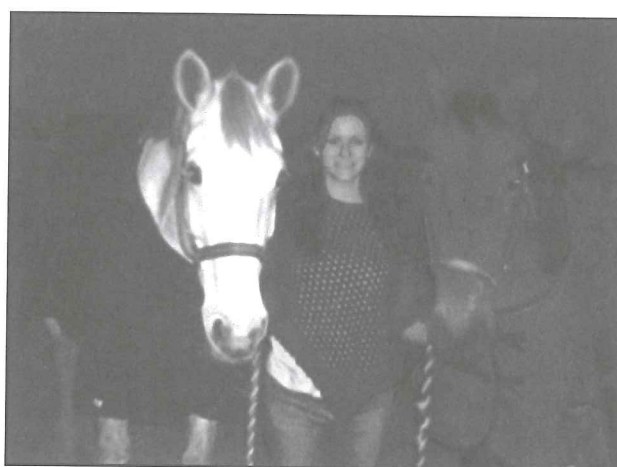
contact; dislike of forced touch and distress at unfamiliar sights and sounds.

Monty Roberts describes his belief that, 'perhaps it is not surprising that the horse, a visual thinker with an extraordinary ability to sense the intentions of its rider, is quite comfortable being ridden by autistics and, furthermore is able to cope with their often

unusual behaviour'. (*Horse sense for people*, 2000)

Hence, from my own experiences I can now understand and feel very glad that my Asperger syndrome has significantly enhanced my relationships with animals, especially horses. This example of unusual skill is one of many factors that support my view that the

unique psyche of the individual with autism has an enormous contribution to make to our world. I believe that the autistic way of thinking, which is often highly creative, unusual and alternative can only serve to enrich the lives of others when allowed to blossom in the appropriate environment.



Martial Arts - David Shamash

I have been doing martial arts for 11 years. I started in January 1994 when I moved to North London. Every Thursday evening at Jewish Care we have a martial arts class. I am sure there are other places where one can learn martial arts or gymnastics. Perhaps in future Autism London or The National Autistic Society might hold these classes, which can help improve co-ordination.

The class is meant to make one defensive not aggressive.

What we learn is good for people with Asperger syndrome or any one else for that matter. It could be a little harder for someone with Asperger syndrome if one is not well co-ordinated and also people with Asperger syndrome might find it difficult to know what other people are thinking - the tutor told me that.

We do physical exercises and self-defence, which is very good for co-ordination. We practice various things includ-

ing trying to set ourselves free when being held, and punching a punch bag. We are also taught that it is good to avoid fighting and the best method of self-defence is to run away. There is nothing wrong with running away. He also taught us that the law only allows you to hit someone in self-defence. It is not self-defence to run after some one who has hit you in order to hit him back. Retaliation does not count as self-defence. It is the job of the police and the courts to punish.



letters to the editor

Thank you to those who responded to my article about lack of services for able autistic adults, and my fears for the future. Clearly it resonates with a number of people.

My living situation has changed drastically and for the better, in the last few months, and I am left with little time/energy to follow up suggestions of sending copies of my article to other publications or to MPs. However, I would be very happy if anyone wanted to send me details of other publications where they would like to see it, or if you want to copy it (in its entirety only, please) to send to your own MP or care/support service provider – though please let me know you are going to do this.

I can be contacted at:
bettelheimsbaby@hotmail.com
or via *Asperger United*.

Ametrine Ruth Lavender

Dear Editor

I have read the letter by Mrs Bennett in the last issue and thought I'd tell readers about the problems I'm having.

I live in the community in a flat. We have many neighbours. I have had no end of problems with noise from others in the block and with children running around the gardens and car park. I have asked the children and other neighbours if they could be a little quieter but all they do is shout abuse at me.

My mother will not be alive for ever so I think that we need somewhere to live that is just for people with Asperger syndrome and high functioning autism, where you can get support when you need it. I think the government should build flats for people with autism in every community, where we can be safe.

Richard

Dear John

Thank you for a brilliant and informative magazine which is a great way for people like myself, who have Asperger syndrome, to share our own experiences about our lives and how we perceive the world around us. I have read some very interesting articles that readers like me have sent in, and it will encourage other readers who are new to the whole thing to write in and share their own stories.

Over the last year I have got a pen pal whom I write to every few weeks or so, and I am glad that I have got someone to talk about things to.

Are there any plans for articles that could contain photographs? Contact groups, for example could send photographs of days out or meetings. I just think it would be nice to see some of our readers. Understandably privacy would be an issue.

For the readers in Inverness and surrounding areas, I think that it would be beneficial to have a house or housing for people with autism and ASD. The benefits of such housing would be enormous for those like me, who are living alone and also for couples who are in need of some support. Inverness needs some kind of specific housing for people with autism but it will take a number of us to make the government realise that it is absolutely necessary as it will improve the lives of so many of us in all sorts of ways.

Daniel

AU is happy to publish photographs but please make sure that all those pictured have given their permission before passing the photos to us.



How to reply to Pen Pals

- Please remember to let us know the name of the person who your letter is for.
- To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.
- We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- Please note that all penpal letters sent via *Asperger United* are opened before being passed on
- Young people under the age of sixteen must have parental permission before placing a pen pal advertisement in *Asperger United*.

****Important notice - please read****

Asperger United is happy to publish pen-pal advertisement but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *Asperger United* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Hi, my name is Lucy and I'm 17. I have AS and would love to have a pen pal no matter what their sex, age or hobbies. My interests include embroidery, singing in a choir, current affairs, reading anything I can get my hands on and being an altar server. One of my favorite authors is Evelyn Waugh. Please write if you would like to talk about anything at all with someone who always replies to letters, and if like me you want to feel as if you're not the only person who is different. Thank you for your time.

My name is Stephen, I'm 49 years old and have Asperger syndrome. I enjoy going for long walks, watching TV, reading and going to the pub. I would very much like to correspond with someone who also has AS.

My name is Paul and I have Asperger syndrome. I am 33 years old and I live in Scarborough. I go to the Asperger group in Scarborough once a month. I would like to have a female pen friend who also has Asperger syndrome in the hope of forming a friendship. My hobbies are watching videos, going to the cinema and playing 10 pin bowling. My obsession is Dr Who.

My name is Magdalen, I am 37, and have recently been diagnosed with AS. My interests are in creative writing, reading, animals and plants, prehistory, photography and abstract painting. I would like to write to other adults with AS, particularly if they are living in the South West area - though anyone with AS in other parts of the UK are also welcome.

More pen pals / letters

Hello, I'm Marcus, I'm 27 and live in North West London. I was diagnosed with AS in 1990 and also suffer from OCD and depression. I've lived in residential care for people with Asperger syndrome for the last three years and also go to college. My interests include science fiction, science documentaries, movies, music and art. I would like to make friends with people in my area through socialising, writing and telephone.

Billy is 43 and lives in the Derbyshire area (Buxton). He is looking to set up a self help/support group for people with autism/AS in the Buxton area in conjunction with the Peak and Dales volunteer bureau and the Grapevine Café. Anyone interested contact via AU.

Collin Morris and I are trying to form a steering group. The aim is to work to a deadline of late Autumn 2005 to form an Aspergers self-help/support group in the Harlow area of Essex. We require individuals who have creativity, vision and good knowledge of AS to join Colin and me for regular planning meetings. A diagnosis of Asperger syndrome would be useful but not essential. If anyone out there has successfully established such a group, I should be grateful if they would contact me or Colin with any advice they may wish to give. Thank you. Contact Tim Collins 07815 792113 or Collin Morris 01279 315830

My name is Andrew and I have got Asperger Syndrome. I am 39 years old and my hobbies are rugby league, NHL Ice Hockey, Dutch League Soccer and the Coper America. I would like a female pen pal around the same age.

Hi, my name is Anna. I am 20 years old and live in Northampton. I was diagnosed with Asperger syndrome in August 2004. I have many interests such as going to the cinema, listening to music and I have recently joined a gym. I would like to find penpals of either sex and of similar age. I would particularly like to find some new friends, either as pen pals or for socialising with, in my area.

Colin. Mid-40s. Christian. Living in Essex. Diagnosed with AS four years ago. Interested in history, the older the better. I follow sport quite closely and I'm interested in travel when I'm feeling up to it. Also keen on modern Christian music – Twila Paris, Nichole Nordeman, etc. I work as a computer programmer. I date from the mainframe era, so no PC jargon please. All responses welcome.

Dear John

I have Asperger syndrome. My first remarks arising from *AU* edition 42 refer to the Nottinghamshire group. Irrascibility, anger, indignation and duplicity are not Asperger traits but general human ones. I hope the group members will be alert and not create negativity for others. I suggest you read all Donna Williams' books and also read Wendy Lawson's *Build your own life* and Jerry Newport's *Your life is not a label*. They can all inform you far better – from the same experience as us – than the made up 'Mr Bean' people can. Being positive, what I get from the 'Bean' character is his success.

In reaction to Mrs Bennett's letter, it is time for recognition of autism spectrum conditions as a bodily disability and not a 'mental health' problem. It's time for people who don't have these conditions to accept this and put an end to this discrimination by authorities.

Now to Louisa's letter. I have been desperate for advice on career, property and medical matters in the last year and have found that advice tailored to me is scarce and non-existent.

Lastly to G. Ball, I have found relatives think *Curious Incident* is like a person with Asperger syndrome but people with the condition confirm that it is not like them. To inform themselves about this condition, everyone should refer themselves to the very many writers who write about their condition from experience.

Michael

Romance on the Nile

I am 61 years of age and, one year ago, my husband, then aged 54, was diagnosed with Asperger syndrome. He and his family were not aware that he had had this disability from birth. Mike and I only met eight years ago and have been married for six.

I tell the tale of a happy pair
and the love that's grown for them to share.
A trip to Egypt was how they met.
The circumstances they won't forget.
Arriving in Cairo they went to their rooms.
Each spent time alone in the pyramid tombs.
On sightseeing trips an occasional word
was exchanged but, as yet, no emotions had stirred.

They flew to Aswan where they boarded a boat.
Then sat down together for dinner afloat.
She wore a red dress that inflamed his desire,
but he just didn't know how to kindle the fire.
The following days brought them closer, as they sailed along down the Nile, chatting more all the way.
They went out on deck to see stars and a comet, each feeling attraction but recoiling from it.

At last, at the Temple of Karnak – a touch!
A huge step was taken, but did it mean much?
In the city of Luxor they spent time together.
They walked and they talked in the sweltering weather.
Their chat on the aircraft as homeward they flew was personal, intimate, honest and true.
The following week, oh so nervous, they met.
Just how would things happen? How close would they get?

The more the days passed, the more eager they got to see one another. All else went to pot!
They drove and they strolled and then one night – a kiss!

But what did it mean? It was certainly bliss!
They tried to deny but they just couldn't fight it. The feelings were strong and it all felt so right. It grew faster and stronger, until one Spring day
They acknowledged their love. This would not go away!

They decided to wed for they knew beyond doubt
That their lives were entwined and they wanted to shout
To the world that they'd both found a love to endure.
As soulmates together they'd grow, they were sure.
"A simple love story", I hear you all cry, but read on and you'll see that it's not – and here's why.
Well he is autistic, though didn't know then. His behaviour was different – not like other men.

Disabled from birth, he had lived on his own, unable to socialise, friendless, alone.
He'd reached middle age with no girlfriends at all,
But, emotions awakened, he now could stand tall.
He's gentle and caring and upright and true.
Though I know that not everyone thinks like I do.
But with Asperger's Syndrome for all of his life I am honoured that he chose to make ME his wife!

V Simpson

Discrimination, the Law and Further and Higher Education **James Graham**

In 2001, the Government passed amending legislation, the Special Educational Needs and Disability Discrimination Act (SENDA).

This Act gives rights to disabled people - those with a "physical or mental impairment which has a substantial and long term adverse effect on the ability to carry out normal day to day activities." Most people with AS are likely to be "disabled" within the meaning of the Act.

- All educational providers are covered by this section of the Act.

What is unlawful under the Act?

The Act makes it unlawful to discriminate against a person with AS:

- in the enrolment process
- by refusing or deliberately omitting to accept an application for enrolment
- in the provision of services and this includes teaching methods and classroom or college provided wholly or mainly for students or those enrolled on courses. This includes provision such as courses of education, training, recreation, leisure and catering facilities or accommodation.
- local education authorities or education authorities may not discriminate in the "services" they provide or offer to provide for people wholly or mainly enrolled on courses.
- Responsible bodies of institutions have an additional duty not to discriminate against disabled students by excluding them temporarily or permanently from the institution on the grounds of their disability.
- Responsible bodies for Youth and Community Services may not discriminate

against disabled people in any of the provisions they make.

What does "discrimination" mean?

There are two ways in which a disabled person can be discriminated against:

- when a responsible body treats a disabled person less favourably, for a reason relating to the person's disability, than it treats (or would treat) a person to whom that reason does not, or would not, apply and that treatment cannot be justified.
- when a responsible body fails to make a reasonable adjustment when a disabled student is placed, or likely to be placed, at a substantial disadvantage in comparison with a person who is not disabled, without justification.

Less favourable treatment

Some examples of less favourable treatment:

In admissions: an adult education centre has an enrolment evening. The staff member registering students instructs a blind enquirer to wait to be called until someone else can help him with his form, rather than registering him immediately. The enquirer is not called and, by the time he himself approaches the desk, the course he wants to join is full and he is told it is too late to enrol. This is likely to be unlawful.

In exclusions: a student who develops a visual impairment is excluded from college because staff fear that he will not be able to cope with the course. They have no evidence to substantiate this fear and no attempt has been made to address this issue with him. This is likely to be unlawful.

In the provision of services: a student who is registered blind is told that she cannot train on the college sports track because of this, although other students are allowed to train there. This is likely to be unlawful. For a responsible body to discriminate against someone by treating him or her less favourably because of a disability, it needs to know about the disability. If the responsible body did not know and could not reasonably have known that a person was disabled, then the disabled person has not been treated less favourably for a reason relating to the disability. In order to claim lack of knowledge about a disability, the responsible body must have taken reasonable steps to find out about the person's disability.

Can a responsible body justify less favourable treatment?

Less favourable treatment may be justified only if one of the following conditions is fulfilled:

- it occurs in prescribed circumstances
- the reasons are both material to the circumstances of the particular case and substantial
- it is necessary to maintain about other prescribed standards
- it is of a prescribed type
- (no regulations have been made in relation to these last two justifications, so they do not apply at present).

If a disabled person or student can show that he or she has been treated less favourably than others for a reason relating to his or her disability, it is for the responsible body to show that the action taken was justified. The justification must fall within one of the categories listed in the above paragraph.

The responsible body can only use one of these justifications if the justification would still be valid even after a reasonable adjustment had been made.

The duty to make reasonable adjustments

The Act says that:

The responsible body for educational institutions must take reasonable steps to ensure that, in relation to the arrangements it makes for determining admissions, a disabled person is not placed at a substantial disadvantage in comparison with a person who is not disabled, and in relation to student services a disabled student is not placed at a substantial disadvantage in comparison with someone who is not disabled.

A local education authority, an education authority, or the responsible body for a school or Youth and Community Services must take reasonable steps to ensure that, in relation to the arrangements it makes for enrolling people on a course and in relation to services provided or offered by it, a disabled person is not placed at a substantial disadvantage in comparison to someone who is not disabled.

The main requirement to make reasonable adjustments was implemented from 1 September 2002. There are two exceptions to this, however:

- reasonable adjustments relating to auxiliary aids and services are not required until 1 September 2003
- reasonable adjustments to physical features are not required until 1 September 2005.

A responsible body's duty to make reasonable adjustments is an anticipatory duty owed to disabled people and students at large. It is not simply a duty to individuals. This means that responsible bodies should not wait until a disabled person applies to a course or tries to use a service before thinking about what reasonable adjustments they could make. Instead they should continually be anticipating the requirements of disabled people or students and the adjustments they could be making for them, such as regular staff

development and reviews of practice.

Some examples of reasonable adjustments:

- All teaching staff in a prison produce all their handouts in electronic form thus ensuring that they can easily be converted into large print or put into other alternative formats. The staff are anticipating reasonable adjustments that might need to be made
- A university encourages its lecturers to put lecture notes on the institution's intranet. It introduces new procedures to ensure that all notes put on the intranet meet established guidelines to ensure there is no conflict with specialist software or features that students with dyslexia may be using. It therefore anticipates reasonable adjustments that it might need to make for certain disabled students
- A student with a visual impairment is following a distance learning course. She sends in her essays electronically but receives marked essays by post with hand-written comments in the margins that she is unable to read. A likely reasonable adjustment would be for comments to be returned electronically.

Do I have to disclose my disability?

There is nothing in the Act which says that you have to disclose your disability. However, if the institution did not know and could not reasonably have known that person is disabled, then failure to make an adjustment for a disabled person or student is not discrimination. This means that if you do not disclose, the institution may be limited in what adjustments it has to make for you. In order to justify any failure to make an adjustment though, the failure to make an adjustment and the lack of knowledge must be connected.

For example: a man makes a written request to a college and asks for information about courses. He does not tell the college that he has no sight. Although the college produces its

prospectus in electronic format, he is sent the print version which he cannot access. The college's failure to make an adjustment for the enquirer is due to lack of knowledge about his disability. This is likely to be lawful.

Can a responsible body justify the failure to make a reasonable adjustment?

There may be rare occasions where a reasonable step might be taken, but there is a justification for not taking it. If this is the case, then the failure to take the reasonable step is not considered discriminatory in law. The failure to take a reasonable step can only be justified if the reasons are both material to the circumstances of the particular case (ie relevant to that particular case) and substantial (ie more than minor or trivial).

What can I do if I think that I have been discriminated against?

If you have been discriminated against, you can take your claim to the county court in England, Wales and Northern Ireland (the Sheriff's court in Scotland) and claim compensation for any loss you have suffered (for example, if you have lost out on a job opportunity because your study has been deferred as a result of the discriminatory treatment, you can claim for the loss of earnings); compensation for injury to your feelings ; and/or an injunction (or interdict in Scotland) to force the responsible body to comply with the Act.

- Court proceedings can often be lengthy and expensive: you may be able to get assistance with your claim - further details are contained below.
- There is an alternative to court proceedings though: the Disability Rights Commission has a Conciliation Service which can mediate between you and the responsible body. If you use this service, and don't come to a settlement, you can still take your case to court, and you will have an extra two

Word from the professionals (continued)

months added to the time limit (taking it to eight months). The service can be accessed by contacting the Disability Rights Commission on 08457 622 633.

The DDA and employment, goods and services, pre 16 education, housing and your rights

Visit the **Disability Discrimination Act (DDA) homepage** for separate information on various aspects of the Disability Discrimination Act (DDA) 1995. Or contact Liz Woskett at: liz.woskett@rnib.org.uk

- They provide advice, information and in limited situations, representation. Please call 020 7388 1266 and ask for the DDA department.

Further sources of advice and information

- The Disability Rights Commission has produced a Code of Practice for the post-16 duties. The Code explains the law and provides examples of how it might work. Many of the examples in this factsheet are based on those in the Code. The code has to be taken into account by the courts and

tribunals where relevant. You can obtain a copy of the Code, free of charge, from the Disability Rights Commission - call their helpline on 08457 622 633. Alternatively you can download it from their website at:

www.drc-gb.org

- Skill: National Bureau for students with disabilities produces information about the DDA both for students and course providers.

Information Service: 0800 328 5050

Website: www.skill.org.uk

Email: info@skill.org.uk

- Law Centres provide advice and information. Details of your local Law Centre can be obtained from the Law Centres Federation on 020 7387 8570.
- You may be able to get help from the Community Legal Service Fund to pay for a solicitor to take on your case. You should contact the Community Legal Service for details of solicitors in your area who can help you - they can be contacted on 0845 608 1122.

James Graham is the Principal of INTERACT, a specialist college in London for people with Asperger syndrome.

New autism resource - Autism Alert cards



We are very pleased to announce these new cards, developed by The National Autistic Society in consultation with people with

autism or Asperger syndrome and their families.

The Autism Alert card is a concise mini-information pack for situations when communication may be difficult or things may be stressful. The pack includes key facts leaflet about autism and Asperger syndrome, with a credit-card style insert for emergency contacts.

The Autism Alert card is available from NAS publications

020 7033 9237 and costs just £2.50 plus postage and packing.

For a limited time we are offering these cards completely free to readers of *Asperger United*.

To get your free card, please send a self-addressed envelope to *Asperger United* at the NAS – address on page 2

Offer valid until 30 September 2005 – sorry, one card only per reader.

Dear Readers - upon being recently diagnosed with Asperger syndrome, I have had mixed feelings...

My initial reaction was one of relief, for the diagnosis explains why I have encountered so much difficulty in the past and why so many things have gone wrong in my life. As a result I feel less embarrassed about my present situation and less likely to think of myself as a 'loser' or a 'social misfit' (at 37, I am still living with my mother, have no friends, partner or children, and, despite having a degree, no career). However, feelings of anger and resentment then set in.

In the mid 80s, a year after I left school, I knew that there was something not quite right about me. I have obsessive interests, and would approach the people at college to talk incessantly about them. I would also panic when surrounded by large numbers of people, and found it difficult to socialise in the usual way.

I went to see a therapist, and found myself being passed from one to another. I could not put my problems into words. I saw so many therapists that I lost count and since I only saw each therapist once or twice, they could not take the opportunity to get to know me. As a result, they could teach me nothing of value. Some of them were very

unsympathetic, as if dismissing me as an attention-seeker. Feeling that I was getting nowhere with the therapists, I stopped seeing them.

My obsessive interests continued and, having been given no guidance on how to control them, I allowed them to rule my life and to blur my view, so that I had no concept of how to plan my future in a constructive way. As a result, during my working life, I found that I could only take tedious, low-status, low paid jobs. In relieving the boredom and resentment I felt I made many mistakes, going in pursuit of irrelevant ventures – joining women's groups and New Age cults, none of which helped – in fact, such ventures left me in a worse state of mind than before.

However, after remembering one or two misunderstandings that led to my encountering hostility or ridicule, I began observing and listening to the social interactions of others, in this way eventually learning for myself what behaviour is appropriate, though I was still tempted to express myself by talking about my interests, and still did so.

By this time, I was in my mid-twenties, I felt that my life was going nowhere. I then decided to go back into education, eventually going on to university. Yet the difficulties did not end there. Since

university is an environment that places great emphasis on social interaction, I found it difficult to cope, and so began seeing a counsellor in the Student Union building. Though she did not detect AS, the counsellor was nevertheless very good. In helping me to identify and to understand various family conflicts that I had been in the middle of whilst growing up, she inadvertently helped me to control my obsessive interests further, leading me to discover and to develop a wider range of interests, and to eventually lose all desire to foist my obsessive interests onto others. Plus, I finished the course and passed the degree.

I still have obsessive interests and difficulties in interacting socially, but limit all social contact to basic greetings, comments and requests as appropriate to the situation that I find myself in, otherwise preferring to keep myself to myself. I am not ashamed of what I am, but this tactic makes life much easier – both for me and for those around me. Having the diagnosis has made it easier for me to understand myself and to thus deal with difficulties that may arise without feeling as confused or agitated. If I had received my diagnosis earlier, I may well have made fewer mistakes and so be leading a more productive life today.

Magdalen

My experience taking part in Asperger syndrome research

Day visit to the University of East Anglia, Norwich to see Helen Johnson, Clinical Psychologist

I took the early train to Ely, where I had a 30 minute wait for the train to Norwich. I arrived at 10.30. A friend picked me up and took me straight to the University. It's a big place – a person could get lost. We arrived just in time. Helen was waiting for me. She was very smartly dressed and polite. We had a chat about what the tests would entail. There would be a written test and tests using a computer. I did not want to do the computer test as I was afraid that I would mess it up.

I found Helen very prompt and to the point. I felt this was really good. Some of the tests

were timed. There was one which was like a jigsaw. I took too long with it, I knew where the pieces should go but I could not do it in time. On one of the tests Helen was able to show me the results – I was most surprised to find that I had passed. I was not able to see the other results. Helen said all results will be sent in the summer. It will be interesting.

My travel fare was reimbursed. This is very good otherwise I would not have been able to go. I took part in the survey to help other people with AS. AS is so misunderstood. It affects people in many different ways.

I am taking part in another AS survey in a few months time, at the Institute of Cognitive Neuroscience, UCL in London. It will take four hours.

I have to say though, I am greatly disappointed and upset at the Institute of Child Health. I telephoned three times. I spoke to a lady, gave my telephone number and address three times and a message saying that I would like to take part in the research advertised in *AU*. No one got back to me. A reply of some sort would have been something but nothing at all. It upset me a lot.

M. Kent

Noise cancelling headphones

Because I have Asperger syndrome, I am very sensitive to certain background noises, especially people talking in large groups. If I don't do anything about this, these situations cause me to become overloaded. By this I mean they wear me down and tire me out. I become irritable and withdrawn and find it difficult to function in the social setting. In extreme cases I become distrustful and a little paranoid. Sometimes I close down completely and am unable to communicate at all.

For a few years I have used a combination of avoidance – escaping physically from the situation or keeping away altogether – and using foam

ear-plugs. With ear-plugs I am able to cope with some situations like shopping at a supermarket, provided I am only exposed to the overloading situation for about half an hour.

Recently I bought some noise cancelling headphones. I tested these out in combination with the ear-plugs at my local Scrabble club because this situation can be quite overloading, some weeks less so, some weeks more so, and it lasts for nearly three hours. I found this to be a big improvement over using ear plugs alone, and I felt calmer during the evening and much less drained afterwards than usual. With this success I was

emboldened to attend a local Scrabble tournament which had 50 competitors. I had previously found this sort of situation to be too much for me with ear-plugs alone. This also involved traveling with a group of six people by car for an hour and a half each way. This was a big success and I will be attending more tournaments in future. And I even managed to get third place in the top section and win a bottle of wine!

I hope this information will be encouraging and perhaps useful for those Aspies with these kinds of sensitivities to noise.

David

Following my retirement I spent Easter in Europe visiting some of the famous sites. I thought I would share my experience with you...

I travelled to Brussels on Eurostar. I celebrated St Patrick's Day by attending Mass in Flemish in Brussels Cathedral and then witnessing some racing from Cheltenham in an Irish pub in the city! I also took a city bus tour. I moved on and repeated the bus tour experience in Berlin where I attended Mass in its Catholic Cathedral and visited other churches, some of which are used as art galleries.

I then moved on to Warsaw, again visiting its Cathedral and other churches. I also attended mass in two churches and attended a James Joyce exhibition in a gallery named after Adam Mickiewicz, a famous Polish writer.

Moving on to Prague I visited its cathedral and other famous sites, including the church in Karmeliska, which houses the shrine of the Child of Prague,

a miraculous statue given to the nobility in the 17th century. I celebrated Holy Thursday and Good Friday in St Stephen's Basilica, Budapest where I also created problems for myself by taking a train out of the city when I intended to go in! However, it was fortunate that the Good Friday Liturgy was at 6pm in St Stephens, so I made it just in time. St Stephens is a church dedicated to the first Christian King of Hungary, who lived in the 11th century.

Holy Saturday morning I went to Vienna, where I had the Easter liturgy in another St. Stephen's church. This church was dedicated to the first Christian martyr. I then took the city bus tour which included visits to the Hofburg and Schonbrunn Palaces.

One of the paintings in the Schonbrunn depicts the

wedding of a daughter of Empress Maria Theresa, mother of Marie Antoinette. In all of these cities I had hostel accommodation which was booked on the internet. In Paris, my last port of call, I arrived too late to claim my hostel room – it was not held for me. I had nowhere else to go so I spent some time wandering the streets of central Paris, and part of the night in conversation with a local outside St Lazare station.

Because I had not been able to buy a return Eurostar ticket in London, when I sought to buy one in Paris I was told that a one way single from Paris would cost more than one from London. I ended up taking a coach home, arriving back early on 1 April – tired but safe.

John Joyce

Memory Gardens Summer School

Memory Gardens sculpture club, Legard Road, Arsenal

Human shelters - a four day course for adults July 5 - 9. 10am - 4pm. Cost £12. Concs. £5

Highlights to include permaculture gardening, making a shelter in the woods, creating a drip painting on cloth and making outdoor sculptures. We will also work with clay, beads, wire and mosaics

For further details contact Ruth on 020 8806 1129 email yellruthtoday@yahoo.co.uk

We also run a youth mentoring club for children on the autistic spectrum age 8-14. The club is held every other Sunday 11am - 1pm. Voluntary work experience is available for young adults with Asperger syndrome (expenses paid). Please call Ruth for more details.



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