

autism london

Bi-Monthly Bulletin

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Contributors

Contributors: Dee King, Gill Lea-Wilson, Ethney Anderson, Tanya Camilleri, Louis Baworowski, Simon Humphreys, Michael Feldman, David Shamash.

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We would welcome any feedback related to information printed in this publication.

The views and opinions expressed in Autism London's bulletin
are not necessarily those of the organisation.

Dear Reader

Welcome to the February - March issue of the Autism London Bulletin.

You will notice that your Bulletin is arriving a little early this month. This is partly because we are just super-efficient (!), but also because there is some information we want to get to you quickly. Please see our Notices and Conferences section for details of the Music for Autism concerts; the London one takes place on 29th January, so you will need to book ASAP if interested.

Feedback please!

You will also notice that we have enclosed a feedback form as a loose flier, and also a return addressed envelope, as mentioned in the Support Services Update. As well as helping us to learn how to improve our service in the future, feedback is also useful to enable us to show potential funders how people have been helped by our service. We are asking that you complete this form and return it to us as soon as possible, preferably by the 24th January. The reason that we are giving this tight deadline for returning the forms, is that we are currently in the process of making applications for funding, and your statements could help back up our applications. Any brief statement describing what support you have received and how it was helpful to you would be really helpful, so PLEASE take a few minutes to complete and return the form with your feedback.

Staff changes

Quynh, who was our admin temp has moved on, and we now welcome Elena into the role. She will be working with us part-time, 21 hours per week.

In this issue:

Please see inside for a Support Services update followed by a slightly extended Supporters Forum including an article about a readers experience of the NAS employment support agency, Prospects, and some feedback about a recent ALAG meeting. Remember, we are always keen to hear from our Supporters, whether adult, child, carer, sibling or professional with news of what they've been up to so that we can include it in the bulletin. Please send any articles/ letters to:-

**Bulletin Ideas, Autism London, 1 Floral Place, London, N1 2FS or email
info@autismlondon.org.uk**

Also in this issue we have an interesting article by Simon Humphreys RIBA FRSA, on Autism and Architecture, as well as our regular Book Reviews by Louis Baworowski. This time Louis reviews books by Junee Waites and Helen Swinbourne, and also by Bob Woodward and Marga Hogenboom.

Wishing all our Supporters a very Happy New Year,

Best wishes,

Gill Lea-Wilson – Service Development Officer

Message from Richard Tucker, Manager at our residential service in Leyton:

“This is not really an article but just a word of complement and thanks to the staff for the hard work they have put in since I took over as manager of the service. This was manifested in the CSCI report of the last inspection of the home. I just want to say that this is just the beginning of a positive future. We have set a high standard that we need to keep up with. I ask that we double our effort at work and in completing the NVQ as soon as we could.

We had three service users take a long weekend break in Devon and we had a smashing Christmas party at the house.

I hope that the Christmas holiday was a restful time for everyone and you are all refreshed and ready for the year ahead. In this month's edition of the bulletin you will find an evaluation feedback form. The feedback form will let us know how we here at Autism London can improve our services to benefit you and your families. We would like you to please return this to us by the 24th January; there is a return-addressed envelope enclosed to make mailing easier.

Dee King – Support Officer

Another year over and a new one ahead!

I was able to take part in facilitating our ALAG group in December, which I have never done before and found it very interesting, listening and speaking with the group members. The topic was Asperger's syndrome and Culture, and many people took part in discussing their cultures and beliefs. We also had some new people who came along and found the support group both interesting and helpful. We hope they will continue to attend these meetings.

Tanya Camilleri –Helpline Officer

I do hope you all had a lovely time over the holiday season and didn't eat too much turkey and Christmas pudding! While we're all detoxing and making secret new years resolutions, let us hope the new year brings peace and prosperity to those who are most in need.

Just a few words about the Parent/carers Support Groups, which have been well attended throughout 2004. Several topics were covered including Direct Payments for respite care, ABA (Applied Behavioural Analysis), the Statementing process and Educational Tribunals. Parents and carers have found this group to be extremely helpful especially when sharing experiences about what has and hasn't worked for them. It is always rewarding when a parent/carer meets others at the group who have had similar experiences and find they have so much in common.

Ethney Anderson– Support Officer

Parent/Carers Support Group

Date and Time	Venue Details	Speaker	Topic
12 th January 1.30pm – 3.00pm	Autism London 1 Floral Place (off Northampton Grove) Islington London N1 2FS	Dee King & Ethney Anderson (Support Officers at Autism London)	Open meeting for parents to come along and talk.
26 th January 10.30am – 12.00pm	The Limes William Morris Hall 6 Somers Road Walthamstow E17 6RX	Jo Radford	Lovaas Programme & LEAP Organisation
9 th February 10.30am – 12.00pm	The Vida Walsh Centre 2b Saltoun Road Brixton London SW2	Kate Walton	DASL Service –Information on the Direct Payment Scheme
23 rd February 10.30am – 12.00pm	Kulubi Centre 2c Falkland Road Kentish Town London NW5 2PT	Jo Radford	Lovaas Programme & LEAP Organisation
9 th March 6.30pm – 8.00pm	Oakleigh School Oakleigh Road North Whetstone London N20	Dee King & Ethney Anderson (Support Officers at Autism London)	Open Meeting for parents to come along and talk.
23 rd March 1.30pm – 3.00pm	Autism London 1 Floral Place (off Northampton Grove) Islington London N1 2FS	Dee King & Ethney Anderson (Support Officers at Autism London)	Open Meeting for parents to come along and talk.

To help us cater for demand, if you would like to attend any of these groups/talks please let us know you will be coming by calling 020 7704 0501 and leaving a message specifying the date of the meeting you will be attending.

Supporter's Forum

Where you share your news, ideas and creations!

PROSPECTS REFERRAL

by Michael Feldman, a member of the ALAG group.

Having been diagnosed with High functioning Autism (or HFA for short,) I was seeing my Disablement Employment Advisor (DEA) for an unrelated matter. In passing, I recounted that I had HFA and that because of my autism, I might not always be 'with it' in the working environment. At this point, I was to learn about Prospects; a Job Employment Consulting Agency aimed at helping those with Aspergers Syndrome or, HFA find work.

After waiting about 4 months or so, I underwent a Personal Development Program (PDP.) While there, I joined two other clients. There, we performed role-play and interview practice sessions. These were to last for four weeks.

The next stage of the exercise was to undergo one to one sessions. There, I did exercises. EG. Additional interview practice, body language. What to say and what not to say in the office etc.

Once I was tested for my reaction in a mock work change predicament. I had to adapt to a shift environment. My attitude to this was rather negative. Following on, my support worker and her partner taught me how to be more Subtle in my manner.

Following the one to one sessions, I then joined Prospects at their newly-refurbished office off Essex Road, Islington N1. There, my support worker gave me guidance on the type of work that I should go for and helped me with the application forms. In particular, the tricky bit where they ask for that dreaded statement. Still, with the correct guidance, I was to become successful more than once with securing an interview. Some of those attended, I did very well. On one interview, my support worker thought I put myself across better than the mock interview itself - previously.

Eventually and with perseverance, I secured a filing clerk position with a building consultants firm. This vacancy came to the attention of another DEA who learnt about it through the Company. They were advertising a position for a disabled person. It was then, that my DEA thought of me and contacted Prospects.

Following on, I went for the interview with another advisor. Later that day, I learnt that I was accepted for the job working for the Company.

Supporter's Forum

Where you share your news, ideas and creativity

LIFE AND FAMILY MAKES US WHO WE ARE

a letter by David Shamash, ALAG group member

Thanks for having an ALAG meeting on Asperger's Syndrome and different cultures in December 2004. I think it is important to be aware that we are who we are not only because of Asperger's Syndrome, but also because of the family we are born into, and life experience. I do not think Asperger's Syndrome is a culture; it just makes it more difficult to cope with our different life situations.

I think it would be interesting to do research into how people with Asperger's Syndrome who come from minority cultures cope with being different from the general population and other problems they may encounter.

For example: Jewish people celebrate two New Years: the Jewish New Year in the autumn and the secular one in January. My poem about fasting, published in the previous Bulletin, refers to atoning for our sins ten days into the Jewish New Year.

I hope for the secular New Year 2005, Autism London will try to improve our lives by trying to provide voluntary work for ALAG members and help us find courses. I am pleased that I read one Autism London Bulletin carefully as I read about free computer training in Angel.

There I learned how to send emails and other computer skills. I have been going there for over a year. Their address is platform 1, Donegal Street, London N1 9QT, Tel: 76895020

David Shamash

ASPERGER'S SYNDROME FROM THE HORSE'S MOUTH

*By Desmond Meldrum, an adult who has recently been
diagnosed with the condition*

Desmond Meldrum is available to give talks on his personal experiences as well as general advice in coping with Asperger's Syndrome to organisations and support groups for a negotiated price on application.

Desmond has over three years experience in communicating to groups and organisations on this subject and has also written a book published through Autism London which shares his observations and experiences of the condition.

Excerpt from book

'I started developing strange habits such as standing in the playground with my head cocked sideways and my mouth wide open staring into space, thus attracting even more attention. I also used to jump about in a peculiar manner while indulging in a fantasy world of my own' (Desmond Meldrum 1994)

Since 1993, Desmond also has been an active volunteer in the field, providing much valued support to the work of Autism London and in 2001 became a member of Autism London's Management Committee.

***For more information please contact Desmond Meldrum at
Autism London on 0207 704 0501***

AUTISM AND ARCHITECTURE

an article by Simon Humphreys RIBA FRSA

All people are affected by buildings, whether consciously or sub-consciously, they play a part in every day life, every day. They provide a source of shelter and protection as well as a space for function.

People with ASD have in various guises a more heightened sensitivity to that which exists outside as well as inside their physical body and mind. Autism as we know is a complicated disorder and there is a vast range of abilities and sensitivities within the spectrum.

In education and life care of children with ASD there is no common approach, in many cases each child learns in a different way to another and an adult will have varying responses to different therapies.

However there can be a common thread as to how you approach the design of a space, which will help with the setting for these people in order that they may respond more positively to personal teaching and therapies. This common thread being based on some common principles and values for humanity and also common traits in autism.

Architecture is described in the following way: “ The art or practice of designing buildings for human use, taking both aesthetic and practical factors into account” It can be further expressed in another way. “ You employ stone, wood and concrete and with these materials you build houses and palaces; that is construction. Ingenuity is at work. But suddenly you touch my heart, you do me good, I am happy and I say: “ This is beautiful” That is architecture. Art enters in.

The human condition is such that it will respond positively to good quality and with architecture it will respond positively to correct scale and proportion, natural ingredients such as light, air and materials as well as thoughtful construction that will encompass structure and fabric, how a building is put together.

Some simple principles can be applied to a design which will assist in the uplift of a space: they are as follows:-

A sense of calm and order in a building

Complexity can cause stress; it is not harmonious. People with ASD are unable to discriminate separate noises, shapes and space easily; it can cause them discomfort. An environment that has a calm sense of clarity and order can be easy to use and therefore can reduce tension.

Good levels of natural light and ventilation

Good natural light levels uplift, low natural light levels can depress and create gloom. High even levels of natural light help to assist in the visual understanding of a space as well as being close to nature. This ease can help to reduce frustration and anxiety for people with ASD. Natural ventilation is healthier than artificial means and therefore provides a more balanced healthier environment.

Reduction of detail

Buildings can be complex in detail. People with ASD can sometimes be absorbed and sometimes obsessed with this sometimes ‘picking’ at small junctions. If the design of a building reduces the need for complex visual detail it will be more restful. A broad bold detailing approach using a limited pallet of materials and solutions could reduce stimulation and obsessive behaviour.

Good proportion

The Greeks developed a system of proportion from mathematical equation that provides a proportion that human beings find pleasing. This proportional system is known as the ‘ Golden Proportion’. It is this proportion that can be found in nature abundantly. It is possible to introduce these proportional systems into buildings at no extra cost and people with ASD may benefit from this pleasure of proportion and it may manifest in their behaviour.

Proxemics

Proxemics deals with the amount of space that people feel it necessary to set between themselves. Proximity is the condition of being near or close. Proxemics can also be termed as personal space

around the body. A person with ASD can be more guarded about this space and any infringement is seen as a potential threat. They need more space. Movement around a building requires space; therefore the space should be as large as possible to reduce this perceived threat which can create a sense of unrest.

Containment

It is necessary at times to ensure that people with ASD are safe and secure in their environment. This can mean secure boundaries. It is how these boundaries are designed that is important. If they are subtle, natural but secure it will allow possibilities for the person to wander at ease and also allow staff and carers to be more relaxed when this happens. Freedom of movement can be extremely liberating.

Easily managed natural durable materials

People with ASD can be extremely demanding on buildings. Therefore it is important that the specification of materials reflect this without resorting to an institutionalised feel. It is perfectly possible to detail a building using a limited pallet of materials to meet this demanding need.

Good observation

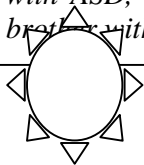
It is useful to be able to observe the movements of people with ASD without them feeling constantly under surveillance. Therefore a design should be such that observation is possible without it being obvious. Good observation will put the carer at rest, which will help their well-being and this can only benefit the person with ASD.

Good quality acoustics

People with ASD are extremely sensitive noise and at times unable to discriminate different noises. It is possible to design a space that has good sound qualities through good proportion as well as detail materials that assist in good acoustic

Applying these principles offers the opportunity to provide a sensitive ‘blank canvas’ whereby when a building or space is occupied the child or adult can, with the carer, have and understand any input they may have on the space. But more importantly a calm simple low stimulus environment which has the ingredients to meets the need, provides a stable base from which that person can live and learn.

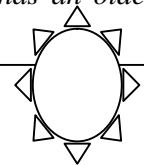
Simon Humhpreys is a qualified architect who has designed a number of buildings for people with ASD, including schools, residential units and day care facilities. He also has an older brother with ASD.



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or email at yellruthtoday@yahoo.co.uk

BOOKS

by Louis Baworowski

June Waites and Helen Swinbourne, *Smiling at Shadows: A Mother's Journey Raising an Autistic Child* (Berkeley, California: Ulysses Press, 2003) ISBN 1-56975-323-7

Its lyrical title notwithstanding, I can think of few works that give as clear and detailed a picture of the challenges that parents can encounter in raising an autistic child. Unlike Barry Neil Kaufman's *Son-Rise* or Catherine Maurice's *Let Me Hear Your Voice*, this is not the story of an intensive programme of early intervention producing a relatively swift transformation. Rather, it portrays the development, from birth through to his mid-20s, of a young Australian called Dane. With a great deal of sensitive teaching and handling by his devoted parents, family contacts and some of the professionals consulted Dane makes tremendous progress, but he continues to be a person whose successful functioning is dependent upon a degree of special support even today.

Dane was born by forceps delivery. He was absolutely silent for his first three weeks but then started to cry, apparently because of colic. One day the cries "turned into prolonged, ear-splitting screams that began each afternoon and didn't cease until late evening" (ps. 2-3). While these by-the-clock episodes eventually stopped, outbursts of screaming, rage and frustration triggered by particular events and susceptibilities continued well into his teens.

As a small child, Dane smiled at leaves moving in the wind, at the shadows they made on the wall, and at clouds. He also loved straight lines. He would tie thread or string to objects and, pulling the lines straight between them, would link a whole group of items with lengths of line. The parents referred to these assemblages as "hang-ups". Dane did not, however, show any interest in his parents or make eye contact. This distressed the mother: "Fearfully, I began to suspect that I was of no more significance to my son than a table or chair." (p. 7)

Dane's traits at one time included rocking his head from side to side before going to sleep, having screaming fits when the family car stopped at traffic lights or drove along two specific stretches of road, and only using the colour black when painting. Many years later, he was able to explain that his head shaking helped him to block out sounds, that the traffic light tantrums simply had to do with wanting the car to keep going, and that the stretch of road upsets were because (at one of the stretches) "I was scared the cows and horses would fall off the steep hills" and (at the other) "I was scared that the clouds were going to break the trees" (p. 233). The mother writes of Dane's love of trees and clouds and that, at the latter location, "a bank of low clouds often appeared to hover on the horizon, over a grove of trees" (p. 233). Dane painted in black because "you don't see through with

black.” Dane disliked change and his mother observes that black “didn’t change. Unlike other colors, black wasn’t translucent; nor did black-on-black produce an unexpected third color.” (p. 197)

Dane was heard to speak for the first time at the age of four but then – apart from being able to sing words he could not speak – was preverbal again for a time. It was only at 5 and 6 that speech really started to establish itself. At the age of 11 he was still showing very little affection but then began “rushing up and kissing people we’d pause to speak to” (p. 112). A strategy called the circles concept was used to address this problem and, with explicit instruction, Dane was quickly able to learn about social distances and correct his behaviour. The circles image, “explains differences in relationship and appropriate degrees of intimacy by placing the student – ‘me’ – in the center of five concentric rings. Closest to ‘me’ is the ‘hug’ circle, followed by ‘handshake’ and ‘wave.’ The furthest is ‘stranger circle, do not touch.’” (p. 112)

Over the course of many years, Dane’s life and social skills developed greatly so that, for instance, as a young man he passed his driving test and was a successful participant in sports. June Waites writes: “I believe we have helped our son to live in our world, and to be happy... And yet...Just making sense of his surroundings and our confusing social expectations will always be confronting him.|| From time to time he still says, ‘It’s so hard, Mum. It’s so hard.’” (p. 237)

The whole family, in fact, went through a series of harrowing experiences – at times at the hands of the very professionals supposedly most qualified to help them – that brought them to a state of near collapse. To the intense distress of the loyal parents, it was, on three separate occasions, suggested to them that their son should be placed in care. One paediatrician advised that Dane should be put in an institution and that the parents should “just walk away and forget all about him” (p. 13). At another time, when Dane had to be admitted to hospital overnight, his parents found that staff had tied him to the bed. During his teens, Dane’s awareness that he was different “tore him apart” (p. 237). Low self-esteem set in and he started getting belligerent, uncooperative and depressed. At around the age of 16, he was saying that he was “waiting to die” and actually walked out in front of a truck, which luckily managed to halt in time with “a terrible screech of brakes” (ps. 155-6). With the help of both a change in medication and sympathetic counselling this crisis passed.

The parents were fortunate in having a loving marriage, adequate material resources and being gifted with the kind of personalities that enabled them to establish an extensive network of personal and professional contacts. Notwithstanding the bad experiences to which I have referred, these contacts, taken as a whole, have helped provide Dane with the quality-of-life and therapeutic experiences that have made it possible for him to develop to the extent that he has: it is not without reason that the book contains five pages of acknowledgments. While some of

these experiences have been of therapies in the conventional sense – ranging from correcting his eyesight with laser surgery to the use “social stories” to teach him appropriate responses – there have been innumerable other life enhancing elements involved. These included everything from working in a café, which he hugely enjoyed, to bicycle rides; from using a computer during breaks at school (in his case to escape his difficulty at knowing how to conduct himself during unstructured time) to helping on a farm. We are also told: “Dane loved to stand on the veranda as summer lightning skipped from mountain to mountain” (p. 163). At the end of the book, Dane was still only in his 20s and, with continuing support, there seems every prospect of substantial further achievement.

Bob Woodward and Marga Hogenboom, MD, *Autism: A Holistic Approach* (Edinburgh: Floris Books, 2000) ISBN 0-06315-311-9

While Rudolf Steiner's spiritual understanding of man or "anthroposophy" is one of the features of this book, it also draws on the Camphill community's decades of practical experience of working with autistic people. It therefore contains much of interest even to those who like to steer well clear of what they regard as mysticism. "Autistic children," we are told, "are not just handicapped or badly adjusted – they are injured by a world that is foreign to them. Their symptoms are efforts to find their way in this world within the specific limitations of their ability to relate" (p. 196). It also stated: "We are unanimous...in understanding that the symptoms shown by autistic children are linked with perceptual disturbances and with the co-ordination and processing of different fields of perception." (p. 227)

Notices & Conferences

Music for Autism

Following the overwhelming success of *Music for Autism concert*, Create and OSJ are pleased to announce a further series of events in London, Reading and Sevenoaks.

Venue: Conway Hall

25 Red Lion Square

London WC1

When: Saturday 29th January 2005

Time: Concert 1: 11.30am

Concert 2: 2.00pm

For further information call Emma on: 020 7374 8485

Let's Get Real

Jan Hawkins is a mother of an adult with autism and has 23 years of experience in the fields of Special Needs and Lecturing in Psychology. Jan's sessions are for parents only, and they aim to enable them to explore issues about being a parent of a child with special needs in a friendly relaxed environment.

When: 12th, 19th, and 26th January 9.30 –1.00

For further information contact Centre 404 on: 020 7445 8005

Chicken Shed Theatre Company

National Inclusive Theatre Training & Development Programme

Venue: Stoke Newington Secondary School

Clissold Road

London N16 9EU

Day: Tuesdays

Details: The project has two groups, a children's theatre for 7 - 11 years and a youth theatre for 11 - 16 years olds. (The Children's workshops are usually from 5.30 - 6.45 p.m. and the Youth Theatre from 7.30 - 8.45p.m.)

Contact: Andrew on 07950 838238

*Please note there are many more projects over different boroughs for further information call:
020 8351 6161*

AFASIC

Details: Youth Information Pack.

The pack is for young people aged between 14 to 25 who have difficulty with speech and language. Topics covered include; driving, managing money and personal safety. Also in the pack is a Afasic Identity Card. This will be carried by the holder who has speech and language difficulties. There is a cost for this pack.

For more information contact: AFASIC 020 7490 9410 www.afasic.org.uk

Bromley Autistic Trust

Date: Friday 11th February 2005

Venue: Bromley Central Library

Details: One-Day Seminar, Autism as a Metabolic Disorder

Time: 10am – 3pm

Cost: £20.00 for parents & £35 for professionals

For more information telephone: Julia Pithouse 020 8464 2897

Notices & Conferences

Direct Payments

Date: Friday 11th February 2005

Venue: Centre 404

Details: Direct payments are a way of arranging services for disabled children and their families. Come along and find out how to apply and what support is there.

Time: 9.30am – 1.00pm

Contact: To book call: 020 7445 8005

Play Group for Children with Autism (5-16)

Organiser: NAS (Lambeth Project coordinator)

Location: Slade Gardens Adventure Playground, Lambeth

When: One Saturday/month 4-7pm until March 2005

Details: A playgroup for children aged 5-15 with autism, their families and friends.

An opportunity to relax and meet others. Climbing, games, jumping, playing, swinging, music, reading, running!

Costs: Free. First come first served.

For details telephone: Monica Graham 07881 980 157

Dyslexia

Date: Friday 4th and 11th March 2005

Venue: Centre 404

Details: Come along to learn a practical and low-cost way to support your child. Learn about the Revised Code of Practice and how it works up to Statutory Assessment.

For further information or to book call: 020 7445 8005

Tackling Bullying

Date: Friday 18th March 2005

Venue: Centre 404

Details: How to approach the school and what they can do to support your child.

Richard Hill from ACE (Advisory Centre for Education) speaks to parents about this problem and helps to give advice and understanding around this.

For further information or to book call: 020 7445 8005

Autistic Spectrum Disorders

Date: Saturday 19th March 2005

Venue: Dallow Road Nursery, Luton

Details: Guest Speaker Wendy Lawson shares her knowledge, understanding and experience of the autistic spectrum.

For further information contact Gill Christmas on: 01234 350704

Information Update

The National Autistic Society's Helpline number has now changed to 0845 070 4004

Monday – Friday 10am – 4pm
