



autism london

*providing support for those affected by autism
and Asperger's syndrome*

BULLETIN

Dec-Jan
2005/06



autism london



Bi-Monthly Bulletin

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In this December - January 2006 issue...

- Introduction and update
- Apology from Autism London
- Support Services Update; news and information about the services we offer you.
- Support group meetings and service closure dates over the Christmas period.
- Autism Ethnic Communities – piece written by Nurun Ahmed
- Supporter's Forum
- Book Reviews by Louis Baworowski
- Notices & Conferences

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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,

Well, it's that time of year again, yet another year has flown pass for all of us. We have seen valued staff members leave and equally valued staff members join our service. Vince has now handed over the reins to Gordon, the new Senior Manager at Floral Place.

Hello from Gordon...

A short note to introduce myself to members and stakeholders of Autism London and to say hello to those who I have yet to meet.

I joined MCCH three weeks ago as Senior Manager for East London, covering Learning Disabilities and Mental Health Services and of course, the Autism London Services. My previous role was as a Joint Commissioner for Learning Disability Services with a London Council and I have been working within the Social Care profession for over 12 years.

Having met most of the staff at Autism London and at Salisbury Road, I am reassured that I am inheriting a competent and enthusiastic team whose knowledge, skills and experience will be invaluable to me during the first few months in my new role.

With the New Year just around the corner, I hope that it will bring with it, new opportunities for both services to hone and develop a person centred approach in every aspect of our work as well as offering us the chances to really present Autism London as a valuable link to accessing the specialised care and support many of those using the service need.

Both Janice and I will be reviewing how we can create better opportunities for Autism London and how we can secure the acknowledgement we need to create improvements within the community for those who use our services.

With my best wishes for our future,

Gordon Pownall

Senior Manager

East London and Autism London

****Apology from Autism London***

In the last issue of this bulletin, alterations were made to Louis Barorowski's regular book review column. We inadvertently made erroneous changes to certain names and passages, correctly quoted by Louis in the material he submitted to us, as well as changes to his column's usual format. We did this without consulting him and contrary to the agreement we have with him. We would like to unreservedly apologise to Louis and express our appreciation for his continuing support as one of our contributors.

Inside this issue...

- Information update from the Support Service Team, including support meeting dates and also Christmas closure details of this period.
- Autism ethnic communities.
- Supporter's forum.
- Book Reviews by Louis Baworowski.
- As well as our usual notices and conferences section.

Also included in the bulletin we are pleased to announce that we will be having a New Year's Party in January – please note this will be on a **first come first serve basis** as we cannot accommodate more than 100 people. We are also selling t-shirts and autism ribbons towards funding future events; if you are interested please contact Tanya at autism london. You will also find a flier regarding the sale of our Christmas cards – you still have time to place your orders! All that leaves us to say is to wish you a very Merry Christmas and good wishes for the coming year.

Tanya

Support Service Update

Dear Supporters,

It's good to be able to report back from our Support Services and give feedback about the work we've been doing throughout the year. 2005 has been an incredibly busy year for us and it really *has* raced by. Our ALAG and ALWAG meetings have been well attended and

the lively group discussions covered topics ranging from employment, bullying, and sensory issues to relationships.

On the subject of relationships, some of our members requested some follow-up information, which we are listing here as it may be of interest to others: The following books are published by Jessica Kingsley; *Asperger Syndrome and Long-Term Relationship* by Ashley Stanford, *Asperger's in Love* by Maxine Aston & *Living The Good Life* by Edgar Schneider.

Website details are: www.jkp.com. Another website which may be of help is: www.asperger-marriage.info/index.html.

It's also been great to see so many new faces at all our support meetings and the sharing of a wide range of experiences have served to enhance the meetings.

As well as giving feedback, we welcome your comments and suggestions as to how we can improve our services - after all we are here to meet *your* needs - so do let us know if you have any ideas as to how this can be achieved.

Another aspect of the work we do here at Autism London is to continue building relationships with other support groups and organisations involved with Autism. We also sit on development committees, attend training and conference events and give advice and support to other professionals. This area of work ties in well with the support we offer to our service users.

So thank you once again for your continued support and your kind donations. We look forward to working together and further develop our support services in our commitment to meet the needs of our service users and their families.

Here's hoping you all have a lovely Christmas! Take care and God bless.

Ethney Anderson & Dee King

Support Officers

News from Salisbury Road: Staff Training At the Residential Home

Six members of staff and one of the parents from the residential home had a three-day training in makaton and autism awareness with the Senior Speech and Language Therapist for Waltham Forest (John Summers), at Coleridge Road in East London. The training involved using basic sign language, symbols, objects of reference and pictures to enhance communication between staff and our service users.

We also had a day's session in autism awareness. This was in light of raising the knowledge of staff about autism and the best way to support people with autism.

John would be having a follow up visit at the home on Friday the 11th Of October to see how staff are getting on with the areas we discussed during the training and any further assistance he could offer in communicating with our service users.

Another six members of staff would be taking part in the next session that would start in two week's time. The two Health and Safety representatives at the residential home, would be undertaking a three-day training workshop at our head office in Maidstone, from Monday the 14th to Wednesday the 16th November 2005.

Staff training remains a high priority on the agenda at the residential home in East London.

Richard Tucker

House Manager

Helpline Service Update



It's almost here!!

Where has this year gone? The year has pass by so quickly and now it's time to order that Turkey and make sure there's enough mince pies for Santa!

The past few months I have been involved in several different things including attending meetings involving autistic spectrum disorders for both children and adults and also taking part in our monthly adult support group *ALAG*.

The support group turnout is truly astonishing; between 20-30 adults both male and female attend to give an insight of their thoughts, experiences and accounts. It is also a good way for many people to socialise with each other, as many people find this extremely difficult to do so. I would like to thank everybody who has attended the group this year and hope you all continue to do so!

December Office Closing
The office will be closed from Friday 16th December and re-open on Wednesday 4th January 2006.

Below is a list of alternative Helpline numbers:

Helpline Services/Organisations	Contact Number:
National Autistic Society- Autism Help-line	0870 600 8585
AFASIC (for people with speech and language impairment)	08453 55 55 77
OAASIS (info and support re special needs)	0891 633201
Contact a Family (for families of children special needs)	0808 808 3555
Carers UK, Carers Line	0808 808 7777
Shelter line (housing/homeless help-line)	0808 800 4444
Benefit Enquiry Line	0800 88 22 00
Supportline (emotional support to any individual)	020 8554 9004
NSPCC	0808 800 5000
Disability Alliance (right's advice line)	0207 247 8743
Disability Living Foundation (information service)	0845 130 9177
Refuge (safe accommodation for women and children)	0808 808 9999
Network 81 (special education needs)	0870 770 3306
Samaritans (emotional support)	0845 790 9090
Mencap (learning disabilities helpline)	0808 808 1111

Remember our Helpline operates Monday – Friday 11am to 2pm on 0207 359 6070 or alternatively you can email me: tanya@autismlondon.org.uk



Autism London is currently selling autism awareness ribbons in order to continue to raise awareness about the disability. The ribbons are £1 each (not including postage), for an order form please contact me on the details above.

It just leaves me to say to you all, have a peaceful and enjoyable Christmas and good wishes to you all for the New Year!

Tanya
Help Line Officer

Parent/Carers Support Group
Invites you to attend a series of talks.

Date and Time	Venue Details	Speaker	Topic
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14 th December 1.30pm – 3.00pm	Autism London 1 Floral Place Northampton Grove London N1 2FS	Support Officers from Autism London: Ethney Anderson & Dee King	Open meeting for parents to come along and talk.
11 th January 2006 10.30pm – 12.00pm	Autism London 1 Floral Place Northampton Grove London N1 2FS	Support Officers from Autism London: Ethney Anderson & Dee King	Open meeting for parents to come along and talk.
18 th January 2006 10.30pm – 12.00pm	Autism London 1 Floral Place Northampton Grove London N1 2FS	Rosemarie Manson	Parent of a child with ASD, and H.A.N.D.L.E Therapist
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.			

**autism london
Women's
Asperger's Group**

Dates for meetings from January – March are:

No Meeting in December

No Meeting in January

Thursday 23rd February

Thursday 30th March

**Come along and give it a try; if you are coming, please try to arrive by 2pm.
Light refreshments, i.e. teas and coffees etc will be available.
Contact Dee/Ethney for further information on: 020 7704 0501**

**autism london
Asperger's Group**

This is a support group for adults with Asperger's syndrome living in the London area. It is a chance to meet others, to talk about common issues, and to support and help each other.

The group meets at the Autism London offices at: 1 Floral Place London N1 2FS

Dates for meetings from December 2005 – January 2006 are: -

Tuesday 6th December
Positive aspects of AS/Individual strengths

No Meeting in January

Tuesday 7th February
Voluntary work/work experiences and employment issues

**Come along and give it a try; if you do come along, please try to arrive between 6.30pm and 7pm. There will be light refreshments/ snacks available.
Contact Dee/Ethney for further information on: 020 7704 0501**

Autism Within Asian & African Communities

Autistic spectrum disorders affect an estimated 1% of the population, and therefore it can be estimated that there are likely to be around 17,500 families in London from black and minority ethnic communities affected by autism. Autism is on the rise in communities from India, Pakistan, Bangladesh, Sri Lanka, Nepal, Bhutan, Maldives and Africa.

It is estimated that the prevalence of severe learning disability in the South Asian community may be higher than that in the general population. There is a lack of information about the prevalence of mental illness and /or challenging behaviour in young people with learning disabilities from the South Asian community. The overlap of challenging behaviour and mental illness in young people from the South Asian community often clouds the detection and diagnostic process and access to appropriate services. There are several barriers which prevent parents from the Asian and African community from accessing appropriate help and support, due to the lack of understanding of Autism and Asperger's Syndrome. The main barriers are listed below:

- Knowledge and Awareness
- Stigma
- Language Barrier
- Self Reliance
- Suspicion
- Religious Beliefs
- Inability to Get Help
- Reluctance to Get Help
- Perceptions/ Beliefs
- Real Help Versus Religious Help

Over 10% of UK citizens are from a minority ethnic group. From within this group there has been a rise in the numbers of adults and children with Autism and Asperger's Syndrome. What we are not seeing are culturally appropriate services to meet the growing needs of ethnic minority communities across the UK. By 2010 ethnic minorities in some of Britain's major cities will be in the majority. Local councils, local education authorities, NHS Trusts, social services need to be prepared for these changes. ***So what needs to be done?***

- Data on ethnicity and Autism needs to be researched to identify the size of the problem.
- Need for Bi-lingual advocacy services for South Indians and African languages, as for many parents English is not their first language.
- We need to be mindful of the fact that by 2010 major demographic changes will result in the ethnic minorities being the majority in places like Tower Hamlets, Southall, Hounslow, and Tooting. Local councils, LEAs and NHS Trusts will need to have culturally appropriate services for people with Autism and Asperger's Syndrome.
- Information in various languages to be made available and accessible on websites, in schools, advice centres, health clinics etc. Also workshops targeted at parents and carers of Autistic children from the ethnic minorities.
- A network of Bi-lingual workers from various sectors to reach the ethnic communities.
- Increased recruitment activity of SEN workers from ethnic minority groups.

Nurun Ahmed
Administrator

Supporters' Forum

I had 2 weeks holiday in Ibiza San Antonio Bay in September 2005. I enjoyed my holiday but had difficulties managing the safe and I even lost my safe key and my return bus ticket from Luton Airport to London.

I had difficulty finding the food in the buffet hall, so the headwaiter helped me for the first few meals in showing me where the food was.

I did say on the suggestions form that every thing we needed such as safes and drinking water should be included in the original price of the holiday.

I went swimming all most every day and did some boat trips. On the Boat trips we saw lovely country scenery including cliffs by the sea. I met people and enjoyed some of the entertainment such as shooting and bowling and other games. I also won a few prizes.

The weather was varied, most of the time it was like a hot English summer. It also poured with rain some of the time.

On one of the boat trips, I was worried that we might fall in the sea, as it was rough and windy.

Every night there was a great deal of noise because of the parties. On my very last night I thought it was drunken louts throwing things about, I looked out of my window and I saw there was a mini hurricane blowing things about so my holiday ended with a bang.

David Shamash

Excerpt from a novel by Desmond Meldrum

'Geri and George were in the middle of the floor dancing and George was trying to get to know his recently acquired girlfriend a little better. In fact he seemed to Geri to be somewhat more communicative than on the time they first met.

"Where do you work?" He asked. Although they had a brief conversation the previous Saturday, the subject of work was, for some reason, never brought up.

"In the city, for a management consultancy"

"Like it?"

"It has its moments and the pay is good. What about you?"

"I'm in an insurance office".

Just then the record of the discotheque stopped and the couples who were dancing on the floor went back to their seats. The next record was a fast number and George and Geri decided to sit it out. George sat on his seat uneasily putting his arm around Geri. He was feeling awkward with himself and was frustrated with his lack of social skills. He was also constantly dismayed by the fact that other people seemed to know what to do in these situations and he did not. Geri also noticed this and since the beginning of the evening it had crossed her mind several times that she would definitely make this the last date. She would come clean and tell him about Nick but now as this second meeting progressed, it seemed harder to do this. She was beginning to find George rather intriguing, as he did not seem to be like other men. She then started thinking that perhaps if she stayed with him, it would be an excuse to get rid of Nick for once and for all. She was shaken out of these thoughts when George suddenly suggested that they should go and meet his friends.'

If anyone requires further information, please email me at gdmeldrum@tiscali.co.uk

BOOKS

Louis Baworowski's career has included social work, academic research and journalism. For several years, he also worked as a volunteer writer for the National Autistic Society, preparing abstracts (summaries) of scientific and general articles on ASD for the Society's database. He is the father of Osian, a 24 year-old with autism. The aim of this regular column is to cover works of interest to readers of *Autism London Bulletin* irrespective of publication date. Where non UK-English spellings appear in titles, names or quotations, it is due to

By Louis Baworowski

O. I. Lovaas, *Teaching Individuals with Developmental Delays: Basic Intervention Techniques* (Austin, Texas: Pro-ed, 2003) ISBN 0-89079-889-3

As a physical object, this hefty manual has all the charisma and handling characteristics of a telephone directory. Nevertheless, it is ideally suited to its purpose. While undeniably requiring the investment of a great deal of effort, it is designed to be understood by the average layman, so long as it is tackled in an appropriately systematic manner. Written by the legendary Lovaas himself and no fewer than 13 of his associates - which by itself guarantees that this is no amateurish effort but one that draws upon what must be almost unparalleled reservoirs of knowledge and practical experience - it sets out the principles of ABA (Applied Behaviour Analysis). It also details what to teach, how to teach it and how to set up a team of helpers, to assist with the major task of putting in the very large number of one-to-one teaching hours that is needed. For parents who are really serious about coming to grips with Lovaas's ideas, and perhaps implementing a programme of early intervention based on them, there is no better book.

The work does, however, dispel any notions of Lovaas being a panacea. There is, for instance, reference to three distinct outcome groups emerging when intensive behavioral treatment was given to preschool-aged children, including a small residual group that gained little. 40 hours per week of one-to-one teaching is needed; ten is inadequate. Lovaas tells us: "Most parents...may have been led to believe that 47% of all the children treated with this intervention reach normal...functioning. However, this statistic has been obtained only under the most optimal clinic-based...conditions. Workshop-based treatment is estimated to yield a recovery rate between 10% and 20% provided the workshop leader is qualified...recovery outcome for workshops led by persons who are not qualified may not exceed 5%." (p. 25) It is also worth stressing that the

47% figure relates to treatment in which all the children were under 46 months of age at the time of their enrolment for intervention.

A. Hewetson, *Laughter and Tears: A Family's Journey to Understanding the Autism Spectrum* (London: Jessica Kingsley, 2005) ISBN 1-84310-331-1

Notwithstanding its homely title, this is a rather cerebral account and could even be described as a case study of a person by his own mother. It is a record of the first 30 years in the life of Mark, a high functioning man with ASD, who has a history of sensory and other problems, as well as an exceptional rote memory and a genuine musical talent. It details his parents' unremitting efforts, over a period of decades, to work with their son. Their continuous home teaching projects and other interventions have undoubtedly been of decisive benefit to Mark, hugely adding to and complementing the input of schools. The book also devotes a good deal of space to autism as well as psychological and medical topics *per se*.

Mark was not a cuddly baby. At the age of 10 months his mother noticed him rocking "rhythmically back and forth, moving to some internal clock" (p. 9). At 12 months, reacting to the busy environment of a shopping mall, he went "bar tight, all muscles clenched rigid" (p. 10). At around the same age, he began to have screaming fits for no apparent reason, that would last for hours before ceasing abruptly; screaming episodes were a feature of his life for the next two years. Mark exuded an aura of aloneness.

As a toddler, Mark appeared to lack perception of depth and would, "scramble up on a chair and then try to walk out onto the air" (p. 19). Observing him at the age of three, his mother concluded that he did not feel pain and that he found, "no sense in sensation. Either he is not aware of it because he cannot feel it or, having felt it, he cannot decipher it or find where it is coming from...He constantly gives the impression that he is not aware of his limbs or does not recognize that they belong to him." (p. 30)

At around six, he was enunciating the Latin names of shrubs. At nine he developed a passion for bridges and lighthouses and within weeks could recite, "the exact specifications of every lighthouse around our coast – giving name, location...height, single flash/group flash, quick single flash/quick group flash, isophase one/isophase two, three...[etc. etc.]" (p. 80).

Thought and language, however, did not keep pace with memory. At the age of eight, he was reversing his pronouns and did not understand that time moved in one direction only. He asked his mother: "When ...you're three again will I take you to the zoo again to feed Jill [the elephant]?" (p. 62). Given the peculiarities of Mark's speech, this translates as: "When...I'm three again will you take me to the zoo again to feed Jill?" At 11 he coped with four languages (English, Irish, French and Latin) but continued to misuse pronouns, spoke in a stilted fashion by manipulating learned phrases, and had little abstract thought or grasp of cause and effect.

His understanding of language could be bizarrely circumscribed. On being introduced to a boy called Robin, Mark observed: "No feathers, no beak, no red breast" (p. 95). Robin's mother laughed, on the mistaken assumption that Mark was joking. Still on a theme with, in this case, an ornithological connection, Mark had synaesthesia, a kind of sensory cross-wiring: "the sound of a wood-pigeon cooing...produces sharp spikes of a brilliant purple/grey colour which dominate his vision, while at the same time he feels the needle-sharp spikes with his hands." (p. 205)

Mark also experienced difficulties in face recognition (prosopagnosia). “People with prosopagnosia,” states the mother, “can neither recognise faces nor recognise emotional expressions...for them there is no such face as a familiar one” (p. 145). My own understanding is that this is by no means always the case and that prosopagnosia can vary in severity and even in character. It has been posited that individuals with autism have greater difficulty recognising faces than normal people and the fact that many have problems in reading facial expression is well established. Recognising faces and reading facial expressions are nevertheless independent abilities. According to *The Blackwell Dictionary of Neuropsychology* (Oxford: Blackwell Publishers Ltd., 1996) p. 341, the loss of overt recognition in prosopagnosia is only “often” total and “other aspects of face processing, such as the ability to interpret facial expressions...can remain remarkably intact in some (though by no means all) cases.”

Despite his problems, Mark attended normal schools and coped well academically. By his early 20s, he is said to have, “moved along the spectrum from the severe end of classic Kanner-type autistic disorder to the HFA/AS end” (p. 168). His mother considers that he was no longer impaired in communication and socialisation, but still had limitations in the area of imagination – she uses the term in a rather specific sense, to suggest that Mark lacked the ability to plan realistically, not being able to “imagine” the consequences of particular decisions. At the book’s conclusion, having suffered some setbacks of mood and mental health along the way, Mark had graduated from a three year horticultural course and had a very positive attitude to life.

Notices & Conferences

Help Required

Details: Autism London would like to hold a New Year Party – in doing so we request your help in helping us make this happen. Autism London's New Year Party requires any volunteers with skills in children's entertainment: clowns, puppeteers, face painters etc. Also requires volunteers who would like to lend a hand in helping out on the day. Help in raising money towards this event would be much appreciated. Could you spare some time selling t-shirts, xmas cards and ribbons towards the funding of the party?

Please contact Tanya: 020 7704 0501 or email Tanya@autismlondon.org.uk

Volunteers required

Details: Autism Research Centre, University of Cambridge.

Is running a study at UCL in London and request the help of any right-handed males participants with AS or HFA, aged 18 or over.

For more information telephone: Ilaria Paluello on: 01223 746 030

CAPS

Details: Children with Asperger's Parents Support, Tea and coffee will be provided, please bring your own lunch. Parking vouchers available from Hamara at 50p each.

Venue: Hamara Family Project, Barnardos
Cartel House, 1b Priory Avenue
Walthamstow E17 7QP

Date: Monday 5th December 2005

Time: 12:30 to 2:30pm

For more information telephone: FSU Waltham Forest on 020 8539 0004 or email: wfaspergers@hotmail.co.uk.

Coffee Mornings

Details: Coffee mornings for parents of children with special needs.

Venue: Centre 404 Camden Road, London N7 0SJ

Date: 1st Tuesday of the month

Time: 10.30am to noon.

For more information telephone: Caroline/Lauren on: 020 7697 1325

Statements

Details: IPSEA are repeating their popular sessions. The first session covers an overview of assessment and statementing, looking at common problems and what you can do about them. The second is how to deal with annual reviews and get amendments to statements.

Date: Wednesdays 30th November and 7th December 2005

Time: 10.00am – 3.00pm (including lunch)

Venue: Centre 404, 404 Camden Road, London N7 6LB

For more information telephone: 020 7445 8005 to book your place

Stars Shine For Autism

Details: A Christmas concert in aid of the National Autistic Society

Venue: Cadogan Hall,

Date: Monday 12th December 2005

Time: 7.00pm

For more information telephone: Cadogan Hall Box Office 0207 730 4500

Notices & Conferences

Memory Gardens

Details: For children between the ages of 8-14 on the autistic spectrum; build outdoor sculptures, care for plants and feed wildlife. Places are limited.

Day: Start date Sunday 30th October then every other Sunday 11am – 1pm

Contact: For further information please contact Ruth Solomon Tel: 020 8806 1129

Website Launched

Details: The Asperger's Syndrome Foundation have launched their website. The site gives information sheets, book lists and links to other sites, which are useful to those involved with Asperger's Syndrome.

For more information log on to: www.aspergerfoundation.org.uk

Creative: space events

Details: Creative Space (*formerly Music for Autism*) announces a forthcoming event in London. Children with ASD to take part in this musical event, including percussion and listening to music made. Tickets for the event are: £4.00 children and £6.00 adult

For more information please contact: Helen on 020 7374 8485 or email helen@createart.org.uk

Calm Classrooms Music

Details: Calm Classrooms Music is an effective way of helping children of all ages and abilities learn more effectively. A TES article and the executive summary of the Worcester University thesis on the project are both available.

For more information telephone: Vo Fletcher on 07801 067386 or Email: vo.fletcher@btinternet.com

Sensetoys

Details: The SenseToys website brings together a carefully selected range of original toys, activities and books, from a wide variety of sources, in one easy to use online shop. The SenseToys range is suitable for all, but particularly for children with special educational needs. Each product is individually tested, is of the highest quality and educational value, and comes with simple and effective play tips.

For more information visit: www.SenseToys.com or email: lesley@SenseToys.com

CD of Music for ASD

Details: Jessica Curry is a composer who was awarded a bursary from the Royal Society of Arts (The RSA) in 2003. Jessica has composed a CD of music specifically aimed at young people with autism, to be used by teachers and parents.

For more information telephone: Jessica Curry Tel: 02392 838198

ABA4Autism.com

Details: ABA4Autism.com and the Psychology Department at the University of Tennessee at Martin are conducting a second survey on the causes on Autism Spectrum Disorder (ASD).

This survey is for the mothers of children with ASD as well as mother of normally developing children who are ten years of age or younger. Mothers who participate in the survey will receive a free ABA program to teach their children to follow directions as well as free ABA mini programs for common problems like sharing.

For more information visit: www.ABA4Autism.com