



Autism London

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

BULLETIN

Oct-Nov
2005



autism london

Bi-Monthly Bulletin

1 Floral Place, off Northampton Grove
London N1 2FS

Helpline: 020 7359 6070
General: 020 7704 0501
Service Development: 020 72267234 (Temp)
Finance & Administration: 020 7226 7234
Fax: 020 7704 2306
Email: info@autismlondon.org.uk
Website: www.autismlondon.org.uk

In this October - November 2005 issue...

Introduction and update
Support Services Update; news and information about the services we offer you.
Support group meetings
Supporter's Forum
Book Reviews by Louis Baworowski
Notices & Conferences
Autism London needs your help!

Contributors

Contributors: Vince Brown, Dee King, Ethney Anderson, Tanya Camilleri, Richard Tucker,
Louis Baworowski, Michael Feldman, David Shamish, Tim Loder.
Production: Thanks to Tanya and Nurun, for producing the Bulletin

Editorial contact: Tanya Camilleri
email: info@autismlondon.org.uk / tel. 020 7704 0501

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,

As you know, last month saw the departure of two members of staff from our team here at Autism London. Gill Lea-Wilson who most of you all know and Elena Hall who was our administrator. I am pleased to welcome to our service two new members of staff to our team, Vince Brown and Nurun Ahmed, here they introduce themselves....

Hello from Vince.

I am pleased to have been asked to take up the management role for the services provided at Floral Place. I hope that my input will help bridge the gap left by Gills departure and the recruitment process. I also hope that my presence, although time limited, will contribute towards enabling the continuation of the valuable help line and support services provided to people via the Floral Place team.

I would like to thank the team at Floral Place for their welcome and support.

Vince Brown

(Senior Manager Supported Living Services.)

Hello / Salam / Namaste / Haye

Greeting to all the supporters from every corner of the continent! Here's a quick intro on me! I recently got married and moved to London from Peterborough. I was employed with Anglian Water and was also a volunteer for the community projects that the company is involved in. I have experience in working with children and adolescents through the Prince of Wales Young Enterprise schemes and mentoring.

I am delighted to have joined the team and very excited in working on future projects with Autism London. Since joining the team I have been enjoying this rewarding experience. I endeavour to continue in providing an outstanding service for the community and hope to develop a trusting relationship with you all.

In the coming months, I will be working on various projects which will entail in developing the existing service Autism London offers. In order to do so, I will require your continued support, so please don't forget to donate your loose change as every penny will count and will go towards future events, such the New Years party which I will be organising in the next few months.

That's all from me now, I wish you all a happy Halloween and don't forget to wrap up warm for autumn! For now, goodbye!

Nurun Ahmed

Administrator

Inside this issue...

Information update from Support Services, including support-meeting dates and times. Update from our team at Autism London's Residential Home. Supporter's forum, Book Reviews by Louis Baworowski, as well as our usual notices and conferences section. Also included in the bulletin are two fliers, we are pleased to announce that we are selling t-shirts towards funding future events such as our 'Summer Trip' and New Year's Party. You will also find a flier regarding the sale of our Christmas cards – yes it's almost that time again!

Tanya Camilleri

Helpline Officer

Support Service Update

Dear Supporters,

Welcome back to those of you who were fortunate enough to go away on holiday this summer and to those who, like myself, were left behind working throughout those lovely, hot summer days only pausing to go to the Autism London Legoland Trip, and getting drenched all day! Apart from the soaking, it was lovely to spend the day with so many of our service users, chatting and having a laugh on the coaches and meeting up for lunch or bumping into each other throughout the day. All in all, we had a great time.

Earlier in the summer, I attended a **Black, Minority Ethnic** (BME) conference called “Building Bridges” organised by NAS and held at Friends Meeting House in Euston. The conference was very well attended and covered a wide range of information, experiences and good practise recommendations. The presenters were professionals in the field and a parent called Rose Edumejeke, who gave a moving account of her experiences and difficulties accessing services for her son. Rose now runs a parent support group in Greenwich called ‘Just Talk’.

The main theme of the programme was that people with learning difficulties including autism from BME communities are likely to have many unmet needs, be unaware of services and also how to gain access to them. Often they are offered services that are far from person-centred or culturally appropriate.

A clear message was conveyed that a commitment from service providers for a renewed ethos of welcoming diversity, respecting other people’s customs and beliefs and being prepared to challenge each other’s stereotypes and assumptions. A new project introduced and run by NAS called the BME Community Project was also publicised at this event.

Ethney Anderson
Support Officer

Hello once again to all our supporters old and new. I hope the summer holiday has been restful, or do you need another holiday to recover from the one you just had? I had the opportunity to go to Jamaica for two weeks in June and I was happy to come back to the UK to more good weather.

Recently I went to revisit an organisation that I had been to see during my induction period at Autism London. The organisation is called Pashun, and I was equally impressed with their services as I was on my first visit to them three years ago. Pashun have relocated their building to Tottenham in Willoughby Lane. The organisation aims to provide one to one support for clients who have Autism and severe challenging behaviour. They strive to work in a manner that enables each individual to be socially valued and treated as an equal citizen with equal rights within the wider community. The centre provides a wide variety of activity for service users, and the staff are given regular training to enhance their experience in working with their client group. The organisation also organise short breaks away to various holiday resorts to provide respite.

I continue to look forward to meeting parents and carers at our support groups and we are always interested to hear about your experiences (especially the good ones). Until next time this is Dee signing out.

Dee King (Support Officer)

Helpline Service Update



Well the summer holidays have now gone by, and autumn is now upon us.

I would like to take the time in thanking everyone who made our trip in August to Legoland possible, and how nice it was to meet up with so many families who came along. The weather did start out looking promising until we got on the motorway and the rain came down! But we went on, determined that it would not spoil our trip. You can read more about the trip if you visit our website & also in this bulletin from one of our service users who also came along.

We are currently selling t-shirts in support of our service and also Christmas cards. All money raised will go towards future events such as our New Year's Party and Summer Trips. For more information please see fliers enclosed.

Well until next time, take care.

Regards

Tanya Camilleri

Helpline Officer

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

Date and Time	Venue Details	Speaker	Topic
28 th September 1.30pm – 3.00pm	The Kulubi Centre 2c Falkland Road Kentish Town London NW5 2PT	Support Officers from Autism London: Ethney Anderson & Dee King	Open meeting for parents to come along and talk.
12 th October 10.30pm – 12.00pm	The Limes William Morris Hall 6 Somers Road Walthamstow E17 6RX	Support Officers from Autism London: Ethney Anderson & Dee King	Open meeting for parents to come along and talk.
19 th October 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.
9 th November 1.30pm – 3.00pm	Autism London 1 Floral Place Northampton Grove London N1 2FS	Megan Karnes from OCD Action	Obsessive Compulsive Disorder Support and advice officer, speaking about the service
23 rd November 10.30pm – 1.00pm	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.			

‘We are currently receiving good attendance for our ALAG group, which run’s every first Tuesday of the month at 6.30pm – 8.30pm. We have noticed a few of our supporter’s turning up earlier than advertised and ask politely if all people attending ALAG to attend no earlier than 6.30pm as staff are still working and unable to supervise those who have arrived at this time.’

autism london
Women's
Asperger's Group

Dates for meetings from October 2005 - January 2006 are: -

Thursday 29 th September
Thursday 27 th October
Thursday 24 th November
No Meeting in December
Thursday 28 th January

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

Or email us at: dee@autismlondon.org.uk or ethney@autismlondon.org.uk

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, off Northampton Grove, London N1

The group currently meets on the first Tuesday of the month
in the evening from 6.30pm to 8.30 pm.
(Polite request: please do not attend before this time)

Dates for meetings from October 2005 - January 2006 are: -

Date	Topic
Tuesday 4 th October	Obsessive Compulsive Disorder
Tuesday 1 st November	Relationships
Tuesday 6 th December	Positive aspects of AS/Individual strengths

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

Or email: dee@autismlondon.org.uk or ethney@autismlondon.org.uk

News from Salisbury Road

Hello all how are you doing hoping you are all fine. We here at the residential home are doing fine. We have really enjoyed the summer and hoped that you have too.

There have been quite a few things going on since our update. We are happy to inform you that we have joined the on-call of MCCH. From August Salisbury Road will be part of the East London on call service with the rest of MCCH. This will enable us get assistance during out of office hours and the weekends. Those who will be taking part in this will be Aboo (Senior), Monica (Deputy Manager) and Richard (Manager).

Cont..

We have had three sets of resident's holidays. One in July for three service users, a second when two service users went to Breen Sands in Somerset and they had a lovely time in August. There is another set in Sussex at the moment (we hope they have a nice time) All seven of our service users went out on a day trip last week to Sidcup in Kent. First they went fruit picking and collected a good amount of fruits. They then went on to the seaside for the rest of the day and got back home exhausted but had a whale of a time. The day services have now resumed after the summer break and most of our service users have gone back to their different day services i.e. Mark House, Wally Foster Berkley Farm and A.C.S.

We have also been able to enrol two of our service users in Newham College for this year we hope they have fun.

In all everyone has had a very nice summer and are calm and relaxed

Richard Tucker

House Manager

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*

If you are reading this, then perhaps you would like to send something in for others to read next time? This is your space, whether you are a person with ASD, or a sibling, partner, parent, carer, or friend. Whether as an article, story, poem, or picture, we welcome your experiences, views and ideas to share with others.

Please send any articles to Bulletin - Supporters' Forum, Autism London, 1 Floral Place, London N1 2FS, or email them to Tanya@autismlondon.org.uk

Supporters' Forum

Because of the lousy forecast, I nearly did not go on the outing. Still, I decided to go as the forecasters promised that the weather would improve as the day went by. This unfortunately, was not so. Although the rain did ease for a short while only to return.

On arrival, staff members who boarded our coach met us, giving out our tickets. By then, it was absolutely 'tipping it down.' It would however, would have been a different story had we went the day previously as the sun was shining. Then, those wishing to see the outdoor exhibits had to arrive early. Otherwise Legoland would have refused entry to late arrivals.

Legoland is worth visiting and the attraction does offer discounts if advance group bookings are made. Full details about this can be found at:

<http://www.lego.com/legoland/windsor/GroupSales/>

Following on from here. Some attractions worth seeing are models of the space shuttle, famous London landmarks such as Tower Bridge, Tower of London, the London Eye etc. There is also a model of the world famous Sacre Cuer Church in Paris, Amsterdam's canals and many more attractions. All of which, can be found in MiniLand.

Despite the rain, I did however decide to take some photos and some are shown here. Looking back, maybe I should have returned to Legoland under favourable conditions, then taken photos. Still, because of the admission costs, plus travelling, eating out and obtaining any souvenirs, it would probably remain too expensive. On a positive though, if there are any further outings, then I shall visit this attraction again under favourable weather conditions.

Michael Feldman

Autumn

Autumn, autumn,
It is Autumn
The leaves are-a-turning
The squirrel is-a-scurrying
(for nuts)
His tail is-a-flurrying

Autumn, autumn,
It is autumn
The swallows-a-part,
Are-a-departing
Brisk is the wind,
Through leaves-a-whisperin'

And then the blast,
The leaves fall a-fast
Indian Summer's now-a-past

Tim Loder

Jewish New Year

Autumn for us does not only mean the weather changing. It also means the Jewish New Year, which is this year on October 4th, and we have a complete 25 hour fast on the Day of Atonement, which starts at sunset on October 12 to nightfall on October 13th.

David Shamish

BOOKS

By Louis Baworowski

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 the spellings employed in the relevant sources.

A. Lovell, *Simple Simon: The Story of an Autistic Boy* (Tring, Herts: Lion Publishing, 1983 paperback edition) ISBN 0-85648-554-3

This is a book whose impact remains in the memory, long after that of more superficially dramatic and eventful accounts has faded. It is not a story of some triumph against the odds nor a catalogue of exotic behaviours. Rather it is a profoundly moving tribute to a person with special needs by his mother and, at the same time, an exceptionally poignant expression of parental hopes, fears and reflections. The work includes an extract relating to “holy fools” from the 14th century masterpiece *Vision of Piers Plowman* and was, in fact, originally titled *In a Summer Garment*, whose words are taken from the poem.

Simon's mother writes: “I did not know which star had presided at his birth, but it must have been a star of great ruthlessness, to produce a human being so beautiful, and so defenceless...He has grown up into one of the gentlest of people – into someone who has, quite simply, none of the more tormented aspects of human nature. He cannot understand the concept of competition. He has never, in his life, tried to be first. He has never, ever, shown the least aggression towards any creature except in pure imitation...He has grown up trusting people even though he cannot understand them” (ps. 26, 28 and 140). By the end of the book, Simon is living in Somerset Court. Life in the ordinary world would be, “...terrifying to think of. The world is not an affectionate place. Evil is present...And he would not stand the slightest chance, were he to meet it. The sheltered community where he lives...exists to protect Simon and his like, to enable them to lead useful and dignified lives despite their vulnerability.” (p. 140)

Edited by J. T. Neisworth and P. S. Wolfe, *The Autism Encyclopaedia* (London: Jessica Kingsley, 2005) ISBN 1-84310-314-1

An autism encyclopaedia will be of value to many users and this is, in the main, a well conceived and produced work. It is not, however, without its faults, and would benefit from revision in future editions. Despite the claim on the front cover that it is intended for parents as well as professionals, there is wide variation in the quality of the entries, and some of them use language and unexplained technical terms with flagrant disregard for the understanding of a lay readership. The entry on “intelligence tests”, for instance, refers to intelligence being a “construct” and the entry on “positron emission tomography” is harbouring the delusion that the average reader is familiar with “oxidative metabolism”. There are also topics of significance that are not covered at all and others which are inadequately dealt with.

Why is the item on “aetiology” (the causation of autism being a topic of interest to almost everyone concerned with the condition) only seven lines long? Why is there no entry on “Option/Son-Rise” or “Higashi”, both of which are extremely well known approaches? Why is the contribution on “epilepsy” written by someone who is described as a “behaviour analyst”, whose listed qualifications do not include medical ones? There is an entry on “face recognition”. However, readers, who may wonder about this, are not advised that people can have difficulty recognising faces (prosopagnosia) without problems in reading facial expression – even if it is the case that the latter often *also* occur in autistic spectrum disorders. The entry on “proprioception” makes surprisingly little reference to autism, though many parents will look up topics solely in the hope of finding clues relating to their children's difficulties. The entry does cite a piece of research pointing to autistic people over relying on

proprioception and under relying on vision, but does not appear to be aware of the wealth of material concerning proprioception in personal accounts. We are not told how the findings of the cited research square with the poor sense of their own bodies reported in (and by) a lot of people with ASD, nor the rationale of the dependence on vision of some well known approaches used in autism, e.g. the Picture Exchange Communication System (PECS).

The editors of this encyclopaedia, which was first published in the US, are two American professors of special education. More than a hundred individuals, most of them American, have contributed to the writing of the 500+ entries. Whether all of the contributors, to go by the blurb on the back cover, fall in the category of being “the most respected autism experts” is debatable – some are described in the book merely as graduate students or doctoral candidates – but certainly they do include a quota of professionals of high standing, Eric Schopler and Simon Baron-Cohen among them. The fact that the encyclopaedia is primarily oriented to an American readership is mostly of no disadvantage, but it does mean that references to legislation pertain to US not English law, and that there are occasional differences in terminology and other details. There is, for instance, no entry called “speech therapist” but we do find its transatlantic equivalent of “speech-language pathologist (SLP)”. Many of the contributions are excellent but some exhibit the faults I indicated earlier. Under “diet therapy”, for example, we are informed that this is a “therapeutic modality” (why not simply “therapy”?) in which, “path physiologic mechanisms of symptom relief from elimination diets include reductions in exposure to neuroactive digestive products (e.g. opiate peptides from milk, excitatory amino acids)...” etc. The author of this entry, and indeed the book’s editors, have either forgotten, or chosen to ignore, that even among professional readers – who may well include teachers, social workers and nursery staff in higher proportion than neuroscientists, biochemists and researchers – the vocabulary of science may be alien. It is true that there are separate contributions on both “peptide” and “amino acids” and that, in any case, it is possible to use a work of reference alongside others, such as dictionaries of medicine, biology and chemistry. I don’t, however, regard this as much of a compliment.

The entry on “diet therapy” is also illustrative of a lack of appreciation of families’ need for an adequate statement of the facts. The entry does tell us that “numerous dietary components have been implicated in contributing to the observed signs and patient-reported symptoms of autism” and identifies some of the mechanisms involved. However, it then goes on to say that the “benefits from elimination diets must be balanced against the social stress of eating differently, the psychological stress of viewing foods as threatening to health, and the importance of preventing nutrient deficiency.” But how we are supposed to make a “balanced” decision when, in the absence of being provided with precise medical information, it is not even possible to determine what is on the scales! Nutrient deficiency can, of course, be prevented in people on diets – which leaves us puzzled over the remarks about stress. Are we being informed that, medically, it makes so little difference whether a child goes on a diet, that we can neglect to take action simply because it might be too troublesome? But Paul Shattock has suggested that there are people with autism who lack the ability to break down gluteomorphins (found principally in wheat) and casomorphins (from milk) sufficiently, with the result that chemicals reach the brain that do not belong there and produce “drastic effects on transmission and development”

(<http://osiris.sunderland.ac.uk/autism/durham95.html>). Is the encyclopaedia implying that Paul Shattock is wrong, or that his ideas are too weakly established to be taken very seriously? Presumably it cannot be stating that he is correct, but that parents should allow “drastic” damage to occur in their children, if they happen to find the prospect of a diet stressful.

Notices & Conferences

Day for Autism

Details: NAS Day for Autism 2005 hosting a fun packed event for all the family

Venue: Leicester Square. London

Date: Sunday 25th September 2005

Time: 12 Noon – 6pm

For more information telephone: 020 7833 2299

Theatre Resource

Details: Drama workshops and more

Venue: Theatre Resource

Chipping, Ongar

For more information telephone: Theatre Resource on 01277 365 626

Influence online

Details: Scope has set up a virtual parents group for parents of disabled children. The group will feed parents views and experiences into government departments. It is hoped that this will help parents to influence future government policy.

Contact: If you are interested please contact Scope for more information on 01432 370 860 or email: earlyyears@scope.org.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

Islington Information Directory

Details: A directory of services in Islington for children with special needs, produced by Islington Children's Information Service is now available online.

To download the information: www.islington.gov.uk/childrensinformation-service or contact Islington Children's Information Service on: 020 7527 5959 for a copy.

NAS Seminar for Adult Siblings

Details: NAS has arranged a seminar aimed primarily at siblings (aged 16+) who are related to people with ASD.

Venue: NAS Head Office, 393 City Road, London EC1V 1NG

Date: Saturday 5th November 2005

Time: 10.30am – 12.30pm

For more information telephone: NAS 020 7833 2299

Sunflower Therapy

Details: Sunflower Therapy is a unique holistic approach to improve performance, health, success and self esteem of children with learning difficulties.

For further information contact: 01483 531 498 or visit the website www.sunflowertrust.com

Notices & Conferences

The Sound Learning Centre – Open House

Details: Come and learn about the methods of tackling the underlying causes and conditions of many learning and sensory difficulties such as Asperger's Syndrome, Autism and ADD/ADHD

Venue: 12 The Rise, Palmers Green London N13 5LE

Date: Thursday 20th October 2005

Time: 7.30pm onwards

For more information telephone: 020 8882 1060

Hop Skip and Jump

Details: Dance class for autistic children (5-12 years old), siblings can also come along and join in.

Venue: Jackson Lane in Archway

Time: 5pm – 6pm

For more information telephone: Nevin Perry 020 7281 7712

ADHD Support Group

Details: New group meeting

Venue: Northern Health Centre

Date: Every third Thursday of the month

For more information telephone: Valda 020 7272 6933

Statements

Details: John Wright from IPSEA is again repeating their popular sessions regarding statementing.

Venue: Family Resource Centre, Camden Road, London N7 0SJ

Date: Wednesday 30th November and 7th December

Time: 10.00am – 3pm (including lunch).

For more information telephone: Resource Centre 020 7445 8005

Co-ordination

Details: Laura Perez-Adamson, Occupational Therapist – practical strategies to cope with everyday life.

Venue: Family Resource Centre, Camden Road, London N7 0SJ

Date: Wednesday 9th November and 16th November

Time: 11.00am – 2pm.

For more information telephone: Resource Centre 020 7445 8005

Centre 404

Details: From the end of September, Centre 404 will be running a drop –in sessions for parents with school age children with special needs.

For more information telephone: Family Support Officer 020 7697 1325
