

autism london

Bi-Monthly Bulletin

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Contributors

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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 June - July issue of the Autism London Bulletin! We are back on schedule with our Bulletin production, so I hope you are receiving this within the first couple of days of the new month.

Thank you to our Supporters:

Firstly, a very big THANK YOU to all of you who have already returned your subscription renewals, and an extra big Thanks to those of you who have also supported us by making donations.

N.B. If you have not yet renewed, you should find a reminder with this Bulletin. Please note we can only continue to include paid-up Supporters on our Bulletin mailing list!

N.B. If you are sending in a cheque as payment for your subscription, or for anything else, as of April 05 please make your cheques payable to MCCH Society Ltd.

Summer Day Trip gets the Go-Ahead!

With the donations from IPCSEN, our Supporters, and one or two company donations, plus the donation of time from a new volunteer, who will be helping to organise the event, I am happy to confirm that we will be able to run the Summer Day Trip to Legoland on 24th August. As usual we will be able to offer tickets for this event at the same greatly subsidised rate as last year i.e. £8.00 for Supporters, which, I am sure you will agree is quite a bargain, and includes travel by coach and entrance into Legoland. Staff and volunteers are on hand on the day to ensure you have an enjoyable day, and some refreshments are available for the coach journey. The Supporter rate applies to the immediate family member only: if other friends or relations wish to come they may pay the non-supporter rate, but as places will be limited, priority will be given to paid-up Supporters.

Please see enclosed booking form for details, and please make sure you complete all sections of the form, then return it with your payment. You should book early to avoid disappointment(!) but in any case not later than Monday 11th July.

Volunteers Week 1st June to 7th June 2005

Its Volunteers Week this week, and I would like to take the opportunity to thank all those who have given their time in some way to help the work of Autism London over the past year. This includes those who volunteered their time to: help at last years Summer Trip, give talks at meetings, help set up support meetings, help with mail outs, be members of the Autism London Advisory Board, contribute to the Bulletins and so on. Your contributions are invaluable so THANK YOU! A special mention goes to Desmond who volunteers each week at our office in Islington, and whose willingness to help out with whatever is needed is really valued!

Also in this issue:

Please see inside for all our regular features, including a Support Services update with dates for future support meetings, Supporters Forum, Book Reviews by Louis Baworowski, and Notices and Conferences section.

With best wishes,

Gill Lea-Wilson – Service Development Officer

Support Services Update

Hello Supporters,

Once again it is time for us to share news and information with you through our regular bulletin. I have recently attended two forums held at The National Autistic Society. The first discussing Special Educational Needs Policy and the recent changes regarding Statementing in Scotland, where transport provision, and SEN Statements generally, are becoming harder and harder to obtain. The second was the Family Support Workers Forum, which brought in a guest speaker Steve Vincent to talk about The Spectrum Centre, at Axton Chase School in Kent. The school has a range of facilities, and provides ongoing education and support at secondary level for pupils with Autistic Spectrum Disorders.

At our last parent and carers meeting in Waltham Forest our guest speaker Penny Gosai came along to talk about Waltham Forest Mencap, and the services they provide. We will be having this topic again in July, and we would like those who missed the last one to attend the one in July. Until next month stay well and thank you for your continued support.

Dee King: Support Officer

Dear friends,

Tuesday 3rd May saw another well-attended ALAG support meeting at Floral Place. It was good to see many of our old (young) regulars as well as some new faces. The topic for the evening was 'Noise and Sensory issues' and most members expressed their feelings and perceptions on the effect of noise on their senses.

Some of the new people I spoke to at the end of the meeting said they were very happy to have discovered the group and they felt comfortable being with people who understand some of the issues they are experiencing. Look forward to seeing you all again on the 7th June!

Ethney Anderson: Support Officer

Dear All,

A big thank you to everyone who has made a contribution through donations the past few weeks! We are all currently working on ways to continue fundraising, and always welcome any new ideas for raising funds for the future.

Regards

Tanya Camilleri: Helpline Officer

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

| Date and Time | Venue Details | Speaker | Topic |
|---|---|--|--|
| 15 th June 6.30pm – 8.00pm | Oakleigh School Oakleigh Road North Whetstone London N20 | Support Officer from Autism London: Ethney Anderson | Open meeting for parents to come along and talk. |
| 22 nd June 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. |
| 6 th July 1.30pm – 3.00pm | The Limes William Morris Hall 6 Somers Road Walthamstow E17 6RX | Penny Gosai Family Support Officer | Waltham Forest Mencap |
| 20 th July 1.30pm – 3.00pm | The Kulubi Centre 2c Falkland Road Kentish Town London NW5 2PT | Rosemarie Mason | Parent of a child with ASD, also 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. | | | |

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Women's Asperger's Group

Dates for meetings from April - September 2005 are: -

Thursday 30th June

Thursday 28th July

No Meeting in August

Thursday 29th September

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

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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.**

Dates for meetings from April - August 2005 are: -

Tuesday 7th June

Depression/other mental health issues

Tuesday 5th July

Asperger's Syndrome in the past
(Optional 2nd topic – Sleep Problems)

Tuesday 2nd August

Holidays- experiences and issues
(Optional 2nd topic – Special Interests)

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 Gill for further information on: 020 7704 0501

Or email: info@autismlondon.org.uk

Calling all past Autism London Supporters:

Please remember to renew your membership if you have not done so already as it costs us time and money to send out 2 or 3 reminder forms and reduces the size of your Bulletin. A reminder form is enclosed with this issue.

THANK YOU!!!

Supporter's Forum

Where you share your news, ideas and creations!

A PILL TO CURE ASPERGERS SYNDROME? by John Harrison

Despite Gill Lea-Wilson's firm chair(wo)manship, at the Asperger Group we are not always good at keeping on subject. At a recent group one of the members as an aside mused that it would be nice if someone invented a pill to cure Aspergers Syndrome as they would be very keen to take it. Two or three members endorsed that view; then Gill brought us back to the subject we were supposed to be discussing and the pill question was left dangling.

I did not participate in this brief discussion, but I have previously thought about this subject. I would not want to take such a pill if it were ever invented, at least if it were permanent in its effect. If the pill were reversible, that might be different. I could try "life on the other side" and, if I did not like it, go back. If the effect were permanent, however, to take it would seem to be almost tantamount to committing suicide. Perhaps a few years ago when I was being badly bullied by a boss at work who had absolutely no comprehension of how to deal with me (or indeed neurotypical colleagues!) and I was regularly off sick, my answer might have been different, but now I have changed jobs and experience much more sympathetic management, that is no longer the case.

At another Aspergers Group, one of the members described Aspergers Syndrome as an "alternability" rather than a disability. It does have debilitating effects – I do find some social relationships quite difficult, I have not progressed in my career as I might have expected, I have difficulty coping with situations where I feel put down and then letting the issue go, etc. On the other hand Aspergers has many advantages.

I work as a town planner and, though not qualified as a lawyer, have a very good knowledge of the complicated rules and regulations of planning and tend to act as the "legal beagle" in our office, helping all colleagues including more senior ones with such issues. Aspergers tend to develop special interests and planning law has become one of mine. Furthermore, Aspergers have good memories and that helps me remember the minutiae of the legislation and though at times the law is not always logical, there is a certain logic to it and Aspergers helps me follow this logic.

Planning law is not my only special interest. Long before I was diagnosed as having Aspergers, I had become one of the country's leading authorities on vehicle registrations and I edit a newsletter on the subject. Again Aspergers helps me follow the logic of the complicated British registration system and remember what particular new combinations to look out for. I sometimes say that my interest in registrations is utterly, completely and totally useless, but if I enjoy it that is justification for it in itself. In fact, I do find I regularly help people with queries relating to registrations, e.g. classic car owners who want to find out details of previous owners of their cars, so it is sometimes a useful hobby. Incidentally, my diagnosis as having Aspergers and subsequent discussions with fellow hobbyists has made us realise that quite a few of us have Aspergers or are at least that way inclined.

Supporter's Forum

A PILL TO CURE ASPERGERS SYNDROME? by John Harrison: continued

I have a keen sense of humour and Aspergers helps me to see jokes others would miss. This is because I can appreciate both the literal meaning of things which are said and what the speaker really means. To quote an example, one day at work a colleague told me that someone had been trying to phone me for the last 100 years. I knew quite well she meant that he had been trying to phone me for no longer than a day or two, but I could also follow the literal meaning of what she said. I therefore answered, "Well clearly he was completely wasting his time for the first 45 years as I wasn't born then"! These are just a few examples of how I see Aspergers as being a very positive thing. I was diagnosed with Aspergers Syndrome comparatively late in life, aged 51. This diagnosis has on the whole been very positive for me. I can now see where I fit into society. It explains how I relate to other people. It gives me licence to be slightly eccentric without worrying – for example, if I am writing a particularly complicated sentence in a report at work I will put my hands over my ears to drown out background noise and colleagues may think this is slightly unusual behaviour but they can understand the reason why. My diagnosis has enabled me to recognise how I am and I can just enjoy being myself.

Quite often articles end with a rider such as, "The views expressed in this article are the views of the writer and not necessarily those of his employers". I perhaps should end this article with a rider that these views are my views and not necessarily those of the other Asperger Group members. In fact the brief "pill" discussion in the group suggests others' experience is not the same as mine. I have Aspergers Syndrome relatively mildly and others who it affects more severely may find Aspergers more debilitating and this no doubt accounts for their greater keenness to take a pill if one were offered.

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*

All Party Parliamentary Group on Autism : Post Election update.

After a phone call from one of our ever-watchful Supporters who was concerned about the effects of the recent general election on the All Party Parliamentary Group on Autism, I thought the time was right to give you an update.

The APPGA is a formal cross-party backbench group of MPs and Peers who share an interest in autism and Asperger syndrome. It was set up in February 2000. Its role is to campaign in Parliament for greater awareness of autism and Asperger syndrome, and to lobby the Government for improved services for people with autism and Asperger syndrome, and their carers.

APPGA has so far published two reports, “ The Impact of Autism”- June 2001, and “ The Rising Challenge”- December 2001. On Wednesday 14 May 2003, it launched its Manifesto for Autism, which sets out four general principles and eleven specific objectives to deliver better services and support for people with autism, to be achieved over ten years. It stems from extensive consultation across the autism movement, with contributions to the Manifesto coming from people with autism, parents and carers, local groups and national organisations.

Since its launch in May 2003, over 330 MPs and Peers signed up to the Manifesto for Autism.

Many of you will have helped this happen by writing to your MPs. The general election on May 5th meant that some of those MPs who signed up lost their seats. However this is in part balanced out by new MPs who pledged their support during the election campaign: according to the Autism Counts website, 281 of the new MPs are signed up to it.

All the Officers of the APPGA have retained their seats, but some members of the group have been lost. The APPGA will be holding its AGM in June, where decisions will be made about Officers’ positions, post-election; this will be followed by an inaugural meeting of the new group.

For more information on the APPGA, the Manifesto for Autism, and for a sample letter for you to use to write to your MP to ask them to sign up, check these websites:

www.autismcounts.org.uk, and www.nas.org.uk/appga, or contact APPGA via the National Autistic Society at appga@nas.org.uk, or 020 7903 3769.

Gill Lea-Wilson

Service Development Officer

Autism London Residential Service Update

Greetings from all at the Residential Service in East London. We are all doing very well and very much looking forward to the summer. Some service users had a long weekend break away back in March, which was very much needed. We are already planning a weeks break in the summer to places like the Isle of White and the Lake District.

We will be having another inspection shortly, and we are positive it will go well.

Thank you all for your continuing support.

Monica
Deputy Manager

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 autism and special needs 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.

By Louis Baworowski

Edited by Robert A. Catalano, MD, *When Autism Strikes: Families Cope with Childhood Disintegrative Disorder* (New York and London: Plenum Press, 1998) ISBN 0-306-45789-X

Both my reviews in this issue relate to the ominously named Childhood Disintegrative Disorder. In the current edition of the authoritative *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) of the American Psychiatric Association, CDD is classified as a condition in its own right. Like autism, Asperger's syndrome and Rett's syndrome, it belongs to the group known as Pervasive Developmental Disorders and is sufficiently akin to autism to make it of interest to *Bulletin* readers. For the very few families with a CDD member, this collection of parental accounts (with a foreword and preface by Professor Fred Volkmar and Dr. Robert Catalano respectively) is, of course, especially relevant. It enables them to inform possibly sceptical professionals about a known medical condition, in which seemingly wholly normal and well cared for children can lose acquired skills without discernible cause. Just *one* of the DSM-IV criteria that has to be satisfied for a diagnosis of CDD is that of: "Apparently normal development for at least the first two years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior."

It is not so much the type of behaviour that emerges which distinguishes CDD children from those with the more frequently encountered forms of late-onset or regressive "autism," as the features of the onset itself. Professor Volkmar of the Child Study Center, Yale University states that classical autism almost never develops after 3 years of age but that CDD, which has also gone by the name Heller's syndrome and Disintegrative Psychosis, usually appears between the ages of 3 and 5. CDD is a rare but, according to Professor Volkmar still underrecognised disorder, because of, "a presumption that... [it] represented 'late-onset' autism or was the result of the insidious onset of some progressive neuropsychological process. As a result, this condition is unfamiliar to clinicians...Several lines of data have supported the...recognition of CDD as a disorder apart from autism. The onset...is highly distinctive and an essential feature of the diagnosis...sometimes there is a period of nonspecific agitation as the child begins the dramatic regression that is the hallmark of this condition." (p. x)

For many years, adds Dr. Volkmar, there was "the presumption...that CDD was the overt manifestation of some *identifiable* neurological or other medical condition...this has turned out not to be the case." In the main "exhaustive medical evaluations do not reveal a specific medical 'cause' although nonspecific abnormalities consistent with some as yet undiscovered neurobiological process or processes of seizures or abnormal brain wave activity are sometimes observed" (ps. x-xi, Dr. Volkmar's italics). There is no treatment other than that used for autism generally, but long-term outcome tends to be worse than in autism.

Of the eight personal accounts in this book, the one I found most poignant, is that provided in the opening chapter, written by the father of a Swedish boy called Per. The following is an extract from this chapter:-

At 4 years 3 months, Per's regression occurred. He started running back and forth and could not be calmed. He put everything in his mouth including nonfood items such as grass, gravel, stones, flowers, and once even fly agaric...Per's talking decreased and he

seemed depressed, although hyperactive. We lost contact with him...I felt he was looking through me. When I asked him something, he answered with the same question. Before his regression, Per could lay for hours on the kitchen floor drawing in his book or cutting papers. Now he could not even hold a pencil or scissors properly. When he tried to cut and found that he could not, he was so upset that he cried. In 2 weeks, Per's personality completely changed. It was so fast that the doctor suspected bleeding or a tumor in his brain. Per was immediately tested with a CT scan. Later he had an EEG and other tests. All results were normal...[Between the ages of 5 and 6] a strange episode occurred...Per had been saying only one or two words every day. He did not want to have any physical contact with us such as sitting on our laps. Suddenly one morning Per climbed up on my lap, looked me straight in the eyes, and pointed with his finger to my head. Per said, 'There's an old man sitting in there.' I was so surprised that I did not know what to do. (p. 4)

Craig B. Schulze, *When Snow Turns to Rain: One Family's Struggle to Solve the Riddle of Autism* (Rockville, Maryland, USA: Woodbine House, 1993) ISBN 0-933149-63-8

I first read this book several years ago, but was reminded of it just recently, because Craig Schulze is also one of the contributors to *When Autism Strikes*. At the time of the writing of his own book, he thought of his son, Jordan as having "delayed onset autism" (p. 157). However, he has since learned about CDD, and now sees this as the condition that properly reflects what happened to his child. He tells us: "I am unable to conceive of his [Jordan's] life as having anything less than two parts...at one point...Jordan learned, displayed affection, enjoyed social interaction, and had a positive disposition. By twenty months of age all of these attributes were less in evidence, and by three and a half they were virtually gone...his life derives some of its 'before and after' quality from the fact that there exists a specific moment in time when we [the parents] go from seeing Jordan as a peculiar but normal child to realizing that his peculiarities threaten his very humanity...It is as if he had died from one existence and returned in another form." (p. 35)

When Snow Turns to Rain is an absorbing account of the first eight years of Jordan's life and his parents' attempts to help him using series of approaches. They try (among other things) Lovaas-inspired behaviour modification, the drugs fenfluramine and naltrexone, as well as Option and Higashi. Though Jordan does make progress in some areas, he remains very disabled. However, one person's reactions cannot be taken as a measure of the value of particular interventions *per se* given: i) The variability in individual response; ii) That outcomes, and in a sense the very nature of an approach, can differ according to the competence and persistence with which it is implemented; and iii) That the personality of the therapist(s) or educator(s) and their relationships with the disabled person can be of critical significance.

The book contains some good writing and striking observations, although there are times when we hear as much about the father's near-despair as about Jordan himself. The family's visit to the Option Institute is vividly described. Elsewhere in the narrative, Craig Schulze makes a point about the differences that can exist between "autistic" children, by skilfully contrasting his son's behaviour with that of another autistic child known to him called Darren, while also drawing our attention to the way in which both Darren and Jordan stand out in a group of non-autistic special needs children (ps. 62-4). Autism is stated to be "the inverse of the Hindu sense of God – not one thing that men call by many names, but many things for which there is but one label" (p. 63). And, in a perhaps short jump from theology to cosmology, we are further informed that autism in the form manifested by Jordan is, "the antipode of what...Thomas Berry has suggested are the fundamental processes of the universe: differentiation, complexity and connectedness. Against this mainstream Jordan clings to his sameness, simplicity and isolation." (p. 184)

Notices & Conferences

Music for Autism

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

Venue: The Undercroft
St Nicholas Church
Upper High Street
Sevenoaks, Kent

When: Saturday 18th June 2005

Time: 11.30am - 2.00pm

For further information call Emma on: 020 7374 8485

Stand Up, Speak Up!

Enfield Parents & Children service is now 10 years old! As part of their anniversary year they would like to present the following conference – Stand Up, Speak Up in recognition of EPC achievements over the last 10 years and a debate on the challenges ahead. Mixing entertainment with speeches, theatre and art.

Venue: The ArtsZone
54-56 Market Square
Upper Floor
Edmonton Shopping Centre
London N9 0TZ

Day: Thursday 9th June 2005

Time: 9.30m – 2.30pm

For further information contact EPC on: 020 8373 6346 or email: de.pa@enfieldparents.org.uk

Would you like to contribute to research into parents' views of autism?

This study gives parents of children with autism the opportunity to 'have their say' about autism, and make a valuable contribution to research. The study uses an approach called Q-methodology, which is similar to a questionnaire style.

Details: The study would take approximately 30 minutes to complete and your participation would be greatly appreciated. The only criteria for being eligible to take part is being a parent of a child of any age with autism or Asperger's syndrome.

If you would like to participate in the study, you can access a web version at:

<http://psychology.dur.ac.uk/researchprojects/awm/>

Contact: Alternatively, if you don't have access to the Internet or would prefer complete a paper version, please contact Amy Wood-Mitchell by email: a.j.wood-mitchell@durham.ac.uk or by telephone: 07941 128286

Key Connection Family Fun Day

Children/young people (0-19yrs) with disability/SEN and their families/friends are invited to Britannia's key Connection family day.

Date: Sunday 5th June 2005

Venue: Britannia Leisure Center
40 Hyde Road
London N1

Time: 10am – 4pm

For more information telephone: Kunbi Jones 020 7729 4485

Notices & Conferences

A new way of working for special needs children?

Date: Wednesday 29th June 2005

Venue: Family Resource Centre
Northern Health Centre
580 Holloway Road
London N7 6LB

Details: Information day for parents of children with special needs in Islington, introduction by Paul Curran Director of Children's Services London Borough of Islington.

Time: 9.30am – 3.00pm

Contact: Caroline or Wendy for further information on: 020 7445 8005

Transition Post-16

Organiser: The National Autistic Society

Location: Chichester Golf Club
Hunston Village
Chichester
West Sussex PO20 6AX

Date: Saturday 9th July 2005

Time: 10.30am – 12.30pm

Details: The National Autistic Society is pleased to invite you to attend a seminar on Transition aimed primarily at parents of children with an autistic spectrum disorder.

Costs: Parents/carers £5, for parent couples £7.50 & professionals £25

Contact: For further details telephone: Judy Lynch 020 7903 3526 or email judy.lynch@nas.org.uk

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 10th July then every other Sunday 11am – 1pm

Also- adult 2-day course: including building an outside dwelling.

To start early July as apart of the outdoor living summer course.

Contact: For further information on both these groups please contact Ruth Solomon tel: 020 8806 1129

Walk Far for NAAR (UK)

The National Alliance for Autism Research (NAAR) would like you to join them in a walkathon. All money raised will go towards research.

Venue: Windsor Great Park

When: Sunday 10th July 2005

For further information please call Lynn Hart: 0149 141 2311

AUTSCAPE 2005

Details: Autscape is a conference organised and run by and for autistic people to be held for the first time this summer. The first event will be held in a peaceful rural retreat centre surrounded by extensive and picturesque grounds.

Day: Tuesday to Friday, July 26th – 29th 2005. Deadline for registration is 17th June.

Contact: For further information email: autscape@paradox.freemove.co.uk

