

Umbrella Autism
eNews March 2004

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Next Umbrella Open meeting:
Improving the diagnosis and care experience

The meeting will be on Monday 29 March at Hilltop Carers Centre, Primrose Street

(off Victoria Road) at 7.30pm. Allow time for parking in nearby streets. Small car park at the end of Green Road, with stairs up to the centre.

This meeting is on local progress towards improving the experience of diagnosis and care for families with children or young people on the autistic spectrum. Professionals have been looking closely at what could help --- like having a single key worker as a point of contact instead of lots of different workers each asking the same questions! This meeting will update us on what is being proposed, what progress is being made, and will give a chance to express our views about what we need. Professionals involved locally in the planning for future autism services for children and families are especially welcome: this is a chance to consult families. Don't miss it!!

The Cambridge Science Festival launch lecture

is on autism!

The opening Lecture will be given by Professor Simon Baron-Cohen, Director of the Autism Research Centre. It is entitled *The Essential Difference: men, women and the extreme male brain* on Friday 12 March 7.30pm - 8.30pm Babbage Lecture Theatre, New Museums Site, Pembroke Street. The official summary is:

"A new theory suggests that the two sexes differ in the mind, in two fundamental ways: females, on average, tend to be slightly more focused on empathy, and males, on average, tend to be slightly more focused on systems. Of course, some individuals don't fit these trends, and science is exploring why a given person is typical or atypical of their sex. The causes of these typical sex differences appear to involve both upbringing and biology. But what happens when, for biological reasons, the typical male profile becomes exaggerated? Here, it is suggested, we meet autism: individuals who have degrees of difficulty empathising, but who can systemise normally or even to a talented degree."

The Science Festival website, www.cambridgescience.org, is the place to go to find out about all the events and activities of the Science Festival week, many of which will appeal to children as well as adults.

Discussion on the Extreme Brain and the research on which this theory about autism is based

AWiSE (UK Association for Women in Science and Engineering, (Cambridge Branch)(cambridge.awise.org) and CU Umbrella Autism Volunteers Project (www.umbrella-autism.org.uk --- updated version to be launched soon) present Juliet Mitchell (Professor of Psychoanalysis and Gender Studies) in discussion with Simon Baron-Cohen (Professor of Developmental Psychopathology) and author of *The Essential Difference: Men, Women and the Extreme Male Brain*. Monday, 19th April, 2004 (5pm - 6.30 pm,) Keynes' Hall, King's College. All welcome. Refreshments available.

Best to read the book first and come armed with your questions! It's now out in paperback from www.amazon.co.uk and soon in local shops. Discussion could (and should) get technical. An underlying issue is likely to be tensions between different views of "science", "evidence", "research" and how these are (or whether they should be?) reconciled with being PC (Politically Correct).

Umbrella Update

The last Open Meeting with Brian Gale from the LEA was well attended and well received by those attending. It was a consultation evening for parents of children with autistic conditions to hear about, comment on and make suggestions concerning the education service plans. The new Educational Psychologist who will take the lead on Autism, Nicola Gardiner was introduced. We hope to have notes for those who could not attend available in time for our next Open Meeting. Brian has offered to join us at Open Meetings in future and we are delighted with the offer. Welcome, Brian!

The A Team, our youth club for children aged 9-12 with Asperger's Syndrome, continues to be a great success thanks to our dedicated team of Cambridge University Umbrella volunteers under the direction of Alison Spark, who also coordinates the volunteers across a range of activities (read more about the CU Umbrella volunteers below). The group is full now and until the older members move on next school year.

A Girls Group for girls with AS or similar aged 13-18 is about to start. It's a chill out group, staffed with its own staff and aims at being a stress-free group for people who may have interests and preferences in common. No therapy and no social skills training, just an unpressured club. This is likely to be a very popular group and there are (initially, at least) only a total of six spaces in the group. If you think you know someone who might be interested in joining or checking it out, contact Karen on 01223-413032 immediately to register interest. (More details below under New Girls Group).

The Aspirations Education Programme is for teens and adults with Asperger's Syndrome and similar social communication challenges, across three age groups. There are only a few vacancies at the moment, but there is a waiting list. The possibility of adding a one-day-a-week programme for GCSE age pupils is being investigated by Turning the Red Lights Green, the charity that manages the programme with input from Umbrella. For information ring Susan Owen on 01638 508430.

The Support Group for parents of older teens and adults continues to be a valued and upbeat monthly get-together. For information ring Phyl Lewery 01223-709827.

A group for parents of school-age children is being considered and may start this month, probably to run on the same night and same venue (but in an adjacent room) as the Support Group for parents of older teen and adults. If you are interested contact

umbrella@hosking.com or contact Karen (01223-413032) or Robin (01223-368203, and leave a message).

The Social Group for adults with Asperger Syndrome meets in Cambridge on Tuesday each month from 7-9 pm. It's a very small unpressured, "chill-out" group. No therapy or social skills training! There may be a vacancy or two in the near future. Contact rww20@cam.ac.uk (or leave a message on 01223-368203, daytimes).

Conference for parents of children with disability

'Working Together' is a Parent Carers Conference. A celebration of parents working alongside

professionals to plan services for children with disabilities in Cambridgeshire. Monday 26 April 2004 10.00am - 2.30pm (Registration from 09.15am) Burgess Hall, St Ivo Leisure Centre, Westwood Road, St Ives. PE27 6WU. Speakers include: Parent representatives from across the county: Cambridge Huntingdonshire; Fenland; Kathy Pearson - Parent & Carers Council Leicester Chris Bush - Leicester Social Services Representatives from Cambridgeshire Statutory Services Health Education Social Services ConneXions. Workshops in the afternoon: Working with professionals Who Needs to Know? Confidentiality - information sharing & conflicts of interest. Parent & Carers Councils Starting a Parent's Support Group Display Stands with representatives from a variety of organisations. Early booking is recommended please, as places will be allocated on a first come basis, with priority to Parent Carers. There is no charge for this event. Phone, email or write for a Booking Form: Penny Simmonds. 84 Forest Road, Onehouse, Stowmarket Suffolk, IP14 3HJ. Alternatively please book by emailing form to: penny.simmonds@btinternet.com (For further detail) tel. Penny on 01449 672611).

New book just out

The boy who loved windows, by Patricia Stacey, was published last month by Wiley, 9.99, ISBN 0-470-86979-8. You can order it from www.amazon.co.uk if you search for the author. (They've incorrectly given the title of the book, but it's clear from the photo of the cover we've got the right title!) Those with access to the Jan/Feb issue of the magazine of the mental health charity Young Minds will find an article describing and praising the book. According to the article, the book charts the path taken by a couple find a way of connecting with their autistic son. Their experience of Dr Stanley Greenspan's approach to infants and children with sensory integration challenges is captivating. Some readers may want to have a look at Dr Stanley Greenspan's excellent book, The Child with Special Needs, which outlines his very interesting approach. (A copy of this excellent book and interesting book was seen on the shelves at Borders in Cambridge recently.)

Circles of Support Event in Fenland

Introducing Circles of Support (an event supported by the Cambs Parent Partnership). Tuesday 23rd March 2004 at the Oliver Cromwell Hotel in March. Arrival from 9:15am. Event runs from 9:45am-2:30 with lunch provided. Free to parents. (10 for professionals) Will look at how to set up circles of support for children or young people to enable inclusion and introduce "person centred planning". Facilitated by Nadine Jay from the Circles Network CREDO east project with disabled teenagers who have high levels of support need. To book contact Robert Wilson of the Cambs Parent Partnership on 01223-717400 or email Robert.Wilson@cambridgeshire.gov.uk.

Awareness raising event about Young Carers

Did you know that siblings and children of people affected by ASDs are officially carers? (Parents and others who look after people with a disability are carers as well, of course, but the needs of siblings and children often get overlooked) Did you know that Centre 33 has a Young Carers Project in Cambridge and South Cambs? Autism professionals, carers and parents are all welcome to attend an Awareness Raising Sessions about young carers on either Monday 22nd March 10am-12am or Friday 26th March 2pm-4pm. Both sessions will take place at the Hilltop Carers Centre, Primrose Street, in Cambridge. To confirm your place at either of the sessions contact Harry Welburn on 01954-782007 or email: mashitupharry@yahoo.co.uk.

For more information about the Centre 33 Young Carers Project email cambyoungcarers@hotmail.com or ring on 01223 712072 and ask for Alli Bode or Christine Kenny.

Jobs in the Autism Community

Part-time carers to join a team. A, a 34-year-old man with severe learning disabilities and the difficulties typical of someone with autism needs regular carers during the day to support him in activities. Hours flexible. Training provided. Minimum shift is 4 hours, but shift could be shorter, especially if it's a task like going swimming or an outing. 6.00/hr. If interested, please contact: Cambridge (01223) - 242231 (preferably before 11 am and after 4 pm).

Live-in Carer to work alternate weeks as part of a team supporting a demanding but likable young man (age 22) with ASD in rural North Norfolk. Pay is 525 per alternate week. Gradual induction and training. Village setting --- must drive. Be prepared for an active week, getting involved in a range of activities --- cooking, swimming, music

therapy, cycle trips, etc. Applications to Independent Living Norfolk (01603 785200) (ref. SP0301TR) or by email to krose@cambridge.org

We sometimes get calls from people looking to help with ABA or other intensive programmes and we like to put people in touch. If you are looking for this kind of work or for experienced workers, email rww20@cam.ac.uk or leave a message on the answering machine on 01223-368203 with the information.

Looking for a job or career in the autism field?

Try the www.autismjobs.org website which specialises in linking employers and potential workers in this field. The site is linked to www.autismconnect.com. (This website, along with www.nas.org.uk, are great Internet starting places for parents, people with ASDs and workers wanting to find out more about any kind of autism and what's going on in the autism community beyond Cambridge.

Event for Special Needs Workers (not a parents event)

Workers need peer support, too, just as parents and other carers do! This term's Disability Lunch (for workers) is on Wednesday 10th March 2004. The topic will be: Resources for children with autism.. The speakers are: Anna Bainbridge from Sunshine Club and Robin Wallach from Umbrella Autism. The venue is Barnwell Baptist Church, Howard Road, Cambridge from 12.30 - 14.00. Please encourage your colleagues to attend. Bring your packed lunch. Drinks will be provided at a small cost.

Cambridgeshire Neurological Alliance Conference

The Neurological Alliance is a collaborative forum of a wide range of neurological charities (including the National Autistic Society) with the main objective of improving the quality of life for people in the UK affected by a neurological condition, including their carers. Parents and workers are equally welcome. This local conference is about the National Service Framework for services for people with long term conditions, especially neurological conditions. Weds 10 March 2004 10-4pm. at the Papworth Trust Rehab Village in Papworth. Cost 17 includes optional 7 cost of lunch. To book contact Cambridgeshire Neurological Alliance: Diane Newman Tel: 01733 552872 email: www.cambsneuroalliance@hotmail.com

It's Umbrella Family Party time!

The CU Umbrella Volunteers are helping parents plan this year's Family Party and will help to facilitate the event. We're hoping to have a clown, too, and a bouncy castle. Bring and share food. All welcome. Sunday, 9th May, 3-5pm at the Ida Darwin

in Fulbourn. For more details, ring Karen on 01223-413032 or email umbrella@hosking.com.

New: The Umbrella Girls' Group for 13-18s

Following the success of Umbrella Autism's Social Group for adults with AS and the A Team club for children aged 9-12 with Aspergers Syndrome, we are starting another "chill-out" group. This one is especially for girls with a diagnosis of Aspergers Syndrome or related social communication difficulties. The group is aimed mainly at girls in mainstream school. The group (max about 6 girls) has been set up in response to requests by girls themselves for a group which isn't based on the usual male stereotypes of Aspergers. Staffed by a team of our own Cambridge University Volunteers under the supervision of our own paid worker. This small, friendly group will meet in Cambridge every other week term-times only on Mondays in the early evening, times to be confirmed, but probably 5.30-7pm. If you know someone who might be interested, make contact asap as these groups fill quickly. For more information, contact the chair of the Umbrella Youth Clubs Committee, Karen on 01223-413032 or email umbrella@hosking.com.

Good reads: on autism and girls

As Umbrella is about to launch a youth group especially for girls with Aspergers Syndrome, this issues books focus on how autism is expressed in girls and women. National Autistic Society descriptions here include National Autistic Society codes so you can order directly from the NAS (www.nas.org.uk)

Asparagus Dreams, by Jessica Peers. At the age of 12 Jessica was sent to a unit for people with autism. This book is the true story of her difficulties and makes for a very funny and illuminating read. Includes some strong language. Published by Jessica Kingsley Publishers, 2003, 218pp, pbk, illustrated ISBN 1 84310 164 5 Code NAS 496 Price 12.95

Pretending to be normal: living with Asperger syndrome is by Liane Holliday Willey. Chronicling her life from her earliest memories through to her life as a university lecturer, writer, wife and mother, Liane shares the daily struggles and challenges that face many of those who have Asperger syndrome. Liane also offers some very helpful appendices which provide a range of helpful coping strategies and guidance for people moving through adolescence and university life. Published by Jessica Kingsley Publishers, 1999, 144pp, pbk ISBN 1 853027 49 9 Code NAS 115 Price 12.95

A real person: life on the outside, by Gunilla Gerland. This is the moving story of a woman struggling to grow up in a world she has difficulty making sense of. Her inability to cope with the stress created from a dysfunctional family and personal life eventually led her into drug addiction. Remarkably, Gunilla fought back, drawing on her strength as a survivor and her need to be a real person. Eventually in her mid-

twenties she was diagnosed as having high functioning autism, a label that at first distressed her but later helped her cope in today's society. Published by Souvenir Press, 2003, 254pp, pbk ISBN 0 285633 66 26 Code NAS 472 Price 12.99

Nobody Nowhere is by Donna Williams. Donna's book portrays a moving account of her struggle to come to terms with her life with autism and to survive the suffering of an unsympathetic and ignorant world. Published by Jessica Kingsley Publishers, 1992 (reprinted 1998), 200pp, pbk ISBN 1 853027 18 9 Code NAS 114 Price 12.95 (Some people say her sequel, Somebody Somewhere, is helpful to people wanting to understand Asperger's. Look for this sequel in bookshops.)

More to read on the Net about the autistic spectrum and its expression in girls and women:

Asperger Syndrome and Girls: The Pattern of Abilities and Development of Girls with Asperger's Syndrome by Dr. Tony Attwood (September 1999)

www.fortunecity.com/meltingpot/barclay/64/id26.htm

Girls with Social Deficits and Learning Problems:

Autism, Atypical Asperger Syndrome or a Variant of These Conditions

by Svenny Kopp and Christopher Gillberg (1992)

www.asperger.org/asperger/related_kopp.htm

Aspergers Syndrome in Women: a different set of challenges? By Catherine Faherty.

www.autismtoday.com/articles/Aspergers_in_Women.htm

Why do more boys than girls develop autism? An NAS information sheet available at

www.nas.org.uk/nas/jsp/polopoly.jsp?d=108&a=3370

*****STOP PRESS!!! Aspergrrrls! ***** (Great name!) has been being constructed as this eNews has been being prepared. This is a website for girls with Aspergers --- and for people wanting to support them:

www.members.rogers.com/bethkingston/whoweare.htm (Any problems reaching it, go to Google.com and type in "Aspergrrrls" and you will be swiftly transported to a link you can simply click on.)

These are some starting places. If you come across good links on the net, do share them by emailing details to the Umbrella newsletter at rww20@cam.ac.uk. (Autism professionals/researchers: have you got a good reading list on autism in girls/women you can share with Umbrella? If so, do send it along.)

The CU Umbrella Volunteers Project

This scheme, funded by the Active Communities Fund through the University, brings together members of Cambridge University who have a strong interest in autistic conditions. There is a part-time paid Volunteer Coordinator, who volunteers are carefully matched to Umbrella activity needs and then supervises the volunteers, and

ensures workshop and seminar sessions meet the interests and needs of the volunteers. Training and other seminars support and extend their learning about autism and compare it to what they have learned in their studies about autism. So far this academic year we have 16 committed CU volunteers in the scheme. A very big thank you to each of them, and to Alison Spark our able coordinator and group facilitator. 20 children and adults are benefiting on a regular basis, with a further 6 to be added when the Girls Group is established. In addition, the volunteers are helping organise and facilitate our annual family party. Without the CU volunteers we would not be able to our youth clubs. They make them possible. Members of CU (staff or students) with a strong interest in autism and volunteering to support activities in the autism community should contact alison@dickens.emhub.com

Contributions of the volunteers include these. The A Team club for children ages 9-12 with Aspergers is staffed by a team of CU Umbrella Volunteers, under the supervision of a paid organiser. The new Girls Club is for girls ages 13-18 with Aspergers or similar social communication conditions will be staffed by another team of CU volunteers, also under the supervision of a paid organiser. One volunteer gives 1:1 support to an autistic 17 year old helping him learn general day-to-day living skills. Befriending is being provided to one sibling of a child with Autism and one child with Aspergers is being enabled to attend Cubs with a CU 1:1 volunteer supporter. Finally, another volunteer supports the adult AS social group, joining the other regular facilitators and bringing a new face and interests to the group.

Snippets

New Sims. A new version of the popular interactive game is to be released later this year. It is described on www.TheSims2.com as follows:

"The Sims2 is the first entirely-new generation of The Sims, the ground-breaking game that allowed players to create and control people. The Sims 2 challenges you to direct the journey of your Sims' lives as they grow from infancy through childhood, teenage life and adulthood. Starting with a personality that you give them (or that they inherit from their parents), your Sims will develop in unique ways based on your choices and influence. As they progress through life, your Sims will collect memories which shape who they are, what options they have and how they behave. These experiences can have a short or long-term effect on relationships between family members and friends. Experiences between Sims when they are children can affect their relationships as teens and adults. Your Sims can have casual friendships or make life-long enemies."

From book to film! The Curious Incident of the Dog in the Night-time by Mark Hadden, the award winning fiction book about a boy with Asperger's, is described in some detail on www.powells.com/review/2003_07_05.html. They report that "already film rights have been bought by Hey Day, the makers of the Harry Potter movies, together with Brad Grey (The Sopranos) and Brad Pitt." The book was described and recommended in the last Umbrella eNews. Conveys an Asperger perspective really

well, and also conveys really well the contrast between that and the perspective of meaning-well parents doing the best they can to manage juggling their lives and needs with supporting their son.

Looking for visual learning and organisation aids?

Do you use pictures as autism communication aids? For a CD ROM with clear photo pictures of many objects and actions with or without labels, try website www.aba-materials.com

Kidspiration (pre-school/primary) and Inspiration (Secondary/college/and beyond) are award-winning concept-mapping programmes on CD-ROM. It's great for visual learners wanting to organise ideas and tackle text in manageable steps. Use it to plan family holidays to include everyones preferences or plan a busy day. Useful for mapping a special interest. Have a look at the 30 day trial at www.inspiration.com Available by telephone or mail order from a supplier based in Cambridge, Iansyst. Their catalogue can be found at www.dyslexic.com.

Concept-Mapping organisation aids for visual adults (spectrumish or not!) in education or business or at home can be very useful. The best is Mindmanager for planning your day, organising thinking, problem solving and writing your book (or anything else). Not for MAC. Mobile version is available for your Palm or other PDA. Also available through Iansyst at www.dyslexic.com

Parent to parent telephone support (P2P)
volunteers being recruited

We're looking to have a new recruitment drive and training sessions in the summer term for people who are interested in becoming volunteers in our parent to parent telephone support scheme. We get support for this from the National Autistic Society but we have a local team and organiser. For more information, or to register your interest, contact Kathy Pascuzzi on 01223-247702 or email her at kathrynp35@hotmail.com. Past volunteers have found it very rewarding. There's nothing quite like giving others the support you wish you'd had!

Umbrella Dates for your diary

All these meetings (except for the Family Party!) take place at Hilltop Carers Centre, Primrose Street (off Victoria Road), Cambridge at 7.30pm (allow time for parking in nearby streets. There is a small car park at the end of Green Road with stairs up to the centre.)

March

Monday 29th Open Meeting: Improving the experience of diagnosis and care for families and children with autistic conditions

Tues 30 March: Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

April

Tuesday 27th: Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

May

Sunday 9th Family Party (bring and share) 3-5pm ****at Ida Darwin Fulbourn NOT Hilltop!****

Monday 17th Open meeting: topic to be announced

Tuesday 25th Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

June

Tuesday 15th June Open meeting: topic to be announced

Tuesday 29 Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

July

Tuesday 27th Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

August

Tuesday 31st Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

September

Wednesday 15: Open Meeting

Tuesday 28 Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

October

Tuesday 26th Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

November

Monday 15th: Open Meeting

Tuesday 30th Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

December

Tuesday 14th Support group for parents of older teens and adults (For more details ring Phyl Lewery on 01223-708827)

For more information about Umbrella Autism email umbrella@hosking.com with your mailing details and we'll send information or phone Jacqui on 01954-210075 or Sharon on 01954-202586

Send your news, suggestions and comments for the newsletter to rww20@cam.ac.uk

This is a one-off BUMPER 8 PAGE EDITION! Enjoy ... next time, we're back to 4 A4 pages. (Phew!)