Europe's Children Our Concern asbl

supporting children and young people with learning difficulties

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"Together we can make a difference"

ECOC News No. 66 – February 2008

If you have news that you would like us to pass on, or if you would like us to publicise an event or mention a resource that you have found useful, please send us the details.

ECOC News

Update on AD/HD and coexisting conditions: What works

Dianne Zaccheo, MSW FTC, will be in Brussels this month. She is an expert on Attention Deficit Hyperactivity Disorder (AD/HD) and comorbidities and founder of The Coaching Centre, London, where she trains specialised ADHD/Dyslexia coaches.

On **Wednesday 27 February** she will tell us "what works". Come along to the European School, Bld du Triomphe 135, 1050 Bruxelles (near the VUB) at 19.00 and benefit from her experience. There will be interpretation from English into French. Information on the location is at http://www.ee3.org/index.php?id=74

More information from www.ecoc.be

New website

ECOC has a new website! Take a look and let us know what you think. www.ecoc.be
In fact, in future we will be posting this newsletter on the web rather than sending it out so do make regular visits.

News

Children with learning disabilities no longer left out of UK schools' "Olympics"

The UK Equality and Human Rights Commission has told the organisers of the UK School Games that exclusion of children with learning disabilities is discriminatory and unlawful.

This is part of a drive to overturn a Paralympics rule barring athletes who have learning disabilities. The rule was brought in after cheating by the Spanish learning disability basketball team which was infiltrated by adults who were not disabled.

Established in 2006, the UK School Games are a sort of Olympics for under-16s which cultivate youngsters hoping to compete in the adult Olympics and Paralympics in London in 2012. Events in athletics, swimming and table tennis are laid on specifically for children with physical disabilities but until now there has been nothing arranged for those with learning

disabilities. Now the Youth Sports Trust has agreed to lay on special events for children with learning disabilities.

MIT creates web site for high schools

Massachusetts Institute of Technology (MIT) now has a web site that offers free video, audio, and print lectures and course material from the university's classes. These resources target students from kindergarten through to Grade 12. Known as *Highlights for High School*, the online site is an extension of MIT's OpenCourseWare initiative, a project launched in 2001 with the goal of providing free public access to all the university's courses and curricula via the Internet.

While many universities have set up free, online video, audio, and print course materials in recent years, the MIT site (http://ocw.mit.edu/OcwWeb/hs/home/home/index.htm) is unusual both in terms of the volume of information available and its specific organization.

A teacher who has used the site explains that the video lectures allow students who are struggling with a concept, or with the language, to pause, rewind, and replay sections they do not understand the first time, without embarrassment.

The OpenCourseWare site (http://ocw.mit.edu/OcwWeb/web/courses/courses/index.htm) now houses material from 1,800 courses, in subjects such as architecture, physical education, history, literature, and political science, as well as maths and science.

Make chatter matter

The UK Dyspraxia Foundation is supporting Make Chatter Matter. This is a campaign to ensure that children's communication development from birth to five is a priority. Evidence is accumulating in the UK, particularly in disadvantaged areas, that nearly 50 per cent of children start primary school without the typical communication skills they need.

More information: www.ican.org.uk/makechattermatter

Age influences response to ADD medication

Psychostimulants, medications that relieve symptoms of Attention Deficit Disorder (ADD) in young children and adolescents, may also cause euphoria and even abuse among adults. Temple University scientists may have a biochemical explanation for this. They have identified a potential molecular mechanism, the neurotrophin system comprised of brain-derived neurotrophic factor (BDNF) and its receptor TrkB, as the cause. Their findings appear in the current issue of the *Journal of Neuroscience*.

"Our findings suggest that the rapidly developing young brain is able to adapt and protect itself against the rewarding effects of stimulants due to the input of the TrkB system," said Dr Ellen Unterwald, lead investigator and professor of pharmacology at Temple University's School of Medicine and Center for Substance Abuse Research.

Most preclinical studies have found that susceptibility to the addictive properties of stimulants is age-dependent. However, this is the first study to link the TrkB neurotrophin system to those age-specific responses. The hope is that BDNF/TrkB might be used as a target for the development of new treatments for childhood neuropsychiatric disorders or addiction.

More information : Temple University

Hyperactivity caused by lack of sleep

Hyperactivity and lack of concentration have been found to be caused by obstructive sleep apnea. This is a sleep disorder associated with middle age but not uncommon in young children, where it can lead to behaviour easily mistaken for hyperactivity — even though it is actually caused by fatigue.

Obstructive sleep apnea affects two per cent of children and is more common in obese youth. Still, experts say, it is often overlooked by doctors and they fear that some children are being inappropriately diagnosed with attention deficit hyperactivity disorder (ADHD) and medicated, while the underlying sleep problem goes untreated.

“Lots of studies suggest that kids with sleep apnea are more likely to be hyperactive, impulsive and inattentive," says Dr Judith Owens, associate professor of pediatrics at Brown University Medical School, and co-author of *Take Charge of Your Child's Sleep*.

At the same time, the more experts learn about sleep apnea, the more concerned they become. Left untreated, sleep apnea may affect parts of the brain involved in learning, taking a toll on cognitive function and academic performance.

“Sleep apnea is not a trivial disorder,” says Dr. David Gozal, director of the Pediatric Sleep Medicine Center at the University of Louisville School of Medicine in Kentucky, who is one of the leading experts on sleep apnea in children. “We’re very concerned, because we’re not just talking about the immediate implications for quality of life. If not recognized early enough, especially in vulnerable children, sleep apnea may accelerate long-term disease processes, leading to advanced disease by the time they’re in adulthood.”

The recommended treatment in most cases is surgery to remove both the tonsils and the adenoids. If that doesn’t solve the problem, children can learn to sleep with a kind of special nasal mask, called Continuous Positive Airway Pressure (CPAP), that many adults with apnea use. But first a child must have an overnight sleep study. A sleep study is recommended to rule out obstructive sleep apnea if a child is being evaluated for ADHD and has other risk factors for sleep apnea.

More information: http://bms.brown.edu/

Genetic link found to some forms of autism

Scientists have found a new genetic link to a form of autism that appears to affect about one per cent of people with the disorder.

A study published in the *New England Journal of Medicine* by researchers with the Boston-based Autism Consortium identified 25 genes that were either missing or duplicated in 10 children who were diagnosed with autism or a similar developmental disorder.

Experts must now establish which of the genes contribute most to autism. Understanding that could help researchers develop new therapies for the condition or make it possible to develop a diagnostic test for this rare form of autism, researchers said.

This report follows a similar one last month from the University of Chicago Medical Center.

More information: http://www.autismconsortium.org/

Autism linked to maternal antibodies

New research from the University of California Davis M.I.N.D. Institute and Center for Children's Environmental Health has found that antibodies in the blood of mothers of children with autism bind to foetal brain cells, potentially interrupting healthy brain development. The study authors have also found that the reaction was most common in mothers of children with the regressive form of autism, which occurs when a period of typical development is followed by loss of social and/or language skills. The findings raise the possibility that the transfer of maternal antibodies during pregnancy is a risk factor for autism and, at some point, that a prenatal test and treatment could prevent the disorder for some children.

“While a growing body of research is dedicated to finding distinctions in the immune systems of children with autism, this is one of the first studies to identify immunological factors in mothers that could be linked to autism in the very earliest stages of life,” said Judy Van de Water, senior author of the study and professor of rheumatology, allergy and clinical immunology. “Our results should lead to more research on the prenatal environment and the onset of autism.”

"Our outcome leads autism science in many new and exciting directions," said Daniel Braunschweig, pre-doctoral fellow of immunology in the Van de Water lab, lead author of the current study and recent recipient of an Autism Speaks mentor fellowship to further pursue this research. "We now know we should be looking for the clues to the onset and pathology of autism much earlier than was initially assumed. Future studies should consider the immune system interactions between mother and child as a focal point in creating greater understanding of, and eventually finding effective preventions for, this complex neurodevelopmental disorder."

The study, "Maternally Derived Antibodies Specific for Fetal Brain Proteins," is to be published in the March 2008 issue of *Neurotoxicology*. It was funded by the National Institutes of Environmental Health Sciences, the U.S. Environmental Protection Agency and the M.I.N.D. Institute.

More information: University of California - Davis - Health System.

Brain protein involved in features of those with autism

The lack of a particular brain protein may explain the phenomenon of “autistic savants” who learn some tasks better than average but also forget faster, according to researchers at Massachusetts Institute of Technology (MIT).

Mice genetically engineered to lack a key protein used for building synapses (the junctions through which brain cells communicate) actually learned a spatial memory task faster and better than normal mice, according to findings in the *Journal of Neuroscience*. But when tested weeks later, the altered mice could not remember what they had learned as well as normal mice, and they had trouble remembering contexts that should have provoked fear.

"These opposite effects on different types of learning are reminiscent of the mixed features of autistic patients, who may be disabled in some cognitive areas but show enhanced abilities in others," study co-author Albert Y. Hung, a staff neurologist at Massachusetts General Hospital, said in a prepared statement. "The superior learning ability of these mutant mice in a specific realm is reminiscent of human autistic savants."

The absence of this important synaptic scaffold protein, called Shank1, may "trap" the mice's synapses into a state in which the synapses are ready to respond to input but not maintain it in long-term memory, he said.

In humans, mutations in the closely related protein Shank3 have been linked to the autism spectrum of disorders (ASD) characterized by impaired social interaction, absent or delayed language development and repetitive behaviours.

More information: http://www.jneurosci.org/current.shtml

Brain imaging in autism study

By imaging the brains of adolescents with a high-functioning form of autism as they played a social-interaction game, scientists have identified a physiological deficit specific to the disorder. The researchers believe that the change is linked to a diminished sense of self. The findings, recently published in the journal *Neuron*, could help guide future research into the nature of autism and potentially lead to new ways to diagnose and treat the disorder.

"I think this is an exciting advance," says Uta Frith, a professor at the UK University College London, who wrote a preview of the paper for *Neuron*. Most studies find only subtle differences in people with high-functioning autism, "so it's quite impressive to find such a big difference," she says.

Researchers at Baylor College of Medicine, in Houston, believe that they have now identified a specific physiological marker of the disorder. Read Montague, Pearl Chiu, and their colleagues scanned the brains of adolescents with Asperger's syndrome while they played an interactive trust game.

In the game, one person, designated the investor, chooses an amount of money to send to a second player, the trustee. The money is tripled en route, and the trustee must then decide how much to give back to the investor. When played by normal volunteers, the game unfolds in a very characteristic fashion: generous gestures are met with generous responses, while selfish ones inspire selfishness in return.

Brain activity also follows a stereotyped pattern. A study by Montague and his colleagues. published in 2006, imaged the brains of both the investor and the trustee as they played the game. The researchers discovered a specific signal in the cingulate cortex, part of the brain that integrates information from both the cortex and the body, that was detected only when the investor thought about how much money to give the trustee. A second signal was seen only when the investor received his or her return from the trustee. "We see a 'self, other, self, other' pattern," says Montague, director of the Human Neuroimaging Lab at Baylor. "We think that's an unconscious assessment of who the actions should be attributed to."

According to the new findings, people with Asperger's play the game just as a non-autistic person would, but they lack the characteristic "self" signal in the brain. Normal people lack the signal only when they think that they are playing against a computer, suggesting that autistic people view interactions with other people similarly to the way that normal people think about interacting with a computer. "This approach allows a somewhat objective look at something hopelessly subjective--sense of self," says John Gabrieli, a neuroscientist at MIT.

While the findings are clearly intriguing, it is not yet clear what they mean. One popular theory of autism is that people with the disorder lack the ability to imagine the thoughts and actions of others. Identifying a specific deficit linked to thoughts of self could help narrow

down what has gone wrong in that process. "People think autism is linked to a lack of understanding of what a partner is doing," says Chiu. "But maybe they don't understand their own role in the social exchange."

Other autism experts are not so sure. "I'm sceptical about how much [the Baylor College study] tells us about which capacities are intact and engaged in autism," says Matthew Belmonte, a scientist at Cornell University, in Ithaca, NY. "I'm not convinced they have a deficit at all. Maybe they have adopted a different cognitive strategy."

More information: http://www.neuron.org/

Research project about depression
Georgina Andreou is conducting research on factors affecting depression in parents of autistic adults with Asperger Syndrome. Are you a parent living with an adult with Asperger Syndrome? You can help this research in raising greater awareness**.**

For more information please contact georgina@roehampton.ac.uk for an information sheet.

Sound mix-ups and the dyslexic brain
The difference between the sounds "ba" and "da" is not easy to distinguish for many children with dyslexia. And this kind of mix-up may be the root of their reading problems, according to new research that sheds light on the nature of the dyslexic brain. In children with developmental dyslexia, "it's almost like the brain is deaf to the difference between the two sounds," says lead author and pediatrics professor Nadine Gaab of the Laboratory of Cognitive Neuroscience at Children's Hospital Boston and Harvard Medical School.

The research, recently published in the journal *Restorative Neurology and Neuroscience*, also showed that a remedial computer program called *Fast ForWord Language*, which comprises sound exercises, helps rewire the brains of dyslexics. The program, which is sold by a company in which one of the researchers owns a stake, starts with chirps and builds up to syllables, words and sentences.

More information: http://www.iospress.nl/loadtop/load.php?isbn=09226028

Resources
Books

Foundations for the future
A new report has been launched that brings together comprehensive evidence relating to the quality of life of ADHD patients and the opinions and perspectives of those who deal with the condition including specialist doctors, nurses, patient advocates, teachers and the police service. The report encourages clinicians to consider the wider impact of ADHD on a young person's day-to-day life, beyond the school day.

To request a hard copy of the Foundations for the Future report, please send your name and postal address to adhd@virgohealthpr.com.

Alternatively the report is available to view and download by clicking here* (right click and select "Save Target As" to download it).

Understanding Controversial Therapies for Children with Autism, Attention Deficit Disorder, and Other Learning Disabilities
A Guide to Complementary and Alternative Medicine by Lisa A Kurtz

Paperback, ISBN: 978-1-84310-864-1, 208pp, 2008, £12.99, $19.95

Offering a balanced overview of complementary and alternative therapies, this book will be useful for parents of children with autism, ADD or other learning disabilities.

The book covers a wide variety of mind-body interventions and manipulative techniques, as well as energy therapies, biologically based methods, and alternative medical systems. For each approach, the author provides a detailed description of what the treatment involves, which professionals will be working with the child, and an explanation of the rationale behind the therapy. She also offers advice on who to approach for treatment, and includes a list of recommended resources and useful contacts for further information.

This book will be a valuable source of information for parents and professionals working with children who have disabilities that impact their learning or behaviour.

Autism, Discrimination and the Law
A Quick Guide for Parents, Educators and Employers by James Graham

Paperback, ISBN: 978-1-84310-627-2, 144pp, 2008, £14.99, $27.95

Autism, Discrimination and the Law outlines how the legal requirements of the UK Disability Discrimination Act 1995 might be met for students and employees with autism spectrum disorders (ASDs).

- What might discrimination against people with autism look like?
- What can you do to prevent discrimination against people with autism?
- What should you do if you have been discriminated against?

The book includes an overview of current knowledge of autism, and details of the changes in legislation concerning disability discrimination. The main part of the book is devoted to case studies from further education and employment demonstrating how reasonable adjustments can be made successfully.

This accessible book will be an essential reference for employers, policy makers, Local Education Authorities, Learning and Skills Councils, Training providers, schools and colleges, personnel officers, careers officers, charities, residential homes, parents, indeed anyone working with people with autistic spectrum disorders.

Families of Adults with Autism
Stories and Advice for the Next Generation edited by Jane Johnson and Anne Van Rensselaer

Paperback, ISBN: 978-1-84310-885-6, 192pp, 2008, £13.99, $19.95

Families of Adults with Autism is a collection of real-life stories of people on the autism spectrum growing up, as told by their parents and siblings.

The individual accounts explore the challenges that families of people with autism have faced, and the techniques they have used to improve the quality of their children's lives, from mega-doses of vitamins and dietary changes to intensive interaction. The contributors also relate how they have worked with their children or siblings to help them to function at their highest possible level, be it showing an awareness of their environment, holding down a full-time job in a local store, competing in the Special Olympics, or achieving international recognition as an artist.

This book will offer practical and heartwarming advice to families who are affected by autism spectrum disorders, and provide insights for professionals working with people with ASDs.

Can't Play Won't Play
Simply Sizzling Ideas to get the Ball Rolling for Children with Dyspraxia by Sharon Drew and Elizabeth Atter

Paperback, ISBN: 978-1-84310-601-2, 176pp, 2008, £13.99, $19.95

Learning to roller skate or ride a bike should be an enjoyable experience, but for a child with developmental co-ordination disorder (DCD, also known as dyspraxia), these activities can lead to frustration and failure. *Can't Play Won't Play* is full of practical information, tips and hints to enable children with DCD to access and enjoy activities that other children take for granted.

Whatever game you choose to try with your child, this book will offer handy hints for developing the necessary skills to make it a fun and rewarding experience. From football and rugby to swimming, skipping and skating, the advice covers all the regular childhood activities as well as games to improve physical organization and social skills. The authors provide useful equipment lists and safety tips, and include photographs and diagrams to demonstrate the activities. The delightful illustrations add to the book's appeal, making it a friendly and accessible guide to dip into when you are in need of inspiration.

C*an't Play Won't Play* is an essential resource for parents, teachers and all those working with children with DCD.

Asperger Meets Girl
Happy Endings for Asperger Boys by Jonathan Griffiths

Paperback, ISBN: 978-1-84310-630-2, 112pp, 2008, £11.99, $16.95

Men with Asperger's Syndrome, young and old, experience difficulty with social interaction, which can be a stumbling block when it comes to getting a girlfriend. Here is a book that demystifies the enigma of 'relationships' by explaining everything in Asperger-friendly terms (some of them mathematical, naturally).

Asperger Meets Girl provides hope for all hopeless wooers by offering a choice of three interrelated abstract models for understanding boy-girl relationships. And, to make life easier, these models are presented in graph form where possible. The book also gives valuable practical tips for maximising one's chances of successfully developing a relationship, such as how to start a conversation without scaring the other person off, avoiding the inclination to stare and understanding the concept of 'personal space'.

HOW CAN I TALK IF MY LIPS DON'T MOVE? Inside My Autistic Mind by Tito Rajarshi Mukhopadhyay

Arcade. 219 pp. $25

Tito Rajarshi Mukhopadhyay is 19 and has published two memoirs, a book of short fiction and poetry. Tito's new book starts with his relationship to a mirror; 3 years old and mute, he told it stories and believed it wanted to tell him stories in return. He related to the world by focusing intently on selected features of it: spinning under ceiling fans, in order to feel his body; climbing stairs; "mapping" his body and environments to learn to dress and to eat.

His mother Soma's teaching is integral to Tito's narration. She capitalized on his areas of focus -- using stairs to teach counting, telling stories about shoelaces to teach knot-tying. She taught language by having Tito point to letters on a signboard. Tito moved on to writing on paper, then to a computer keyboard; he speaks, but with difficulty, and sometimes uses a voice synthesizer. We don't get much sense, however, of the mechanics of Soma's teaching: The fact that she speaks to him in constant response to what he is doing, however trivial, never comes up. Even the history of the family's frequent moves is told through the impressionistic wash of Tito's senses: They go from Mysore to Bangalore to Los Angeles without much connective tissue. But this book documents a consciousness, one that hypothesizes about brain function, cites thinkers from neurologist Antonio Damasio to physicist Erwin Schroedinger, includes the author's poems, mulls over what "neuro-typicals" may be thinking -- all from an adolescent who, at 3, was declared to lack self-consciousness.

Conferences and events

19 février 2008
TDA/H : comment en parler ? comment l'annoncer ?
Brussels

Contactez info@tdah.be

27 February 2008
Update on AD/HD and Coexisting Conditions: What Works
European School, Boulevard du Triomphe, Brussels

Dianne Zaccheo, MSW FTC, expert on Attention Deficit Hyperactivity Disorder (AD/HD) and comorbidities and founder of The Coaching Centre, London, where she trains specialised ADHD/ASD/Dyslexia coaches, will speak.

More information: www.ecoc.be

7 March 2008
Coping with challenging behaviour
Ramada Hotel & Resort, Birmingham, UK

More information: http://www.bild.org.uk/

8 March 2008
The Rose Report on Literacy
Helen Arkell Centre, UK

Sir Jim Rose expands on his report (The Rose Report on Literacy). This promises to be a fascinating morning for those interested in literacy.

More information: courses@arkellcentre.org.uk

12 March 2008
Difficulty with maths
Helen Arkell Centre, UK

A half day course for parents of Primary School children who have difficulty with maths.

More information: courses@arkellcentre.org.uk

19 mars 2008
Une fois le diagnostic de TDA/H posé comment accepter, comment avancer ?
Brussels

Contactez info@tdah.be

27 and 28 March 2008
Care and Treatment of Offenders with a Learning Disability
Preston, UK

The 7th International Conference on the Care and Treatment of Offenders with a Learning Disability - organised by the: Faculty of Health University of Central Lancashire Preston,.

Conference flyer (pdf) Booking form (Word)

27-29 March 2008
BDA International Conference – Dyslexia: Making Links
Harrogate, Yorkshire, UK

Chaired by Professor Margaret Snowling, the conference will consider the relationship between dyslexia and related learning difficulties from the perspectives of research and practice.
More information: : www.**bda**dyslexia.org.uk

21 avril 2008
TDA/H et adolescence
Brussels

Contactez info@tdah.be

23 April 2008
Access to technology by people with disabilities
London, UK

E-Access Bulletin's fourth annual conference and exhibition

More information: www.headstar-events.com/eaccess08/

29 April 2008
Royal Society of Medicine Conference on Autism and Aspergers Syndrome
Birmingham, UK

This conference aims to provide a comprehensive look at both Autism and Aspergers Syndrome in relation to the epidemiology, research and current issues in providing services to individuals and their families.

More information: http://www.rsm.ac.uk/academ/autismbham.php

22 mai 2008
Traitement du TDA/H avec la participation d'un médecin spécialisé
Brussels

Contactez info@tdah.be

Tip of the month

Tips for teachers that really work

The US Council for Exceptional Children (CEC) has a web site for teachers that promises to tell all about the hidden curriculum and networking, how to use "homebase" to prevent discipline problems, and more. Plus, your questions answered by expert special educators. All at CEC's Blog for teachers.