



Europe's Children Our Concern asbl

supporting children and young people with learning difficulties

Under the Patronage of Her Royal Highness Princess Mathilde

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"Together we can make a difference"

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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

Mind mapping – back by popular demand

Mathieu Kleinschmager will again lead a practical workshop on this technique for recording information in a more "brain friendly" way. In French. Scotland House, Rond-Point Schuman 6, 1040 Brussels – 15 April – 18.15 for registration.

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

UN marks first World Autism Awareness Day

United Nations Secretary-General Ban Ki-moon praised the courage of children with autism and their families on the first World Autism Awareness Day, and called for all countries to respond to their needs.

Ban commended the initiative taken by Qatar's emir, Sheikh Hamad bin Khalifa Al-Thani, and his consort, Sheikha Mozah Bint Nasser Al Missned, in spearheading the drive to have the General Assembly designate 2 April as a day to focus on those who suffer from autism.

The resolution adopted by the General Assembly asks all nations, UN bodies, international organizations and non-governmental groups to take steps to raise awareness of the disorder. It expresses deep concern at "the prevalence and high rate of autism in children in all regions of the world and the consequent developmental challenges".

More information: <http://www.nas.org.uk>

Two studies published to coincide with World Autism Day

Two new studies were released earlier than the planned date in the April edition of *Pediatrics* to mark World Autism Day: one looked at a possible risk factor for development of the disorder, while the other considered the financial toll that having an autistic child takes on a family.

The first looked for early autistic behaviours in premature infants who were born at a very low birth weight and found that several factors associated with these early births were linked to a positive result on an autism screening test.

"The bottom line is that there appears to be a high prevalence of positive screening for autism in survivors of extreme preterm birth and ongoing follow-up is needed to understand if this initial positive screen is transient or persistent," said study author Catherine Limperopoulos, the Canada Research Chair in Brain and Development in the department of Neurology and Neurosurgery at McGill University in Montreal.

"There is a suggestion [from this study] that preterm infants may be at risk for developing autism, but this is really a preliminary finding that needs to be replicated in a large, prospective study," said Andy Shih, vice president of scientific affairs for Autism Speaks, in New York City.

Limperopoulos and her colleagues studied 91 babies who weighed less than 3 pounds at birth from birth on. Twenty-five percent of these toddlers tested positive on the Modified Checklist for Autism in Toddlers (M-CHAT) at around 22 months suggesting that they had an increased risk of developing autism.

Limperopoulos said this study was not designed to determine causality, but that some type of prenatal or perinatal insult might increase the likelihood of autism.

The second study assessed some of the financial impact that having a child with autism can have on a family's finances, and found that when a child has autism, a family earns an average of US\$6,200 less each year, or about 14 per cent.

"We think parents are making different decisions about labor participation," said study author Guillermo Montes, a senior researcher at Children's Institute in Rochester, in New York. "In some cases, one parent stays home, another may turn down a promotion or might take a job that doesn't require as much travel," which ultimately reduces the family's earning power.

Petition for the UK Prime Minister to ratify the UN Convention on the Rights of Persons with Disabilities

UK disability organisation Scope is calling on the Government to ratify the UN Convention on the Rights of Persons with Disabilities as a matter of urgency.

The Convention is the first treaty in history to give the millions of disabled people across the globe comprehensive human rights and recognise that disabled and non-disabled people share a common humanity. Deadline to sign Scope's petition: 18 August 2008.

[More about petition](#)

[Sign up online](#)

A Life Like Any Other?

On 6 March 2008, The Joint Select Committee on Human Rights of the UK Parliament published their report on human rights and learning disabilities. It paints a picture of generally poor standards of care, unwelcoming environments, a lack of care planning and little or no involvement of people in choices or decision making. Front line staff are poorly trained and supported, with a lack of supervision, management and leadership. The quality of the support offered is often not monitored or checked.

Andrew Dismore MP, Chair of the Committee, said, "There is a real gap between the Government's policy which is designed to improve the lives of adults with learning disabilities and their everyday experience. We were particularly shocked by witnesses who told us that even in cases of horrific abuse or neglect, staff simply did not know that what they were doing was wrong. We heard compelling evidence that people with learning disabilities wanted to play a greater role in speaking up for their rights."

The report *A Life Like Any Other?* [can be downloaded](#) from www.parliament.uk. An easy read summary is available - [click here to download](#).

New advisers help get learning disability issues heard

Professionals from across the private, public and voluntary sectors have come together to fight for a fair deal for people with a learning disability in the UK. The newly formed advisory board has been set up to support the Learning Disability Coalition in its work to raise the profile of learning disability issues.

Members of the advisory board include former senior civil servant Sir Christopher Kelly, who is currently the Chairman of the Committee on Standards in Public Life, Chairman of the Financial Ombudsman Service and Chairman of the NSPCC; Professor Eric Emerson, Professor of Disability and Health Research at the University of Lancaster and Visiting Professor in the Faculty of Health at the University of Sydney; David Brindle, Public services editor, *Guardian*; Dr Stephen Ladyman MP, Labour MP for South Thanet and former Care Services Minister and Transport Minister; and Professor Martin Knapp, Director of the Personal Social Services Research Unit at the London School of Economics, Professor of Social Policy and co-director of LSE Health and Social Care.

Professor Martin Knapp said, "Gathering sound evidence about demographic trends that are causing an increase in demand for services for people with a learning disability is crucial. Without this information, the Government cannot know what level of resource to allocate and how to use this to best effect. Our aim is to work closely with Government. After all, we all have the same aim - a better quality of life for a group of people who are often overlooked."

The Learning Disability Coalition is formed of ten organisations:

- Mencap
- Foundation for People with Learning Disabilities
- Association for Real Change
- British Institute of Learning Disabilities
- Down's Syndrome Association
- National Forum for People with Learning Disabilities
- People First
- Sense
- Turning Point

- United Response

More information: www.learningdisabilitycoalition.org.uk

Toddler tantrums and ADHD

A study of the behaviour of about 280 children between the ages of 3 and 6 compared the tantrums of normally developing children with those of children suffering from disorders, such as major depression and ADHD (attention deficit/hyperactivity disorder).

In the study, which appeared recently in *The Journal of Pediatrics*, researchers at the Washington University School of Medicine in St. Louis found that the tantrums of troubled children differed from normally developing children's in several ways, from violent or self-harming behaviour to being unable to calm themselves down.

"At any one time, it's not unnatural or atypical for a child to engage in any one or more of these behaviours. But if it's consistent, that's when to be concerned," said Andy Belden, a developmental psychologist who took part in the research.

There are five warning signs identified in the study:

- Consistently being aggressive toward caregivers or violently destructive toward an object or both.
- Intentionally hurting themselves during tantrums.
- Having an excessive number of tantrums, such as more than five a day on multiple days while outside the home. (Numerous ones at home can be a sign too).
- Frequently being unable to calm themselves down without help. These are the children who basically are "unable to regulate their own emotion," Belden said.
- Having marathon tantrum episodes, usually lasting more than 25 minutes.

ADHD-eating disorders link in girls

Adolescent girls with ADHD appear to show a significant risk for developing eating disorders. Researchers from the University of Virginia discovered they frequently develop body-image dissatisfaction and may go through repeating cycles of binge eating and purging behaviours.

Team leader UV Psychologist Amori Yee Mikami, says the behaviours are consistent with bulimia nervosa.

"Our finding suggests that girls may develop a broader range of problems in adolescence than their male counterparts," Mikami said.

Mikami also noted that because ADHD is more common in boys, many girls with the disorder may go undiagnosed and untreated.

The study was conducted with an ethnically diverse sample of 228 girls in the San Francisco Bay area; 140 who had been diagnosed with ADHD and 88 matched comparison girls without ADHD. They were first assessed between the ages of 6 and 12 and again five years later.

Girls with the "combined type" of ADHD (those with both inattention and hyperactivity/impulsivity) were most likely to have adolescent bulimia nervosa symptoms, relative to girls with the "inattentive type" of ADHD (those with inattention only) and girls without ADHD.

Girls with both types of ADHD were more likely to be overweight, to have experienced harsh/critical parenting in childhood, and to have been peer-rejected than girls without ADHD. Mikami said she believes these factors could contribute to the bulimia nervosa symptoms.

The findings appear in the current issue of the *Journal of Abnormal Psychology*.

More information: [University of Virginia](#)

The Inclusion Development Programme is now available for dyslexia

The Inclusion Development Programme (IDP) is part of the UK Government's strategy for SEN outlined in *Removing barriers to Achievement*. The four-year programme provides professional development materials for teachers, trainee teachers and practitioners working with pupils of all ages from Early Years through to secondary with a range of special educational needs.

The first set of materials on speech, language, communication and dyslexia are now available from the National Strategies website

<http://www.standards.dfes.gov.uk/primary/features/inclusion/sen/idp>

Decoding dyslexia

Watch a film entitled *Decoding Dyslexia* on <http://www.teachers.tv/video/23168>

UK National Epilepsy Week 2008 (18-25 May 2008)

For National Epilepsy Week 2008, Epilepsy Action will be highlighting the lack of awareness about epilepsy that exists. They will be encouraging supporters to help to educate more people, from MPs and other key decision makers to the general public, about epilepsy.

More information: mmiller@epilepsy.org.uk

Health watchdog issues warning of anti-epileptic drugs and suicide tendencies

The US [Food and Drug Administration](#) (FDA) has issued [new information to healthcare professionals](#) over a risk of people taking anti-epileptic drugs (AEDs) having suicidal tendencies.

The FDA has analysed reports of suicidal behaviour (completed suicides, suicide attempts and preparatory acts) or having suicidal ideas from nearly 200 studies of 11 AEDs. In the analysis, patients taking AEDs had approximately twice the risk of suicidal behaviour or ideas (one person in 232) compared to patients taking a placebo (one person in 454).

The increased risk of suicidal behaviour was seen as early as one week after starting the AEDs and continued for 24 weeks. The results were generally consistent among the eleven drugs. Four of the patients who were taking one of the AEDs committed suicide, whereas none of the patients in the placebo group did.

As most trials included in the analysis did not extend beyond 24 weeks, the risk of suicidal thoughts or behaviour beyond 24 weeks could not be assessed.

The FDA has suggested to healthcare professionals that all patients who are currently taking or starting on any AED should be closely monitored for notable changes in behaviour that could indicate the emergence or worsening of suicidal thoughts or depression.

Epilepsy groups challenge patients to take charge of their health

Less than half of patients with active epilepsy in the United States are informed by their doctors about treatment options, according to a survey by the [American Epilepsy Society](#) and the [Epilepsy Foundation](#).

Fewer than half (47 per cent) of those surveyed said their doctor had discussed alternative treatments with them, with neurologists more likely to do so than primary care providers. Least likely to be discussed was surgery, a finding that the authors suggest means that a significant number of potential surgery candidates might not be aware of this option. The survey also suggests that people with poorly controlled seizures do not get referred to specialised epilepsy centres that focus on more difficult-to-control epilepsy.

Around a quarter of patients surveyed said they did not know what their doctors would rank as a significant improvement in seizure control. While more than half (51 per cent) of all patients feel that a 90 per cent reduction or no seizures at all would be a significant improvement, only 35 per cent feel their doctor would agree.

First ever UK epilepsy care plan announced by Welsh Assembly

New plans to improve care for thousands of people in Wales with epilepsy have been announced by [Welsh Assembly Government](#) health minister Edwina Hart.

The plans include measures to reduce the incidence of epilepsy, help people to self-manage their condition and provide more care closer to people's homes – reducing the likelihood of hospital admission. It is estimated that well-managed medication procedures can help around 70 per cent of people with epilepsy to be seizure-free – thereby reducing the risk of emergency admission. It is the first time such a plan has been outlined in any UK country.

Consultation on the plans will close on 2 May 2008.

Impaired cognitive function linked to later onset of type 2 diabetes

Impaired cognitive function at age 11 appears to be associated with an increased risk of developing type 2 diabetes later in life, a study indicates.

"Type 2 diabetes is associated with decreased cognitive function in adults, particularly among elderly people," Dr Gunilla Olsson, of Uppsala University, Sweden, and colleagues write in the medical journal *Diabetes Care*. "Less is known about cognitive function in children who will subsequently receive a diagnosis of type 2 diabetes in adulthood."

The researchers analyzed the general ability and reading comprehension at age 11 years of some 9000 members of a 1958 UK birth cohort in relation to a subsequent diagnosis of type 2 diabetes.

The subjects with type 2 diabetes by 42 years of age had significantly lower assessment scores at age 11, the investigators found.

There are several possible explanations for this association. "It is possible that cognitive deficits present in childhood influence lifestyle factors that increase the risk of type 2 diabetes," Olsson and colleagues suggest. Another possibility is that poorly controlled blood glucose levels "may influence both cognitive development and the risk of type 2 diabetes."

More information: *Diabetes Care*, March 2008.

Resources

Books

Animal-assisted Interventions for Individuals with Autism

by Merope Pavlides

Paperback, ISBN: 978-1-84310-867-2, 208pp, 2008, £13.99, \$21.95

This book looks at how therapies involving animals can be used to help individuals with autism to develop skills, including sensory and social skills, to manage challenging behaviours, and improve quality of life.

Whether participating in therapeutic horse riding, using a trained dog, visiting a dolphin therapy centre, or simply experiencing companion animal therapy, people with autism can reap a multitude of benefits from interaction with furry, feathered, and finned friends. Merope Pavlides relates the success stories of different animal-assisted interventions, as well as noting the challenges of working with particular animal species. She also emphasizes the importance of tailoring interventions to the specific needs of the individual and of monitoring progress.

With recommendations for resources and further reading, this book will be of great interest to people with autism, their parents, and the professionals who work with them.

Dasha's Journal. A Cat Reflects on Life, Catness and Autism

by T O Daria

Paperback, ISBN: 978-1-84310-586-2, 176pp, 2008, £12.99, \$17.95

The feline perspective provides a new outlook on autism conditions, challenging long established stereotypes and analysing controversies in the field with an unbiased attitude and humour. The text is interspersed with Dasha's 'wisdoms', 'research notes' and definitions of concepts based on her own understanding, such as 'A pet shop is a place where humans come to be adopted by the animals who are brave enough to take a responsibility of looking after them.'

Dasha's Journal provides research-based information in an amusing and accessible form and makes serious and complicated issues such as sensory perception, memory, communication, savant skills and challenging behaviours in autism easily understandable for the general reader.

Providing Practical Support for People with Autism Spectrum Disorder

by Denise Edwards

Paperback, ISBN: 978-1-84310-577-0, 192pp, 2008, £15.99, \$24.95

One element at the heart of effective service provision is an understanding of the service user's needs. This book unravels some of the common misunderstandings between people with autism spectrum disorders (ASD) and providers of support services, and offers practical advice on how to ensure that the needs of people with ASD are catered for effectively.

Denise Edwards writes directly from her own experiences of finding appropriate support for her adopted son, John Paul, who has Aspergers syndrome, but she also draws on the experiences of a broad range of service users. She emphasises the importance of understanding and conveying the nature of ASD so that support services can meet a person's needs effectively. She discusses common areas in which difficulties arise, including communication, social situations and the organisation of information, examines the implications of support in wider society - education, employment, the legal system - and makes practical suggestions for changes that can improve access to benefits and services for people with ASD.

Informative and down-to-earth, this book is essential reading for the providers of services for people with ASD for service users themselves as well as formal or informal carers, friends, family, related professionals and policy makers.

ADHD - Living without Brakes by Martin L Kutscher

Hardback, ISBN: 978-1-84310-873-3, 192pp, 2008, £14.99, \$22.95

This concise and highly accessible book contains everything that parents and busy professionals need to know about ADHD.

The author describes the spectrum of ADHD, the co-occurring symptoms, and common difficulties that parents face. The rest of the book focuses on solutions, based around four rules. Rule number one is keeping it positive: punishments can change behaviour, but only positive approaches can improve attitude. Rule number two is keeping it calm: it's difficult thinking clearly enough to solve problems logically if you are feeling overwhelmed. Rule number three is keeping it organized: this rule relates particularly to the child's school life. Rule number four is to keep doing rules one to three. Finally, Dr. Kutscher discusses the role of medication for treating ADHD. The concluding chapter summarizes the information covered and can also be read as a complete, freestanding text. Useful checklists and further reading recommendations are also included.

Realistic and optimistic, this book is the ideal source of information and advice for parents and professionals who are trying to keep up with children who are living without brakes.

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 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.

Mind/Body Techniques for Asperger's Syndrome. The Way of the Pathfinder
by Ron Rubio

Paperback, ISBN: 978-1-84310-875-7, 152pp, May 2008, £13.99, \$19.95

People with Asperger's Syndrome (AS) typically experience difficulty with balance, coordination and sensory awareness. The mind/body exercises in this book help young people with AS improve these skills, leading to greater self-confidence, and independence.

Easy to use, with photographs to show how exercises are done correctly, these techniques can have an effect on how an individual stands, sits, moves, thinks of him- or herself, and relates to others. The author's approach integrates ideas and practices from disciplines including martial arts, Eastern principles of mindfulness, techniques of visualization, breathing, posture, and movement, and the practice of mentoring.

Mind/Body Techniques for Asperger's Syndrome is an introduction to Pathfinder training techniques for both parents of adolescents with AS and professionals including physical therapists, pediatricians, and special education teachers who work with them.

What is Dyslexia? A Book Explaining Dyslexia for Kids and Adults to Use Together
by Alan Hultquist

The author provides information about all the most common types of dyslexia: trouble with sounds, trouble remembering how letters and words look, trouble finding words, and mixed dyslexia. He deals with the basic facts and adopts a style which is accessible to children without talking down to them. The book includes clear examples which children will be able to understand, as well as activities for parents to do with their children. The author emphasises that everyone has strengths and weaknesses and that having dyslexia is okay.

This book will be valuable for parents of children with dyslexia, as well as other adults working with children with dyslexia.

Conferences and events

15 April 2008

Mind mapping

Scotland House, Rond-point Schuman 6, 1040 Brussels

Mathieu Kleinschmager will again lead a practical workshop on mind mapping – a way of recording information in a brain friendly way – in French. 18.15.

More information: www.ecoc.be

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 review both Autism and Aspergers Syndrome in relation to the epidemiology, research and current issues in providing services to individuals.

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

2 May 2008
Speech, language and communication skills
Ramada Hotel, Sutton Coldfield, Birmingham UK

The nasen summer conference 2008 dedicated to the development of speech, language and communication skills. nasen have invited Chris Beek, National Director of the SEN/LDD Programme and Advisory Team with the National Strategies and Alex Hall, Director of Development, I CAN, to deliver the keynote speeches.

More information : [Speech, Language and Communication application](#).

8 May 2008
Dyslexia screening
Birmingham, UK

An introduction to screening techniques organised by the British Dyslexia Association for teachers.

More information: www.bdadyslexia.org.uk

15 May 2008
Dyscalculia
Canterbury, Kent, UK

A conference organised by the British Dyslexia Association.

More information: www.bdadyslexia.org.uk

17 May 2008

Dyspraxia and maths problems

Farnham, Surrey, UK

A presentation with Amanda Kirby, author of *Dyspraxia: The Hidden Handicap*.

More information: courses@arkellcentre.org.uk

22 mai 2008

Traitement du TDA/H avec la participation d'un médecin spécialisé

Brussels

Contactez info@tdah.be

12 & 13 June 2008

International Conference and NIPPA AGM 2008

Derry City Hotel, Northern Ireland

The theme will be "Enjoyment of Learning". The keynote speakers are Professor Guy Claxton and Dr Larry Schweinhart.

More information: www.early-years.org

30 June 2008

Practical solutions for students with dyslexia in the normal classroom

Wimbledon, London, UK

The first in a series of conferences offering practical solutions for classroom teachers, this concentrates on reading. Subsequent conferences deal with spelling and writing.

More information: www.bdadyslexia.org.uk

8-19 September 2008

Children's Rights in a Globalized World: From Principles to Practice

Ghent and Antwerp

An international study session.

More information: www.iccr.be

27 September 2008

Dyspraxia

Sheraton Hotel, Heathrow, London, UK

Spanning the years: A joint approach to dealing with dyspraxia. A one-day conference for health, education professionals and anyone working with children and adults with dyspraxia.

[Call for Abstracts: Dyspraxia Foundation Professional dyspraxiaConference 2008](#)

6&7 October 2008

Autism neuroscience
London, UK

The Autism Research Centre at the University of Cambridge will be hosting an autism neuroscience conference.

The conference will include lectures summarising the latest international research on the nature and causes of autism. Abstracts are invited on these topics for both oral presentations and poster displays at the conference.

For further information, to register and to download the abstract submission form visit www.arc-conference.com

Tip of the month

Listen to the children!

Preschoolers who talk to themselves when trying to learn something do better than those who do not, according to a new study. Adam Winsler of George Mason University says that paying attention to what those children say can help adults.

"Young children often talk to themselves as they go about their daily activities, and parents and teachers shouldn't think of this as weird or bad," says Winsler. "On the contrary, they should listen to the private speech of kids. It's a fantastic window into the minds of children."

He found that 5-year-olds did the same or better on tasks when speaking to themselves than when they were silent, whether they naturally did the talking or were asked to by an adult. The study also showed that children with behavioural problems, such as those with ADHD, tended to talk to themselves more often. Winsler said that may mean that teachers need to learn to distinguish between disruptive behaviours and what he called private speech.

The study was published in *Early Childhood Research Quarterly*.