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April 2009 Newsletter

The Autism Bill - A giant stride forward on a long road

Achieving the second reading of the Autism bill on the 27th February with the help of eight Hertfordshire MPs is a significant milestone in the fight to get appropriate services for people with autism and their families.

However, we must not fool ourselves that we have achieved all the aims of the bill, yet. The Government has offered a 'compromise' package which may deliver some (but not necessarily all) of what we wish to attain. What concerns me is that they are shying away from committing to statutory measures (with the backing of law) towards yet more guidance. We have had guidance 'implemented' for many years, without achieving the major steps forward we require in services. This is because we have to prove in a court of law, test case by test case, that the service provider is failing in their duty, for each and every clause in that guidance. For people who have been struggling for years to support their autistic offspring, this is often a battle too far.

We have received letters from an MP with phrases such as "the Government is doing all it can" and "The Government aims to bring about many outcomes desired...". Neither of those phrases inspires any confidence in me that they will deliver all that we expect from them in full. Then there is the issue of timeliness. Where is the study into adult prevalence, promised last year for publication this year? Where is the

guidance document "Improving Commissioning Services for Young People and Adults who have Autism Spectrum Conditions" in final draft last year but still not published? Do they not realise that some people have been waiting nearly 60 years for support appropriate to their condition and needs?

I think we will need to go back to our MPs, and to the relevant ministers: Ed Balls, Alan Johnson, Phil Hope, Sarah McCarthy-Fry and Gordon Brown. So be prepared to put pen to paper again soon.

You may ask: why the lull? The answer is simple. We have been overwhelmed by cries for help sparked by all the publicity raised around the Autism bill. Proof, if proof be needed, that services are inadequate and are not reaching those in need.

Laurence Griffin
Branch Officer

World Autism Awareness Day

April 2nd is World Autism Awareness Day, and the NAS is working in partnership with other autism charities to use the day to call for autism to be understood and recognised as a condition distinct from learning disability and mental illness, and for appropriate support, services and rights for people with autism and their carers. Under the theme "Stand Up for Autism", a number of joint activities will be organised.

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Some are yet to be confirmed, but will definitely include national advertising and a video project where celebrities will film a video on the theme of "Stand Up for Autism", which will be promoted on YouTube and Facebook. The video project may also be extended so the public can also upload videos, though this is still to be confirmed. In the meantime people can upload photos of themselves "standing up for autism" now via www.worldautismawarenessday.org.uk. How about writing to your local paper to remind them of this day and the importance of The Autism Bill to your family's life and wellbeing.

Please let us know if you do anything special for Autism on this day.

Hertfordshire Train Walks

As we mentioned last November, **harc** are organising a Train Walk, a Thomas & Friends™ themed mini-sponsored walk for all the family. The event will take place in June, with the likely venue being Welwyn Garden City. We are looking for volunteers to help organise and run the event, so if you can help, please contact the office.

If you live in another part of the county and would like to organise your own local event, **harc** will be happy to offer guidance and support so please let us know if you are interested in running such an event.

Hertfordshire NAS Resource Centre

From Alison Carpenter, Resource Centre Manager:

A new NAS Resource Centre has opened in Hertfordshire! We are based in Hemel Hempstead but will be covering all of Herts. We will be looking at developing services for children and adults over the coming months and years. At present we are working jointly with Adult Care Services in developing the Social Group for adults with Aspergers/High Functioning Autism. A second group will be

starting after Easter. We are also busy sorting out our office and getting started! If anyone would like further information regarding the Resource Centre or Social Group please contact Alison Carpenter or Helen Hart on 01442 247046. We will keep you updated through the HARC newsletter of developments over the coming months.

Request for Expert IT Help!

The Branch Committee are looking at ways of working more effectively and would like to set up a "virtual office" - a central electronic repository available remotely for access to shared files, emails and telephone forwarding if possible. If there are any members with expertise in this area who could advise the Committee, they would be very grateful! Please contact the office if you can help.

DiSH

DiSH is a single access point for people with disabilities, older people, carers, advocates, voluntary organisations, services providers, Social Services and Health professionals. They can give information on benefits, access, support, advocacy, Disability Discrimination Act, education and employment, financial help, leisure, transport and travel, plus numerous other subjects. Freephone telephone number is **0800 181067** and opening hours are Monday to Friday from 10am to 4pm with an answerphone for out of office hours.

Free Education Advice for Parents

The Advisory Centre for Education (ACE) is a national charity that provides independent advice for parents and carers of children aged 5-16 in state-funded education. ACE aims to provide the information, support and high-quality advice that parents need to help their children at school, particularly where there are problems. They offer free advice on many subjects like exclusion from school, bullying, SEN and school admission appeals.

How to get advice: Text the keyword ASKACE to 68808 and follow the instructions for free booklets, tips and advice tailored to your questions.

General advice line (Mon-Fri 10am-5pm):
0808 800 5793

Exclusion information line (24hr answer phone):
020 77049822

Exclusion advice line (Mon-Fri 10am-5pm): **0808 800 0327**

The Hertfordshire LINK

The LINK now has its own website. You can access the website by following the link below:

<http://www.communityvoicesonline.org/LINKs/home.aspx?id=61>

or you can go to

<http://www.communityvoicesonline/> and enter your postcode

Please register on the site, using the full registration process if possible (this will give the LINK more information for its monitoring services and help it improve the way it works.) More information will be added to the site as time passes.

"talk about autism" is now open!

talk about autism is a new online social networking community for parents, carers and people who work with autism. The online community is now open to registration for founding members at:

<https://www.treehouse.org.uk/user/register>

Once you've registered you should receive an email with your log in details. Go to the login page <https://www.treehouse.org.uk/user/login> and enter these details. You can then post in the discussion areas.

Getting to the Community Area

To go to the community area you must use this

url:

<http://www.treehouse.org.uk/talk-autism>

The main discussions are located here:

<http://www.treehouse.org.uk/forum>.

As this area has not been launched publicly, there are no links to the community area elsewhere on the website (which is the TreeHouse website). So if you get lost, or click away from the community, just go back to the link above. It might be useful to bookmark or save this link somewhere.

Further Information

The office can provide more details, or contact Paula Barrett, the site manager, direct at: paula@talkaboutautism.org.uk

Transition Information Network

Issue 14 of *Getting a Life*, TIN's policy e-newsletter, is now available to download from: <http://www.transitioninonetwork.org.uk/view/1/0/31>

Help with Holidays in France

happykidsholidays is a non profit making association aimed at supporting families with children and teenagers with Autistic Spectrum Disorders who want to come on holiday in France.

Visit www.happykidsholidays.com for more information

Special Educational Needs Funding

Maxine Crawley is the deputy mayor of St. Albans and a mum of a child with Special Needs, who is standing for County Council in June. She would like to hear from anyone in the Redbourn and Wheathampstead areas concerned about special needs funding issues, and can be contacted at:

MaxineCrawley@aol.com or via Commonsense2@btinternet.com

ICE - Emergency Mobile Contact

Many people will already have seen this, but worth repeating:

We all carry our mobile phones with names & numbers stored in its memory. If we were to be involved in an accident or were taken ill, the people attending us would have our mobile phone but wouldn't know who to call. Yes, there are hundreds of numbers stored but which one is the contact person in case of an emergency? Hence this 'ICE' (In Case of Emergency) Campaign. The concept of 'ICE' is catching on quickly. It is a method of contact during emergency situations. As mobile phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be contacted during emergency under the name 'ICE' (In Case Of Emergency). The idea was thought up by a paramedic who found that when he went to the scenes of accidents there were always mobile phones with patients but they didn't know which number to call. He therefore thought that it would be a good idea if there was a nationally recognised name for this purpose.

In an emergency situation, Emergency Service personnel and hospital Staff would be able to quickly contact the right person by simply dialling the number you have stored as 'ICE'. For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

In the Press

From Lesley Zorlakki:

Article on how teachers "fail to recognise special needs" at:

<http://www.guardian.co.uk/education/2009/feb/06/pupil-behaviour-school-discipline>

From Laurence Griffin:

This Daily Mail article is about a new, possibly high, prevalence (1 in 60) for autism. There are

a number of comments about how this is due to poor parenting and lack of discipline. You can add your own comments and rate other peoples comments. Have a go!

<http://www.dailymail.co.uk/news/article-1163606/One-child-60-suffers-form-autism.html>

Books

From Lorna Andrews:

New books regarding ASD's:

Not Stupid: The story of One Mother's fight to Rescue the Lives of her Children from Autism by Anna Kennedy (2008)

The Horse Boy: A Father's miraculous Journey to heal his son by Rupert Isaacson. Published by Viking on March 5 @ £12.99. To order a copy (p & P free) call 0845 155 0720

Children and Teenagers with Asperger's by Anna Van Der Post. E book version now available and paperback in March/April. Visit www.asteens.co.uk www.chipmunkpublishing.co.uk

NAS Update

We have received the following information from National Autistic Society:

Employment and Support Allowance: share your experiences

We are still keen to speak to adults with autism, and their parents/carers, who are in the process of applying for the new Employment and Support Allowance. This research is really important as it will inform our next campaign about work-related benefits, to be launched in the autumn. If you know anyone who may be interested in taking part, please ask them to get in touch, or to complete an online form at:

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1895&a=18370>

In addition we will be sending a follow-up survey to some of the people who took part in the research for the *I Exist* campaign, focusing on their experiences of applying for work-related benefits.

We also are looking for parents/carers and people with autism who would be interested in taking part in an expert panel which will analyse the new system for awarding Employment and Support Allowance. The aim of the panel is to identify parts of the process which might cause difficulties for people with autism so that we can raise these in our campaign. Members of the panel will have experience of applying for work-related benefits, or knowledge of others' experiences which they can contribute to discussions. If you are interested in taking part, please contact the HARC office

Short breaks services for disabled children

With extra money for short breaks services coming through now as part of [Aiming High for Disabled Children](http://www.autism.org.uk/ahdc) (see <http://www.autism.org.uk/ahdc>) , and a new duty on local authorities to provide short break services coming into effect in April 2011, local authorities should be taking a look at what they currently provide and how they will meet the duty from 2011.

Families of children with autism often tell us that there is no provision locally that can meet the needs of their son or daughter, so we need to make sure that the extra funding is used to change this. The Every Disabled Child Matters campaign has set up an email action which you can use to ask your local authority how they are planning their short breaks services now and beyond 2011 with the new duty in mind. Find out more at <http://www.edcm.org.uk> .

Ed: Carers in Hertfordshire are working with parent carers to make sure that an effective involvement structure develops in Hertfordshire. If you would like more information about how you can get involved, please contact Maria Kiely, Parent Carer Participation Project Worker, on 01442 253344 or email west.team@carersinherts.org.uk.

Parent to Parent service

Parent to Parent is a free confidential telephone support service for parents and carers of an adult or child on the autism spectrum. You can call the service at any time and leave a message. A volunteer will then call you back as soon as possible, at a time which suits you, including evenings and weekends.

The service is provided by trained parent volunteers, both mothers and fathers, across the UK who offer telephone support from their own homes. Volunteers have personal experience of autism and the impact it has on their own families and want to do something to support others in similar situations. These volunteers are able to genuinely empathise and give support to other parents, providing the opportunity for parents to talk through issues, feelings and problems. They can also point you to other sources of information and support. Please call 0800 9520 520 and leave a message on our 24-hour answer phone.

To find out more about volunteering for the service phone Nicole Rae on 0115 8473516 or email parent2parent@nas.org.uk

Creativity exhibition

Last year we launched a Creativity Competition for adults with autism as part of the *I Exist* campaign. We had over 200 entries, all of which demonstrated the incredible talent and potential that exists in the autism community. This month we have held an exhibition of selected entries in Glasgow and London, and in April selected pieces will be on display in the At-Bristol Café in Bristol.

You can also view all the entries to the competition in our online gallery at: www.think-differently.org.uk/gallery.aspx

Training workers who support people with autism

Skills for Care and the Valuing People team are currently developing a "knowledge set" about supporting people with an autistic spectrum condition. The knowledge set will be a list of what workers who are supporting people with autism need to know. Knowledge sets are used to inform the development of training for the adult social care workforce.

It's fantastic that an autism-specific knowledge set is being developed and it's really important that people with autism and parents and carers get involved in the process. For more details see

<http://www.skillsforcare.org.uk/participation/consultations/knowledgesetsupportingpeoplewhohavealearningdisabilityandorautisticspectrumcondition.aspx>

Have you been sent a Health and Wellbeing screening questionnaire?

The Department for Children, Schools and Families (DCSF) has recently sent out a "Health and Wellbeing" questionnaire to 400,000 families selected randomly from the national pupil database. In the survey families will be asked whether or not any of their children has a disability or health needs, and say whether they would like to be involved in further research.

If you receive this questionnaire please don't throw it away, it's very important!

Responses to this first questionnaire will be used to identify families to take part in a further survey, the Disabled Children's Services National Indicator survey. This survey will ask parents about their experiences of the services they receive from education, health and social care, and each local area will be given a score based on parental experience as measured in the survey.

This is a unique chance to have your say and it's absolutely vital that families of children with autism complete the screening questionnaire so that your experiences are reflected in the National Indicator survey.

Scope's Disablism Audit Series examines how much progress we are making towards eliminating the disadvantage experienced by disabled people, both in terms of improvements over time, and compared to non-disabled citizens. This year, they are focusing on the experiences of families with disabled children. To take part in the Scope Family Survey 2009, visit www.timetogetequal.org.uk/familysurvey

Communication Magazine

Miranda Kemp is planning a feature on holidays in the summer issue of Communication. Miranda will be referring to the extensive

information the NAS already has on this subject but would love to include some real-life recommendations from people with autism and their families. Please could you contact Miranda if you know of any particularly good autism-friendly holiday companies or places to go for breaks that have proved themselves to be particularly autism-aware. Miranda Kemp is the Editor of the Communication magazine and can be contacted on 01273 475257.

From Communication Magazine:

Special Care Dental Treatment

Visiting the dentist can be an ordeal for some people with an ASD but, with extra time, patience, and a build-up of trust, this need not be the case. More information on special care dental treatment is available from www.bsdh.org.uk. Copies of the leaflet **Dental care and autism**, by senior dental officer Michelle Golding, are available from the NAS Autism Helpline (**0845 070 4004**, Monday-Friday, 10am-4pm) or you can download a copy at www.autism.org.uk/dentist

Information for Professionals

Transition Support - new website

The Council for Disabled Children and partners are working as the national transition support team (ntst) for the Transition Support Programme. The ntst has developed a website to give further information about how the Transition Support Programme is progressing. It also includes a number of resources such as a Planning and Development Tool, designed to be used by local areas to help develop their transition practice. The website features an online discussion forum for people who work with disabled young people.

If you have any issues about transition that you would like to discuss or you would like to share an example of how your area is developing their transition services, please visit <http://www.transitionssupportprogramme.org.uk/forum/>

AET Blogs: Call for Professionals

Work on the new AET website is coming on apace. We need professionals who work with children and young people on the autism spectrum who are active bloggers to come forward for inclusion on the blogs page of the new website. If you are interested in getting involved, please drop us a line with the link to your blog to info@autismeducationtrust.org.uk.

KIDS - London SEN Mediation Service

Resolving School Based Disputes

Is your Local Authority increasingly delegating SEN funding to schools?

Are disagreements arising between schools and parents regarding SEN provision?

KIDS London SEN Mediation Service can provide a Mediation Awareness workshop for schools in your Local Authority. Contact us for more details on 020 7837 2900 or email audrey.dorival@kids.org.uk

An increasing number of cases referred to us are school based disputes regarding SEN provision for children on School Action or School Action Plus. Whilst we are aware of the arguments for and against delegated SEN funding, this is currently the climate in which we are all working. There is much debate about parental anxiety and lack of parental confidence in the SEN process. Schools and parents need to be supported. In our experience, the underlying issue for many of these cases is a breakdown of communication, trust and confidence between schools and parents.

Benefits of Mediation

If these cases are referred to us at an early stage, SEN mediation can help to:

- * Establish and clarify the real issues in dispute
- * Give parents and schools a neutral and supportive forum (professionally facilitated) in

which to express their views and achieve resolution

- * Rebuild trust and positive communication between parents and schools
- * Open up a dialogue for the future which benefits the child.

If disputes are not addressed effectively early on, schools and parents can become more entrenched in their positions and far less willing or able to resolve matters.

Diary Dates and Events

Online Training

From Mel Peeke:

If you haven't come across Greenspan before, he's the creator of the 'Floortime' approach to dealing with ASD (and other types of learning disability). This basically involves spending time on the floor with your child directing the play - but of course there's more to it than that! I think this costs around \$250 but given the amount of stuff covered over a six week period it might be money well spent for someone with a young child/early diagnosis who really wants to get into home therapy.

THE BASIC COURSE ON THE DIRR/FLOORTIME™ MODEL

Taught by Stanley I. Greenspan, M.D.

Clinical Professor of Psychiatry and Pediatrics, The George Washington University Medical School, Supervising Child Psychoanalyst, Washington Psychoanalytic Institute, and Chair, Interdisciplinary Council on Developmental and Learning Disorders

The course will be available online to registered participants for a six-week period from April 1 through May 13, 2009

The Basic Course Topics include: Assessment, Diagnosis and Intervention for Developmental and Emotional Disorders

Post-Conference Workshops

Meltdowns: Helping infants, children and

adolescents overcome behavior problems, aggression and tantrums: An 8 hour workshop for parents and professionals taught by Stanley I. Greenspan, M.D.

Regulatory Sensory Processing Disorders including Autism Spectrum Disorder, Regulatory Disorder, ADHD, Behavior Problems and Learning Challenges: A 12 hour workshop for parents and professionals taught by Rosemary White, OTR/L and Stanley Greenspan, M.D.

Workshops will be available online for a 4 week period, from April 15 to May 13, 2009.

Download a brochure with complete details and registration materials at:
<http://www.stanleygreenspan.com/PDF/BrochureIEC2009Brochure.pdf>

Parent Carer Action Group

(for parents of children with special needs up to the age of 19)

The next meeting of the **Parent Carer Action Group** is on Tuesday 21st April 2009 in a **new venue** - Campus West, Welwyn Garden City, Herts AL8 6BX at 10.30 - 12.00

Sheila Reynolds, Disabled Children's Service, Children Schools & Families, will speak about 'eligibility criteria' for Disabled Children's Services. Following this meeting there will be an opportunity to experience a taster of the Families in Focus programme for parents of children with special needs from 12.30 - 2 p.m. If you would like more information about this meeting or about how to become involved with the Parent Carer Participation Project, please contact Maria Kiely at west.team@carersinherts.org.uk or at *Carers in Hertfordshire*, 22a High Street, Hemel Hempstead, HP1 3AE - telephone number **01442 253344**.

Hillingdon Autistic Care and Support

CONFERENCE ON AUTISM
Saturday 16th May 2009

The speakers are:

Chris Mitchell, an adult with Asperger's Syndrome - will give a presentation entitled "Frozen in Time while Coping with Life's Impermanent Flow - A Personal Journey with Asperger's Syndrome"

Mitzi Waltz, Lecturer in Autism Studies at the University of Birmingham, who will give a presentation on "Autism and the Family"

Enquiries: HACS Tel No: 01895 271211

Fax No: 01895 273511

Email: enquiries@hacs.org.uk

(flyer and booking form also available from HARC office)

Free Parent Workshops

Cambian Education (provider of specialist residential provision for students on the Autistic Spectrum) would like to invite parents of children with Autistic Spectrum Disorder or Asperger Syndrome to Free Parent Workshops. The workshop will be chaired by a Parent Liaison Officer (Cambian Education) and speakers will include an Education Solicitor, Deputy Head and a Care Manager (Cambian Education). One of Cambian's former students will also talk about his experience and his journey through education and life.

The aim of the workshop is to learn about: Practical behavioural support strategies for parents, Legal strategies for statementing, Sensory strategies for parents and Meet other parents and experts

There are 2 workshops in June:

15th June 2009 - Birmingham
The Deaf Cultural Centre, Ladywood Road
Birmingham, B16 8SZ

16th June 2009 - London
Dragon Hall, 17th Stukeley Street
London, WC2B 5LT

For more information, please visit
www.cambianeducation.com

Listening to Carers

Carers in Hertfordshire are holding a Listening to Carers event in the Broxbourne Civic Hall for residents of the Borough of Broxbourne on 3rd April. The day is free to carers. You do need to register their interest due to the size of the venue and numbers for lunch.

To book your place please contact Roma Mills or Jayne Griffiths at *Carers in Hertfordshire* on 01992 586969

Hertfordshire Learning Disability Carers Forum

The Hertfordshire Learning Disability Carers Forum feeds directly in to the Hertfordshire Learning Disability Partnership Board (the body who oversees all the provision of services in the county). The Forum meets every 2 months at a central locality and all carers of adults with learning disabilities are welcomed and encouraged to attend. The aim is to provide family carers with the opportunity to talk about their experiences of the planning of the Community and Health Care Services for those with a learning disability in Hertfordshire. It is not primarily a support group providing emotional care but rather a means for carers to discuss how they can influence planning and development of Learning Disability services within Hertfordshire. The Forum provides information and an opportunity to meet other carers and also to hear speakers on issues relevant to Learning Disability.

Wellfield Room, Birchwood Leisure Centre,
Hatfield

Date of Next Meeting - Wednesday 22 April 2009 10 (ish) until 12.30

Health Facilitation Nurses will be coming to update the Forum on their work.

It's your life, take control - the story so far

Come along to a celebration of Hertfordshire's achievements in providing individual budgets to

people with learning disabilities.

The event will launch:

. a DVD of the first hand experiences service users, their families and carers and social workers

. a report written with 'In Control', a national organisation, capturing the journey for all those involved

People with learning disabilities, carers, service providers, and others are invited to join us for a presentation and to enjoy a buffet lunch on **Saturday 18 April 2009, 10am - 3pm** in Robertson House, Stevenage.

Contact Helen Potts on 01438 844456, or Jo Renney on 01438 843212, for more information and to book a place.

Westminster Briefing

There is to be a full day Westminster Briefing conference entitled "Healthy Lives, Brighter Futures, A New Strategy for 21st Century Children's Health" which will be hosted by The House Magazine on Wednesday 20th May 2009 in Westminster. Details at:

<http://www.westminster-briefing.com/?p=1472>

Challenging Behaviour Training for Parents

Hertfordshire's Special Advisory Service ASD Team have been offering this course to schools for two years now, and it has been very popular. They decided that it would be sensible to also offer it to parents (separate to schools so parents don't feel inhibited to say what they want). They have initially identified four venues in county, and the training will run over this coming Summer term. If it's popular, they will continue with it. See attached flyer for details and how to book.