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The National  
Autistic Society

harc HERTFORDSHIRE BRANCH

## September 2008 Newsletter

### *Imagine Thinking Differently*

Our joint project with Carers in Hertfordshire finally comes to partial conclusion on 2<sup>nd</sup> October at our Stakeholder Day at Robertson House, Stevenage. If you have taken part in this project by giving your story we would like you to attend this very important event. (An invitation to attend the stakeholder day is included). It is essential at this stage that we have good representation from carers of/and people with autism. During the course of the project we have spoken to approximately two hundred people who have a link or interest in autism and from this we have developed six propositions that will go forward to the event on 2<sup>nd</sup> October. We can still take your story if you wish to give it, the more people we talk to the more impact this project will have. You can contact Jo Willis at Carers in Hertfordshire ([jo.willis@carersinherts.org.uk](mailto:jo.willis@carersinherts.org.uk)) or Ann Griffin at harc ([support@harc-online.org.uk](mailto:support@harc-online.org.uk)), please head your email 'Imagine' or you can telephone Carers in Hertfordshire on 01922 586969.

### *I Exist Update*

Hertfordshire County Council have responded to the National Autistic Society's request for information on the services offered by HCC and the number of adults in Hertfordshire receiving services from or known by them.

"The "I Exist" report revealed that two thirds of local authorities do not keep records on adults with autism in their area, but 80% agreed that more information would help with long-term planning. Does your local authority have a system in place to record the numbers of adults with autism?"

*Hertfordshire County Council's Adult Care Services Department (ACS) and its partner, Herts Partnership NHS Foundation Trust (HPFT), both keep records of Adults with Autistic Spectrum Conditions (ASC) on their databases. This information has been used in the past three years to develop services for adults with ASC. We are in the process of further developing prevalence and needs information with other partners from the Private and Voluntary sector to inform future planning. Our aim is that this will inform future service developments, but that we will also use this to provide a comprehensive signposting system to assist adults looking for support. Known to services at this time are 50 adults with HPFT and 120 with ACS. (Editor's Note: Current Government thinking suggests that there are approximately 10,000 people with ASD in Hertfordshire).*

In line with Department of Health guidance, please can you tell us whether you have a team/individual with responsibility for Autism

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Spectrum Disorders (ASD) in your local authority, and who this is?

*Hertfordshire has leads for ASC in ACS and HPFT at a management level. We have a member of staff with a master's degree in Asperger syndrome, a lead who has a diploma in Asperger syndrome and a workforce of over 100 staff who have received a comprehensive 5 day course covering the autistic spectrum. A further 100+ staff from Health, ACS and the P&V sector along with family carers will receive the 5 days training over the next year. \*\**

Any further information?

*Hertfordshire County Council, its partners from Health, and the private and voluntary sector have been working to provide services and support for over 4 years. We now have 3 specific residential resources for adults with ASC in 3 separate areas of the county, all with trained staff.*

*In partnership with HARC (charitable support group) we have developed a very successful social group for adults, and it is our intention to expand this to other areas.*

*We have a specialist domiciliary care service for adults with ASC, this provides support and guidance with health, housing, education, work and leisure as well as practical support from buddy mentoring to advocacy.*

*We have developed a "pathway" document for adults who come in to our services, making the process much more ASC friendly.*

*We have a 3 year training programme, which is now 18 months in; the aim of this is to ensure we have an adequately trained workforce across all care groups, to provide a high degree of skills when working with adults with ASC.*

*As changes take place, we ensure that the needs of people with ASC are addressed, for example we are developing a new transition service over*

*the next year and this will enable us to develop a seamless service for younger people with ASC as they enter in to adulthood. All adults with ASC are also included as part of all other developments within Hertfordshire, including, Individual Budgets, Direct Payments, and Person Centred Planning.  
June 2008"*

**Jargon:**

HPFT - Herts Partnership Foundation Trust (Health)

ACS - Adult Care Services (Hertfordshire County Council)

\*\* The training referred to in the statement is: *Understanding Asperger syndrome and ASC for Professionals and Carers*

Dates for next training sessions are:

October 6<sup>th</sup> - 10<sup>th</sup>

December 1<sup>st</sup> - 5<sup>th</sup>

January 19<sup>th</sup> - 23<sup>rd</sup> - all held at The Pastoral Centre, Shenley. For further information or to book your place please contact Prime

Performance:

Tel 0845 257 3600

Mobile 07788 745510

Email [info@pps-training.co.uk](mailto:info@pps-training.co.uk)

**Do you agree with Herts County Council statement?**

If you are an adult with ASC or the parent/carer of an adult or a young person approaching transition please let us know if this statement reflects your experience. The more we know the more we can praise County or challenge their perceptions.

**I Exist Launch - cont'd**

Our last newsletter reported the launch of I Exist in Hertfordshire. The following is from a talk given by an adult with Asperger syndrome about the difference that attending the social group has made to her life. This is the social group, run in conjunction with harc, mentioned

in the HCC report on services for adults with ASC. It was hard for anyone at the launch to ignore the fact that such a low level and relatively low cost intervention makes such a huge difference in the lives of adults.

"I exist" Launch - WGC - 12 June 2008 -  
Representing the AS Group in St Albans -

The presentation started with this quotation:

"If a man does not keep pace with his companions, perhaps it is because he hears a different drummer. Let him step to the music which he hears." Henry David Thoreau

The AS group we have in St Albans, is the only means we have to reset our clocks at the rest of the world's time, without altering our rhythm.

A reassuring landmark - The feeling of deep relief when you have been lost for a long time, even your whole life, and you finally see a familiar sign you recognise, a sign that you have made it home.

Home from home - The only place where we can be and feel ourselves: normal, accepted, valued and worthy of life. Somewhere we know we will always belong.

A safe haven - A group of genuine friends who will never pressure you to conform, to be someone you can never be.

True professionals - Great carers, mental (health) nurses and organisers who are, probably for some members of the group, the only people who can give us really practical support on every aspect of our lives: personal concerns, social life, financial matters, work solutions, medical situations, even self-improvement.

The best well rounded out mentoring service - Every organiser is a great listener. They use

great therapy techniques to calm our fears, boost our self-esteem and give us the confidence to face the world again, week after week. They also follow our progress without prying into our private lives.

Fulfilling our needs and wishes - Every organiser is well informed and always willing to take the time to explain how to get the best help. They immediately put us in touch with the right people and follow the situation through, until it has been resolved, even if it necessitates a home visit. They take the time to look out for potential sources of worry and discuss all the possibilities to ensure we get both our needs and wishes fulfilled.

So well organised - Various activities in the form of debates, games and quizzes, designed to help us become more aware of others, more observant, develop self-esteem, to name just a few. We also have speakers who give informative talks on vital issues of concern, such as personal safety, financial matters, OCD (Obsessive Compulsive Disorders) and depression.

Group discussions (take place) where everyone is shown the same respect and everyone is treated with the same dignity. The debates are well monitored, allowing everyone to voice their opinion and influence the choices for future activities.

We all wait for Monday morning with great anticipation. We cannot imagine a week without our group: there is no better way to start the week.

Thanks to all their help and constant support, we feel that we can make our dreams come true. We now feel that we have the right to enjoy life!"

## ***Forthcoming Activities***

### **Hadrian Exhibition**

The British Museum are offering a special opening time for disabled visitors who would like to visit the Hadrian exhibition when it is less crowded. You can visit the exhibition from 9.00am Friday 3 October. If you would like more information or details you can contact Naomi Braybrooke at the British Museum - details are below:

Naomi Braybrooke  
Access Manager  
The British Museum  
Great Russell Street  
London WC1B 3DG  
Email: [NBraybrooke@thebritishmuseum.ac.uk](mailto:NBraybrooke@thebritishmuseum.ac.uk)  
Tel 020 7323 8506

### **October Half Term Scheme - North London**

Resources for Autism are offering an opportunity for young people with autism aged 8 - 19 to attend this five day scheme during the October half term. Booking form and further information attached.

### **Transition Information Network - Seminar**

The next Transition Information Network (TIN) seminar is on the theme of 'The Ten Year Youth strategy -disabled young people too!' It will be held on **Thursday 30th October 2008** at:

National Youth Agency  
Eastgate House  
19-23 Humberstone Road  
Leicester  
LE5 3GJ

This seminar, organised by TIN with the National Youth Agency (NYA), will provide an opportunity for professionals who work with young disabled people to hear about

developments in youth services and provision, national policy updates and examples of regional and local good practice, as well as having an opportunity to reflect on learning and discuss how it might impact on their work.

A draft programme with information on how to book a place is attached.

## ***Update from the NAS Regional Office***

The Regional Office recently sent the following update to us.

### **SENCO success**

The Government has announced £10 million a year for training for special educational needs co-ordinators (SENCOs) in schools. Training for SENCOs was a key demand of the *make school make sense* campaign and, following our lobbying during the campaign, the Government has assured us that the training includes a focus on autism.

This announcement builds on other recent Government commitments which meet our *make school make sense* campaign demand to get "the right training for every teacher". These include regulations to ensure all SENCOs are qualified teachers, and a commitment of £500,000 for training for new teachers in SEN and disabilities, as well as new guidance on bullying of children with SEN and disabilities. You can read more about the National Autistic Society policy and campaigns team's recent successes at <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1318>

The NAS have also recently gained a number of concessions on the current Education and Skills Bill going through Parliament, to ensure **protections are in place for children with autism who may be removed from school premises** as a result of their behaviour. We are continuing to lobby to ensure that appropriate

support is in place for children with autism who are excluded from school, as well as on a number of other areas of education policy.

### **Autism Adviser post in the Department of Health**

Interviews took place recently for the specialist autism adviser post in the Department of Health. An appointment is expected shortly.

This was one of the key demands of the *I Exist* campaign and the NAS are delighted that this has been implemented so quickly. One of the roles of the adviser will be to lead the development of a national autism strategy - a fantastic achievement just a few months into the campaign, and testament to the fantastic efforts of the NAS branches and other supporters.

We all need to keep up this momentum to ensure that this progress at national level is matched by local action. Please continue to encourage people in your area to get involved in the campaign at:  
[www.think-differently.org.uk/takeaction](http://www.think-differently.org.uk/takeaction).

### **Creativity Competition: first exhibition venue confirmed.**

Thanks to everyone who has already sent in examples of their work to enter the creativity competition. NAS have received many examples of written work, so are particularly keen to see more of people's 2D artwork and photography. Please keep the entries coming by encouraging as many of your contacts as possible to take part!

(Note: If you have lost your entry form/information contact [harc](mailto:harc) and we will send you one)

The shortlisted entries, along with a selection of other works, will be displayed as part of an exhibition in February next year. The first venue for the exhibition will be the Mitchell Library, Granville Street, Glasgow, where it will be on display from Monday 16 - Friday 20

February. For further information about this please contact Anne Kennedy by emailing [anne.kennedy1@nas.org.uk](mailto:anne.kennedy1@nas.org.uk) or calling 0141 285 7111.

### **New Facebook application launched**

NAS have just launched an exciting new application, which allows Facebook users to find out more about autism and support our campaigns at the click of a button as well as getting the latest news from the NAS and signing up for regular updates.

The application is available to download at [http://apps.facebook.com/the\\_nas/](http://apps.facebook.com/the_nas/). If you use Facebook please download it today and encourage your members to do the same.

NAS have also had a very successful Facebook group which over 8,500 supporters have joined since the launch of think differently about autism in October, and a MySpace profile ([www.myspace.com/nationalautisticsociety](http://www.myspace.com/nationalautisticsociety)).

The NAS hope that by developing a presence on these social networking sites they can raise awareness of autism among a whole new audience as well as making it even easier for existing supporters to get involved in their work. This is a relatively new area for NAS, so if you have any comments or suggestions about the application or the way that they are using these sites generally, they would love to hear from you. Please email [thinkdifferently@nas.org.uk](mailto:thinkdifferently@nas.org.uk) or call 0207 923 5799.

### **Aiming High for Disabled Children**

Last year HM Treasury and the Department for Education and Skills (now the Department for Children, Schools and Families) carried out a joint review aimed at improving services for disabled children in England.

The report from the review, *Aiming High for Disabled Children: Better Support for Families*, committed the government to providing an

additional £430 million to transform services for disabled children.

This includes an extra £370 million which has been allocated to local authorities in England from April this year to develop additional short breaks services for disabled children and their families. It's really important that the money is spent in a way which will benefit children with autism and their families, and NAS have prepared a briefing which explains how you can influence this. Please visit [www.autism.org.uk/ahdc](http://www.autism.org.uk/ahdc) to find out more.

### **LINK**

Local Involvement Networks are currently being set up in every local authority area in England to allow people to influence their health and social care services. Any individual or group can join and you can choose whether you want to just comment on issues when contacted by the LINK or whether you want to get more involved.

The Department of Health has produced an easy-to-read guide to LINKs, which can be downloaded [here](#).

This could be a great opportunity for you and your members to influence service provision in your area, especially as the Networks are at a formative stage and only beginning to decide what their priority areas of work will be. To find out more simply contact the local authority official responsible for the LINK in your area.

*(Editor's Note: you will be aware from previous newsletters that we have a representative on the Hertfordshire LINK, Sue McCann, however, Sue is on the LINK as an individual and feels that we would be well represented if we had a group representative as well. If you read the information on the NHS site and decide this is something you would like to be involved in please let us know and we will forward your details to the appropriate person).*

### **Changes to SENDIST - latest news**

Following up the forthcoming changes to SENDIST, the NAS has submitted a response to the draft Health, Education & Social Care Tribunal rules. As mentioned previously these rules have caused a lot of concern and confusion as they have been released without an additional document which will explain how these rules will apply specifically to SENDIST, known as the Practice Directions. Without these Practice Directions we, along with everyone else, have had to respond to the rules assuming a worst case scenario.

As a result of the concern and misinformation that is circulating at present, SENDIST has also published a newsletter to try to allay people's fears. Further information, along with the NAS response to the consultation and the SENDIST newsletter, can be found on the NAS website at [www.autism.org.uk/SENDIST](http://www.autism.org.uk/SENDIST).

The NAS are calling for the Practice Directions to be released into the public domain as soon as possible to end the uncertainty which is currently causing parents so much anxiety. You can support our efforts to do this by writing to your MP to ask them to raise your concerns with the Secretary of State for Justice.

The NAS Advocacy for Education service is still very much involved in the ongoing negotiations. We want to reassure you all again that we are doing everything possible to represent your interests to ensure that whatever changes do eventually take place, parents will not be disadvantaged by the new system.

### **Minister's visit**

Disability Minister Anne McGuire visited Mansfield House in Croydon. The Minister met with a group of adults with autism, who directly quizzed her about what more the government could do to empower people with autism. During the visit Anne also met with staff from the service and NAS Chief Executive Mark Lever, who stressed to her the importance of ensuring

that people with autism receive the right support.

The visit was a great success, thanks to all those involved, and clearly made a big impression on the Minister. Later that day at the launch of the Welfare Reform Green Paper, the Minister publicly stated that her experience that morning had highlighted to her the importance of people with autism getting the specialist support that they need to work. She went on to cite the NAS as a shining example of how this support can be provided, based on the work that Prospects does in partnership with companies like Goldman Sachs.

### **Charity of the Year**

The National Autistic Society has just been shortlisted for KPMG's charity of the year - if we win, we will receive £750,000 over two years for boosting our befriending programme. So if you work for KPMG or know anyone who does, **please encourage them to vote for us!**

### **Web enquiries**

If you have a problem or query related to the NAS website, please remember to address your enquiry to [webeditor@nas.org.uk](mailto:webeditor@nas.org.uk) - this email is answered on a rota basis and means that you will receive a reply more quickly than if you address it directly to a named person.

### **Christmas cards**

National Autistic Society Christmas cards will once again be available to branches at a special price of £2.40 for a pack of 10 cards (sale or return, minimum order 20 packs and no additional postage charge).

We have held the price for branches this year, and it is a big discount on the normal price of £3.50-£3.95 per pack. We have another great selection of cards this year - for details please see [www.autism.org.uk/Christmascards](http://www.autism.org.uk/Christmascards)

***Please see the catalogue included with this newsletter.***

### **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 freephone 0800 9520 520 and leave a message on our 24-hour answerphone.

To find out more about volunteering for the service phone Nicole Rae on 0115 8473516 or email [parent2parent@nas.org.uk](mailto:parent2parent@nas.org.uk)

### **Support for Parents**

esSENTial is a support group for parents of children with ASD/ADHD in Hemel Hempstead. A flyer about forthcoming support meetings is attached for information.

### **Carers**

**Date for your Diary - Carers in Hertfordshire  
Parent Carer Action Group**

30<sup>th</sup> September 2008 -10.30a.m. to 12.30 p.m.  
meeting at Oxlease House, Hatfield.

*Buffet lunch 12.30p.m. - 1.30 p.m. Please contact Carers in Hertfordshire for further details (01922 586969)*

### **Training Courses run by Carers in Hertfordshire**

Please do look at the workshops that Carers in Hertfordshire are organising -although not specifically for Parent Carers (information in your recent local Carers in Hertfordshire newsletters or on the website <[www.carersinherts.org.uk](http://www.carersinherts.org.uk) under Carers Calendar of events) - some of which you may be interested in e.g. relaxation and how to recognise stress, being a carer. Contact your local team to book a place. You will note that different workshops are being run in different areas.

### **NAS concerns highlighted by parliamentary committee**

The Work and Pensions Select Committee, an influential committee of MPs, has published its report 'Valuing and supporting carers'. This report contains the findings of their Carers Inquiry which looked at the Department for Work and Pensions approach to Carers and was largely concerned with benefits and employment opportunities. NAS were heavily involved with the Inquiry, giving both oral and written evidence, as a result autism is mentioned throughout the official report, which is fantastic.

NAS are quoted throughout the report, for example giving evidence for the NAS, Amanda Batten drew attention to the pitifully low level of Carers Allowance and her comments are quoted in the report:

"Just to demonstrate how inadequate Carer's Allowance is, even if you did the minimum caring hours of 35 hours a week, that is equivalent to £1.44 an hour compared to a minimum wage of £5.52."

Amanda also presented the case of a carer who has two sons with autism and who had written to the Prime Minister itemising all the additional expenses their family faced and highlighting the failure of the benefits system to meet these.

This had a particularly strong impact on the Committee.

We placed strong emphasis on the need for Carer's Allowance to be increased to better reflect the contribution made by carers and on the need for improved access to advice on carers' rights and entitlements, especially post diagnosis. As a result of this the report makes repeated references to the failure of the current benefits system to recognise the needs of people with autism and their carers.

The Government is required to respond to Select Committee reports, so will need to address the issues we've raised.

You can read the full report and the NAS' evidence at:

<<http://www.publications.parliament.uk/pa/cm/cm/mworpen.htm>

Rebecca Rennison  
Policy and Parliamentary Officer  
The National Autistic Society

### **Research and Surveys**

We receive many requests to ask our members to take part in research and surveys. Whilst we always try to offer the opportunity to our members it does not mean that we endorse these in any way. Participants must make their own assessment to take part or not.

We have received the following request from Lydia Luke a PhD student in the Developmental Psychiatry Section of University of Cambridge.

"I hope you don't me contacting you. I'm a PhD student at the University of Cambridge, and I'm carrying out a survey of the decision-making experiences of adults with autism spectrum conditions. The survey is supported by the NAS and was advertised in Communication earlier this month.

I would like to work with adults with autism spectrum conditions, and family members of adults with autism spectrum conditions."

If you are interested in taking part in this survey please contact Lydia by email to [lrl29@medschl.cam.ac.uk](mailto:lrl29@medschl.cam.ac.uk) or telephone 01223 746031.

This request comes from Victoria Miller, Melbourne, Australia.



### Investigating the Gender Profile of Autism

"My name is Victoria Miller and I am inviting parents and teachers to participate in my investigation on the profile of autism by gender. I am conducting this study with my supervisor, Associate Professor Mark Stokes, for the thesis component of my Doctorate of Clinical Psychology at Deakin University in Melbourne, Australia.

The purpose of my research is to investigate the possibility that some girls and boys with High Functioning Autism or Asperger's Syndrome are not being diagnosed because they appear differently - these girls and boys just seem 'different' in some way but people don't properly understand why.

Being able to better understand high functioning autism (HFA) and Asperger's Syndrome (AS) may allow more girls and boys with HFA and AS to be referred and diagnosed during early childhood rather than later in adolescence and therefore access services such as early intervention programs. This may prevent some of the later difficulties that can develop for these groups such as mood disorders like anxiety and depression, educational problems and an increase in social and

relationship difficulties during high school. For my research I am seeking parents of children and adolescent males and females with and without HFA or AS to fill out a 20 minute questionnaire about their child or children in order to better understand the ways in which males and females with HFA are similar and different in areas such as appearance, communication, peer relationships and behaviour at home and school.

This might help us to make important gains in beginning to understand the role of gender in HFA and AS. If you would like to participate in this research, or would simply like some more information simply follow the link below link to our online questionnaire:

<http://www.deakin.edu.au/psychology/research/genderprofile>

If you have any comments or questions please feel free to contact myself [vcm@deakin.edu.au](mailto:vcm@deakin.edu.au)), or my supervisor Professor Mark Stokes ([mark.stokes@deakin.edu.au](mailto:mark.stokes@deakin.edu.au)).

We look forward to hearing from you."

### Common Assessment Framework

One of our members has suggested that we write something about the Common Assessment Framework (CAF). CAFs have been put in place since April 2008. The following is information taken from the Every Child Matters website referring to CAF. [www.ecm.gov.uk/caf](http://www.ecm.gov.uk/caf)

The Common Assessment Framework (CAF) is a key part of delivering frontline services that are integrated and focused around the needs of children and young people. The CAF is a standardised approach to conducting an assessment of a child's additional needs and deciding how those needs should be met. It can be used by practitioners across children's services in England.

The CAF will promote more effective, earlier identification of additional needs, particularly in universal services. It is intended to provide a simple process for a holistic assessment of a child's needs and strengths, taking account of the role of parents, carers and environmental factors on their development. Practitioners will then be better placed to agree, with the child and family, about what support is appropriate. The CAF will also help to improve integrated working by promoting co-ordinated service provision.

12 local areas formally trialled the CAF and the role of the lead professional during 2005-06; trials were evaluated by the University of East Anglia (UEA). Over two-thirds of local authorities chose to use the CAF during the trial year and materials were issued in April 2005 to support implementation. An evaluation report will be made available on the [DCSF research website](#) in the near future.

Alongside the UEA evaluation, we worked with the trialling groups to identify any early lessons, enabling them to share good practice and inform further development of the CAF materials. Following wide consultation, revised CAF materials have been issued, including practitioners' and managers' guides, CAF form, pre-assessment checklist and supporting tools.

All local authority areas are expected to implement the CAF, along with the lead professional role and information sharing, between April 2006 and March 2008."

There are ten districts in Hertfordshire and each have a team of people who sit on a MAST - Multi Agency Support Team. The MAST consists of managers who can make decisions relating to their service and is called into action where the individual agencies do not make the decisions they should according to the lead professional. The Lead Professionals role is to coordinate the services required to ensure the child's needs are met. A CAF can only be put in place with the agreement of the parents.

Training for the CAF is ongoing particularly for those who are deemed to be lead professionals.

Through my working role I sit on the Welwyn Hatfield MAST and the Welwyn Hatfield District Children's Trust Partnership. There is a close link between both the MAST and DCTP. Many agencies have one person who represents their service on all ten district MASTs. I believe that once the CAF is fully operational and understood that it will benefit children with ASD/ADHD as its role is to coordinate all the services that are required to ensure the child's needs are met.

I have often felt that this holistic approach will pay dividends for a child with Autism. I have also asked Adult Care Services and Herts Partnership Foundation Trust why this CAF approach cannot be used for adults with ASD. This suggestion was met with silence.

The CAF comes into being when a professional dealing with a child recognises that more agencies need to be involved and at that stage the professional will complete the framework (questionnaire) and become the Lead Professional. A CAF register will be held to ensure that Lead Professionals can check to see if a CAF has already been drawn up. If so they would then make contact or be able to see what has happened to date. This approach should mean that you, as parent, do not have to keep repeating your story over and over again. That in itself is a good step forward. Your child's school will be aware of the CAF and many teachers will become Lead Professionals. CAFs are in their infancy and I suspect will take a little time to really show their worth. If you have any questions that you think I may be able to answer then please contact me via the harc office or email.

Ann Griffin

## Disability Living Allowance (DLA) Information

Following a Support Group Meeting earlier in the year on how to apply for DLA, Frank Pittfield, the speaker from the Wembley Disability Benefits Centre, has put harc on his circulation list to receive regular updates on benefit news. The latest two updates concern DLA and Employment and Support Allowance (ESA).

<http://www.dwp.gov.uk/lifeevent/benefits/dcs/newsletters/2008/news-may08.pdf>

The following are links to the Disability and Carers Service website and the Department of Work and Pensions (relevant to advisers).

<http://www.dwp.gov.uk/lifeevent/benefits/dcs/>

<http://www.dwp.gov.uk/advisers/>

It is worth having a look at these sites to help to keep updated. ESA replaces Incapacity Benefit and Income Support for some people from October 2008. Remember that if your child is aged 16 and not in full time work they may be able to apply for Incapacity Benefit although this may change from October this year. The following has been 'captured' from the website and hopefully gives an understanding of the changes that are imminent.

### Key facts about Employment and Support Allowance

The key things you need to know about Employment and Support Allowance.

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#### New customers only

For new customers, Employment and Support Allowance will replace Incapacity Benefit and Income Support paid on incapacity grounds. Existing Incapacity Benefit or Income Support customers will initially continue to receive their

existing benefits, so long as they satisfy the entitlement conditions.

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#### Personalised support

Employment and Support Allowance offers personalised support and financial help if people are not working due to an illness or disability. It gives people access to a specially trained personal adviser and a wide range of further services.

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#### Medical assessment

Central to Employment and Support Allowance are the new medical assessments which examine what people can do, rather than what they can't, and identify what personal support they might need.

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#### Work-focused interviews

Most people claiming Employment and Support Allowance will be expected to take appropriate steps to help prepare for work, including attending a series of work-focused interviews with a personal adviser.

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#### Support Group

Under Employment and Support Allowance people with an illness or disability that means they are unable to undertake any form of work-related activity will get increased financial support and will not be expected to prepare for a return to work.

For more information about ESA go to the DWP website ([www.dwp.gov.uk/esa](http://www.dwp.gov.uk/esa)) or contact Money Advice Unit on 019921 556370 also see attached information flyer.

#### Donation to harc

A huge thank you to our Treasurer Paul Phillips parents, Leo and Muriel Phillips who very kindly

asked for donations from friends and families rather than gifts to celebrate their golden wedding anniversary. We are delighted to receive this very generous donation of £340.

### **The NAS says "thank you" to harc**

"The National Autistic Society is running its help2 seminars Sept 16th/17th at the Gosling sports park again. These have always been so well attended by parents in the Hertfordshire area that we decided to come back and meet that need. harc have very kindly offered to pay for the venue and we would like to thank them for this very kind offer. It means that we can hold these seminars at a venue that is popular with parents, so ' Thank you harc ".

Jacqueline Smith  
help 2 Programme Officer  
South East Region  
The National Autistic Society  
Mob: 07825 193204  
[Jacqueline.smith@nas.org.uk](mailto:Jacqueline.smith@nas.org.uk)

### **A Cautionary Tale**

For those of you with young adults who own mobile phones the following may be of interest to you.

A young man with Asperger syndrome was offered a new handset by a mobile phone company. This handset came with a big screen making it much easier to view internet pages. He happily sat hour after hour downloading files from the internet and then received his first bill for £900+. He kept this information from his family and tried to deal with the mobile phone company himself. The next month his bill had risen to £2000+. He again rang and asked them to cap his account, told them he had Asperger syndrome and was finding it difficult to make the call and to understand all that they were telling him. By the end of month three his bill was over £4000. He rang the mobile phone

company again and they told him he would have to set up a payment plan and in the meantime they disabled his account. The payment plan he had to agree to (because they told him that was what he had to do) was for £600 per month. This young man works one day a week and earns about £200 per month. He used what little savings he had and went to the bank and took out an overdraft for £2000. Still he couldn't pay off all of the bill. He told his parents the day before the debt collection agency were to take him to court.

This had gone on for months with the young man being scared to open the door or answer the phone in case it was bailiffs. He was fortunate that he lived at home or he could also have been homeless. Once his parents knew about the problem and contacted the mobile phone company they were able, within a week, to get the bill waived and all money he paid to them back. He now has a 'pay as you go' account and hopefully the knowledge that he needs to involve his parents earlier. One of the key points that his parents made to the mobile phone company was the fact that although he disclosed his disability no-one responded to him. The parents therefore gave the mobile phone company information about Asperger syndrome in the hope that this might help others in the future.

The lesson in this story is to be aware that downloading from the internet does not equate to time spent on there but to the size of the file being downloaded. This is very difficult to see and can soon run away with you.

### **Open Day at Kestrel House**

Kestrel House is a new school for children aged 1 - 12 years old with Autism. They are hold open days in September for professionals and parents. For further information please see attached flyer.

## **Awareness Raising Sessions in Schools**

Awareness raising sessions in Hertfordshire schools have begun again with the start of the new academic year. We have some more scheduled for this first term. We want to get into as many schools as we can to deliver our session so if you think your child's school would benefit please let us know or ask the school to contact us. We will go wherever we need to in Hertfordshire.

## **Membership**

We are pleased to tell you that membership of harc continues to rise with a further 10% increase since June.

## **NAS Resource Centre at Boxmoor House - Hemel Hempstead**

harc are delighted that the NAS are opening a Resource Centre on the site of the Boxmoor House School. This is a very innovative step for the NAS. They have opened resource centres in many areas of the UK, however, these have usually been opened where an existing provision exists. The difference with Boxmoor House is that no existing provision is here. NAS will employ a project manager to apply for funding and tender to deliver services that will help people with autism throughout Hertfordshire. The NAS have committed to this project for two years after which time harc will manage the provision.

Interviews are due to take place for the Project Manager and Administrative Assistant roles. Applications for these roles are currently being short listed with a view to the centre opening in January 2009.

This is a very exciting time for Hertfordshire and harc are very pleased that the NAS have chosen Hertfordshire for this project.

## **Support Group Meeting**

Our next support group meeting is our volunteers afternoon on **27<sup>th</sup> September between 1.30 and 3.30 pm** at the Gosling Sports Park, Welwyn Garden City. You should have received notification of this event. Please think about whether you can help us regularly or whether it is with one off projects. If you think you can give us just a little of your time, or know someone else who could, please come along. There is still much work to do and we need a good cross section of skills to ensure we do the best we can for people with autism.

If you can offer some time but are unable to attend on 27<sup>th</sup> September, please let us know, we will be happy to meet with you separately.

## **Ten Minute Rule Bill**

Don't forget the second reading of Angela Browning's 'Autism Bill' takes place on October 17<sup>th</sup>. Following discussions with NAS the bill has now been expanded to cover the issues facing both adults and children. The bill will be published in the next few weeks. Please urge your MP to support the bill on October 17<sup>th</sup>.

## **And Finally .....**

*This is your newsletter, please let us have your stories, your views, your comments. Have we got the balance of stories/articles right? What do you want to see in here? If you think we have the content and balance about right then please tell us, just a quick email to tell us yes or no will make such a difference.*



# October Half Term Scheme

Are you looking for something fun to do this Half Term? Would you like the chance to meet other young people? Mums and Dads would you like to have some time to yourself? Then look no further than Resources for Autism's Half Term Scheme!

Our Half Term Scheme will be running for 5 days in North London. Places will be allocated in individual days, 10am until 3pm. Monday to Friday 27<sup>th</sup> October to 31<sup>st</sup> October.

There will be a range of activities within the playscheme, both centre based and in the community depending on the needs of the group. The main objective is to have fun!!

The cost for the club is £20.00 per day. This will be payable by invoice in advance. Concessions may be available on application. If payment is not made before the start of the scheme the place offered will be cancelled. Young people need to be aged between 8 and 19.

If you are interested then please complete the booking form below first and return as soon as you can. As we are trying to make the groups as safe as we can it may mean that we cannot offer you the day of your first choice. Places will be allocated on a first come first served basis. Therefore please return the form as quickly as possible to book your space.

Please return completed forms to Catherine Ely, Resources for Autism, 858 Finchley Road, Temple Fortune, NW11 6AB Tel. 0208 458 3259 email: catherineely@resourcesforautism.org.uk

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## **OCTOBER HALF TERM SCHEME 2008**

Name of child/young person.....

Name parent/s or carer/s.....

Address.....

Telephone.....

Please indicate which dates you wish to attend

.....

***Free Seminar for professionals***

**‘Ten Year Youth strategy – disabled young people too!’**

**Thursday 30<sup>th</sup> October 2008**

**National Youth Agency  
Eastgate House  
19-23 Humberstone Road  
Leicester  
LE5 3GJ**

**Aims**

This seminar, organised by TIN with the National Youth Agency (NYA), will provide an opportunity for professionals who work with young disabled people to hear about developments in youth services and provision, national policy updates and examples of regional and local good practice, as well as having an opportunity to reflect on learning and discuss how it might impact on their work.

**Draft Programme (subject to change)**

- |       |   |
|-------|---|
| 10.30 | Arrival, Registration and Coffee  |
| 11.00 | Welcome and introduction to TIN and NYA   |
| 11.10 | Policy update, Sarah Hargreaves, NYA and Lucia Winters, TIN   |
| 11.40 | Policy links and what’s happening at local and regional level   |
| 12.00 | Going places: ensuring the play and youth strategies deliver for disabled children and young people – a chance to hear about the Every Disabled Child Matters campaign's latest work with disabled young people |
| 12.30 | Lunch   |
| 1.15  | Workshops will provide a chance to examine issues in depth<br>Turn over for details   |
| 2.30  | Feedback from workshops   |
| 3.00  | Panel discussion – disabled children’s section and Youth section, announcing piece of joint working/targets   |
| 3.30  | Close   |

## Workshops

### **Workshop 1: Wecan2 – Mencap project (Confirmed)**

Hear about the **Wecan2** project that was led by young people with a learning disability. The young people researched barriers to their involvement in formal participation and looked at ways they could overcome them and take part more fully. They met with youth service staff and looked at ways of involving disabled young people.

This workshop will be co-presented by Paul Smithson, Youth Participation Officer, Mencap, alongside young people who took part in the project.

### **Workshop 2: Youth Services in NE Lincolnshire (TBC)**

**In this workshop you will hear how disabled young people access youth service provision in NE Lincolnshire.**

### **To book a free place**

Please contact Victoria Wright on 020 7843 6006 or [vwright@ncb.org.uk](mailto:vwright@ncb.org.uk). Please give your name, telephone number, email address and any access or dietary requirements.

# esSEntial support

Physical disabilities

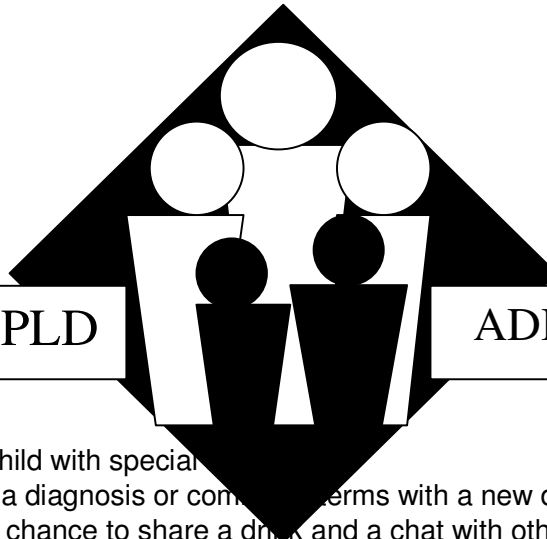
Autism/ASD

Chromosome  
Disorders

Speech &  
Language

Dyslexia/SPLD

ADHD



- Do you care for a child with special needs?
- Are you waiting for a diagnosis or coming to terms with a new diagnosis?
- Would you like to have a chance to share a drink and a chat with others to celebrate your child's achievements or even have someone to share the more challenging times?
- Would you like to find out more about your child's needs and the provision available?

**Come along to for informal chat, occasional speakers and children's events**

The second Monday each month 8:00 'til 10:00

8<sup>th</sup> Sept

13<sup>th</sup> Oct

10<sup>th</sup> Nov

8<sup>th</sup> Dec

12<sup>th</sup> Jan

9<sup>th</sup> Feb

9<sup>th</sup> March

April (Easter) No meeting

11<sup>th</sup> May

8<sup>th</sup> June

13<sup>th</sup> July

**Pat Lewis Child Development Centre**

Heath Lane

Hemel Hempstead

Herts

HP1 1TT

For further information please email [essentialsupport@ntlworld.com](mailto:essentialsupport@ntlworld.com) and we will get back to you.