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The National
Autistic Society

harc HERTFORDSHIRE BRANCH

February 2009 Newsletter

Autism Bill

Welcome to the first harc newsletter of 2009. We signed off the last one in the hope that 2009 would bring us the changes we need to support those we care for. Hopefully you will have seen or heard the exciting news that Cheryl Gillan presented the Autism Bill to Parliament in January. The Bill goes to its second reading on 27th February, this is a Friday and MPs are not normally present in the House on a Friday. It is very important that one hundred MPs are in the House and prepared to vote for the Bill to take it to its next stage. Just to remind you the Bill is structured to amend existing Acts and the headlines are as follow:

1. Duty to record number of disabled children
2. Duty to promote effective transition for young disabled people
3. Duty to recognise the needs of adults with autism
4. Duty to promote support services for persons with autism

We enclosed a copy of the draft Bill with the last newsletter. If you have mislaid it and would like another copy let us know and we will send it to you.

To date 90 MPs have committed to supporting the Bill, two of these are Hertfordshire MPs, Anne Main (St Albans) and Mike Penning (Hemel). There are another six MPs in Hertfordshire, please contact them to ask them to support the Bill or better still can you arrange a face to face meeting with them? If so, can you organise for a group of people to attend? There is no doubt that speaking directly to people makes a difference. Is your MP serious about autism?

The NAS are also asking us to write to our local newspapers to raise the issue. Their view is that MPs read local papers so it is another way to bring it to their attention. You can do this on line through the NAS website (www.autims.org.uk) or writing directly to your local editor. If you need any help, support or guidance with this please contact the office, we are happy to help.

Family and friends in other parts of the country can also help by contacting their MPs and asking them to support the Bill and writing to their local newspapers.

Thank you to all those who have contacted your MPs. It is likely that Cheryl Gillan presented the Bill because one of our member contacted her. It shows that we can and do make a difference. Don't forget to let us know about

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any contact you have with your MP or pass it directly to the Campaigns Team at the NAS.

We have been congratulated by the NAS for the way we have been effectively campaigning for this Bill. Thank you to everyone who has helped us.

NAS Campaign Update

From Laurence Griffin - Branch Officer:

I wanted to update you on a few things that the NAS campaigns team are working on at the moment, which you may want to get involved in.

The Gary McKinnon case

Many of you may be aware of the case of Gary McKinnon, a man with Asperger syndrome who is appealing against extradition to the US where he will face charges of hacking into US defence computer systems.

On January 20 2009, a hearing was held to determine whether Gary McKinnon's case can go to judicial review. This is the last legal challenge that could prevent his extradition to the United States, where he could face up to 60 years in prison.

Unfortunately, Gary only recently received his diagnosis of Asperger syndrome, and so neither the district judge nor the High Court were able to take his condition into account when they reached their decisions in favour of extradition.

The National Autistic Society has already written to the Home Secretary, Jacqui Smith, urging her to take Gary's Asperger syndrome into account when making a decision on his case, and now we need as many of our supporters as possible to do the same.

The NAS launched an email action to the Home Secretary on Wednesday 14th January. The High Court has now granted a Judicial Review of the decision to extradite. This review does not guarantee that Gary is not extradited so urgent action is still required.

If you would like to help with this campaign please visit <http://www.autism.org.uk>, where the action will be on the front page and please encourage as many of your contacts as possible to do the same.

Employment and Support Allowance: Case studies urgently needed

A new benefit, Employment and Support Allowance (ESA), was introduced in October for people who are incapable of working because of illness or disability. The NAS have a number of concerns about this new benefit, and are conducting research to establish how it is working for adults with autism in practice.

The NAS urgently need to find adults with autism who have applied for ESA, or their carers, who are willing to participate in our research. If you are interested, please complete our online form at

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1895&a=18370>, or contact the NAS directly.

We'd be very grateful if you would also forward this link to anyone you know who might want to take part in the research.

APPGA Inquiry into Transition: have your say

The All Party Parliamentary Group on Autism (APPGA) - a formal cross-party backbench group of MPs and peers who all share an interest in autism - has launched its first ever inquiry on transition.

As we know, the transition stage between age 14 and 25 can be a difficult time for people with autism, but unfortunately it is often overlooked by policy makers. The inquiry will gather written and oral evidence into a final report. Members of the APPGA will then use this evidence to take forward the report's recommendations in Parliament.

The inquiry is a great opportunity to get parliamentary time for this important issue, and your contributions will make the report much stronger. You can submit evidence as an individual or an organisation and you could also encourage others to get involved.

To find out more about the inquiry and to submit evidence using our online form, please visit www.autism.org.uk/appgainquiry. Although the closing date for this was February 6th, you may still be able to comment.

I Exist Creativity Competition Exhibition: Dates for your diaries

We will be holding exhibitions of work entered into the I Exist Creativity Competition in February. Dates and venues below - further details will follow in the newsletter at the end of this month:

16th - 20th Feb: Mitchell Library, 201 North Street, Glasgow, G3 7DN

24th - 28th Feb: The Galleria Pall Mall, 30 Royal Opera Arcade, London, SW1Y 4UY

C4A Meeting

The C4A is a forum for carers (parents, carers, spouses, siblings) of adults with AS/HFA. The group is facilitated by Carers in Hertfordshire and meets monthly on a Monday in Hatfield. The next meeting is:

Date: Monday, 23 February 2009 at
Venue: Oxlease House, Travellers Lane,
Hatfield
Time: 7.30 until 9.30pm.
Topic: Speaker from the Individual Budgets team to talk about how this system of financing care works.

For more information contact Jo Willis at Carers in Hertfordshire on 01992 586 969 or email: jo.willis@carersinherts.org.uk

NAS Update

We have received the following information from National Autistic Society in their November bulletin:

New guide to assessing the needs of adults with autism

Research for the *I Exist* campaign shows more than two-thirds of local authorities think that care managers don't have sufficient training in autism. Yet, with greater understanding of the way autism affects each person differently, assessors can make sure that support and resources are directed in the most appropriate and cost-effective way.

That's why we have recently published a new booklet "Social care: assessment of need for adults with an autism spectrum disorder", which has practical advice for staff preparing and carrying out assessments for adults with autism. Whilst it is principally aimed at assessors, it would be useful reading for anyone supporting a person with autism.

(Editor note: harc have a number of these booklets, we agree that they are an extremely useful tool in assessing adults with autism. If you would like a copy let us know).

Supporting adults with autism: how is your authority doing?

On 1st December we went live with our progress tables showing how every local authority in England, Wales and Scotland has responded to the *I Exist* campaign. The tables are online at www.think-differently.org.uk/campaign.

As well as publishing their full response, we've also ranked authorities based on whether or not they have a system in place to record the number of adults with autism in their area (including work to identify those not currently receiving services) and whether they have appointed a named individual (at management level) or team with responsibility for autism.

The aim of the tables is to provoke discussion and to encourage those local authorities who are ranked lower do more to support adults with autism. We have written to local authorities to tell them about the tables and a number have already contacted us to ask what they can do to improve their ranking.

(Editor note: Hertfordshire came 27th out of all local authorities, we continue to work with them to ensure they reach top ten status!).

Reviewing the child DLA form

The Pension, Disability and Carers Service (PDCS) are reviewing the Child Disability Living Allowance (DLA) form and assessment process, and this month (November) the NAS attended the first meeting of a working group taking the review forward. We regularly hear from parents of children with autism who are having difficulties in claiming DLA, and therefore we pushed hard to be included in the working group.

Work on this is at a very early stage and the form is unlikely to come into use before 2010 at the earliest. However, first indications are that the new form will include more positive language (where possible asking what a child can do rather than what they can't) and will no longer require parents to compare their child to a child of the same age who does not

have a disability (a separate comparator will be developed by the PDCS for decision-makers to use).

We will keep you updated as the review moves forward next year. In the meantime, if you are having difficulties claiming child DLA or other benefits, you can contact the NAS Welfare Rights service by emailing welfarerights@nas.org.uk or calling the Autism Helpline (0845 7070 4004) to make an appointment.

Chancellor announces Christmas Bonus for benefits claimants

In his Pre Budget Report on 24th November the Chancellor announced an additional payment of £60 on top of the 2008 £10 Christmas Bonus paid to people receiving Carer's Allowance, Disability Living Allowance or Attendance Allowance, Incapacity Benefit (long term rate) or Employment Support Allowance and State Pension.

The annual £10 payment will be paid from 1st December 2008 and the additional £60 will be paid between January and March. It will be paid automatically so customers do not have to apply for the additional amount. Christmas Bonus is a tax-free payment and is not taken into account in the income-related benefits.

If you or your members have any queries about the additional payment, the government has set up a dedicated number – **0800 141 2591** – to deal with customer enquiries.

The NAS has released a statement in response to the additional payment. Head of Policy and Campaigns Amanda Batten said,

“We welcome the Government's recognition that Christmas is a difficult time for disabled people and their families. However, this is a one-off payment and if the government is to meet its commitment to end child poverty then it is vital that it does more to support people with autism and their families. In particular we call for an uprating of Carer's

Allowance which is currently paid at the pitifully low rate of £50.55 per week."

New Community Care helpline service

The Autism Helpline now has a Community Care Case Worker who can offer advice, information and support about community care issues. This includes finding out what help you can get from social services (direct payments, day centres, respite, housing options, direct payments, etc), how to access the help, and how to make a complaint to social services if you are not happy with their decisions or services.

To use the service please phone the Autism Helpline on 0845 070 4004 (Monday-Friday, 10am -4pm), where details of the query will be taken and a telephone appointment with the Community Care Case Worker will be arranged. They will then call you back at the agreed time to discuss the issue in detail. Alternatively you can email your enquiry with as much detail as possible, along with the name of your local authority, to communitycare@nas.org.uk.

New website helps families of disabled children to save money this Christmas

Family Fund Extra, a new online shopping site from charity The Family Fund has just been launched.

Any family with a disabled child aged 25 and under, as well as disabled young people themselves, can join *Extra* for free and get discounts of up to 25 per cent from leading online retailers, including Comet, Argos, BSM, Haven Holidays and Stone Computers.

And everyone else can help disabled children at no additional cost simply by doing their online shopping via the *Extra* site, which links through to nearly a hundred leading retailers, including Tesco, Marks & Spencer, Amazon, Boots, HMV, John Lewis, B&Q, Dell, PC World and Halfords.

Retailers will give *Family Fund Extra* commission on every purchase, and this new income will allow the fund to increase its discretionary support for families with severely disabled children.

To find out more or to get shopping, visit www.familyfundextra.org.uk

Celebration Giving

Celebration giving is a great way to support a cause you care about and to raise awareness of autism among the people you know.

Whether you are celebrating a birthday, anniversary, wedding/civil partnership, or Christmas, we'd be delighted if you asked your loved ones to help you mark the occasion by helping people affected by autism.

Many of our other supporters have been doing just this and, rather than receiving gifts of, as one said, 'more unwanted toasters', they asked their friends and family to make a donation to the NAS to support our work with people affected by autism.

Whichever special event you choose to share with us, we're here to support and guide you all the way. Contact Sunny Sunshine on 020 7923 5704 or email sunny.sunshine@nas.org.uk today for a celebration giving pack.

Investing in Brighter Futures

The Bankers Benevolent Fund and The National Autistic Society have been working in partnership since November 2007 to support families that have a child with autism in the banking community. Through the Investing in Brighter Futures programme we have been able to support 137 families with autism by offering them a number of free services which include Life Membership to the NAS, Help!, Autism Helpline, £100 of free publications, Befriending, Parent to Parent and Advocacy for Education.

Investing in Brighter Futures is a unique programme as it is fully funded by the Bankers Benevolent Fund which means the services on offer are completely free to all applicants. For some families this has made a huge difference to their lives with some even describing the free Life Membership as a "life line". A number of the families have also become case studies for the NAS helping to highlight the benefits of the programme to others in the banking community.

Investing in Brighter Futures has now been extended until November 2009 as well as furthering its support to include adults with autism. As part of the new adult programme we will also be offering additional services which will include welfare rights, e-befriending, social groups, community care and help! 2.

If you would like to promote the programme within your branches please call 0207 7903 3587 and speak with the Investing in Brighter Futures Co-ordinator Jennie Chambers. Alternatively please visit www.autism.org/bbf for further information.

AGM

On Saturday 29th November almost 200 National Autistic Society members attended a very lively AGM and London & South East Members' Network Day in London.

Following the formal AGM business, there was a very exciting and encouraging talk from Mark Lever, our new Chief Executive, which was followed by a very passionate talk from Louise Foley of the new Isle of Wight Branch. The morning was rounded off with the day's keynote speaker Elaine Hill, who is the newly appointed government specialist adviser for autism (see more on this below). The afternoon session included a choice of five workshops: welfare rights; meeting your child's sensory needs; managing anger in younger people with Asperger's syndrome; getting involved in NAS campaigns; and fundraising.

Throughout the day there were chances to network with other members, as well as the

opportunity to go around to the various stands and talk to a number of NAS teams about their work.

This is the first time that we have combined the SE Member's Day with the AGM and we are pleased that members' feedback has been very positive.

I Exist campaign win – new autism advisor appointed

The Department of Health has appointed Elaine Hill as its new Specialist Adviser for Autism. We campaigned for the post as part of our *I Exist* campaign and also secured a commitment to develop a national autism strategy which Elaine will oversee.

Youth Council

The NAS are working with Autism Education Trust to establish a Youth Council. The following is from Victoria Erbes a consultant in the Education Support Service based at the Ivories in London.

"We are currently working collaboratively with the Autism Education Trust (AET) who are setting up a youth council. The aim of this is to enable young people with autism to express their views and have their voices heard over school related issues. The AET hope to have 12 individuals with wide-ranging backgrounds, geographical area, age and ability in order to provide a cross-section of experience on the council.

If you know of any children/families who might be interested in this please let me know. If they agree to take part their involvement would be thus:

A member of the Education Support Service would travel to their school to interview them about specific areas. The questions will be tailored sympathetically to their understanding

and ability and specific need, supported by symbols if necessary. The interview will last up to 30 mins, again dependent on specific need.

The child would need to be withdrawn from class for this time and will need to be supported by a TA or equivalent.

There will be approximately one visit per term during the school day.

Once collated, the information will be published on the AET website. All personal details will be removed to retain confidentiality.

Any thoughts, contact me via email or the detail below.

Victoria Erbes
Consultant
Education Support Service
National Autistic Society
Unit 9, The Ivories
6/8 Northampton Street
London N1 2HY
0207 704 3801
07876 392398 “

Hertfordshire PASS

Have you heard about Hertfordshire PASS?

Hertfordshire PASS (**P**ersonal **A**ssistance **S**upport **S**ervice) is a 'user-driven charity enabling people with disabilities to live more independently' - using work and employment as the primary means to achieve such independence.

Hertfordshire PASS currently operates 3 projects:

- [WorkABILITY](#) which enables disabled students to access work tasters, work experience and apprenticeship opportunities (funded by The Big Lottery Fund) - as described in 'User-Driven' a book published in 2008 ([view here](#) and [buy here](#))
- [Payroll](#) which supports nearly 150 people with disabilities in the payment of wages to their own care staff, and
- The development of good practice in '[user-driven](#)' work.

Hertfordshire PASS has over 600 current or past users largely resulting from its days when it held the Direct Payments Support Service contract. One of these users has established pa-pool which Hertfordshire PASS is supporting and promoting. <http://www.papool.co.uk/> is a website for PA users (people with disabilities) who are recruiting, and PAs (carers) who are looking for work.

You can find out more about Hertfordshire PASS on their website www.hertspass.com

Autism Support Dogs

This may be of interest to those of our members with younger children. If you contact this organisation please feedback to us:

Autism – Supportdogs, 21, Jessops Riverside
Brightside Lane
Sheffield
S9 2RX

An assistance dog programme to improve the quality of life of families with autistic children, aged 3 – 10

Telephone: 0114 261 7800

Website: www.support-dogs.org.uk

Email: supportdogs@btconnect.com

Advice, Support and Therapy

Pre School Swimming

We have received the following information from Amwell View School.

Amwell View School has recently become a Specialist Sports college and as such we would like to forge links with the community using our facilities. We would like to set up swimming classes for pre school children with disabilities. We offer a fabulous learner pool which is warmer than a public pool in attractive surroundings.

Classes would be held on Thursdays from 12.00-12.30 at Amwell View School, Stanstead Abbots.

We hope these sessions will enable children to have fun and gain water confidence. We also hope that through the classes parents may find they make friends and gain support of others. Please Penny Wamwell directly for further information. Penny can be reached at

school on 01920 870027 at home on 01920 465276 or by e mail pennywamwell@yahoo.com . If you have any further queries please do not hesitate to ask.

Penny is happy to show the pool to any parents who may need a little more reassurance before committing themselves.

Thanks to Lesley Zorlakki for this information.

Robots at University of Hertfordshire

If you saw an event advertised recently for families with children on the autism spectrum to 'Come and Play with our Robots' at the University, you may well have been disappointed to know that this event reached its maximum numbers very quickly. I am happy to tell you that Lynn Bhanja (University of Hertfordshire) is planning to hold a second session. Please email her your details to make sure you go on the list. Lynn's email address is l.bhanja@herts.ac.uk

Contact a Family Survey -

We have just received the following news release from Contact a Family. Please do take part as it helps to make sure that autism is noticed in all arenas.

News release

What makes families with disabled children stronger

Contact a Family is asking families with disabled children "what makes you stronger?".

The UK charity supporting all families with disabled children wants to hear from parents and other family member carers about their biggest priorities to strengthen their family practically, socially and emotionally.

Contact a Family has compiled an online survey to find out families' current experiences and to ask what they would wish for if more help and support were available.

Claire Pimm, Director of Policy and Communications at Contact a Family, said: "We know from our work with families with disabled children that they want to lead ordinary lives.

"Living without fear of debt and poverty, the opportunity to work, the chance to enjoy leisure activities as a family, getting an education to meet a child's needs and the importance of a good night's rest are essential to making any family stronger.

"The results from our What Makes My Family Stronger survey, will form new research and will help us campaign for better lives for all families with disabled children. We will also use the findings to raise awareness of what life is like raising a disabled child."

If you are a parent or another family member caring for a disabled child who would like to take part in Contact a Family's What Makes My Family Stronger survey, please visit
<<http://www.cafamily.org.uk/surveys/strongersurvey.html> >
<http://www.cafamily.org.uk/surveys/strongersurvey.html>

For further information telephone Elaine Bennett in the press office of Contact a Family 020 7608 8741.

The Hertfordshire LINK Stronger Voice – Better Care

The **Hertfordshire LINK** is an independent, statutory watchdog for health and social care in the County. It is independent of the NHS and the County's social care services.

The creation of **Hertfordshire LINK** makes it easier for local people to share their views on the myriad of organisations that provide health and social care in their area. By taking part in **Hertfordshire LINK**, people can have their say, and get a response from providers, on issues that affect them and their community.

Hertfordshire LINK does not deal with individual complaints about services but encourages individuals to do so through procedures already set up by both NHS and social services.

Our role is to ensure public involvement in the commissioning and provision of health and social care and to influence the Hertfordshire NHS and social care decisions by providing a strong patient and public voice. Hertfordshire LINK can campaign for responses from Commissioners as well as Providers.

All members of **Hertfordshire LINK** and its governing board are volunteers, ensuring a neutral voice that represents the local community. Anybody can take part in LINK, and the organisation hopes to attract people of all ages and backgrounds.

The current Board assumed responsibilities in April 2008. The **Hertfordshire LINK** is currently run by a management board, consisting of 20 elected individuals and delegates from voluntary and community organisations. All board members are volunteers and provide a wealth of experience of health and social care services.

The Shaw Trust were appointed as Host to support the **Hertfordshire LINK**. This means that the **Hertfordshire LINK** have the backing of a large organisation, and the appointed dedicated Hertfordshire team are progressively developing that role.

Already we have community groups and individuals raising issues with us, including **autism services** and **transitional planning** for children with disabilities.

We welcome new members. Anyone can join. You can be generally involved, or bring issues to the Board's attention. You can, of course, continue to campaign as an individual, but the issues affecting you may well be more widespread and together with **Hertfordshire LINK** we can create a stronger voice. And a stronger voice means better care.

If you would like to join the ever growing public voice and be heard, please contact the **Hertfordshire LINK** team to request a membership form.

Together we can make a difference.

Susan McCann
Board Member of Hertfordshire LINK

Hertfordshire LINK contact details:

Address: Foundation House, 2-4 Forum Place, Hatfield, Herts AL10 0RN

Telephone: 01707 275978 (Automated message. Please leave your details)

Email: herts.link@shaw-trust.org.uk

Update from harc

Awareness Raising Talks

These talks continue. We have been into more schools, the majority are mainstream primary schools. We have also recently spoken to Teaching Assistants undertaking a Foundation Degree at the University of Hertfordshire and to a group of police officers from around the county. We have further school talks already booked. Please remember, if you think your child's school will benefit please let us know. We received the following feedback from one school:

"I just wanted to thank you so much for such a wonderful presentation yesterday. Rarely, if ever, have we had a staff meeting that has interested, informed and inspired us as much as yours did. Teaching assistants don't usually attend our staff meetings but those who did were extremely pleased to have done so and I wanted to pass on to you that I have received very positive feedback from everyone who attended. Everyone felt that, as a result, some aspect of their teaching will improve, which is an amazing result."

Adult Care Services

We continue to have meetings with Adult Care Services and have a commitment from them about extending the current social group to two sessions a week with plans to start groups in the East and North of the county.

Working with the LINK (Local Involvement Network) Chairman we are working to open broader discussions with Director of Adult Care Services regarding the 'I Exist' report.

Imagine Thinking Differently

This work continues with the steering group putting together an action plan to take to Commissioners.

Transition

We have begun work with the Transition Development Manager to look at transition and how it is working for young people on the autism spectrum. If you have any evidence (positive or negative) you would like us to take forward please let us know. The more evidence we have of what works and what doesn't the better.

Campaigning

We continue to campaign for services for adults with autism in line with I Exist and following on from Make School Make Sense. We are currently working hard with the NAS campaigns team to highlight the need for the autism bill.

harc Support Group Meeting

Our next support group meeting is on 10th February at Southfield School, Hatfield. CSF Autism Advisory Team will be talking about their work in schools to develop the social skills of children and young people on the autistic spectrum.

Volunteering

We have asked you all to do something this time around. We do realise how limited your time is with your caring responsibilities. The best voice we can give those we care for is theirs and ours. If by writing to your MP you have found that you do have a little time to do other things would you consider offering that time to harc? Even if it is only an hour now and then to help us to organise events and activities please let us know. Remember, we too are parents/carers so we won't overburden you, we just need those extra

pairs of hands to help us to deal with post and emails, support families, raise awareness, liaise and negotiate with service providers, identify funding opportunities and put on events.

And finally

Thanks to Susan McCann for the following:

I read the following on a discussion board on the internet and I thought that it might be helpful to people who are trying to explain to the uninitiated, i.e. those who know little or nothing about autism. It occurred to me that from the Help Course that I attended, there were Mums there who needed to explain to their child's school exactly what the problems are and I felt that the following paragraph said so much - I don't know whether you will agree, but what a creative Headteacher to have responded to a parent in this way!:

" You know, there is nothing wrong with his intelligence! It's us that can't communicate at his level of communication. The task we have is to find and meet him at the place where he does understand and can verbalise himself. That way we can 'walk' with him as he grows. Simply put, he is perfect in every way except that his brain is wired up differently. This just means that the way he connects his thoughts is a little different to how you and I think. So, let's meet him where he is comfortable and then let's all work together and see if his brain can create new connections."