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April 2007 Newsletter

*Welcome to the
Hertfordshire Branch of*

The National Autistic Society

We are now well down the route to becoming
harc the Hertfordshire Branch of The NAS.

It is not a simple task to wind up one charity
and become part of another, but we are getting
there. We are already reaping the benefits of
this change with the outstanding support we are
receiving from The NAS Regional Team.

One of the questions we are being asked is:
what will be the effect on our members? Part
one of that answer is: nothing, we are still a
local group, supporting local people and fighting
local issues. Part two of the answer is: massive
support from a national organisation which has
the resources to help us do our job more
effectively.

By the time the next newsletter comes out, we
hope to be able to say that we have completed
this transition.

Laurence Griffin – Branch Chairman

harc Membership Renewal

You may recall from the last newsletter that we
would not seek renewal of membership until
becoming a branch was finalised.

This has now happened and we would now like
you to renew your membership of harc. The
good news is that the membership will not
increase this year and remains at £21 for family
membership. The even better news is that if
you are a member of the NAS you will receive a
£4 discount.

Membership renewal forms are enclosed and
remember if you are a tax payer you can gift aid
your membership which means that the Inland
Revenue will contribute to harc.

Signpost: a new way of accessing information

The NAS launched a brand new online service
called Signpost in March. Designed for people
with autism, their parents and carers, Signpost
extracts key pieces of information from the
NAS website and the Autism Services
Directory and pulls them together for users.
Visitors are asked to enter basic details about
themselves or the person they care for, and
then are presented with personalised
information relevant to their needs according to
age, diagnosis and where they live.

Visit Signpost at: www.autism.org.uk/signpost

The views and opinions expressed in this newsletter are not necessarily those of harc or the NAS

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Help for children with Autism in understanding emotions

A new cartoon DVD, "The Transporters", which helps children with autism learn about emotions has been released. The BBC news site has an article on this item and you can play clips from the DVD from the BBC site. You can order your own free copy of the DVD from the Transporters site.

A copy of this DVD is included for you with this Newsletter. We understand that it will not be suitable for all families, but we hope that you will be able to find another family or school who might appreciate you passing it on to them on behalf of harc. Any surplus copies can be returned to harc at one of our meetings.

BBC Article:

<http://news.bbc.co.uk/1/hi/health/6241733.stm>

Order online:

<http://www.transporters.tv/getcopy.html>

The DVD is also available from the harc library

Asperger Social Group

The Asperger Social Group, being run in conjunction with harc and the Community Learning Disability team (Apsley) started on 19th February with four young adults with Asperger's Syndrome. The second week this increased to five and we anticipate another six or so joining over the new two to three weeks. The group runs on a Monday morning between 9.30 and 12.00 at the Pioneer Youth Club in St Albans. Anyone who wishes to attend must make a referral to the team. This can be a referral made by a parent/carer, social worker, or can be a self referral. Activities include, pool, table tennis and football and listening to music.

Speakers are being invited in to speak to the group about things such as managing finances, healthy living, employment and personal safety. It is staffed by qualified Community Learning Disability Nurses who have an interest in Asperger's Syndrome. If you know of anyone who may be interested in this group please contact Alison Carpenter or Claire Toseland on 01442 454444, fax to 01442 454422 or e-mail Claire.toseland@hertscc.gov.uk.

New harc Website

The new harc website has come on leaps and bounds in its development, so much so that we are looking for you to help refine its look and influence its content.

We are looking for about a dozen members to access test the website. To advise of any remaining problems or inconsistencies to advise on content and even to provide content for the site.

If you are interested and have a little spare time, a computer and access to the internet then please contact harc, usual address

SEN Funding in Mainstream Hertfordshire Schools

Parent Partnership has been holding workshops for parents on the new funding strategy for SEN in mainstream schools. If you were unable to attend any of the workshops you may find the following information useful.

This change is being brought about as part of a review of funding and also to ensure Hertfordshire complies with the national SEN strategy 2004. The new arrangements will start in the financial year beginning April 1st 2007 with the news that £1.7 million more funding will come into mainstream schools for SEN.



HCC inform us because of the system changes and schools being responsible for the spending of their budgets that:

- Resources will be made available more quickly
- There will be better and more focus on children's needs rather than head office administration
- Benefits from schools sharing and building their expertise will manifest.

Schools will work in clusters of eight to twelve schools across the age range, from nursery to secondary. Each cluster will be supported by specialist services, for example Educational Psychologists, Advisory Teachers etc. Clusters will meet on a termly basis and heads or SENCOs will represent each school.

£7.9 million of funding will go direct into schools for their 'predictable needs'. Funding predictable needs relates to the more common SEN needs (including autism and Asperger Syndrome). This will enable schools to plan for SEN staffing on a more long term basis.

A further sum of £2.8 million will be "held back" by the authority to meet 'exceptional needs' (those children with the most severe and complex needs).

Exceptional needs allocations will be decided by a district panel, which will comprise of one school representative from each cluster. Cases will be discussed initially by the cluster who will look to see if there is any expertise within the cluster to find a way forward or a strategy to deal with the issues or agree that the case should be taken to the panel to request exceptional funding.

A child does not need a statement to receive exceptional needs funding. There will be a county wide moderation process to ensure consistency across decisions. There are no plans for an appeals process.

HCC officers see the benefits as:

- More resources directly in school
- Builds on schools good practice and knowledge of children
- Enables schools to plan their resources more efficiently
- Time and effort will be focussed on meeting needs not bureaucracy

If your child currently has a statement it will remain and will be reviewed annually (as now). Under this new system you will not have to apply for a statement to get extra support in a mainstream school. However if you think your child needs a special school place a statement will still be needed.

SEN funding is 'earmarked' which means it cannot be used for any other purpose by the school.

During the transition to the new funding formula children with statements allocated more than 15 hours per week at primary and 20 hours at secondary will be funded from the exceptional needs budget (this also gives an indication of the kind of needs currently considered "exceptional"). Existing statements below these levels will be funded by the schools through the predictable needs funding.

There are many concerns as to how the new system will embed. Harc has been represented at 3 of the 9 meetings run and we have raised the following concerns so far:

- How will the Council ensure the new system is monitored to evaluate how well the aims are being met
- How will they ensure all schools comply and in particular use their funding appropriately
- How will they ensure that the schools who think ASD is more to do with naughty children and do not support the parents take the case to the cluster for more expert help and support



- How will they ensure that schools that get a reputation amongst parents for dealing effectively with special needs are not penalised by having more pupils currently statemented or new pupils with similar needs than other local schools
- How will the initial funding allocation to the schools be made so that in particular it does not adversely affect ASD children. (As we write, schools are learning about their new budgets and any interim adjustments they will receive.)

We have also requested that the clusters report to parents on a termly basis, with examples of how the new system is working.

At harc we are very interested in hearing about our members experiences of this new funding system. We anticipate that there will be a few teething problems until it is properly embedded. If you have any particular experiences to share – positive as well as negative, please let us know by contacting Paul Phillips at paul@brianpaul.co.uk with either your information or a contact number and suitable time to call you back. (All information received will remain anonymous).

If we are able to build a county wide picture of how the system is working for children on the autistic spectrum we can report back to officers as a group. We are particularly interested in hearing from parents of those children without statements to see if support is easier to obtain under this new system. For those parents looking for a new school place for a child likely to need extra support we are also interested in hearing of your experiences.

Parent Partnership can help you with any queries and can be contacted on 01992 555847. (An "FAQ" sheet is available on request)

South East Regional Members Meeting held on 3rd March at the University of Westminster

Jane Vaughan welcomed all members to the meeting. Harc were mentioned as a new branch of the NAS. As a result of last year's meeting a member had written to Jane and her letter had been forwarded to her local authority. As a result of this Wandsworth Council set out to ensure every school in Wandsworth is autism friendly.

Robert Pritchett spoke about his vision for the NAS, to be:

- A Service Provider
- An Enabler - to help other organisations to deliver services
- An Influencer through lobbying nationally, regionally and locally.

A key message from Robert was that local politicians will listen to the electorate rather than the NAS. The NAS plans to work more with branches next year as we have the power and the NAS have the solution.

There was a presentation from Chloe Phillips - principal of the Sybil Elgar School. Chloe spoke about the three NAS schools in the South East. Radlett Lodge is now extending its respite care to weekends and holidays and not only for on-roll students. Ofsted highly commended the school.

Chloe emphasised that the work they do with the students is to rehearse situations over and over again to ensure they know what is expected of them.

Carol Povey - Head of Adult Services spoke about the work going on in the South East region. They are moving away from standard day care type services into one of domiciliary care and social groups. Carol told the meeting



that there is a need to be really flexible in the services offered that we can't fit people into services, it has to be the other way round. Services must be individualised but funding from local authorities is tight, there is not enough money and expectation from carers is high. Over 40% of adults over 25 years of age still live at home. There is a lack of clarity about who has responsibility and a lack of evidence based research/understanding of what works best for ASDs. More evidence is required as there is a poor understanding of numbers of adults in communities.

It is important for all of us to do something meaningful in our working lives and it is no different for people with ASD. NAS are looking at providing the services people want when they want it, if that means one day a week canoeing that is what will be arranged. However, there is a recognition that the NAS is a small organisation and cannot provide all the solutions.

There was a request from the membership to hold a conference on services for adults with AS. This was roundly applauded and agreed.

Matthew Downie - Membership spoke about the benefits of membership and about a new DVD called transporters that has been developed by Autism Research Cambridge and Dr Simon Baron-Cohen to help young people with AS to recognise emotions. He demonstrated this to the audience and it was well received. Free copies are available to NAS members.

Chris Gibbons - Campaigns updated on the Make School Make Sense Campaign which ends later this year. He urged anyone who hadn't yet done so to write to their MP and Allan Johnson. See the NAS website www.nas.org.uk/campaign. NAS are currently gathering information through a questionnaire for the forthcoming campaign for adult services

due to start 2008. If you have a questionnaire, please complete it and return it to the NAS.

We have included a copy of the questionnaire and would urge you to complete it to help to build a picture of the services available for adults and their families. If you can't use it please feel free to pass it on to someone who can. If you would like some more let the office know and we will send it out to you. Deadline has been extended to 8th May 2007.

Asperger Working Group

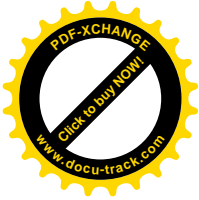
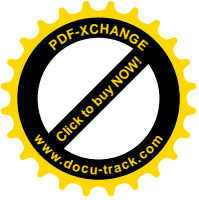
Mark Dixon was the project manager for the Asperger Working Group until December 2006 when his contract came to an end and the decision was taken not to extend the project. This led to some intense lobbying of Hertfordshire County Council members and MPs by many members of the Caring for Autism group (C4A). The result is the following response from Sarah Pickup - Director Adult Care Services.

"Response from Sarah Pickup (Nov 2006)

I am writing on behalf of Hertfordshire County Council in response to recent correspondence, which has come to both County Councillors and officers regarding arrangements to support people with Asperger Syndrome (AS) and High Functioning Autism (HFA).

The two year project management role, undertaken by Mark Dixon, comes to an end this month, but I would like to assure carers that our work to ensure people with AS and HFA receive appropriate support will continue.

Mark Jordan, Head of the Joint Commissioning Team, will be working with Sue Darker, Service Manager in Adult Care Services (ACS), and a senior manager from Hertfordshire Partnership Trust (HPT) to agree how work will be taken forward across our health and social care teams in both ACS and HPT. This will include further



staff training, arranging appropriate services for people who are assessed as being eligible to receive a service, and continuing links with carers. We will be taking work forward in line with national policy and guidance, including the Department of Health clarification note issued last week, "Better Services for People with an Autistic Spectrum Disorder".

I understand that Mark Jordan met with carers in the Autumn of this year, and Mark, with colleagues from ACS and HPT, will arrange to meet again with carers to outline how we plan to take work forward, and to agree how carers are kept involved and informed. We anticipate this meeting being arranged for the New Year.

Yours sincerely,

*Sarah Pickup
Director of
Adult Care Services
Tel No. 01992 556301
Comnet No. 26301"*

It has now been agreed that Mark Dixon can continue to lead the Working Group and later this month Mark Jordan (Joint Commissioner) will come to the C4A meeting with Sue Darker (Adult Care Services) and Andrew Thiedeman (Hertfordshire Partnership Trust) to tell us how they intend to move forward with services for adults.

Employment Survey

Understanding *autism and employment* is important for people with autism, Asperger syndrome and other conditions on the autism spectrum, as well as for their families:

Little is known about how caring for a child with an autism spectrum disorder affects parents' employment decisions. Many adults with an autism spectrum disorder find it difficult to maintain employment.

With an estimated 535,000 people with autism in the UK alone, this is an issue that requires attention.

These are important issues that we believe have a huge emotional, physical as well as financial impact on people with autism spectrum disorders and their families. For this reason, we would like to know more about your feelings and experiences. To do this, we are conducting a simple questionnaire study to identify the employment-related issues that are most important to you, both as carers of children with autism and as adults with an autism spectrum disorder.

Investigators:

*Dr Elisabeth Hill & Dr Jo Yarker
Department of Psychology
Goldsmiths, University of London*

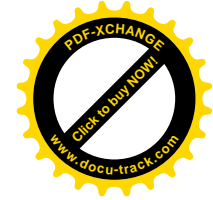
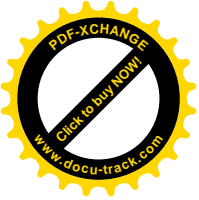
Link:

<http://homepages.gold.ac.uk/autismandemployment/>

Source: Margaret Thomas-Baptiste

Do you know a good Cognitive Behaviour Therapist that you would be happy to recommend?

One of our members is searching for a therapist to do CBT for their daughter who has social anxiety difficulties. As they live in Hatfield they need to find someone who would be accessible from Hatfield by public transport. He has been given the name of a therapist in Finchley called Vanessa Schjelderup. He would be keen to hear from anyone who has experience of Vanessa's work. Also would like to know about people to steer clear of. If you can help with this, then please contact the office by phone or e-mail. Contact details are at the top of this newsletter.



PM Petitions

I don't think we will be able to emulate the success of the 'road pricing' petition, but you might like to think about supporting some or all of the 'autism' petitions that have been brought to our attention:

<http://petitions.pm.gov.uk/AspergerLeeds/>
<http://petitions.pm.gov.uk/aspergersupport/>
<http://petitions.pm.gov.uk/Autism/>

Parent Support Group Meetings & Workshops

A very successful workshop on sexuality and autism was held during February with Lynne Moxon. Feedback from those who attended was very positive.

Caroline Wells - Senior Advisory Teacher (Autism) was the speaker at the PSGM held in March at Southfield School. Caroline's talk focussed on visual strategies. One key point that came from Caroline's talk is that most of the strategies that are put in place for children with autism will also be of benefit to other children.

Another workshop on sexuality and autism is scheduled for 12th May and will be targeted at parents of children in special schools. Look out for more information coming soon or alternatively if you are interested contact the office.

We are planning PSGMs for the near future including wills and trusts and the Disability Discrimination Act and your rights and the rights of the person you care for. If there are any topics you would like us to find speakers for, or if you have heard of anyone you would like us to approach please let us know.

Can you help with a study?

Steven Stagg is currently running a series of studies at Goldsmiths College, University of London, investigating how children with Autism and Asperger Syndrome perceive the social world. He is finding some interesting differences between these groups but needs more participants diagnosed with High Functioning Autism in order to make any firm conclusions. The study investigates whether children prefer looking at scenes of social interaction. The participant spends about 15 minutes looking at images on a computer screen, whilst they do this their eye movements are recorded so he can see which images they prefer to look at. He will also take measures of your child's verbal and non-verbal IQ and a measure of social functioning. If you would like to know the results of these measures you are welcome to have them. He is looking for HFA children between the ages of 10 and 14, the study would involve coming into the university and he can provide a small fee for your child. If you would like further information please contact him by phone (07894 080082) and he will ring you back, or by e-mail, s.stagg@gold.ac.uk

Please note that harc and the NAS do not in any way endorse this study and you should make your own checks before participating.

What is C4A?

C4A is a group of parents / carers / spouses of adults with Asperger Syndrome or High Functioning Autism. The group is co facilitated by harc and Carers in Herts and meet on a monthly basis. There is a campaigning element to the group but also it is there to support and a great deal of networking takes place. If you are the carer of an adult (you don't have to be a harc member) and would like to come along and meet us please contact Jo Willis at Carers in Herts either by phone 01992 586969 or e-mail jo.willis@carersinherts.org.uk