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January 2008 Newsletter

Launch of harc as the Hertfordshire branch of the NAS

On Wednesday 5th December harc officially launched itself as the Hertfordshire branch of the NAS. The evening was combined with an autism awareness raising event tied into 'think differently about autism'. We invited all county councillors and MPs, service managers, Carers in Hertfordshire, commissioners, SENCOs, members and non members of harc and older siblings of people with autism. The event was held at Southfield School in Hatfield and our thanks go to Mike Philp (Headteacher) who is a wonderful supporter of harc. We were also extremely pleased to welcome Jane Vaughan, SE Regional Coordinator of the NAS and Mel Carr, Regional Officer.

The evening started with a quiz based around the latest report from the NAS called 'think differently act positively'. The first question was how many people in Hertfordshire are affected by autism? (100 - 1,000 - 10,000). The answer is an estimated 10,000 or 1 in 100 which is one percent of the population of Hertfordshire. When you add an average of three people per family whose lives are affected by Autism then that figure rises to 40,000 or 4% of the population of Hertfordshire. This figure raised a few eyebrows!

Part way through the evening a cake was cut by Laurence Griffin (Branch Officer) and Jane Vaughan and both made short speeches. The next part of the evening was to discover the future vision for harc. Everyone worked in groups and came up with their top idea. The remit for the groups was not just to say what but the how as well. As soon as all of the ideas are analysed we will report back to you.

This was an extremely sociable evening and people leaving told us how much they enjoyed it and also how much they had learned. Sally Haynes had a 'stall' at the event to publicise the 16+ siblings group that she is proposing to establish. More about this in our January PSGM.

A press release prior to Wednesday resulted in articles in at least one local Hertfordshire paper and three local newspaper web-sites as well as a radio interview with Mercury FM that also went out on Chiltern Radio. Please let us know if you see articles about harc in any of your papers or local radio stations, it helps us to gauge how well press releases work.

We could not have run this evening without help from the following people:

Emma Rawlinson, Helen Hart, Helen Rankine, Tracy Behakris, Nick Bury, Sue McCann, Sally Haynes, Kevin Casey, Louise Wiltshire, Anna

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

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Harper and Dave the Photographer. Not forgetting Mike Philps, Mel Carr and Jane Vaughan who rolled their sleeves up and 'got on with it'. Thank you all of you, you made the evening work.

Welcome to harc - the Hertfordshire branch of the NAS.

Growing Together, or Drifting Apart?

Children with disabilities and their parents' relationship

Fiona Glenn - **One Plus One**

This review examines research involving families of children with disabilities and the growing body of evidence that maps the important link between the parental relationship and outcomes for their children. It is hoped that in bringing this evidence to the attention of policymakers, practitioners and other professionals, services for families caring for a child with a disability will be informed by its findings and responsive to the external pressures and challenging dynamics that characterise these families.

<http://www.oneplusone.org.uk/publications/growtogether.pdf>

Older Siblings Group

It has long been recognised that siblings play an important part in the lives of those on the autism spectrum. As the siblings get older, it is quite likely that they become a supplementary carer and supporter to their brother or sister and of course their parents. Sometimes as parents we can overlook their needs especially if they appear to be coping quite well. We have been approached by a sibling who would like to set up a group to give other siblings an opportunity to meet and support each other in much the same way as we the parents do.

This group will be for those aged 16+. It is anticipated that initially the group will be small whilst it establishes itself. The first meeting to be held will discuss items such as:

- ⇒ Group name
- ⇒ How often meetings will take place and the duration of the meeting
- ⇒ Ground rules
- ⇒ Place of contact for example on Facebook

harc is supporting this initiative and our Parent Support Group Meeting in January will establish the group. Please help us to move this important initiative forward by attending the meeting. Please see details of Parent Support Group Meetings at the end of the newsletter.

Parent Support Group Meeting 20th November 2007

Yvonne Deal from the Money Advice Unit gave a very informative talk about the benefits available to parents and carers and people with autism. The Money Advice Unit offers benefit advice to families with children from 3 months to 19 years. Often they are approached by parents of very young children following a diagnosis and a referral via the Child Development assessments by Health visitors and Speech and Language Therapists. Older age groups come in from different areas but mostly by word of mouth. The Money Advice Unit help about 450 families per year with advice about benefits and assistance to complete Disability Living Allowance (DLA) forms.

Yvonne told us that claims for children with autism tend to go through first time, however, it is more difficult for Asperger syndrome/high functioning autism. these claims tend to go to appeal. It is often the case that it is necessary to paint a composite view of the worst days and

it is important therefore to try to keep a diary of events prior to completing the form. It is often difficult for parents to put down their worst experiences as it can be quite a painful process and we don't always want to look at the negatives in terms of the behaviours we are always dealing with. It is especially difficult when applying for DLA for a young child because there is a view (and one we may share) that we are their parent and shouldn't we be doing this for them anyway. It is worth asking yourself at this time the question "Is this what other families without autism have to cope with?" the answer of course is always "no". It is the level of support we are putting in that is different, the sleepless nights, the anticipating every next step. The words you use in the application are also very important and this is exactly where the Money Advice Unit can help you. DLA is not income based, it is paid as a recognition that there will be additional costs associated with the disability. The Money Advice Units can come to your home or help you over the phone if that is your preferred way. They always try to provide an accessible service

To access this service you need to ring 01992 556370 and ask for the Duty Adviser. The Duty Adviser assesses the call and will refer on if necessary if they are unclear about eligibility for claiming DLA. The MAU will take cases to appeal and tribunal on behalf of the client and also to the Commission for Social Care. They are keen to promote take up of benefits to those aged 16+, so if your child is on the Autism Spectrum and is 16 years plus then contact the MAU for advice.

Those children aged 16+ may be eligible to apply for Incapacity Benefit. In order to claim they must undergo and satisfy a personal capability assessment. Yvonne's experience is that those children in special schools find this benefit easier to get, although it should be borne in mind that if you are in receipt of tax credits you may

not get an overall benefit. For those at special school they qualify as a result of their complex needs and if they are in receipt of higher rate care DLA or registered blind they do not need a medical certificate.

If they do not satisfy the DLA criteria then they will require two medical certificates that state that they have been unable to work for 190 days because of their ASD and a forward certificate stating they are unable to work for the next six months.

Children in post 16 education can apply for Incapacity Benefit but whether they are successful will depend on the number of hours of study. The Disability Employment Adviser at the Job Centre should be able advise people to go onto Incapacity Benefit. If they are successful in their application they can undertake some 'permitted work' and job trialling.

If you want more information about any of these benefits then please contact the Money Advice Unit 01992 556370 and they will be able to help you.

As a result of this meeting we are considering running a workshop with the Money Advice Unit that you would be able to attend to get initial advice on whether to claim benefits and how to. Please do feedback to us whether you feel this would help you and tell us where you think would be best to run it. If you know of any venues in that area then let us know.

Parent Carer Forums

The latest HAND Newsletter contains information about Parent Carer Forums. Invitations to take part in these forums have been sent to all parents of children on the HAND list. The purpose of these forums is to

give an opportunity for parents/carers of children with additional needs and or disabilities to have a cup of coffee and share experiences with other parents/carers. The Parent Partnership are working with the Disabled Children's teams to set up most of these forums. Dates so far are:

Broxbourne Weds 23rd Jan 2008 9.30 - 11.30
venue to be confirmed

Welwyn Hatfield Mon 3rd March 2008 9.00 - 11.00
Oaktree Children's Centre, Holwell Road,
Welwyn Garden City AL7 3RP

Events have already taken place in St Albans, Stevenage and Welwyn Hatfield and there is a plan to roll out these forums across the following districts:

Broxbourne	St Albans
East Herts	Hertsmere
Welwyn Hatfield	Three Rivers
North Herts	Dacorum
Stevenage	Watford

If you are interested contact the Parent Partnership for more details.

Sure Start Children's Centres

HAND News contains some interesting articles about Sure Start Children's Centres. By 2010 Hertfordshire aims to have a total of 82 Sure Start Children's Centres providing or giving easy access to services for young children and their families. The aim is to bring support services together and therefore ensure more joined up working between health and education and social care providers and will encourage parents and carers to become involved in planning the services to meet the needs of their families.

This would appear to be very beneficial to families affected by autism as often complaints centre around the lack of joined up services.

Sure Start will support the roll out of Early Support for young disabled children and their families. The latest HAND News documents Early Support. If you haven't got a copy please contact the office and we will send you one.

Bercow Review of Speech and Language and communication needs - call for evidence

The Bercow report is an independent review of services for children and young people with speech, language and communication needs. The review is supported by the Government departments for Children, Schools and Families and the Department of Health and was launched on 23rd October and runs until 18th January 2008.

The review is currently collecting evidence to support its interim report that is due to be published in March 2009 with the final report in July 2009. There is an outline questionnaire that is also downloadable at <http://www.dfes.gov.uk/consultations/conDetails.cfm?consultationId=1513> or you can email your views to bercow.review@dcsf.qsi.gov.uk. Terms of reference are also available on line. If you are not able to go on line contact the office and will send you a copy of the consultation.

The review will look particularly at the health service commissioning framework and how it ensures speech and language therapy meets the needs of local people analysing good practice in joint working between education and health services including joint commissioning and transition to adult services. If your child is receiving or has received services for speech and language you may want to contribute to the collection of evidence. You may also want to comment if you feel your child should have received services and has not been assessed, or been assessed and no services offered.

harc newsletter

The harc newsletter is for you the members. We hope you find the content interesting and we do understand that sometimes with life as busy as it is we can only look at what interests us at that moment in time.

We think that all of our members have interesting stories to tell, hopefully, some will be uplifting and inspiring. We believe that your story will help others when they are going through difficult times. It may be that you have found a simple strategy that works for you that may work for someone else. We would be very pleased if you would like to write a short piece about your life, it doesn't have to be very long, it might just be a few lines about something that has been said or done that has made a difference. Alternatively, you might like some help with something so why not write us a letter that we can put in the newsletter and see what the combined knowledge of our membership can offer.

Volunteers

We have recently sent letters out asking for volunteers to help us with some of the projects we are undertaking and with running harc. I am very pleased to say that we have had a good response to our request and it will make a huge difference to what harc can now go on to achieve. Thank you! Of course we always need more, the more people we have volunteering the less work for everyone and the more we can achieve for people with autism. So if you haven't done so yet and think you may be able to help with a couple of hours a week or a month then please email volunteers@harc-online.org.uk.

Schools

harc are planning as part of the 'think differently about autism' campaign to mail out

leaflets to all schools in Hertfordshire. The leaflet sets out how to ensure an autism friendly environment, we also include our own two leaflets on transfer to and life at secondary school to all schools in the secondary sector and to primary/junior schools preparing for life at secondary school plus information about harc. This follows a mailing to at least 400 of the infant/junior schools with the Transporter DVD in the summer that also included information about harc and a multi lingual leaflet on autism produced by the NAS. Please do let us know:

- ⇒ If there is anything else you think we could include
- ⇒ Any feedback from the school your child attends

Remember this is your support group and we want to make sure we work for you.

Understanding and Managing Autism and Asperger's Syndrome'

As a parent of a young man with Asperger Syndrome, I was very pleased, a year ago, to hear that Herts Adult Care Services had secured £100,000 for training professionals and parents, to give them a greater understanding of AS, behavioural tools and strategies for a better independent life.

Last month I was delighted to attend a week long course 'Understanding and Managing Autism and Asperger's Syndrome' run by Prime Performance Solutions Ltd. I was there with 21 ACS professionals (Social workers, Care workers, Occupational Therapists and so on) and 3 other parents. I was concerned I would be out of my depth, but all the professionals said they were so glad that we parents attended, because we had 24/7 first hand experience, and by the end of the week I realised our experience was invaluable.

All three well qualified trainers, also had first hand experience, and helped increase my understanding of my son's condition by covering Autism, Aspergers syndrome and co-morbid disorders. They also gave us several very useful tools and coping strategies when they covered Communication and Behaviour, Strategies for Life and Behavioural Tools. We all know that you have to approach AS very slowly, but I now have more tools and greater understanding to :-

- ⇒ increase my son's quality of life and independence
- ⇒ improve his relationships with his family
- ⇒ improve his understanding of his condition
- ⇒ help me increase others' awareness of his invisible disability.

I'm very grateful for the chance to attend and hope the knowledge gained will cascade across the county. It will change a lot of people's lives.

Art & Drama for siblings

Are you aware of a company called ActOne ArtsBase at www.artsbase.org.uk . They are an inclusive arts organisation delivering a wide range of performing and visual arts activities in Herts, including DanceBase in Hatfield and Hoddeston and an inclusive club called UV.

Also, Paul Bamblett of www.actability.org.uk provides drama workshops across the Eastern region in schools, colleges, day centres and many other settings. The company can create specially designed work to fit in with current themes within your own work or present one of their own active and vibrant workshops.

If you want to find out more eg, see if they can work in your area, please get in touch via website. Lesley Zorlakki

Parent Support Group Meetings

Our next meeting will be held on Tuesday 29th January at Oaktree Children's Centre in Welwyn Garden City 7.30 - 9.30. The first part of the meeting will be aimed at establishing an older siblings (aged 16+) support group to be run by siblings. The second part of the evening is to be a support meeting to enable us to network with each other, find out what works, what doesn't, be able to let off steam about our autistic people without being judged, or simply to have a bit of time out. You can bring to the meeting anything you like, there is a lot of expertise within harc so hopefully someone will have an answer or a view or even a strategy that may help. We'll provide the tea and biscuits.

A flyer will be sent out nearer to the date but please put this date in your diary now.

We are also planning to bring you a session on Social Stories. Social Stories are extremely useful tools when working with people with autism. This will be a morning session in January and will be run by Pamela Reitemeier. Details will follow as soon as they are confirmed.

We have plans for a meeting in February to invite the Hate Crime Police to come and talk to us so that we can establish links with these officers. We will look at trying to establish something in each part of the county.

March meeting will be on Wills and Trusts and Lasting Power of Attorney, date and venue to be confirmed.

Please tell us if there is any topic you would like us to cover or speakers you would like us to invite.

We would like to wish all of our members a very Happy New Year



partnership
HERTFORDSHIRE

Early Support
Helping every child succeed



'Integrated Practice is Everybody's Business'

Your local Children's Centre community invites you to attend a brand new course which includes training for the integrated working processes and the **Common Assessment Framework**

The course is called:
'Working in partnership through Early Support'

The **'Working in partnership through Early Support'** is an important two day, multi agency course for Early Years practitioners from the private, voluntary and independent sector and the statutory agencies.

What is Early Support? Early Support is about improving integrated, co-ordinated, family focused services for young disabled children and their families.

Hertfordshire will be implementing Early Support and integrated working practice including Common Assessment Framework processes in 2008.

The courses aim to enable practitioners to understand and implement Early Support and integrated working practices as well as develop an appreciation of the links between the Early Years Foundation Stage and Early Support materials.

Who should attend: All those involved with working with children under five and especially practitioners supporting young children with additional needs and their families.

Cost: It's free with refreshments and lunches included for all participants.

In addition: Each participant from the private, voluntary and independent sector (including childminders) will be able to claim £100.00 to support supply cover for their setting.

Where are the courses being held? Each course is being hosted within a Children's Centre community so that participants from the private, voluntary and independent sector and the statutory agencies can train together in local areas to support integrated working practices. **Timings:** 9.30am until 4.30pm.

Early Support
Helping every child succeed

attached the application form. Contact below for dates &



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‘Working in partnership through Early Support’ course

Application Form

Please complete and return as soon as possible to:

The Early Support training admin co-ordinator,
Room 152, County Hall, Pegs Lane, Hertford, SG13 8DF
Email: Christine.plastow@hertscc.gov.uk
Telephone number: 01992 588585
Fax number: 01992 555486

Name:

Role:

Address:

Email address:

Contact telephone number:

Name of your Early Years setting and town if applicable:.....

.....

Dates of the course you wish to attend:

Venue of the course you wish to attend:

Any Special Requirements i.e. dietary or accessibility

.....

.....

Thank you

You will receive confirmation of your place from the Early Support training admin co-ordinator within two weeks of the training admin co-ordinator receiving your application form. Please contact the Early Support training admin co-ordinator if you do not receive your confirmation or if you have any queries about the course.



Understanding Neuro-diversity in Education, Employment and the Justice System

***A conference for professionals and those working with young people and adults with neuro-diverse (ND) conditions
Dyspraxia, Asperger's Syndrome, AD(H)D, Dyslexia etc.
Wednesday, March 12th 2008, 9.30 am – 5.00pm
The Resource Centre, 356 Holloway Road, London, N7 6PA***

The theme of this year's conference is the everyday challenges and obstacles faced by adults with Neuro-developmental Differences (NDD) (Specific Learning Differences (SpLD)). We have gathered together a dynamic group of professional speakers including those with a direct experience of neuro-diversity.

Prof. Amanda Kirby - Medical Director of the Dyscovery Centre- A knowledgeable and experienced practitioner in this field - *An Overview of Neuro-diversity (ND) including the Emotional and Psychological Impact*

Melanie Jameson - Specialist in SpLD - *Breakthroughs in the Justice System*

Jo Todd - Director of Key4Learning - Expert in ND and employment - *Advocacy in the Workplace*

Aileen Quinton - A director of DANDA with Dyspraxia, ADD and strong traits of Asperger's Syndrome - *Policing Neurodiversity and the Barriers to Justice across the Board*

Sharon Drew - Author & independent Occupational Therapist - *Neuro-Diversity (ND) in Further & Higher Education*

Dr Nicola Werenowska - Playwright and Mentor/tutor to students with Neurodiversity - *Focus on the experiences of a dyspraxic*

Judge Gordon Ashton - Nominated Judge of the Court of Protection. Visiting Professor of Law at Northumbria University - *Litigant Support in the Courts particularly for people with communication problems*

Conference Fee £90 non members

£75 members

Full programme on booking

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