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November 2007 Newsletter

Press Release - 29th October 2007

The National Autistic Society launches *think differently about autism*

- **an awareness campaign aimed at increasing public understanding of autism**

On 29 October, The National Autistic Society (NAS) launched **think differently about autism**, an awareness campaign that aims to increase public awareness of autism and change the perception of this complex and lifelong disability.

Ann Griffin of harc - The Hertfordshire Branch of the National Autistic Society, who herself has two sons with Asperger syndrome said:

"Living with autism can often be an isolating experience and very few people have a real understanding of the impact it has on the whole family. I know from my own experience that better public awareness would make a huge difference. By encouraging people to think differently and understand more about autism, we want to improve the lives of thousands of people with the condition. We are calling on people in Hertfordshire to act positively to ensure people with autism have the same rights and freedoms as the rest of society."

The *think differently about autism* campaign is motivated by a new report by the NAS, *Think Differently - Act Positively*, which reveals that many damaging misconceptions about autism still remain, with a lack of public understanding and awareness about what it really means to live with the disability.

The report, based on a survey of 2024 people across the UK, revealed considerable confusion about who is affected by autism and whether it is a lifelong condition. 27% of those who had heard of autism mistakenly believed it mostly affects children, and less than half - only 39% - were aware that there is no cure.

In addition, 39% thought that most people with autism had special abilities, for example in maths or art, showing the continuing endurance of the 'Rainman' stereotype. In fact, such abilities are extremely rare. Furthermore, the vast majority of people surveyed - 90% - did not know how common autism is. The condition is estimated to affect 1 in 100 people in the UK.

The report also explored reactions to the typical behaviour commonly associated with autism, with the common scenario of a screaming child in a supermarket. It found that the majority of people felt that

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children were simply badly behaved or the parents were at fault. Many people are not aware that the lighting, noise and busy nature of a supermarket can often disturb or frustrate a child with autism.

Reassuringly, however, the report found that the public would be far more willing to engage with people with autism if they understood more about the condition. Furthermore, 84% of parents or grandparents said they would not be concerned about a child with autism joining their child's/grandchild's class and over two thirds (67%) would be happy to work with someone with autism. Unfortunately however, these positive affirmations are in stark contrast to the everyday experiences of those living with the disability.

Providing a visual element to the campaign, The National Autistic Society will also be launching *As I See It*, a photo exhibition which features photographs of - and by - people with autism. The exhibition launches in London on 29th October and then embarks upon a UK tour.

harc - The Hertfordshire Branch of the NAS is calling on people in Hertfordshire to join the campaign and sign a petition calling on the UK Government to ratify the UN Convention on the Rights of Persons with Disabilities, and take specific action to increase awareness of autism, tackle discrimination and improve training.

To find out more about the campaign and petition go to www.think-differently.org.uk or email thinkdifferently@nas.org.uk.

Please contact Ann Griffin at harc - The Hertfordshire Branch of the NAS for more information by emailing think.differently@harc-online.org.uk.

Media can also call the NAS press office on 020 7903 3593.

Notes:

- harc - The Hertfordshire Branch of the NAS supports people and families affected by autism in the Hertfordshire area. harc - The Hertfordshire Branch of the NAS: offers parent support group meetings; is piloting a social group for adults with Asperger syndrome/High Functioning Autism together with the Community Learning Disability Team (part funded through the Community Foundation Network and Adult Care Services); provides newsletters to members and professionals; has a telephone helpline; is undertaking a year long project with Carers in Hertfordshire called 'Thinking Differently' which aims to build a consensus between service providers and service users in Hertfordshire; represents the needs of people with autism on various working groups and committees; works with a consortium of support groups in Hertfordshire.
- The survey was carried out in June 2007 by market research company GfK NOP. 2024 adults aged 16 and over were surveyed across the UK via a nationally representative face-to-face omnibus. Weighting was applied to the data to bring it in line with national profiles.
- Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over - or under - sensitivity to sounds, touch, tastes, smells, light or colours.
- Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding processing language.

Plans for the 'think differently about autism' campaign

harc plans to:

- ⇒ contact all schools with campaign leaflets enclosing our own transition to & life at secondary school leaflets
- ⇒ send 'autism friendly environment' leaflets to libraries and doctors' surgeries
- ⇒ hold an awareness meeting (more later in this newsletter)
- ⇒ write an article for inclusion in the local press in December
- ⇒ contacting the local press with 'good news' stories to emphasise that positive practice has positive results

We would like to ask you to:

- ⇒ sign the NAS petition (copy enclosed) or go on line and sign up at www.think-differently.org.uk
- ⇒ Ask your friends, families and colleagues to sign the petition. Please send your signed copies back to harc so that we can collate the responses.
- ⇒ Ask your workplace if they will support the campaign
- ⇒ Share your positive stories including examples of good practice from nursery/schools/employers or your GP, dentist or optician with us for the local press. Please let us know, as we would like to try to send at least one positive story a week to the local media, to keep the campaign going in Hertfordshire. As an example: my dentist is some fifteen miles from our home, we continue to go to him because when he has to deal with my Asperger sons he takes his time, he explains every step, he is a calming influence on them and he is understanding. It didn't matter that it

took two visits to complete one small filling.

We would like to collate the good practice examples into a leaflet for use later on. You can send your stories to think.differently@harc-online.org.uk. Please make sure you say whether you wish to remain anonymous or not.

- ⇒ You might want to share some of the things the person you care for does that makes you smile and demonstrates their value to society.

SEN funding

Back in March of this year proposals were announced by Hertfordshire County Council (HCC) to change the basis of SEN funding so as "to ensure monies arrived at schools more quickly and to reduce the surrounding bureaucracy". Meetings were held to explain how the principles would work and to take feedback from us, the public. The feedback we at harc received was that the new proposals seemed half-baked, untested and would cause inequities. We have asked for feedback of actual experiences so that we can pass coordinated comment back to HCC. To date little has been received and we would welcome your views by email to senfunding@harc-online.org.uk or by telephone to the harc office.

HCC always promised to rewrite their 'frequently asked questions' sheet presented to the launch meetings in March this year and have duly done so. If you attended a meeting then you should automatically have received a copy. If you have not and would like a copy please contact Paul Phillips at the email address above or call the harc office and we will supply you with the updated copy. The updated answers raise further new questions and we would like to receive your comments so that we can further represent our members' views to HCC with your concerns.

Paul Phillips

Hertfordshire LINK

What is the Hertfordshire LINK? This is the proposed new way for local people to have their say on health and social care issues and replaces the Patient and Public Involvement (PPI) Forums. LINK is an acronym for Local Involvement Network and is driven by the Department of Health. It will be an independent network of local people and organisations with an interest in health and social care. It will link hospitals, dentists, GPs, opticians, pharmacists and local authority social care.

Its aim is to ensure people:

- ⇒ have a voice
- ⇒ can influence decision makers
- ⇒ have a real say in improving services locally.

Hertfordshire have been one of nine areas to run an Early Adopter Project (EAP). The purpose of EAP was to get ideas from local people on how the LINK will or should work. A range of stakeholders representing the local community, community and voluntary organisations, local authority and health service providers have met on a regular basis and sub groups formed. One sub group looked at who commissions what in the county and whether user involvement is included in the decision making process. Another sub group has been formed to look at procurement of the 'host'. Each local authority will procure a host organisation (costs of this are unknown currently) via a tender process. It is envisaged that the host will be a major charity or agency. The host will be responsible for the establishment, maintenance and support of a LINK.

The LINK will operate independently of the local authority, within its own governance, structure and decision making process. At this stage it is unclear how many members will be on the LINK board and what kind of commitment to time will be required. The host will be accountable to the LINK.

The LINK will:

- ⇒ gather evidence
- ⇒ analyse information
- ⇒ encourage and support local people to participate, including making recommendations to commissioners, providers, managers, Overview Scrutiny Committees (OSC) and regulators.

There are over 1000 voluntary groups in Hertfordshire and clearly it will not be possible to have representation from each of these groups.

I attended a conference on 'Making your voice count in Health and Social Care'. I felt it was especially important that the social care needs of the people we care for was represented.

Earlier this year Hertfordshire County Council held an event to focus on how LINKs would work with people who use mental health or learning disability services. As far as I can ascertain people with autism were not invited to participate and even though the people we care for may not have learning difficulties or mental health problems these are the services we have to apply to for support.

For me one of the key points of the day was that LINK gave a voice to service users. The point I made was: "who gives a voice to those who do not receive or indeed cannot get services".

There was agreement that there was a need for inclusivity, that individuals and representative organisations could either be on the board or could 'dip in and out' with an equal voice.

Protocols will be developed from the Health Scrutiny Committee, Health and Social Care services and Foundation Trusts. The desire is to complement rather than duplicate services at the same time providing value for money and a voice for "the inarticulate".

Service providers and the Health Scrutiny Committee will be remote from the procurement process. Any potential host must step back from that process as well.

The procurement group (HCC) and the Transitional LINK Board will run alongside each other to appoint the host. The Transitional LINK Board will also identify 2008/9 priorities to enable the new LINK to start work immediately.

There is a meeting on 22nd November of the Transitional LINK Board at the Ramada Jarvis Hotel in Hatfield from 10.00 am to 1.00 pm.

"Membership of the Transitional LINK Board is open to everyone interested in ensuring the citizens of Hertfordshire have a strong voice in influencing the commissioning, provision, scrutiny and planning of health and social care services, specifically:

- ⇒ Individual interested members of the public
- ⇒ Service-users and carers
- ⇒ Patients
- ⇒ Voluntary organisations not seeking to provide the LINK host
- ⇒ Statutory sector representatives to be non-voting members"

If you would like to be involved (and have the time) please contact Tim Anfilogoff on 01707 280659 or email tim.anfilogoff@hertsc.gov.uk. It is felt that those involved in the Transitional LINK Board will be busy in terms of time spent at meetings, however, if we can find one person (it might be a grandparent or other family member with time to spare) with an interest in promoting autism onto the agenda then please contact Tim for further information. If you decide to go on to the board please let harc know so that we can support you where necessary and pass on the information pack from the conference.

It will be a shame if the needs of people (children and adults) with autism and their carers are not promoted to the board.

Ann Griffin

Is Autism a disorder?

For an alternate view about whether autism is a disorder or not, read Luke Beardon's article on the NAS website (follow the link: <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=117&a=14621>). If you are unable to access the internet then contact the harc office (leave a clear message with name and address) and we will send you a copy via the post. We would be interested to hear your views on the article.

Ann Griffin

A continuing journey

The morning that our son was born, the sun's rays spread out through the frosted window of the delivery suite. We were so happy and proud, but totally unprepared for the many battles that lay ahead, one of which would be to get a diagnosis of Aspergers Syndrome for him.

During his first three years, he was a cuddly little happy chap, but then our family went through a number of traumatic episodes, and we blamed them for his insecurity and changing behaviour.

He went off to school, and the anxiety that he displayed (we now know caused by his lack of social and communication skills), made him develop lots of little rituals that made him feel better. That grew over the years into the Obsessive Compulsive Disorder he has today. He was above average intelligence and therefore not in need of any extra help. (At nine he won a Webster's Dictionary in a Spelling B Competition, spelling out loud in public)

At six, his hand washing at school was brought to our attention by his teacher, and around the same time the Schools Doctor wrote to our G.P. regarding his hand washing, dyspraxia and enuresis problems. Our G.P. told us we wouldn't want to label him and so we lived with it, although we did attend the local enuresis clinic when it had a doctor to run it.

Finally at ten he was diagnosed, not unlike many others with AS, as being dyspraxic, and having OCD, and three years later I had to ask

the Child Psychiatrist we saw whether he thought AS was a possibility, and he said yes, he had thought that for a while. This news, felt at the time, like a bereavement but, allowed us, with the help of his mainstream school, to apply for a statement of special educational needs. The senior advisory teacher for autism in Herts (a new post in 1996) attended several meetings with the school, regarding appropriate help. She had years of experience of working with autism, but the special needs teacher and school staff could not deliver the appropriate help to enable my son to successfully access "school life". They too needed training and experience, and many were reluctant to take on board that he needed help, because his problems were not the same as another pupil with AS. Both boys needed social skills training, but it couldn't be fitted into the timetable.

He wanted very much to socialise and fit in at school, but wouldn't admit to himself or anyone else, that he needed help. This of course frustrated him and his unwanted behaviour came out at home. Our behavioural management was lacking, and we became worn down by his outbursts. His younger sibling fitted into this and it's only with hindsight that I can see how much. My husband had for years, worked very hard at taking him to various sports classes and uniformed organisations, which gave him the structure he needed, to feel comfortable. The rest of the time, he spent at home with his special interests.

He did well enough academically to do a BTEC course in public services, which was one of his special interests, and he passed with merit, but working in the field was another matter. He took a job in a supermarket, stacking shelves, waiting for the right job opportunity to come up, but it didn't. He had to train in several areas in the supermarket, but having to be a cashier with the public interaction, was undesirable. The store showed little understanding of his condition, and after four and a half years, he left. His anxiety at this time could not have been much greater, as my husband had just passed away

unexpectedly in early 2006, following on from five close bereavements in as many years.

Prior to my husband's death, my son's behaviour was challenging for us all, and at times intimidating. His OCD rituals ruled our house, and in 2004 we asked for a referral to an OCD specialist, because although the rituals helped him with his anxiety, they were becoming impossible for us, and deprived him of many hours of his life. About this time too he asked for bereavement counselling, but wasn't taken seriously, probably because he didn't express himself very well. He saw the OCD specialist in early 2005, and was referred to a psychologist, but her team (Learning Disability Team) could not meet his needs, because his IQ was too high, and so after six months he was taken on by the Community Mental Health Team, in August 2005. Hertfordshire doesn't have any autism specific teams, who would understand his AS, anxiety and OCD, and give appropriate medical help. I asked the National Autistic Society to recommend a counsellor, and I have managed to pay for all three of us to be counselled.

My husband and I "cared" for him in our home, and you may say many twenty-two year olds still live at home with their parents, but they have the skills to enable them to live an independent life, and my son doesn't. I think we would have gone along, coping, the same for many years, if my husband had not passed away, but with hindsight that was not the best way forward for any of us. Our situation forced a "crisis" and that's when help began to appear. I am a fighter, but in March last year I didn't have as much as I would have liked, and I won't always be here, and so I asked for some action to be taken. Things got worse before they got better with him losing his job, and his behaviour becoming too much for two women to handle.

He didn't see why he couldn't carry on living at home. To get things moving I had to evict him, which tore me apart, but he needed to see the benefits of having his own home. I also needed to let go to allow social services, and him, see the skills he lacks.

In the eight month since he moved out, we have all learned a lot of painful lessons, but he has learned that he can cope with moving twice, which is a lot of change for someone with AS and OCD. We all need to empower him to hold down a job, manage his finances, and have as much independence as possible. Ideally we should have an AS trained community team who can give him that. I'll carry on because I'm proud of him and wouldn't want to walk in his shoes.

We can all "take pride in how far we have come, and have faith in how far we can go".

A harc Parent

Parent Support Group Meetings

We had planned to bring you a talk on Wills, Trusts and Power of Attorney in November. Unfortunately, due to the recent changes in the Mental Capacity Act and Lasting Power of Attorney the solicitor we approached has said she will need a few months to review and amend all the leaflets and ensure her understanding of the changes and how it affects people with autism and their carers. We will arrange this meeting for March 2008. We will now try to bring forward our planned January meeting to November. This is a talk by the Money Advice Unit on all issues relating to benefits for children and adults with autism and their carers. We hope to be able to confirm the details of this meeting in the next few days.

Our next meeting will be in the early part of December and is planned as an awareness raising meeting plus gathering ideas for shaping the future of harc. We plan to invite the press, councillors, MPs, consortium members, and NAS officers. We do need your company to ensure that the invited guests hear the true story of what life is like living with autism, the good and the not so good. We also want to make the meeting a little more of a social event prior to the festive period so would like to invite you to share a glass (or two) of wine or a soft drink with us.

We will of course send you the details as soon as they are all confirmed but we wanted you to be aware of our plans for meetings and why we would like you to attend.

Siblings Group

We are in the process of researching and planning the creation of a 'siblings' group for the brothers and sisters of people with Autism. We hope to be able to give more information about this for our meeting in December.

Events at University of Hertfordshire

ASC/Asperger's Syndrome Group

A new group for people with ASC, parents, teachers, TAs, health professionals, social services professionals, local authority staff

Weds 21 Nov 2007, 4:00 to 6:00 - will construct the agenda for the following meetings on Wed 16 Jan and Fri 25th April 2008

Price: *Free*

Booktalk: Every Child included - Dr Rona Tutt

Tue 22 Jan 2008, 6:30

Price: *£7.50*

Understanding Asperger's Syndrome - Dr Rona Tutt

Weds 6th Feb 2008, 9:30 to 1:00

Price: *£55.00*

For further information call: 01707 285618 or email: j.j.plastow@herts.ac.uk

Joint Area Review Hertfordshire Children's Services Authority Area

Published August 2007

A Joint Area Review (JAR) of services for children and young people took place during late spring/early summer 2007. The council has been graded 2 (adequate) for its services for children with learning difficulties and/or disabilities. I have replicated below the relevant statement in JAR:

"A significant minority of young people with learning difficulties and/or disabilities is currently not served as well as they might be. Young people and families requiring support for complex needs (such as autism and attention deficit hyperactivity disorder) often have to wait a considerable time for the care and placements that fully reflect their needs. Early identification of needs is not yet consistently established and diagnosis of problems is too slow. A specialist autism support team is in place, but its capacity is far exceeded by the demand. Transition arrangements from paediatric to adult services are variable for young people with complex needs. Lack of clear information, poor communication and high turnover among social care staff prevent some families from accessing the services they need. Arrangements for parents/carers of young people with physical disabilities to receive direct payments are in place in part of the county. However, while these have been very helpful to some families, they have served to highlight insufficiency in the services available for purchase and a wider range of need than the local authority previously recognised."

The report also highlights that whilst there are good opportunities for young people with learning difficulties and/or disabilities to take part in post 16 education there are fewer opportunities to access work based learning or to progress into supported or independent employment. The report identifies the lack of clarity of where funding allocations and agency responsibilities lie for young people with learning difficulties and/or disabilities transferring from Children's to Adult services.

The report is worth reading and you should be able to download a copy of the report on <http://www.hertsdirect.org/yrccouncil/performance/cpa/hdjar/>. If you experience any problems let HCC know, if you are still unable to access a copy from this site please email: support@harc-online.org.uk or telephone the harc office and leave a message and we will send you a copy.

St Albans Parent Carer Forum

A meeting for parents and carers of children and young people with additional needs and disabilities in the St Albans District Council area.

Venue: Hertfordshire Development Centre,
Butterfield Road,
Wheathampstead, AL4 8PY

Speaker: Geraldine Collins (Leonard Cheshire)

Subject: Direct Payments

Date: Wednesday 14th November 2007

Time: 9.15 am (coffee) for a 9.30 am start

If you would like to come along please contact Louisa Cannon on:

01992 556984 or email

louisa.cannon@hertscc.gov.uk

Places are limited so book early

Guide to Mental Capacity Act

The NAS have published a guide to the Mental Capacity Act. It is available from the NAS Autism Helpline on 0845 070 4004.

Membership fees for harc

We recently sent a letter to all harc members regarding the new membership fees:

NAS Members: Free

Non NAS Members: £5 per year

Did you receive that letter? Have you responded to it yet?

If you didn't receive one please will you either email membership@harc-online.org.uk or ring the office and leave a message and we will send you another one immediately.

If you have received the letter and haven't yet responded, we do need your response, we do appreciate how difficult it is when there are so many calls upon your time. If it is easier then please call the office and leave a message. Thank you.