



H.A.R.C. Hertfordshire Autistic Resource Centre

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November 2006 Newsletter

Harc as a Swan

It may appear as though Harc has been a bit quiet over the last few months, but this does not mean that not much has been happening. Harc is currently acting like a swan, all serene and still above the water, but paddling like mad underneath. So what have we been doing?

We are well down the road to launching a new website and logo. We have substantially finished the design and 'look and feel' of the website and are now working on the management features beneath the surface. As with all technical projects like this, there is quite a bit of 'de-bugging' and checking to be done. The final task will be to create and enter all the 'content' of the site. This will be a mammoth task as we are planning to hold a lot more information on the new site than on the current one. We also plan to keep the new site more up-to-date than was previously possible. If you have some free time access to a computer and would like to help with creating and entering content - please volunteer (via the office email).

I hope all of you are aware of the campaign we are involved with to improve services to adults with ASD provided through Herts CC & Herts Partnership Trust (NHS). This is proving to be quite a difficult task as there is a basic lack of understanding about ASD. A recent Government paper clarifying policy should help us in this

matter. If you would like to join others who have become actively involved in this campaign - please volunteer (via the office email).

We have, jointly with Carers in Hertfordshire, initiated and funded a new support group; C4A (Carers for Autism) - For Carers of Adults with High Functioning Autism or Aspergers Syndrome. This group has held regular meetings at Oxlease House in Hatfield and has proved to be very successful. These meetings have been widely publicised in libraries, doctor's surgeries and recently in CAB offices.

At the recent Harc AGM, you decided we should become a branch of the NAS. We have completed all the paperwork for this change and are waiting for all the wheels to grind very slowly to achieve our goal. When we are ready to announce this change, the NAS will help us to make a big splash and we are hoping that this will coincide with the launch of our new website.

Laurence Griffin - Chairman

Government Clarifies Policy for ASD Services

We're very pleased to let you know that the Department of Health has just issued "Better services for people with an Autistic Spectrum

Disorder: a note clarifying current government policy and describing good practice". This is the first time that the Government has produced such a document specifically for adults with an ASD and it is intended to clear up much of the confusion that surrounds the difficulties adults with an ASD face in receiving services.

The NAS policy team have been working hard behind the scenes both to make the case for clarification, and to make this document as strong as possible. This is not guidance, but clarifies how existing policy relates to people with an ASD (the position on access to learning disability services as set out in Valuing People is unchanged).

Existing Government Policy makes the following clear in relation to services and support for people with an ASD:

"The current position whereby some people with an ASD 'fall through' local services - in particular between mental health and learning disability services, is unacceptable and contrary to the intention of government policy.

Proper individual assessments, based on eligibility criteria as set down in 'Fair Access to Care' are the starting point for people getting the services they need. This should be supported by the use of person centred approaches.

The services required to meet identified needs are best provided by local services that have the right skills and trained staff to provide what an individual requires. This 'most competent' approach is better than deciding that mental health, learning disability or physical disability services should provide all ASD related services as a matter of principle.

Services and supports should focus on supporting each person's inclusion in society on their own terms, rather than being based on assumptions relating to a diagnostic label

New approaches to funding and support such as direct payments and individual budgets should be made available to people with ASD in the same way as everyone else.

Service provision should be determined and driven by a clear contractual framework and service specification with regard to ASD from PCTs and Local Authorities.

This whole approach should be underpinned by effective planning partnerships, including not only the relevant service sectors but also local representatives of people with an ASD and their families."

The documents are available through the Internet at:

http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4140485&chk=wghqJJ

They should also be available through your local library.

Subscriptions to harc

Normally at this time of year we would be seeking £22 annual subscriptions for the calendar year 2007. With our proposed move to become a branch of the NAS nearing reality the Executive Committee believe that we should align our subscription year with that of the NAS and to this end will be aiming to collect for the period to 31st March 2008 in early 2007.

Paul Phillips - Treasurer

Flu Jabs for Carers

If you are a carer you are entitled to a free flu jab. Contact your local surgery and make sure your records are 'tagged' to show you as a carer and arrange your appointment.

Access Arrangements for GCSE Examinations

Do you have a child with Aspergers's Syndrome who is due to take his GCSE exams in the near future? Have you thought about what access arrangements are available to him/her? How sympathetic and understanding is your child's school?

My son is taking his exams in the summer 2007. His school is extremely supportive and have ensured that he can have use of his laptop for his exam and can have the standard 25% extra time (even though they recognise that for most of these exams he wants to be in and out in the shortest possible time!) he can also have rest breaks as some of his exams are 2½ hours. He can also have a prompter, someone who taps the table to remind him to move onto the next questions.

My son's "normal" way of working (and this is key to accessibility) is having his Teaching Assistant or his teacher prompting him with why, what, where, who, how. He has the answers he just doesn't realise that you don't know. He cannot write or talk about or evaluate those things that are outside of his experience. Often in exams three questions are wrapped up as one. A major difficulty for many of our children, by the time they have read the question, it is doubtful they will have picked up all the questions anyway, but it is most likely that they will answer the last part as they will have been overloaded by three questions. I have asked that my son is allowed to have a prompter to prompt him with how, where, what, why, when and to have questions segmented, onto separate pages preferably.

In order for my son to demonstrate his ability and knowledge he will have to overcome his disability. Rita Jordan (Professor in Autism, Birmingham University) likens it to a blind person attending an exam and being told "we know you are blind, however, for the purpose of this exam we will pretend you can read the

questions" A person who is blind and a Braille reader will have the question translated into Braille. My son has Asperger's, who will translate his question paper into Asperger's for him?

The awarding bodies are extremely inflexible, less flexible than my Aspie! I believe that they are discriminating against him on the basis of his disability. There is no reasonable adjustment being made for him, we are expected to pretend he is not disabled for the purpose of his exam. It is probably too late for my son, but if you have a child approaching Year 9 I would advise you to begin liaising with your examination office and SENCO to highlight what you believe would be appropriate access arrangements now.

A consultation is currently being conducted by the DfES covering the regulations for the extension of the Disability Discrimination Act (DDA) to cover the general qualifications bodies and you can take part in this at:

<http://www.dfes.gov.uk/consultations/conDetails.cfm?consultationId=1417>.

At the same time DRC (Disability Rights Commission) are consulting on a new code of practice for trade organisations and general qualifications bodies. You can have your say at:

http://www.drc.org.uk/the_law/consultations.aspx

Ann Griffin

Free Bus Travel in Hertfordshire

You may be entitled to free bus travel as long as your journey begins and ends in the county and you are the carer of an adult with autism. To obtain a pass, take a passport sized photograph and proof of your age and address to the nearest office of your local district council and they will issue the pass.

C4A (Caring for Autism) - IT'S YOUR FUTURE TOO!

In July, a group of parents and carers of adults with autism met up with a view to sharing information and campaigning for better services for adults with autism. Facilitated by Carers in Herts, the meetings have attracted between 20 and 30 carers. We meet once a month, usually at Oxlease House, Hatfield.

Several HARC members, including the Chairman, Laurence Griffin, have been involved with the Asperger Working Group, led by Mark Dixon, Adult Care Services. There was optimism that such a project, with the influence of HARC parents and carers, could begin to make a difference for adults with autism.

However, over time, although the Authority appears to listen, those who can, don't seem to want to do! Despite various things being identified that could start to make a difference, including the recommendation that Hertfordshire should consider similar provision to that being provided in Liverpool, there has been resistance by the authority to begin to put things in place.

In September, the group embarked on a written campaign urging County Councillors on the Select Committee for Adult Care and Health to, at the very least, appoint a specialist Social Worker for Autism and a Community Nurse for Autism.

The Group were further encouraged by a visit to one of their meetings from Mark Jordan, Joint Commissioning Team and Judith Jackson, Joint Commissioning for Learning Disabilities. Both these officers were left with no doubts as to the major issues that families, carers and autistic adults face.

To say there are none so deaf as those who do not hear is an understatement. The greatest blow to seeing any progress being made in beginning to improve services, is the cessation

of Mark Dixon's post as Asperger Working Group Project Manager from 1 December 2006. A huge amount of money has been invested in Mark, enabling him to gain the specialist understanding and skills needed to really understand the needs of our autistic adults. And now, in one short sighted action, his departure signals the end of all the work done thus far, at a time when the Authority is only just beginning to understand the needs.

But it isn't over till the fat lady sings! The Group continues to fight this ludicrous decision, and will continue to campaign for better services for adults.

Please remember that your children will grow up too. Whatever work we engage in now to try to make things better is more likely to benefit your children than our adults.

By using the Freedom of Information Act, we have ascertained that there are currently 243 adults with a diagnosis of Asperger Syndrome or High Functioning Autism known to Adult Care Services and 40 are in receipt of a service. With just over 500 children in Hertfordshire schools with ASD as a primary need, it doesn't take a brilliant mathematician work out that Hertfordshire County Council are not meeting the needs of today's autistic adults, and unless they start to make the changes that have been recommended, they are unlikely to have made any progress by the time your children grown up.

A document has been published by the Department of Health called "Better services for people with an autistic spectrum disorder: A note clarifying Government policy and describing good practice".

This can be found on the web as follows:

<http://www.dh.gov.uk/PublicationsAndStatistics>

We shall hold the Authority to account by referring back to this document. The National

Autistic Society will also be launching a national campaign in March 2007 designed to raise awareness and influence an improvement in services for adults with autism.

If you require any further information, please contact Ann Griffin on 07980 699067 (outside office hours) or e-mail ann.griffin@orange.net

Next meeting of the C4A group is Monday 11th December and will be a 'bit of a do'. So if you are caring for an adult with Asperger's Syndrome or High Functioning Autism you are very welcome to attend. As this meeting is just before Christmas we have decided to let our hair down and enjoy the art of socialising, so all you have to bring is a food offering (not big - only what you could eat yourself!). We meet at Oxlease House in Hatfield at 7.30. If you want more information please contact Jo Willis (Carers in Herts) on 01992 586969.

Sue McCann

School Exclusion Survey

With this newsletter you will find a letter and a short survey from the harc trustees. This survey has been in the minds of the trustees for some time and we believe will provide hard facts to go with the anecdotal evidence we have that children with autism regularly face exclusion from school in one form or another. In a very timely manner one of our members has sent us an e-mail that contained the following statement:

IPSEA: Sunderland LEA censured for disability discrimination in exclusions
Speaking for IPSEA, Chief Executive Roger Inman said:

"We hear on a daily basis of children with special educational needs and disabilities who are excluded from school because their teachers have not been given sufficient resources or training to meet their needs. Our

casework shows this to be a particular problem for children with autism in mainstream schools.

This decision states clearly that disability discrimination duties do not just rest with schools. It sends out a warning to Local Authorities that they have a duty under the Disability Discrimination Act to support schools in the inclusion of disabled pupils and, in particular, to work actively with schools to prevent any subsequent exclusion of such children. It specifically warns that failure by a Local Authority to ensure the delivery of provision in a Statement can result in a finding of disability discrimination against that Authority. This is a welcome reminder that local authorities cannot wash their hands of responsibility for disabled pupils by relying entirely on schools to get inclusion right."

This refers to a five year-old girl with severe autism who was placed in a primary school without support. Within five weeks she was excluded with the school calling it 'a period of respite' and then went on to record that the child's mother was keeping her away from school on a voluntary basis!

If you want to read more about this case you can on the IPSEA website:

<http://www.ipsea.org.uk/>

Please help us to build a picture of what is happening in Hertfordshire schools by completing the enclosed survey. We also want to know if you have had a positive experience, as this will show us where good practice exists.

Snow Cake Monday 15th & Tuesday 16th January

Just a reminder that Tracks (Autism) are hosting a two night viewing of 'Snow Cake' at Campus West Theatre, Welwyn Garden City. Tickets are £10 and include a pre-film drink and a Question and Answer session.

Contact the Box Office on 01707 357117