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February 2011 Newsletter

Time, Money & Volunteers

It doesn't take a lot to keep harc ticking over, just a modicum of the three commodities in the title. The issue is to ensure that we have sufficient quantities of each, to ensure we deliver the support, campaigning and the partnership working that our members and the wider autism community expect. The challenge is to stretch our remit to take on new areas such as this year's Spring Conference. The world never stands still and we need to build the flexibility within harc so that we can adapt to new challenges and opportunities and can embrace new ways of delivery.

Time...

Time will always be an issue for families with autism. We expend more time looking after our charges than most other families, and that need varies quite dramatically at times. This means that harc needs to be flexible in how we utilise the people who support us. If we cannot deliver with the time our current number of volunteers can offer, then we need to look for another solution.

Money...

We have been very fortunate in the last few years in that we have had a string of people partaking in sponsored events who have kindly raised significant sums of money by their efforts. We have also received an appreciative number of donations, both large and small, from

unexpected and untapped sources. This has put harc in a strong financial position for the time being.

We cannot be complacent about this though, as just a few years ago our finances were in a critical state. We had to commit significant volunteer time to raising what were, by comparison to current fundraising, relatively small sums of money. We were also forced to change our ways of working and to slash the overheads of delivery. We must always be aware that the tide may turn again in the future.

Volunteers...

You can never have too many volunteers! So long as you have the infrastructure to utilise their talent and their time effectively. We are currently in a position where we are working our committee members quite hard. We need to ramp up the number of volunteers we have in a controlled manner which does not adversely impact our core goals.

If you want to become a volunteer for harc, you don't have to be an expert in anything. If you do have special talents, then we may be able to utilise them. If not, you just need a willingness to learn and the passion to make life better for families dealing with autism. Some roles will be within the steering committee of harc, but other roles will be focussed on the mechanics of delivering harc's core goals or ensuring harc is administered efficiently and effectively.

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

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If you are interested in learning more about giving your time to harc then you can find out more by contacting harc by email or by phone. Please be patient (and pleased) if it takes us a little while to get back to you or to find you the niche where your talents can be used most effectively. This would be because we are being overwhelmed by the number of people who have volunteered to help or just the impact of the daily grind of ensuring that families coping with autism can reach the support that they need.

We may be able offer invitations to attend our committee meeting for those who wish to experience how we work together first hand. Again, the number of requests may require a significant waiting time.

Without its volunteers, harc would not exist, with them we have made a significant difference to the lives and expectations of families affected by autism in Hertfordshire.

Current Volunteer Vacancies

Treasurer

To manage the financial well being of harc and to advise the branch committee of the status of the branch financial accounts. Member of the branch committee. Required position by the NAS.

Assess & approve spending,
Sign cheques for approved expenditure
Produce monthly reports for the NAS and the branch committee
Produce annual reports for the NAS and our AGM

Newsletter Editor

To produce the harc newsletter at least four times a year for the benefit of members. May be required to attend some committee meetings.

Commission articles from the committee, members and other sources.
Collate and edit articles from all sources.

Manage the newsletter email account for articles
Present finished copy for publication

Volunteer Co-ordinator

Help with the recruitment and management of our volunteers. May be required to provide reports (written or in person) to committee meetings.

Recruit new volunteers and collate skills and availability
Keep confidential records of volunteers and their skills
Identify and book volunteers for harc events
Arrange CRB checks for volunteers when required

~~~~~ News ~~~~~

You need to know and Conference

The NAS campaign 'You Need to Know' was launched in June 2010 and is concentrating on the impact of Child and Adolescent Mental Health (CAMHS) teams on children on the autism spectrum. The NAS had conducted quantitative and qualitative research with parents and children, members and non-members, and child mental health professionals working in the field. The most commonly reported mental health problems and experienced by the children were:

- o Anxiety (85%)
- o Behavioural issues (62%)
- o Depression (36%)
- o Self harm and self-injury (33%)
- o Suicidal thoughts (27%)
- o Obsessive Compulsive Disorder (21%)

The research also showed that:

- o 71% of children with autism have at least one co-occurring mental health problem, while 40% have two or more
- o 1 in every 10 children who access CAMHS has autism

- o Just 32% of parents felt that CAMHS had improved their child's mental health
- o 9 out of 10 parents said that the mental health problems faced by their child had had a negative impact on their own mental health (88%) and on the family as a whole (91%)

"Autism is not a mental health problem. It is perfectly possible to have autism and very good mental health, just as this is possible for anybody else."

The above is an extract from the You Need to Know report. The report can be obtained from the NAS and is well worth reading. There are many case studies and examples of good practice contained within the report.

I attended a training event for those people involved in the campaign in April last year at London Zoo. I was struck by one story told by a CAMHS professional which really demonstrated to me that some of the most effective ways of working with people with autism are often the simplest. He told the story of a young boy who was experiencing some mental health difficulties and been referred to a clinic where he declined to engage. After two sessions the psychologist spoke to the child's mother and asked what he could do to improve the situation. The mother told him that the boy liked to text so at the next session the psychologist and the boy were sat side by side (no eye contact) and he sent a text to the boy that he instantly responded to. This led to the psychologist being able to work with the boy successfully and all because he took the time to ask the parent for help and ideas and made the decision to communicate with his patient via text.

At that same session was a mother whose son had committed suicide in a secure unit shortly before his 18th birthday. He was her only child. It was devastating to hear this story and the mum was so articulate and dignified and the words that stay with me were "when we had his diagnosis we assumed we wouldn't be grandparents, we never dreamt that we would

outlive him". Her story summed up the worst practice and demonstrated the complete lack of understanding that the professionals had of the seriousness of her son's condition.

Jackie Goodhall, who attended the training event too, was also moved by the experiences of the other parents and felt we should do something to help autistic children and young people in Hertfordshire and so came the idea of our conference, 'we need to know...'. Our idea was that parents, carers and professionals in day to day contact with our autistic children need more information to help them to improve their emotional wellbeing and to identify at an early stage where things might be going a little awry and when/how to get professional help. The NAS campaign is concentrating on improving mental health services and at the same time as supporting them with this we felt we could try and make a difference at a more preventative level. We were also keen to get a mixture of parents, carers and professionals attending as we believe that it is most beneficial for the children and young people when all concerned work together and learn from each other's experiences.

harc have not organised a conference before and the committee are very grateful to Cathy Hill who is supporting us to get the conference underway and make it a reality. We are on the home run now with the conference on 25th March, keynote speakers, Luke Beardon and John Clements, workshop presenters, venue and refreshments arranged and bookings coming flooding in. If you haven't yet booked your place the information on how to book and the description of the workshops is on the website www.harc-online.org.uk, places are going fast so don't delay.

This is the biggest event we have organised to date (catering for some 200-300 people) and we could not have done it without the money that people have raised for us and the time the committee and Cathy have given to it, the time that the workshop presenters are giving to us

for free and for the volunteers helping us on the day. Because of all these things we have been able to ensure the costs are kept to a minimum to ensure people are not excluded on the basis of cost (a conference of this size and these speakers would normally charge in the region of £100 - £200 per person).

Ann Griffin

Autism Heroes

Do you know an Autism Hero? Someone who has made a significant contribution to the lives of people with autism in Hertfordshire? If so, please send your nomination to harc and we will present an award.

Social Stories Presentation

Pamela Reitemeier, a NAS senior councillor, gave a fascinating explanation of Carol Gray's Social Stories™ at Greenside School in October. The evening was well-attended by parents and professionals. Pamela explained that Social Stories are very useful when working with people on the spectrum, and can be effective from very young children through to adolescents and adults. The goal is to offer support and increase understanding - for example, to teach a skill. Social Stories™ should be:

- Accurate and easily understood
- Positive not negative
- Delivered in a patient and reassuring manner

Half of all Social Stories™ should reaffirm something done well.

Social Stories™ are made up of four sentence types:

- 1. Descriptive**
Who, what , where, why
- 2. Directive**
Give direction - phrased as advice. Focus on the desired outcome.
- 3. Perspective**
Other people's reactions such as emotions and thoughts.

4. Control

Sentences given by the learner, who might want to participate in writing the story (not used in all cases)

A good balance is 3-5 Descriptive or Perspective sentences for every Directive sentence.

Variations could include adding pictures or photos for interest, role-playing the Social Story™, audio recordings (good for adults), or writing the story as a PowerPoint presentation. Pamela presented a good example of a PowerPoint designed to teach an adult to close their door when they wanted privacy.

If the subject is likely to be emotive, it may be best to use fictional characters and depersonalise the story.

The language should not set expectations, for instance "the bus will arrive at 8.20" would be better written as "usually the bus arrives at 8.20", and "I will remember" as "I will try to remember".

When introducing Social Stories™ for the first time, Pamela suggested starting with a positive Story before introducing Directives. It might be necessary to repeat the Story a number of times.

Pamela also described Comic Strip Conversations, which are a more adult form of Social Stories, and Powercards, which use a learner's special interest to focus their attention on a specific message. More recently, Social Articles™ have been used, which are similar to Social Stories, but have more age-appropriate level and format for adolescents and adults.

We divided into groups and worked on designing Powercards and writing a Social Story. It proved to be much more difficult than we expected!

Social Story Resources

There are lots of examples on Carol Gray's website at www.thegraycenter.org

"Social Story™ Movies" is a DVD which shows Social Stories™ being used in different contexts.

Book (describes how to write successful and targeted Social Stories):

"Revealing the Hidden Social Code"

Authors: Howley and Arnold (endorsed by Carol Gray)

Published by: Jessica Kingsley

ISBN: 978-1843102229.

Hello

'Hello' is a campaign run by The Communication Trust, a group of over 35 charities and not-for-profit organisations with expertise in children's communication. Complementing the Government's commitment to support children with speech, language and communication needs, 'Hello' will help to achieve the recommendations of the Bercow Review. They aim to make 2011 the year when children's communication skills become a priority in schools and homes across the country.

Details at www.hello.org.uk



Paws for Thought

From NAS magazine Communication:

The PAWS (Parents Autism Workshops and Support) project explores the potential benefits that a pet dog may have for a family. Parents of children with autism attend a series of three one-day workshops across England and Wales, run by child development and dog training and welfare project workers. Workshops cover a range of topics from selecting the right dog for the child and family to practical ways in which the dog can help the child's development.

Following the workshops, the PAWS team offers ongoing support for all families enrolled. The cost of all workshops is £50.

Dates will be added soon for 2011. For more information, call 01295 759836, email paws@dogsforthe-disabled.org or visit www.dogsforthe-disabled.org

Become a Badger

If there is one thing we should have learnt from the campaign for the second reading of the autism bill, it is that if enough people contact a politician, then you can change their mind. If you exclude the two government ministers who were not allowed to vote for the bill, then we reached and persuaded eight out of nine MP's. We certainly did not have those numbers when we started the campaign! If this works for MP's then there is no reason why should not work also for County, Town and Local Councillors.

Having congratulated ourselves on this result, perhaps we should reflect and identify the opportunities we may have missed. Two things immediately spring to mind.

Firstly, letters and email do work, but a face-to-face meeting works even better. We have read an MP's blog which says this does work the best! All politicians at all levels should hold 'surgeries' to listen to the voices of their voters, perhaps you should book an appointment to ensure that all the four tiers of politicians understand what living with autism means and how the cheap and simple things that they can change will make our life so much better.

Secondly, we have talked about campaigns and gaining improvements for the whole autism community. Now we need to consider our own personal needs and difficulties and how to resolve those too. MP's and Councillors are there for these issues as well. They should be working with you on these matters. These politicians should be there to help you overcome the personal issues; they know the mandarins who run the systems and the ins and outs of how it all works. They are a resource waiting for you to utilise.

My final thought is about where autism sits in the scheme of things. We appear to be at the back of the queue and a low priority. A small problem that does not require a universal solution! A small number of people who do not justify services!

Is this partially our fault? Have we been too quiet, too acquiescent? Have we failed to stand up and be counted as individuals? Have we missed a trick here?

If this is the case, then we only have one choice - for everyone to ensure their voice is heard! Each and every one of us needs to ensure that our own message is heard and re-heard. We must use every opportunity to raise our case. We must not take no for an answer. We must support and each other in the fight for what is right. In other words - become a badger...

Laurence Griffin - Branch Officer

News from the NAS

Parent to Parent Service – 0800 9 520 520

Parent to Parent is the NAS' free UK-wide confidential telephone support service for parents and carers of an adult or child on the autism spectrum. The service is delivered by trained parent volunteers; both mothers and fathers across the UK, who offer telephone support from their own homes, providing the opportunity for parents to talk through issues, feelings and problems. They do not offer advice but can signpost parents onto the best source of up to date information and advice within the NAS. All of our volunteers have personal experience of autism and the impact it has on their own families and want to do something to support others in similar situations. Parents can call us on **0800 9 520 520** and leave a message on our 24 hour answer phone and we will call them back as soon as possible, at a time which suits them, including evenings and weekends.

Advice from the Advocacy for Education Service – Home to School Transport

There have been a number of news reports recently suggesting that some Local Authorities are looking to reduce their budgets by cutting the amount spent on home to school transport. Parents and carers can find out more about their rights and entitlements with regard to home to school transport by calling the National Autistic Society's Advocacy for Education Service. Our service can explain the transport eligibility criteria, to help parents work out what their child is legally entitled to. We can also help parents consider the options if their child does not meet the criteria or if the transport provided for their child is discretionary and not a legal entitlement. We recognise that this issue will be causing some level of anxiety for parents. We are not here just to support them when things go wrong, but also to help much earlier to try to prevent problems occurring in the first place. Discussing options with one of our fully-trained volunteers will help parents plan the best way forward. If you have any questions on this or any other topic regarding a child's educational rights and entitlements call us on **0845 070 4002**.

Advice from the Advocacy for Education Service – An important date for your diary

The 15th of February is the official deadline by which Local Authorities should finalise amendments to the statements of children transferring to secondary school in September. However, the work needed to ensure that this deadline is met needs to start much earlier, preferably in the autumn term. For most parents the process will run smoothly. However, difficulties can arise when parents or carers disagree with the Local Authority about what is right for their child. In these cases parents do have a right of appeal to the Tribunal. However, this right of appeal does not start until the Local Authority sends the final amended statement. Most parents and carers receive their final amended statement by the official deadline and an appeal, if needed, can be submitted and heard before school starts again in September. However, in a number of cases where the final amended statement is not sent out on time, the appeal may not be heard until the autumn term. This naturally causes worry and distress for both the parents and the child concerned.

***You Need to Know* Young Campaigners Meet with CAMHS Professionals**

As part of the *You Need to Know* campaign, we are working with a group of young people with autism who have experience of using CAMHS, to develop their own charter for what they want from mental health services. The Young Campaigners have met 4 times now, and have drawn up a charter which will be released in January along with a film about their experiences. We hope that local and national decision makers will sign up to make the ideas in the charter happen.

The Young Campaigners were also successfully involved with the party conferences last month and at the All Party Parliamentary Group on Autism, receiving great receptions at both. More recently the Policy and Campaigns team met with CAMHS commissioners and professionals at a national conference to talk about *You Need To Know*. Two of our Young Campaigners Group, Henry and Hollie, shared their experiences of CAMHS and talked about why they got involved in the campaign. "In the bad times, people with autism, as well as those who look after them, need to be able to turn to experts at their local hospital," Henry told those attending the workshop. "CAMHS has the power to change our lives", said Hollie, "and by working with young people and focusing on what works, we can improve this system for young people with autism and make a real difference to their lives." The commissioners and professionals we met were struck by the sheer determination of Henry and Hollie to make sure other young people with autism and mental health problems don't experience the same lack of support that they have. Delegates were keen to hear more about

the Young Campaigners' Charter for CAMHS and how they could involve young people with autism who they support.

All Part Parliamentary Group on Autism debate on SEN Green Paper

The Government launched a Call for Views on how the education system is working for children with special educational needs (SEN) and disabilities. They will use the information they got from this to write a 'Green Paper' which will set out proposals for reform. The Call for Views on the SEN Green Paper has now closed and we want to thank all those from branches who participated in our focus groups and helped us gather as much evidence as possible. We'll be

running a wider survey of parents in January so there will be more opportunity to get involved then. You can read our response to the Call for Views at

<http://www.autism.org.uk/en-gb/news-and-events/media-centre/media-responses/mediareponses-2010/media-reponse-government-call-for-sen-evidence.aspx>

Further to the NAS focus groups the All Party Parliamentary Group on Autism (APPGA) met at Parliament to discuss the Government's Review of special educational needs (SEN) and how the system can be improved. The meeting was really well attended by professionals from the sector and MPs, including Graham Stuart MP, chair of the education select committee, Russell Brown MP, Robert Buckland MP and Lord Clement-Jones. Sarah Teather, Minister for Children and Families, was also in attendance and made assurances that although cuts to government spending will make it more difficult to improve the system; they will not stop reform from happening. She said that it's "not right" that parents have to battle the system to get the right support for their child and that she intends the new system to be much more 'family friendly'. She also wants there to be a focus on diagnosis and early intervention, giving families more choice in their child's education, and transition to adulthood.

Ralph Hemus, one of young campaigners gave excellent speech about his and his family's experience of the system. Ralph spoke to attendees about how difficult it can be to be a child with autism at a school where there is not enough understanding and how he thinks that teachers and pupils should be educated about autism.

ComRes and Scope want to know the real cost of being disabled

The Disabled People's Panel is designed to help Scope and ComRes understand the views and experiences of disabled people. The data they collect will be used to make sure disabled people's voices are heard by politicians, the media, companies and other decision makers. Their current survey 'the real cost of disability' is designed to create better understanding of the additional costs of living as a disabled person. Do you feel the Government really understands what it's like to be a disabled person? Do they appreciate the real costs you have if you want to change a light bulb, travel to the shops or pay for extra domestic support?

The Disabled People's Panel need your help to make sure the true costs of being a disabled person in Britain today are brought home to David Cameron and Nick Clegg. You can take part in the Disabled People's Panel's new survey at:

<http://www.comres.co.uk/surveys/disabledpeoplepanel/>

What do benefits changes mean for me?

On 20 October, the Government announced several changes to disability benefits, including changes to DLA and Employment and Support Allowance. Lots of people have contacted us, worried about the impact of these changes. We're working alongside other charities to make sure these changes don't have a disproportionate impact on people with autism. Find out more at

www.autism.org.uk/benefitschanges

Mencap is running a campaign regarding the proposal to cut the mobility component of DLA for people in residential homes. This cut will affect 58,000 disabled people, who use this benefit to access the community. You can join us by emailing your MP as part of Mencap's DLA campaign.

The NAS Launches the Autism Legal Network

On July 20th, the NAS launched the Autism Legal Network, which aims to bring together people who are interested in making the law work for people with autism, and promote a better understanding of autism. Membership is free and the network is open to legal professionals, charities and NGOs or people with an interest in autism. We hope that building on existing links with law firms, charities and NGOs across the UK will help us to identify further legal cases that raise issues of public importance for people with autism, where it might be appropriate for the NAS to intervene or provide supporting evidence.

The NAS has provided written evidence to the High Court in the high profile case of Gary McKinnon, a man with Asperger Syndrome, facing extradition to the US to stand trial for allegedly hacking into US Defence computer systems, and has intervened in a case

concerning the correct interpretation of disability, within the meaning of the DDA 1995.

To find out more about our legal development work, visit <http://www.autism.org.uk/en-gb/get-involved/campaign-for-change/campaigning-through-the-courts.aspx> or email legal.development@nas.org.uk.

AuKids Magazine

We are trying to help promote an excellent magazine for parents and families of children with ASD. *AuKids* magazine is a quarterly positive parenting magazine aimed at families with young children on the autism spectrum. The *AuKids* team are a small not-for-profit group founded by Debby Elley, a journalist whose twin sons have autism, Tori Houghton, a speech and language therapist specialising in autism, plus a panel of expert advisors. Originally inspired by the steep learning-curve that Debby encountered when her sons were first diagnosed, the magazine aims to offer parents of children with ASD bite-sized, impartial, upbeat advice and the opportunity to share parenting tips.

If you would like to find out more about *AuKids* or to subscribe to the magazine (you can have a print or downloadable version) please visit www.aukids.co.uk or e-mail aukidsmag@gmail.com

Nominate a Happiness Hero

We want to celebrate the people and organisations, and in particular mental health practitioners, who make a positive difference to the lives of people with autism. So we're collecting stories about *Happiness Heroes* - people who have helped someone with autism to be healthy and happy.

A *Happiness Hero* might be a clinical psychologist, a teacher, someone from Brownies, a youth group worker, a football coach or someone at the local church. It might also be a company or venue that's been really helpful to you. To nominate just complete our online form to tell us who you are, who you're nominating and why.

Christmas Card Competition!

Our Christmas Card competition is NOW OPEN! We have a children's category and also an adult category for people with autism who are over 16. The winning entry from each category will have

their design made into a card and they will receive 50 cards of their design for themselves. In addition, you can see a shortlisted design by an adult with autism as it's the front cover for November's Communication magazine! The submission deadline is 15 February and details on how to enter are below. The designs are judged by Jane Asher and the winning designs will be in our 2011 Christmas catalogue!

Entry details:

- Your design should have a Christmas theme and the size should be at least 210mm by 210mm (but it doesn't have to be square)
- Avoid using shiny colours and objects such as gold, silver and coloured foils in collage work as these are difficult to reproduce. Do not fold your design
- Please write your name, age, address and the title of your design on the reverse of your design
- You need to send an entry form in with your design as well. (available via NAS website)
- You can send your design by post to: Christmas Card Design Competition, The National Autistic Society, 393 City Road, London, EC1V 1NG
- Or you can submit your design in digital format by email to: publications@nas.org.uk, The resolution of your design must be 300dpi (dots per inch) or more. If you email your design, please include your name, age, address and the title of your design in the email
- You must be 18 or over to enter the competition
- The closing date is 15 FEBRUARY 2011 and The National Autistic Society is not able to return entries.

PDA Conference

Pathological Demand Avoidance Syndrome (PDA) is increasingly recognised as part of the autism spectrum. It is a lifelong disability that affects boys and girls equally. People with PDA need different amounts of support depending on how their condition affects them. The main difficulty for people with PDA is their avoidance of the everyday demands made by other people, due to their high anxiety levels when they feel that they are not in control. The NAS is running a conference on 26 January 2011 about PDA in association with NORSACA and the Elizabeth Newson Centre. Information on PDA is extremely limited and there are very few forums for learning about the disorder. This conference is an extremely rare opportunity to hear from

experts in the field and will provide professionals and parents with a clearer understanding of the diagnostic criteria and essential strategies for education, behaviour management and communication

There will be a special rate available to NAS members and individuals on a low income. Visit www.autism.org.uk/PDA2010 for more information, or download the attached brochure.

NAS Education Update

The new "NAS education update" is now up and running. A news story should be up on the website shortly and we are planning some more publicity shortly: we wanted get it up and running first and to let you know about it before we start advertising more widely. You can find it here: <http://nas-education-update.blogspot.com/> The idea is to engage more directly with members and others about new developments in Government policy on education, but we can also use to advertise new information sheets, conferences, fundraising asks (particularly if angled towards children and education).

~~~~~ Resources ~~~~~

FREE BOOKS!

harc have a collection of books that they would like to find new homes for. Most of the titles below are single copies. If you would like any of them please send an email to support@harc-online.org.uk stating the book(s) you would like. All we will ask is that you send an appropriately sized stamped and addressed padded envelope to post it to you. We will inform you of the postage according to the weight, and give you the dimensions of the book by return email.

ISBN	TITLE
1 84310 762 7	"A special kind of brain"
1 84310 178 5	"The adolescent with developmental co-ordination disorder"
1 84310 758 9	"Communicating partners"
1 84310748 1	"Asperger's Syndrome in young children"
1 84310 135 1	"Children with emotional and

- behavioural difficulties and communication problems"
- 1 84310 735 X "The development of autism"
- 1 84310 182 3 "Autism - the eighth colour of the rainbow"
- 1 84310 151 3 "How to find work that works for people with AS"
- 1 84310 766 X "Employment for individuals with AS or non-verbal learning disability"
- 1 84310 126 2 "Asperger Syndrome adolescence and identity"
- 1 84310 777 5 "ADD and me"
- 1 84310 256 0 "Wounded bird of paradise"
- 1 84310 165 3 "Making sense of the unfeasible"
- 1 84310 763 5 "Choosing home"
- 1 84310 774 0 "Parent to parent"
- 1 84310 144 0 "Now you know me think more"
- 1 84310 783 X "Sensory smarts"
- 1 84310 782 1 "Allergy busters"
- 1 84310 792 9 "Hurricane dancing"
- 1 84310 052 5 "A supported employment handbook"
- 1 84310 032 0 "An exact mind"
- 1 84310 753 8 "From goals to data and back"

ALL BOOKS STARTING 1 84310 CAN BE FOUND ON THE JESSICA KINGSLEY PUBLISHERS WEBSITE - www.jkp.com - JUST PUT THE TITLE INTO THE SEARCH BOX FOR FURTHER DETAILS OF THE BOOK

Other non JKP book titles are

- 1 905 722 30 3 "My family is different" by Carolyn Brock
- 1 85302 796 0 "Asperger Syndrome employment workbook" by Roger Meyer
- 1 85302 964 5 "Different minds" by Deirdre V Lovecky
- 1 85302 998 X "Assessing behaviours regarded as problematic" by John Clements
- 1 85302 916 5 "I am special" by Peter Vermeulen
- 0 9666 529 2 4 "How well does your IEP measure up" by Diane Twatchman-Cullen

- 0 9666 529 1 8 "How to be a para pro" by Dianne Twatchman-Cullen

Managing Money

The NAS has announced the launch of their new Managing Money website and workbook, part of the Financial Capability Project funded by the Financial Services Authority (FSA).
<<http://www.managingmoney.org.uk/>>

Information from the Option Group

Some useful information sheets on ASD can be found at:

<http://www.optionsgroup.co.uk/asd-links.html>

Teaching Your Child to Ride a Bike

A useful article at:

http://www.associatedcontent.com/article/5582194/ways_to_help_a_child_with_autism_learn.html

Extended Schools SEN Directory

The WelHat extended schools have created a new Special Educational Needs Information Directory. This Directory is designed to support parents and carers of children with special education needs living in the Welwyn Garden City and Hatfield area.

http://www.hertsexextendedschools.org.uk/wgc/documents/SEN_Directory_FINAL.pdf

If you would like a hard copy of the Directory, please contact Gill Dowling on g.dowling@peartree.jmi.herts.sch.uk

Training

Hertfordshire County Council are offering free training to anyone working, volunteering or in contact with children. The project is entitled "Working to Include Disabled Children and Young People". The courses are available for booking

now. Please note that new courses and venues are being added on a daily basis. The most up to date information can be found at:

http://www.hertsdirect.org/actweb/WDC/sseo/template_001.cfm?pageID=18&template=courseListing

Factsheet on Visual Timetables

<http://www.talkingpoint.org.uk/Resources%20and%20Factsheets/~media/Talking%20Point/Factsheets09/visual%20timelines%20factsheet.aspx>

~~~~~ Help Wanted ~~~~~

Looking for Volunteer Advocates

We are sure that amongst our members we have many people with experience of attending meetings with professionals to obtain services or resources for people with autism. If you have such experience, please consider if you would be prepared to volunteer as an advocate, attending meetings to support adults with ASD, or parents/carers of children with ASD. If you feel you could help, please contact harc.

~~~~~ Events ~~~~~

harc Support Group Meeting 9th February 2011, 7.30 pm

The next harc Support Group meeting is at Greenside School in Stevenage. The topic for the evening is Comic Strip Conversations, presented by Pamela Reitemeier. This is a follow up to the very popular 'Social Stories' held in November last year.

Network 81 weekend training

Network 81 have notified us of two training weekends giving an overview of:

- Special Educational Needs and the law
- Statements, their contents and how to appeal

Weekend 1 - Maidstone March 5th & 6th

- Disability Discrimination in School Law within the Equality Act 2010
- Exclusion and its risk including a guide to unofficial exclusions

Weekend 2 - Hatfield 26th & 27th March

Cost of each weekend for parents of children with disabilities £100 non residential or £150 residential

For further information contact Val Rosier on 0845 077 4056 or email

val.network81@btconnect.com

Welcome to Our World... Living with Autism

The Makaton Charity (www.makaton.org) has been working with the Victoria & Albert (V&A) Museum of Childhood who have created a display called 'Welcome to Our World... Living with Autism'. This thought-provoking new display explores life through the eyes of children with autism and is now open at the V&A Museum of Childhood through until 19th March 2011.

Asperger / HFA Youth Group

The NAS and Youth Connexions are now running a youth group for teenagers, aged 13 to 17 years, that meets on Monday evenings (6:30-8:30pm) in Welwyn Garden City. These sessions will run until Easter 2011 (term time only). There will be an entry fee of £1 for each session.

If you are interested then please contact: Alison Carpenter on 01442 247 046 or Fax 01442 213 923

~~~~~ And finally ~~~~~

### **Working on your behalf**

It's been a while since we told you about all the things we have been doing in raising awareness and working with statutory bodies.

#### **Campaigns**

We continue to work closely with NAS on their different campaigns, Don't Write Me Off and You Need to Know. Don't Write me Off continues, sadly, to be as relevant today as it was two years ago with the Government's review of the welfare system including Incapacity Benefit and Disability Living Allowance. We attended a Department of Work & Pensions consultation led by Professor Harrington looking at the experience of people going through medical assessments. The only comforting thing to arise from this consultation was that a poor experience of medical assessments is not restricted to people with autism. The stories we heard made us despair and feel very sad that people who are at their most vulnerable are put through such negative experiences. Professor Harrington's report, I believe, failed to highlight this fact adequately.

You Need to Know is the basis of our conference in March and we are very excited to have both Luke Beardon and John Clements and a number of very respected Hertfordshire professionals working with us. For more information about the conference go to [www.harc-online.org.uk](http://www.harc-online.org.uk)

#### **Workshops**

We have had the opportunity to give the parent/carer perspective at a series of workshops for Adult Mental Health professionals. The feedback from the workshops has been very encouraging and there are clearly some very committed people working within mental health teams who wish to do the best for their clients. They are having to work in a very different way when dealing with people on the autism spectrum than their training had prepared them for.

We left them with the following key points:

- Everyone is different
- You need to ask the right question
- Understand when it is right to tell rather than ask but don't dictate. It is a fine balance.
- Involve carers, they are an extremely valuable resource but balance their needs against those of your client
- Don't make assumptions - just because they look disinterested doesn't mean they are, just because they don't answer doesn't mean they won't
- Look to the long term and the small steps to get there
- Help us to trust you with the people we care for.

#### **Awareness raising**

We have again given sessions with a carer and a person with Asperger syndrome to the Foundation Degree Teaching Assistants and trainee Clinical Psychologists at the University of Hertfordshire.

We have held a parent 'surgery' for parents at Homerswood School in Welwyn Garden City and are planning another for parents of students at North Herts College in Stevenage. We have also attended our second parents evening at Greenside School in Stevenage to offer parents an opportunity to talk about the things that concern them.

#### **Adult Autism Strategy**

We are working with a steering group looking at the Adult Autism Strategy in Hertfordshire. We have made contributions at every stage of the national consultation of the Adult Autism Strategy and watch the outcome with interest.

We are also part funding a conference with Adult Care Services for Child and Adolescent Mental Health and Adult Mental Health professionals looking in particular at transition between the two teams. Again this is based around the You Need to Know campaign. We are very grateful to again to Sue Darker for her continuing commitment to autism.

### **Social Skills Training**

We are commissioning some training on Social Skills to deliver to SENCOs and Learning Support Assistants. Initially this is proposed to be delivered to schools in the Hemel area and following evaluation we would then look at applying for funding for this to become a rolling programme around the county.

### **Going Forward**

We will continue to work hard to represent Hertfordshire families wherever we are able to at local and national level. Please don't forget that we are very happy to go to schools to raise awareness and offer strategies that have worked for other families, so if you think your child's school will benefit, let us know.

And, there's always a but or an and isn't there? If you would like to contribute to this work we will always welcome you. The broader the view the more information and different strategies we can share with people and we know that we all have a different take on how autism affects our families.

### **Information Liaison Worker**

I am delighted to tell you that the funding for the above post was agreed last year by Adult Care Services and the NAS Resource Centre have now recruited the post. Phillip Hanscombe is the successful applicant to this post and started his role in November 2010. His role is funded until 2013 during which time we have to review and evaluate the success of the role.

This post is a direct result of the Imagine Thinking Differently project that harc undertook with Carers in Hertfordshire in 2007-

8. We are very grateful to Sue Reeve, Chief Executive Carers in Hertfordshire, for her foresight in seeing how an appreciative enquiry would help us to establish the needs of Hertfordshire people, to Jo Willis, Carers in Hertfordshire, for keeping us all on track and to Sue Darker, Deputy Director Adult Care Services, for finding the funding for this role. The project took a long time to reach fruition and those involved in the project gave a lot of time and energy to it.

Phillip is a highly qualified individual having trained as a Community Learning Disability Nurse who also has Asperger syndrome. The best way to contact Phillip currently is via his email address [phillip.hanscombe@nas.org.uk](mailto:phillip.hanscombe@nas.org.uk). The role is partly about sharing information so if there is information you need or you have some information to share please get in touch with Phillip. I'm sure we will hear a lot more about him in due course.