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The National
Autistic Society

harc HERTFORDSHIRE BRANCH

March 2008 Newsletter

I Exist

"She has quite calmly said that when we die she plans to kill herself because she knows she will be completely alone and unable to care for herself. She weeps on a daily basis because she is so scared of the future. There is nobody to help her manage her daily life, and more importantly, who will love here when we're gone?"
This is a quote in the 'I Exist' campaign made by a parent of a girl (adult) with autism.

The NAS launched the next phase of the 'think differently about autism' campaign on February 5th. 'I Exist' is highlighting the lack of services for adults with autism. Laurence Griffin, Branch Chairman, attended the national launch at the House of Commons. We received good coverage via the local media in response to our press release and the NAS Press Office have told us that harc wins the prize for attracting the most media coverage of the launch. The prize? Their undying gratitude! Please, if you haven't already done so, go to the think differently website and 'be counted' www.think-differently.org.uk by entering your story on the Be Counted Wall. The more we tell our stories the more people will begin to understand our lives and those of the people we care for.

As part of the 'think differently' campaign we have recently sent the report 'think differently-act positively' to all County Councillors and

Hertfordshire MPs to raise their awareness. Please see your copy with this newsletter.

Additionally we have sent to all Hertfordshire schools a letter introducing harc and the campaign, leaflets on frequently asked questions, how to make an autism friendly school and environment, a leaflet about harc and our own secondary school leaflets (transferring to secondary school and life at secondary school). Hertfordshire County Council very kindly agreed that they would distribute this information once they had seen and approved the pack. We have also offered the schools awareness raising sessions if they wish to request them. It would really help us to measure the impact of this activity if you could ask your school if they have received the pack, what value it has for them and whether it will help them to support children with autism.

If anyone feels that they would like to help us to deliver the awareness raising session please get in touch with us via the office.

What else can you do?

Please use the enclosed three postcards to send to Sarah Pickup, Director of Adult Care Services, Hertfordshire County Council, County Hall, Pegs Lane, Hertford SG13 8DQ. We anticipate that there maybe at least three people in a household who are living with autism

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on a daily basis and therefore three people may want to send a postcard with their views. This will support 'think differently about autism' and will have impact on the County Council. If you have already sent a card please pass this card onto someone else who can send it and help keep the momentum going. Matthew Downie, campaign director is urging us all to write our own message on the card because this does personalise the postcard and has more impact. Please feedback to us any responses you receive from Hertfordshire County Council

Asperger Social Group

The social group in St Albans continue to be very popular with enough names now to run a second group. Alison Carpenter (lead) is working hard with harc to persuade Adult Care Services to commit to a second session. We recently had to cancel a session when the boiler stopped working at the Pioneer during the cold weather and a pipe burst. Fortunately Alison was able to notify all the members of the group just about in time. However, at short notice, we were told that it was suspected asbestos was present and of course we were unable to use the centre. Instead we were able to demonstrate that it is possible to turn a disaster into a success. Alison contacted all of the members and arranged to take them bowling instead. A great success and a practical demonstration that sometimes change can be positive. Thank you Alison.

Support Group Meetings

January Support Group Meeting - Siblings Group

The older siblings group was launched at our January Parent Support Group meeting. It was agreed that this group would be a support group/network for siblings aged 16+. The first meeting would set out the aims of the group, however, it was agreed that a social network such as 'Facebook' would be a useful forum to use. Meetings would be arranged in coffee

houses or pubs depending on what people wanted but also being mindful of the law relating to pubs and those under 18. An email account 'siblings@harc-online.org.uk' will be set up to enable interested siblings to make contact. A screening process will take place to ensure safety of all participants. In the meantime, if you are interested in the group please email support@harc-online.org.uk or telephone the office and your details will be forwarded.

February Support Group Meeting - Representative from Department of Work & Pensions - DLA

Frank Pitfield from the Department of Work and Pensions came to talk to the group about Disability Living Allowance for adults and children. He also came to listen to our views.

Frank took the group through the various elements of the DLA. He explained the different levels of mobility and care.

To be awarded the lower rate for mobility you would need to demonstrate that the person you care for requires guidance when walking about. For instance, can your child of 12 safely go out and about on his own? If the answer is 'no, not without supervision' and you can identify the additional guidance required to safely allow your 12 year old to be outside of the house then you are likely to be awarded the lower level. We raised the issue that most of our children would not be outside everyday and therefore we would find it difficult to say how regularly this occurred. Frank was very clear that we should be thinking that if they wanted to be outside every day they would need supervision every day.

To be awarded the higher level of mobility we would need to demonstrate severe behavioural issues that lead to the child/adult being a danger to themselves or others. Can your child/adult distinguish between people who mean well and those who may mean to do them harm? Are they vulnerable outside of their normal

environment? How much supervision do they need? Think wider than just the environment they know and feel comfortable in and what would be appropriate for a 'normal' person of that age.

There are three levels of care and this is split between day and night care. If you can show the level of attention or supervision your child/adult requires throughout the day time and Frank explained that day time is all the time you or the household are awake not when your child goes to bed, you are likely to be awarded the middle order of care. Attention was explained as encouraging or guiding the person throughout the day until the household closes down. The care component is also based on bodily functions and whilst there will be a literal translation of this it also applies to communicating and development through play. You need to expand on what you need to do in order to communicate with your child and the level of supervision required that would be more than a child or adult of that age and that it is continual throughout the day.

Social and recreational activity is included in this particularly if you can demonstrate that your child requires more input and supervision in order to access these activities. So for instance, can he attend a cubs without a lot of pre preparation and you being on stand by should things go awry? Do you give your child more attention or supervision than any other child his age? I always think it is worth asking the question "Does the parent of a child in the same class need to do the same things for their child as I do?". The answer is generally 'no' and helps to demonstrate how different our lives are it's just that when we live with it all the time we fail to see the differences because mostly we 'just get on with it'.

If your child wakes up during the night or doesn't go to sleep at all you should be able to claim the night element that will move the care element from middle to higher rate. If your

child is disturbed at night and needs calming down and this is prolonged (20 minutes or more) and repeated more than once than you would be eligible for the higher award. If the person you care for is an adult and disturbs the household after it has closed down at night, even if you don't get up, you should be able to claim the higher element of care.

If you receive the middle or higher order of care and work limited hours or don't work at all you should think about applying for Carer's Allowance.

To receive the lower rate of care:

Under 16 - need to give attention to bodily functions for an hour or more a day but not frequent throughout the day. Remember that 'bodily functions' include communication and development through play and the level of supervision required.

16 plus - As above but is also based on a 'single meal' criteria. If the person you care for is unable to prepare a meal using a conventional cooker then they will be automatically awarded the lower level of care.

Frank recommended that reports are sent with the DLA forms but send copies not originals. He recognised that filling in the form can be a distressing experience as it puts you back in a negative mind set.

Frank advises you to focus on the care and help the person you care for needs from someone else or yourself. In fact it is this element rather than the severity of their disability that will make the difference.

He recognised that the people who assess the forms will have different interpretations which is why you will see sometimes significant differences in awards for the same difficulties. If you feel that you have not been treated fairly then you can go to appeal. He strongly

recommends that when taking this pathway you make sure you are well represented and he told us that Hertfordshire Action on Disability are very good advocates.

Frank has now added harc to his mailing list for updates and has sent links to downloadable information. We will make these available on the website in due course.

If you were unable to attend the meeting but think it would be useful for Frank to visit you we will be happy to arrange a meeting locally to you and that can be day or evening. Please let us know and give us an idea of days and venues and we will do our best to organise it.

We asked Frank why it is that adults and children with autism are asked to continually renew their DLA when their disability will never be cured. He agreed with us and said he would take a recommendation back his managers and see if things could change.

Don't forget for help in completing your DLA you can contact the **Money Advice Unit (01992 556370)** and they will arrange to visit to help you to complete the form. Alternatively you can contact the new Welfare Rights Service from the NAS (see leaflet enclosed).

Support Group Meetings

Our next Support Group Meeting will be on Wills and Trusts. This is a very important topic for most parent/carers of people with autism and it is never too early to start planning. Rachel Brooks from Blake Laphorn Tarlo Lyons is a very experienced solicitor and has recently updated her presentation to take account of the new Mental Capacity Act. We are currently working on Rachel visiting us on 14th April. We will send out a notification to confirm the date and venue as soon as possible. When I saw Rachel in London delivering this talk on behalf of the NAS it provoked many questions I had not anticipated. This will be a very informative for

anyone living with autism, parent, carer, spouse or sibling.

C4A Meeting 21st January 2008

This meeting was attended by Mark Jordan (Joint commissioner), Anne Woodward (Project Manager), Andrew Thiedeman (Hertfordshire Partnership Foundation Trust/Mental Health) and Sue Darker (Hertfordshire County Council/Adult Care Services). The purpose was to feed back to the group on work that has been done so far and look at a clear pathway to services for adults with Asperger syndrome/High Functioning Autism and to improve the quality of the services.

Anne Woodward highlighted that:

- Service users were unclear where to go
- Not clear where Asperger/High Functioning Autism belongs
- Mental Health staff are not confident

The work on this has been undertaken with the Asperger Steering Group, Hertfordshire Partnership Foundation Trust and Adult Care Services. The C4A group has met with the Commissioners and feedback from those meetings has been used.

A system is needed to sort out who deals with AS/HFA, whether it is Learning Disability or Mental Health. Those assessed under 'Fair Access to Care' as at 'substantial' or 'critical' risk will receive services. A diagnosis will not give services, eligibility will be based on need. Anne Woodward reported that there are 50 people 'open' to Mental Health services and 50 to Learning Disability (ACS). 'Open' means receiving services.

Those adults with an IQ of less than 70 will receive their services from the Learning Disability Team. This is usually an indication of learning difficulties. (Most people with AS/HFA have average or above average intelligence.). IQ higher than 70 will seek services from Mental Health teams. (Not all

people with AS/HFA have mental health problems although it is true to say that often the lack of appropriate services leads to an increase in mental health problems).

There is a recognition that whilst some services are very good, services across the county are inconsistent.

The proposal is:

- Clear pathway to services - leaflets in GP surgeries
- Services provided in four sectors of the county
- Comprehensive training strategy to increase skills and knowledge within Mental Health teams
- Links to information about AS/HFA on the HPFT public website and a leaflet for the public to access
- Possibility of developing a support group for service users in SE Herts
- Two support workers in each sector to attend specialist five day training
- One psychiatrist to specialise in Asperger/HFA that will become a county wide resource
- Speech therapy to be provided as part of the assessment process
- One psychologist in each sector to specialise in Asperger/HFA
- All frontline staff to receive basis awareness training in Asperger/HFA
- Specialist assessment to be provided by Mental Health or Learning Disability key worker and psychologist trained in assessing AS/HFA using the Vineland Adaptive Behaviour Scale (it is felt that this is a more sensitive measure of functioning than IQ tests)

A care plan will be developed based on the outcome of the Vineland assessment and is likely to include regular (weekly/monthly) input from named Support Worker. Links will be made with education, housing and employment agencies who

have an understanding of Asperger/HFA. Care Plan will be reviewed regularly.

Regular carers assessments will take place offered by Community Mental Health teams or Community Learning Disability teams. Links will continue with Carers in Hertfordshire and harc and respite breaks will be offered where appropriate as part of the Care Plan.

There will be a continual review with carers to ensure improvements are being made. Feedback from Care Planning approach meetings to inform service development and an annual review of services for people with Asperger/HFA and will include:

1. Number of people living independently with support
2. Number of people in residential health placements
3. feedback from service user/carers/staff

There is a focus on working in partnership with service users, carers, service providers, commissioners and other relevant agencies to continue to improve services. They believe there has been steady progress towards achieving the objectives agreed by the Steering Group. Also that there are clear and measurable plans in place to further improve services over the coming year.

My comments on the proposal outlined above are as follows:

1. The work has been undertaken by the Asperger Steering Group. This group started about a year ago and has re looked at all of the work done by the Hertfordshire Asperger Working Group (HAWG). Recommendations that HAWG made at the end of Mark Dixon's secondment as Project Manager not taken forward.
2. I am very concerned that only 100 people are currently known to be receiving services from Learning Disability and Mental Health.

I know how difficult it is to get any kind of assessment for services and agree with the statement made:

- Service users were unclear where to go
- Not clear where Asperger/High Functioning Autism belongs
- Mental Health staff are not confident

3. I note with interest that IQ is again going to be the deciding factor. If the person you care for has a high IQ and does not have a mental health problem they will not receive services. If you have a high IQ and mental health problems you will receive services. When the mental health problems go away presumably the services go with them.
4. Many of the people present made the point that not only is it a hidden disability but is further hidden when adults live at home with parents who protect and care for their children. An assessment under Fair Access to Care would not necessarily judge that adult children being supported by their parents would be at substantial or critical risk. Of course, that all changes when parents die.
5. The Support Workers in each sector will not be Asperger/HFA specialists. I realise that not everyone can be specialists and they will be receiving five days of training to raise awareness, however, that alone does not make people experts
6. I am pleased that they are putting in an 'Asperger/HFA Team' into each sector, however, the biggest hurdle again is going to be eligibility criteria. If you don't meet the criteria you won't receive any services.
7. I believe we need much more in terms of low level services like the Asperger/HFA Social Group in St Albans. Already enough people for a second group, already issues being identified early and dealt with before they become a crisis, already expert advice and

support for people with AS/HFA. This group is effective particularly if no other service can be provided because they don't meet the criteria.

I would welcome any comments on the above. Remember if you have a child with autism they will become an adult in very short time and you are entitled to have your say.

Ann Griffin

NAS Regional Members Conference - University of Westminster 1st March 2008

The conference was well attended from members across the whole of the south eastern region and was introduced by Colin Barrow, Chairman of the NAS. He paid tribute to the work of the branches and said they were central to the work of the NAS. The NAS have increased the support to branches by employing more staff in the Regional Offices (we certainly have seen the impact of this increase). He spoke that whilst the NAS is a small charity it is a big business. We shouldn't consider ourselves part of an organisation but part of a movement. Campaigning means that we need to shout loudly outside the doors of those who can change things whilst talking quietly inside the doors of the local authorities. This, he said, is politics.

The NAS do not believe in going into competition with other organisations who are supporting autism. He was very clear that there is more than enough autism to go round, so the more that engage in the fight the better. The NAS welcomes other local organisations but will be the national voice for autism. It is very important that campaigns are rooted into the local organisations. We are in a long game where we must keep campaigning and having our voice heard.

One of the very important things that the organisation has had to recently do is to raise the profile of the NAS and whilst they are spending some of the charity's very precious

financial resources it is necessary. The more the profile is raised the more resources can be brought into the autism movement. It will also increase the reach and scope of the charity and NAS will be better able to influence decision makers.

Colin introduced the new Chief Executive, Mark Lever. He comes from six years spent working as CEO of the WRVS. Mark spoke to the meeting and commented that in his view much of what he has seen in terms of services and listening to people with autism is just plain unfair.

Respite Care at Radlet Lodge

Lynda Tucker, Principal of Radlet Lodge School gave a presentation on the successful respite care offered to children under 16 years of age at the school. Children do not need to be pupils to be accepted for respite. Their view is that early respite care can help to avoid crisis situations occurring.

If you want to find out if you are eligible for a short respite break contact social services and ask for an assessment. The local authority has a duty to provide a service for carers and if you are the parent of an autistic child you are also a carer. If you are assessed as eligible for this service you will be invited to an informal meeting at Radlet Lodge following which there will be an in depth care assessment with a care plan drawn up. Social Services will pay directly or give Direct Payments to you, the carer, to pay for the support your child needs.

A transition plan is also put in place to help the child to settle into a new routine. Some parents make a request for no transition plan as it suits their child better not to have too much warning. If you want more information then please contact Radlet Lodge on 01923 854 922. For more information on Direct Payments go to www.dh.gov.uk.

Autism Education Trust - Judith Kerem

The Autism Education Trust (AET) is funded by the Department of Children Schools and Families to the end of this financial year. Currently funding is being sought for Year 2 and 3 of the project following which it should be self sufficient. The AET is a collaboration between Treehouse School, the NAS and the Council for Disabled Children and its aim is to widen participation and create a platform for voluntary, independent and statutory providers to plan and develop appropriate autism educational provision including early years.

Roadshows are taking place to inform interested parties and share good practice. The roadshow in London will take place on 19th April. If you are interested in attending please contact Judith at info@autismeducationtrust.org.uk. The AET website has a 'Have your say' section and you can contribute at www.autismeducationtrust.org.uk. The roadshow will be free or charge and will invite speakers and allow networking time and small discussion group to help to shape and develop the AET and its advisory board.

I Exit update - Matthew Downie

Following the success of 'Make School Make Sense' and getting assurances from politicians on what they will do, the task is now to ensure they do so. Matthew explained that 'think differently about autism' was put in place to continue to raise awareness before moving into the next phase 'I Exist'. Eight thousand people have signed petitions asking the Government to ratify the UN Convention on the Rights of Persons with Disability. This they have now agreed to undertake.

Matthew asked all members to take part in the campaign. There are many tools available on the website with template letters to get you started, however, it does again have much more

impact if you can add your own story to personalise the letters. If you don't have access to the internet and want to take an active part in the campaign then please contact us and we can send you hard copies of the pack.

Parent Support Group - Stevenage

At the end of February a pilot parent support group held its first meeting in Stevenage. This was organised by the autism advisory service in conjunction with other CSF professionals working with children and young people with autistic spectrum disorders in Hertfordshire.

The first session was led by the senior specialist educational psychologist for autism. Parents introduced their children and discussed how their strengths and difficulties fitted into the characteristics of the spectrum.

The group is an excellent example of partnership between parents and professionals - an opportunity to learn from other parents, get to know other families in similar situations as well as learn from the expertise and experience of the professionals present.

If you have a school age child, live in the Stevenage area and would like to know more about the group, please contact Caroline Wells, deputy head of the specialist advisory service by email on caroline.wells@hertscc.gov.uk (or if you are unable to email leave a message on 01707 320697).

Jackie Goodhall

Increased head size in autism

My name is Gemma Morant. I'm an autistic researcher at University College of London. We're currently carrying out a research project under Prof. Uta Frith and Dr. Sarah White, to investigate the relationship between increased head size and a particular cognitive processing style (weak central coherence).

We are interested in hearing from the parents of high-functioning children aged 7-11 years old with ASD who also have a large head circumference to take part in our research.

This research project is part of an ongoing programme of research at the Institute of Cognitive Neuroscience, University College London under Prof. Uta Frith and Dr. Sarah White. We have recently found that unusually large head size (macrocephaly) in autism may be related to a particular cognitive processing style (weak central coherence).

Macrocephaly is found in 20% of people with ASD but only 3% of the rest of the population. Weak central coherence is a tendency to notice small details rather than the bigger picture or 'gist'. This style of processing may be an advantage when analytic skills are required and can also be found in some individuals without autism.

This study aims to investigate the relationship between macrocephaly and weak central coherence further. We hope to confirm whether weak central coherence is only present in individuals with ASD who also have macrocephaly.

As children with ASD and macrocephaly are very hard to find, we would appreciate your help!

We would be extremely grateful if you could measure your child's head size following the instructions provided below. If your child's head size is greater than about 54cm, we would very much like to hear from you. We will also be seeing some children with smaller head sizes so please feel free to get in touch if your child's head size is less than 54cm.

If you are interested in taking part or would like further information, please contact Gemma Morant on 079 4204 1302 or email g.morant@ucl.ac.uk

Instructions:

Take a tape measure and place it around the head, so that the measurement is made over the most prominent part at the back and just above the eyebrows at the front (giving the largest possible circumference of the head). Make sure that the tape is pulled tight.

Is your child registered on HAND?

There are many good reasons for registering your child on Hertfordshire Additional Needs Database (HAND).

- You will receive regular copies of HAND news that contains excellent information about new initiatives taking place in the county, play schemes and updates on Parent Carer forums
- Receive discounts for entry to many places in our area such as Woburn Safari Park
- Last but most definitely not least, registering your child on HAND counts the number of autistic children in Hertfordshire. Why is that good? Well it helps the Local Authority to begin to plan services for the future. We know that there are at least a thousand currently receiving services, if you don't receive services where does your child get counted? HAND will help to bring that information together and begins to build a more realistic figure on what the prevalence of autism is in Hertfordshire.

To join HAND go to www.hertsdirect.org/hand or call the Customer Service Centre to request a membership form, 01923 471500 (if calling from an 020 8 or 01923 area code) or 01438 737500 from anywhere else in Hertfordshire.

Second Most popular search

A recent edition of the *Guardian* was looking at the most popular searches on Google and under the 'Most popular "what is" questions in the world' number one was 'What is love' and number two 'What is autism'. Maybe this is a reflection that awareness is being raised globally.

Quality of Life for people with Autism

A ground breaking one day conference being held on 15th May at the East Midlands Conference Centre, Nottingham. This meeting will reflect a person centred approach and speakers include Luke Beardon. There are some free places for people with an ASC and family carers otherwise £85 plus VAT. Please contact Offshoot Events on 0870 066 3627 or www.offshootevents.com/norsaca.html for more details or to book your tickets.

Updates from Maria Kiely of Carers in Hertfordshire.

Parent Carer Action Group

The next meeting is on Tuesday, 18th March at Oxlease House, Travellers Lane, Hatfield, AL10 8TJ (beside the Leisure Centre) 10.30 - 12.30. I am hoping that some of you who have become involved in improving services will volunteer to talk about their experience to other parents and I will be in touch with you individually. Please do come along to meet other parent carers and to share information and experiences and hear how you can become involved.

Short Breaks Consultation with Parent of Disabled Children in Hertfordshire

You may be aware that Carers in Hertfordshire has been commissioned by Children, Schools and Families Service to carry out a consultation with parents of disabled children about Short Breaks. This consultation will include the views of parents who currently use short break services, those who do not use any such services and those who are potential users of short breaks services. The information from this consultation will help shape the development of respite and other short break services over the coming years.

Every Disabled Child Matters

As a result of the Every Disabled Child Matters Campaign (Contact a Family) a total of £430 million will be spent by English local authorities on improving services, starting in April 2008. There will also be additional money from Primary Care Trusts. The campaign needs parent carers to be involved. Contact a Family are organising a course for parents on 19th March in London from 10.30 - 2.30 so that parent carers can find out how you can have a voice, what's happening in the campaign, how you can ensure your local authority set targets for services, what other parents have been doing and meet other parents. I appreciate that the course is taking place in London but I would be very pleased to hear from any parent carers who feels they would like to come with me and join in this course. Please contact me as soon as possible.

You can contact Carers in Hertfordshire on 01992 586969.

Autism (Un)Friendly Services

I thought the extract below, from Appendix one of the Parent Partnership annual report, dated Oct 07, is a telling reminder (as if we needed it) that people on the autism spectrum struggle to get services from a system that does not recognise their needs and that they are treated like second class citizens in the battle to achieve equal recognition of their rights:

ConSENsus Special Educational Needs Mediation Service

The greatest number of enquiries continued to come from parents whose children have Autistic Spectrum Disorder (46%).

Why can the authorities not see that a system that continues to fail in such large numbers is clearly not fit for purpose? How many more years will we have to put up with this apparent discrimination?

Christmas Card Donations

We were delighted to be the recipients of two very kind donations at Christmas. Both were the result of groups of staff donating money they would have spent on Christmas cards to each other a charity. Many thanks to Templewood School, Welwyn Garden City and to the West Hertfordshire Primary Care Trust & East and North Hertfordshire Primary Care Trust based at Barnwell School East in Stevenage.

STOP PRESS

We have just received our first request to deliver a session aimed at raising awareness to a staff meeting at Roundwood Primary School in Harpenden. Let's hope there are many more requests. This is a result of our continuing campaign to engage with schools in Hertfordshire to offer support and information.

Feedback from harc launch evening

We promised that we would update you following the launch evening in December. Nick Bury has done a great job of evaluating the feedback from the evening. It's good to see that some of the things you thought we should be doing we already are - what we are not so good at doing is telling you what we have done!

We asked four questions:

- What do we do well
- What could we do better
- How could we do it
- What do you want us to do

WHAT DO WE DO WELL?

Family Support
Becoming an NAS Branch
Parental Voice
Impart information (helpline, newsletter)
Get voice of autism heard at planning level - local authority, education....
Raising awareness
Good partnership working
Achieve better services by partnerships working and lobbying
Helpline/Newsletter & Communication with Parents
A strong voice with Herts CC - Lobbying Government - Lobbying Health Authorities
Support of 16+ & Adults

?

WHAT COULD WE DO BETTER?

Be more visible
Attract/reach out to a more diverse population
Link up with all Herts parents
Education
Fund raising
Running sessions - groups for parents & 'sufferers'
Skills registers - members contacts - bid writers, tap into funding
Empower parents of children at special schools <ul style="list-style-type: none">- to have access to services- to have high expectations- to represent them in lobbying for services
Lobby for stakeholder involvement in strategic planning - decision making
Communication of available services to professionals and parents

HOW CAN WE ACHIEVE THIS?

Better distribution of information/networking
Giving all parents a voice
Grants - Bids - People with know how re this - How to successfully apply for grants
Database of users and providers contacts
Specific respite / after school projects
Training for professionals (Move around Herts)
Awareness in schools
Continue local government lobbying
Training professionals
Parental contribution to training
Extend the helpline hours to include emergency - ask who is willing to help - source funding/NAS
More Social Groups/Skills - need a trained facilitator - source advice from NAS
Post 16 education and beyond - suitable employment - suitable housing - raise awareness - lobby L.A.
Joint funding
Partnership working
Information for professionals in easy accessible form for parents ie leaflet sheet sent to schools on what parents can access eg forthcoming meetings (aside from newsletter)

WHAT WOULD YOU LIKE US TO DO?

Research to support campaigns
Social skills groups/sibling workshops
Be a representative in CSF
Transitions
Premises - children's centres for groups
Paid staff
Skilled child care - to help with supporting user groups
Awareness raising at SENCO cluster meetings. Secondary/Primary
Wider geographical spread of activities possible using Children's Centre for parents/children
Youth Groups (Social) Year 9-13 in schools. Use existing facilities

Next Steps

We now need to look at what we can achieve and how we can do that. We are now beginning to work with our new volunteers to help us to move forward. Inevitably if you would like to help us to achieve this then we would be delighted to hear from you. We have certainly begun with the awareness raising in schools, 'Imagine Thinking Differently' is well under way and will support the national 'I Exist' campaign. It does not just look at adults we are trying to map the autism journey from early years to old age so we would like you to tell your story, to give you a voice. We will be in touch with you during the next couple of months.