

# ASSERT

Angelman Syndrome Support Education & Research Trust



ISSUE THIRTY EIGHT NOVEMBER 2004

REPORT

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## National Conference Loughborough 3 – 5 September 2004

*Hello*

*Welcome to a special Conference Edition of the newsletter – we hope you enjoy it.*

It is the day after the conference and I thought I would get some thoughts down on paper before it disappears into a blur (which it is a bit anyway!) There have been 9 intensive months of planning (bit like having a baby!!) I am exhausted and I guess for the families who attended they feel much the same. Overall most people felt that the conference was a success and were extremely appreciative. There were some comments and suggestions but when you consider what the conference cost you (not us – it cost us a lot more than you paid) I am sure you will agree it was good value for money.

Loughborough has up to now been a good venue but we are at maximum numbers – if any of you have any suggestions as an alternative we would be pleased to hear from you – as you know the conference was organised and run on a completely voluntary basis so if there are any people willing to check out or suggest venues for us to look at, it would be appreciated since we do not have the time to travel all over the country looking – it would need to be fairly centrally located, not much further north than Manchester really but near to good transport i.e. trains/airports. It also needs to be good value for money!!!!

Looking back over the weekend – it was great to see so many families enjoying themselves, we had 76 families in all and apparently close to the sizes of conferences held in the US and Canada! The venues for the trips went down well and I at least have a photo of my son on the log flume enjoying himself, as I was unable to go for some reason or another! Thanks to the trustees who went along on the trips – it was a really difficult job as there were so many of you and it was so hot.

The conference itself was jam packed as usual and for some I know it was very rushed – you could have taken time

out of sessions – you didn't have to go to everything although I know it was hard not to! It was the sixth conference I had attended and our third – the biggest yet and almost international – we had a parent from New Zealand (just for the weekend!!), parents from Greece, Denmark, Ireland, Italy – and there were British residents from South Africa and the US. Both the Italian and Danish support groups were represented and we received a message from the President of the IASO Melanie Barton who was unable to attend. I learnt so much from it and undoubtedly the star of the show was Professor Bernard Dan who portrayed the complex, serious topic of neurology and epilepsy in a comedic – but informative, parent friendly way, which we could all relate to and understand. What was particularly interesting to us as a family was finding out about how the way the brain works in AS. To hear an explanation of why our children/adults make ataxic haphazard movements and how hard it is for them to perform simple tasks and how they compensate – there is so much more we can learn about this I am sure, and this helps us to understand our children and young people a lot better and have some sympathy for what it's like to be them. If only we had had knowledge about seizures etc like this when our son was younger.

We began on Friday afternoon with a First Timers Talk – if anyone wants a handout please contact me...this was really an emotional guide to the conference and how we expect people who have come for the first time, to feel. It is a very emotional experience and even myself after all these years is moved to tears at times – there was one particular moment when Professor Calculator showed a video at the end of the session – it was the usual schmaltzy music but as it went on the words portrayed were so powerful – I really had to try hard not to break down – I looked around, as I couldn't bear to look at the screen as I was finding it harder and harder to control myself – many of you were having the same problem

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as I was but you didn't have to compose yourselves to introduce the next speaker like I did!!! Those of you who were there will know what I was like! It was like that the whole weekend – moments when you are fine and in control and then something small triggers a whole set of feelings. We often suppress our feelings and get on with it – the conference is a time when we don't have to do this. I have heard that there were quite a few of you who had quite a hard time when you first arrived on Friday – I hope we helped you over the weekend and that there was more laughter than tears.

We had a Welcome Reception in the bar Friday evening – and a chance to sing Happy Birthday to my husband Ken who celebrated his Birthday (although we as a family didn't get time for cards and presents until Saturday evening). I know some of you went off to bed early as you were tired from the journeying – however, the people that you would have expected to be most tired as they had travelled the furthest (apart from the Irish and Italians) were the people who came from a little known part of the UK in the north – somewhere called Scotland, the Land of the Scots. They kept up their usual first in, last out of the bar regime as they have at other conferences – although I was a bit worried at one point that they may have been beaten by the Irish (all these Celts are the same!) I think the free wine helped a bit and they obviously don't see each other very often!! I have included a photo I took earlier in the evening and threatened would go in the newsletter! On Saturday I have to report it was the same scenario only a different table. We were so fortunate with the weather which was warm and humid (good gnat biting weather) which meant we were able to sit outside as there was no way we would have fitted in the bar otherwise – the coolest place was the foyer and Peter Hammond was there taking his Cranial Morphology images – he will be preparing something for the newsletter in due course, unfortunately the response from families was not as good as last time which was a shame – the images he is compiling will be very useful in helping diagnose Angelman Syndrome from facial features, which will be helpful in the third world where blood tests etc are

too expensive and lengthy and in clinical conditions this would be a useful tool.

It was a hectic non stop rush for me – but it meant there was no time for boredom – one person commented what they least liked about the conference was having to get up in the mornings – yes we were up ready for the day eating breakfast from 7.30 onwards – there's no time for slacking at a conference!

Saturday dawned cloudy but warm – great for the trip to the American Adventure Theme Park – I believe everyone enjoyed the outing and the children came back exhausted and sun burned.



Time for lunch

Dr Dave Hewett began the day and was a hit with most families, he had a relaxed comfortable style which parents liked – also the information and suggestions he gave were very pertinent – like you all I didn't get to everything and because I went to the workshop on Transition as this is a subject close to our hearts at the moment, I missed both Prof Stephen Calculator and Dave – I was very disappointed as both speakers were praised by many families for their practical insights into issues relevant to all of us....next time...

We heard from Maurice Collins about our legal rights and what to do about them, Robina Mallet gave us an insight into the Government White Paper on Valuing People which affects adult services, later she took a workshop in outlining the Transition Process for 14 – 25 year olds as they move from children to adult services. Finn Emmerson and Nadine Farris ran workshops on communication and basic equipment such as switches. Mike O'Connell came from Dynavox to show what families could potentially be looking at if communication aids for their children in future were appropriate. We had a trike demonstration from Bob Griffin and also a buggy and chair demo, Paul Chick was also on hand with leaflets about his designer bed [www.chickies.co.uk](http://www.chickies.co.uk)

We had entertainment laid on in the bar that evening – a



Scots in the All Night Bar...they wished!

magician with balloons and a real rabbit! The raffle and DVD draw raised over £420 for ASSERT so many thanks to all who gave prizes and bought tickets and gave money for the DVD. We had a late licence till 12.00 midnight and I guess the usual people were in the bar until the end. Again it was a warm balmy evening with the biting insects out in force!

Sunday was an early start for us – Matthew was awake at 5.30 – but he did go to bed at about 10.00 p.m. so that wasn't bad. The children and carers headed off for Twycross Zoo and apart from an incident at the end, the venue was a hit.

We learnt more from Bernard Dan, and Stephen Calculator, Dr Jill Clayton Smith joined us and as usual was a hit with everyone – Genetics this time – an extremely complicated area even for Geneticists I think! As usual this was presented in a parent friendly way and I learnt again from her even though I have seen many genetic presentations in the past. It was a great way for parents to ask burning questions, particularly for those without or waiting for diagnosis and also those who may have a more complicated genetic diagnosis of AS. Jill I know also likes to talk to you all as you the families teach her too. We heard from Dr David Clarke about using drugs to control behaviour. Dr Mark Hunter a paediatrician with an interest in AS, hosted a workshop with some of the families. In between we had a lovely lunch (food was great all weekend although I did notice a couple of you weren't over keen) – the majority gave it 5 out of 5 – one family gave it 10 out of 10!

Professor Chris Oliver was there with his research team who have been working on Smiling and Laughter in AS – they produced their results so far – unfortunately the results tell us what we already know BUT in order to research you have to prove everything before you can make the next step. We had a workshop to explore the kind of behavioural research we the parents would like in the future – this also involves application for funding and probably with some other charities – this will be a new and exciting development for ASSERT.

Finally it was time to come together and say goodbye – I found that very emotional as those of you there would have known – I had put my heart and soul into organising the conference and many things in my life were put on hold over

the summer – I thanked my family which started me off as they had all supported me, Ken put up with all my moans and groans and me spending less time at work. My daughter Rachel and her boyfriend Ben were carers for Matthew, who allowed us to bring him for once – without them it would not have been possible. My other daughter Laura also deserved thanks, as she often was the brunt of my bad temper when things weren't going right – she was home alone and I am pleased to report there were no parties whilst we were away! I think the emotion was all part of the relief I felt with a job well done and it had all gone according to plan. Finn Emmerson was my rock in it all – although I did all the admin work she supported me with all the ideas and contacted speakers in the beginning – she kept me on track and spent 9 hours with me making up the Conference Packs and name labels, we met at least once a week throughout the summer holidays and made list after list (she is a Virgo and that's what they do well!) – without her I could not have achieved what I did on my own. My fellow trustees had put their faith in me and let me go ahead with what we had planned and of course were a support all weekend in making sure everything went smoothly. There were some minor technical problems but all in all everything ran well.

Now it is all over and I don't have the feelings of anti climax that I thought I would. I feel satisfied that you all had a great time and got so much out of the experience – I won't personally be doing another one, but if we get a good team together, hopefully there'll be one in 2006 – which will also be the year of the next International Conference in Rome, Italy. Thanks for all the appreciative comments you gave to me at the conference and since. I hope we'll meet again next time!

For those who asked for the video played at the end of Professor Stephen Calculators session on the Saturday morning – here is the information: ÖCREDO OF SUPPORTÓ Norman Kunc and Emma Van der Klift, Axis Consultation & Training Ltd 340 Machleary Street Nanaimo, British Columbia Canada V9R 2G9 phone: (250) 754-9939 fax: (250) 754-9930 email: normemma@normemma.com

## Conference Evaluation

### These are some of your comments from the Evaluations.

*Some topics were not relevant* – in all conferences it is impossible to provide a programme to suit everyone – you cannot cover all aspects of AS in both adults and children and within the different diagnostic categories, and also allow for English/Scottish/Irish Law (something we are conscious of) in a weekend – you have to tailor the conference to the majority – we also cannot invite speakers to travel the length of the country and give up their weekend to have 4 or 5 people in a workshop.

*The Alternative Therapies were disappointing* – as you know Krystyna Proctor, who was recommended by one of our families

was unable to attend and therefore we had no idea of what her replacement was like. Linda Scotson (NRT) also cancelled at the last minute and we had to substitute her video, which arrived Friday evening, we had no chance to vet this beforehand. Unfortunately despite best intentions these things happen. We did try to get a Cranial Osteopath (recommended) but as it was their own national conference the same weekend we were unable to get him or a replacement.

*Some topics were repeated* – this was to allow as many of you to split and do workshops – it was easier for two of you to split and do different ones but for a person on their own it was more difficult to cover everything – it is hard to get the right balance that will suit all as there is so much to know. Maurice Collins was unable to stay for his workshop and therefore Finn had to step in

at the last minute, as did Gerry with the Resuscitation workshop. *Speakers who were more familiar with AS* – as you know AS is a rare condition and therefore even diagnosis in some parts of the country is difficult as some paediatricians may have never seen the condition first hand – also many of our children are still undiagnosed so some professionals could be working with AS without knowing it. In some of the topics we discussed, some had no experience of AS – by inviting them to the conference to participate will perhaps give them a interest and a passion that some of those had who we had to bring in from abroad – everyone has to start somewhere. There is a limit to our funds and it a shame that we do not have the hands on experts with an interest in AS in our own country. Unless you are accessing people who work on a national basis rather than in a small community there do not seem to be any hot beds of experience – if you know of any then please share them with us.

*Scoliosis* – this could be a topic for next time and I will see if my Orthopaedic Surgeon would come – he has experience of AS – but we will have to bow to his good nature to give up time at a weekend.

*Time of year – not in holidays* – When is a good time? Term time is difficult we know but in order to be able to use the University we are stuck to when it is free from students. School holidays are difficult because of people going away plus many of our speakers have their family holidays then too. The weather needs to be good for travelling and for the outings – without the good weather this year we would certainly have had problems in the bar area.

*Bar Area was too small/Soft Play Area in the bar* – This was another issue you may have not been aware of. We were supposed to have our usual bar area but this was being refurbished and should have been finished by our conference weekend. However we didn't find out until just before the conference that the venue was relocated and therefore had no chance to inspect the venue until the weekend. We tried to fit in as many of you as we could at the conference and therefore our numbers have now outgrown all the local bar space Loughborough has to offer. A family also suggested a soft play area, but this is a University and unless we relocated to a pub there are no places with these facilities – unless of course you know somewhere that has them nearby and will take 250 of us!

*Accommodation* – A few were disappointed with the accommodation – well think of the cost. If we were to use a hotel and conference centre facility then the greatest consideration would be the cost – for example a 24 hour delegate staying in the Burleigh Hotel (4 star) at Loughborough University would pay £160 per person per night, this would

mean that ASSERT would have to charge at least half of this and fundraise considerably to support any subsidies – for this conference there were 230 adults – you can do the calculations for yourselves!! However, we can if you like just book a conference centre and let you arrange your own accommodation if this were preferable – of course you were always free to make your own arrangements if you had wished.

*Counsellors* – someone suggested having trained counsellors on hand – this is of course something we would like and have already thought about. But again it is cost related and also finding people with the right experience and empathy is not easy unless from recommendation – also not all counsellors are going to be the right chemistry for all people – unless you can recommend someone....

*Topics weren't in enough detail*, too short, not enough time for questions, constant rush – again it's all about balance – we tried to get in as much variety and use the workshops as a launch pad for you to go and find out more information once the conference is over – longer workshops means less areas covered and perhaps for some who didn't find sessions relevant it would go on too long – I wish we had the perfect balance for everyone. AS cannot be covered in a weekend and as getting time off work is an issue for some – we cannot have longer conferences – they would also be more expensive. We could try longer workshops next time but we will not be able to fit in as many.

*More information for the non deletion groups* – we realise this is a problem – but again it's finding people with the expertise – as you know you are all in the rarer group of AS and as it is a rare syndrome anyway this makes it even more difficult – we could perhaps have a notice board area to identify yourselves or a non deletion session for you to talk to each other. Obviously any other suggestions you have would be good.

*A bookstand* – yes this would be a good idea but how could we organise this – any suggestions? We did try to get Fledglings to come along with the toys etc again but they were unable to attend.

I am pleased to say we had more positive than negative comments and some suggestions for next time – we agree that the clip boards for the workshops was an issue – but the signing up on boards on the wall didn't work last time (the clip boards were portable). In the end everyone got to go to a workshop of their choice, but the clipboards did help to decide whether to run some workshops or not (the NRT for example).

**If anyone has used services or come across any Angelman Syndrome 'Champions' we would really appreciate it if you could let us know for next time.**

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# ASSERT 2004 Conference Evaluation

					
	1	2	3	4	5
Did the weekend fulfil your expectations?		1	1	8	45
Were you happy with the venue?	1	1	3	10	41
Were you happy with the accommodation?	1	2	6	20	18
Were you happy with the food?		1	4	8	41

## Most Valuable

Natural Gestures  
 The workshops  
 Advancement in genetics  
 Updates on medical developments  
 Thanks to the organisers for another successful conference  
 Meeting everyone – Bernard Dan  
 Info about benefits alternative therapy and equipment  
 Meeting other families/Bernard/Jill – thanks for opportunity  
 Just being here  
 Meeting other parents/families  
 Being with so many AS families  
 Alternative therapy and problem behaviours  
 I love the whole experience  
 Dave Hewett, Stephen Calculator meeting families  
 Alternative Therapy  
 Dave Hewett, – good advice, inspirational  
 Prof Bernard Dan – very clear/funny and talk interactive  
 Dr Jill Clayton Smith offering to see my son  
 Great folders – lots of information  
 Switches/Professor Calculator  
 Overall everything was excellent  
 The friendship of other people

## Least Valuable

Nothing – all v good  
 Psychotropic talk  
 Behaviour duplicated  
 Some duplicated

Alternative Therapy  
 White paper for professionals

Constant rush – speakers not finishing  
 Information overload – but unavoidable  
 Alternative Therapy

Timing – back at school  
 Bathroom in my room  
 Alternative Therapy  
 AAC and goal setting  
 Workshops more in depth  
 Parent to parent workshop too formal  
 Talk on behaviour research  
 Everything was Valuable  
 Alternative Therapy  
 Not being able to sleep on in the mornings

## Most useful

Meeting other parents/families 34  
 Seeing other children 2  
 Networking and choosing workshops  
 Various workshops – Stephen, Bernard very interesting 2  
 Meeting other professionals 2  
 Alternative therapies 2  
 All of it 5  
 Practical ideas  
 Dave Hewett/Bernard Dan  
 Having access to specialists 3  
 Dave Hewett/Jill Clayton Smith/Maurice Collins  
 Calculator – too hurried repetitive not helpful  
 Information provided 7  
 Neurology/epilepsy – fantastic  
 Different equipment  
 Jill Clayton Smith/Maurice Collins  
 Neurology

## How useful

Very 19  
 Very but too short – question time was limited  
 Very especially neurology  
 Some more than others  
 Bernard & Jill  
 Dave, Jill, Bernard  
 Very especially therapies  
 Very wide area covered 2  
 Varied workshops 4  
 Dave and Stephen – useful and informative  
 Neurology, psychology, communication and aids  
 Interesting and informative workshops  
 Mainly useful  
 Alternative therapies – disappointing  
 Some workshops useful  
 Neurology good explanation  
 Interesting and informative especially Bernard

### Most useful

Communication switches and hi tech  
Finding out rights  
Having the handouts  
New updated information 2  
Very good speakers 2  
More varied information this time  
Maurice Collins – not long enough  
Hearing the experts  
Natural gestures very practical

### How useful

Behaviour particularly for the older child  
Parent friendly information  
Quite useful 2  
Something for everyone  
Communication & Intensive interaction

### Future Ideas

More 1:1 with speakers  
Soft play in bar  
Cranial Osteopath  
Chill out area/comfy chairs for parent discussion  
Another conference  
More rep stands – Gamma chair/bed safety  
Workshop registration tips 4  
More detailed workshops 5  
More specialists!  
Conductive education  
Lower bar prices  
Scoliosis/sibling workshops  
Maintain balance between children and adult issues  
Lifts/3 days  
Massage demo/brushing  
Alternative therapy stands  
More information about non deletion groups  
Adult/children's services  
Play therapy  
Counsellors  
Not enough time for topics covered 2  
Effects on other members of the family and how families cope  
Region identification on badges 2  
Conductive education/intensive physio  
Carry on with the good work  
Sharing ideas and what works session  
One day and social on second day  
More practical ideas  
Video/audio tapes bookstand 2  
Ground floor rooms  
Trip for all families  
Question time  
Carers of older AS to share ideas  
No children at conference – too distracting

### Comments passed to speakers

Jill Clayton Smith – excellent  
Dave Hewett – excellent inspirational  
Thank you 3  
Bernard – star of the weekend  
Well Done!  
Stephen's talk was aimed at professionals 2  
A very good conference all round  
A big thank you to all the speakers especially Bernard  
Copy of Jill's presentation  
Dave Hewett & Chris Oliver particularly inspirational  
Stephen – you showed great knowledge  
Thanks for your time 2  
Stephen Calculator/Bernard Dan worth coming for alone  
Honoured to meet the experts, thank you  
Get Professor Dan back – brilliant  
Stephen excellent v relevant  
Really enjoyed Dave Hewett's lecture and workshop  
More handouts  
Informative/well presented  
Enjoyed all speeches by all speakers  
Thanks for taking time and making it easy to understand  
  
Stephen Calculator Gestural communication  
Make it easy to follow  
Dave Hewett – fun but useful  
Like to keep up to date with Professor Dan's research  
All very interesting/knowledge was outstanding  
Excellent/passionate about the syndrome  
Excellent weekend  
All very good  
Dan was extraordinary

### Website

For all the latest photos and presentations from the conference please log on to the website [www.angelmanuk.org](http://www.angelmanuk.org)

### Stamps

Please send your stamps to Dick Barton, Thistle Cottage, Winser Road, Rolvenden Layne, Cranbrook, Kent TN17 4NN.  
Please trim them as close to the perforations as you can (don't cut them off though!) as this will save on postage.

# Does Understanding Our Difference Make a Difference?

Have your say on the benefits of genetic testing for learning disability.

Why? Why me? Why am I different? What caused it? These are all questions we have struggled with at least once in our lives. Although it is always hard to ask such questions of ourselves it is often much more distressing to have to ask it about a loved one or relative, especially if we believe – rightly or wrongly – that we are in some way responsible for their condition.

Why? Why did this happen to us? Why is my child, sibling or relative different? What caused it and how can we make it better? Families with learning disability often find themselves asking these complex and distressing questions. In many cases, there is no simple answer or solution. However, at the Cambridge Genetics Knowledge Park we are undertaking a project aimed at alleviating some of the burden on those forced to ask such questions and we hope that your input can provide us with at least part of the answer.

The Cambridge Genetics Knowledge Park is one of six knowledge parks throughout England and Wales dedicated to bringing together different areas of expertise in medical genetics to create benefits for the community as a whole. At the Knowledge Park we believe that difference should be celebrated. It is what makes us unique, individual and special and it is what makes our society work so well. However, we are also aware that society is structured in a way that makes it harder for people with certain inherited physical or mental differences to act or interact in the same way as others. This can impact on their lives and the lives of those who love and care for them. Where this is the case, the Genetics Knowledge Park and the health professionals we represent endeavour to understand the genetic basis for such inherited difference. We aim to use this knowledge to help those whose lives are made harder by genetic difference to overcome the challenges they face.

One of the groups the Knowledge Park is interested in is those with 'learning disability'. Learning disability is an umbrella term used to group people with similar conditions together so as to ensure they receive appropriate recognition, help and support. Generally, it refers to someone who finds it harder to learn, reason, or interact than others. It is also used to refer to situations where a child's ability to learn is not yet clear.

Learning disability may be caused by a variety of factors. However, in many groups that exhibit learning disability symptoms – particularly where those symptoms are severe –

there seems to be an abnormality or difference in their genetic make-up that can be said to have caused the condition. We believe that, as the science and our knowledge advances, even more learning disabilities may be seen to have a genetic cause.

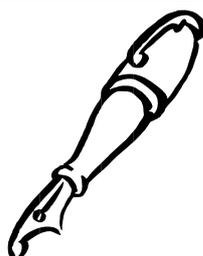
Even now we have in our possession more and more tests that can help us identify the underlying genetic cause of learning disabilities. In many cases there are benefits to be gained from a genetic test. Sometimes it may help us find a treatment. In other instances, it can inform parents about the possibility that any further children they have might also have special needs. Or, it might reveal that the child with the learning difficulty is unique and other family members, their children and descendants will not be affected by the condition. In other cases the benefit of a genetic test isn't so clear and the test will only provide raw data in the form of a diagnosis.

Is simply knowing something's root cause enough? Are there times when it is better not to know? How could we improve the way a test is undertaken, delivered and followed up? We think these are important questions that need to be addressed.

It's vital to draw on the experience of people who are affected by a learning disability regarding how obtaining a genetic diagnosis has impacted, or could impact, on their lives. We aim to use this information and advice to draw up guidelines on the way genetic testing for learning disability occurs. As part of this process, we plan to undertake discussion groups in Cambridge and London (travel and care costs can be reimbursed) supplemented online forums. We are also happy to hear the personal stories of those unable to participate in the above events.

If you, a family member, or someone you care about has a learning disability we would greatly appreciate your expertise and experience. If you would like to be involved, please contact me (Brendan Gogarty) by email [brendan@srl.cam.ac.uk](mailto:brendan@srl.cam.ac.uk), phone 01223 740784 or by post (Cambridge Genetics Knowledge Park, Strangeways Research Laboratories, Worts Causeway, Cambridge CB1 8RN). We hope you can raise our awareness, because in this instance it is you who are the experts and we who need to be educated. Your unique contribution is valuable to us, so please help us make a difference.

**If you enjoy these articles please think about writing one about your family, we really find this the most interesting part of the report. The address to write to on this or any other subject is:  
ASSERT, PO Box 13694, Musselburgh, EH21 6XZ**



**Please note that the deadline for the next edition of the ASSERT Report is xxth month 2004.**



## Moments in Life

There are moments in life when you miss someone so much that you just want to pick them from your dreams and hug them for real!

When the door of happiness closes, another opens; but often times we look so long at the closed door that we don't see the one, which has been opened for us.

Don't go for looks; they can deceive.  
Don't go for wealth; even that fades away.  
Go for someone who makes you smile,  
because it takes only a smile to  
make a dark day seem bright.  
Find the one that makes your heart smile.

Dream what you want to dream;  
go where you want to go;  
be what you want to be,  
because you have only one life  
and one chance to do all the things  
you want to do.

May you have enough happiness to make you sweet,  
enough trials to make you strong,  
enough sorrow to keep you human and  
enough hope to make you happy.

The happiest of people don't necessarily  
have the best of everything;  
they just make the most of  
everything that comes along their way.

The brightest future will always  
be based on a forgotten past;  
you can't go forward in life until  
you let go of your past failures and heartaches.

When you were born, you were crying  
and everyone around you was smiling.  
Live your life so at the end,  
you're the one who is smiling and everyone  
around you is crying.

Don't count the years-count the memories.....

Life is not measured by the number of breaths we take;  
but by the moments that take our breath away!

### ASSERT 2000 Club

As you know we have a draw 4 times a year and it costs £12.00 per entry to join – you can have as many entries as you like – the winnings will be determined by how much money we have in the pot. All profits go to ASSERT. Please see the enclosed form for details.

## Contents of the Newsletter

You will notice that the pieces in this newsletter are drawn from a wide source of places. This is tremendous, and we hope you will agree that it makes interesting reading. However, while we are keen to promote discussion and to pass on many views and experiences, it is also important to appreciate that the opinions and views expressed by contributors to this newsletter are personal ones and not necessarily those of the trustees of ASSERT.

### Conference Funding

Too late for this time but of interest in the future perhaps?  
Family Fund grants to attend group family days  
Does your group have members who would like to attend your family day or conference but who are not able to because of the travel and accommodation costs? They may be eligible for a grant from the Family Fund to cover these costs. The usual criteria will apply: the family must have an earned income of less than GBP23,000 and have a child with a severe disability. For more information about these criteria or to make an application phone the Family Fund help line on 0845 1304542 or check their website at <http://www.familyfundtrust.org.uk>.

### Request from Genetic Interest Group

Dear All,  
A researcher at a TV production company called Wall to Wall has contacted me. They have been asked by the BBC to find some stories about "Amazing Parents". This programme has not been commissioned yet, when it is, it will be for BBC 1.

The programme will not only focus on parents of children with genetic conditions but a range of parents who cope themselves, or look people in extraordinary circumstances. For example they are looking at a lady who brings up a very large family on her own. Wall to Wall are keen to have a family with a rare condition as one of their programmes.

Darcy Cox is looking for a family who would be willing to participate in this documentary. The likelihood is that it will be a one-hour documentary on each family and the filming will probably last for between 5 – 10 days. Darcy is keen to speak to people who would potentially be interested, however you are not obligated to partake and if you would just like further information about the programme this is fine.

If you would like any further information or if you know of families who you feel may be interested in talking to Darcy then please do contact her on the following numbers:

Marcy Cox  
Development Dept  
Wall to Wall  
8-9 Spring Place,  
London NW5 3ER

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# TRANSITION PLANNING – The way ahead?

*Thanks to Lydia from Unique (whom I met at a Family Carer Seminar) who passed on this information which I hope is useful to you. We are currently about to start this Transition process ourselves.*

Growing up, becoming an adult and leaving school are challenges for any child (and their parents!). When a child has additional needs families can face many extra difficulties. Transition Planning is a process that helps young people move through adolescence to adulthood – educationally, emotionally, physically and as individuals within society. It should not be a single event or meeting but a live, on-going process that lasts over a number of years. If your child has a statement then the process will begin in Y9, and the first plan must be completed after the annual review and updated at least once a year. By the time they are 16yrs all the arrangements should be in place so that you will know if your child is going onto Further Education, employment, residential college or placement. Governments in England, Scotland, Wales and Northern Ireland have passed or will pass laws that say this should happen. That's the theory. But if you want to make sure that this process is successful then it is important that parents start to think about transition a lot sooner. A recent study, "Bridging the Divide", carried out by Norah Fry Research and the HFT (Home Farm Trust) has highlighted a number of problems with Transition Planning:

- Young people themselves had little meaningful involvement in planning their future even though legislation stresses that, "their views and aspirations are central to the process".
- Many youngsters had left school without a transition plan
- There was a lack of easily accessible information for parents and young people about what future possibilities might be
- The quality of transition planning varied widely
- The topics covered in transition planning were often quite different from those that families considered to be important such as leisure and social opportunities, information on benefits, housing options.
- Key issues (e.g. transfer to adult health or social services) had still not been addressed by the time some young people had left school
- Whether or not youngsters had received transition planning made little difference to what happened to them after leaving school
- Most transition planning is initiated by schools and tends to focus on college or residential placements There were few post-school options, particularly in relation to housing and employment, available to young people

The most negative part of the whole planning process was the lack of any real options to move on to. If at this point you feel like selling up and moving to a small tropical island, don't despair, there is some good news on the horizon. There are a number of organisations, voluntary and government, who are trying to improve the process using one or more of the following methods: – Person Centred Planning (PCP), Essential Lifestyle Planning (ELP), Families Leading Planning and Circles Network.

## **Person Centred Planning**

Until recently planning for a person's future had always centred on their, 'needs', physical, medical, educational and social. Person Centred Planning (PCP) is a totally different approach that puts the young person at the centre of the plan and then everyone can focus on looking at what that person 'wants'. Plans are developed that consider everything from that person's own perspective. It should involve listening and learning about what that person want from their life and helping them to think about their future. Family, friends, professionals and services work together with the person involved to make the plan happen. The process can help the person and their family and friends think about who is important in that person's life and discover their dreams and wishes. Whatever their level of disability or difficulty in communicating it should be possible to find out what activities that young person enjoys, who they enjoy being with, their likes and dislikes. (Communication passports are one way of describing this essential knowledge about a person – it uses photos, video, tapes, any form of media that can best convey the information about the person and the kind activities they enjoy. How that person likes to sit, eat; videos they watch; shops they enjoy visiting; show who their friends and family are. It's an invaluable source of information about that person which can be very useful when there is any change in support personnel). Partnership boards have been set up in each local authority in order to make strategic plans for developing services across Health, Education and Social Services. They should also have a framework that describes how they are going to put PCP into practice and what training and support is available to families.

## **Families Leading Planning**

Government guidance on PCP says that all families should have an opportunity to learn about PCP and decide what involvement they want. Quite often all they will want is information about what to expect from services and how they will contribute to the plan. Other families will want to play a more direct role and lead the development of the plan themselves. There are a number of ways that families can get help to do this.

- Train with the staff to learn how to facilitate the plan
- Train just with other families
- Get help and support on an individual basis from service staff, independent or voluntary agencies

## **Essential Lifestyle Planning**

This is a way of discovering what is important to a person in their everyday lives. The information can be listed in a way that helps service providers (e.g. Health, Education, Social Services) be consistent in their approach and the way they deliver services. Originally Burke-Harrison and Smull developed it to help people with complex disabilities leave long-term institutional care. Key people in the individual's life are asked to consider the things that are important in that person's life. The information is sorted into three main categories, the essentials or non-negotiable, important or strong preferences and things

that the person likes. From this information it is possible to build up a picture of the people and things that must be present (or absent) in that individual's life in order for them to achieve their preferred lifestyle.

### **Circles of Support**

A circle of support is a group of individuals who meet together with the sole intention of supporting a young person who is likely to become isolated from their community because of their special needs. The group is made up of people who know the person well and who are prepared to listen and help that person realise their dreams and ambitions. Parents, brothers and sisters, friends and committed support workers all work together to discover the information that will give that person a 'voice'. The circle can help present the young person's own contribution towards the planning of their life. The CREDO (Creating Real and Equal Development Opportunities) project is funded by the National Lotteries Board and designed to support young people (13-19 yrs) with profound and complex impairments. There are currently two projects; one in England and the other in Northern Ireland and both are looking at the move from childhood to adulthood. In the CREDO Project, it is the young person with complex needs that owns and controls the process with the assistance of those people in their life who know them best i.e. their circle of support. Often young people with profound and complex impairments only come into contact with people who are paid to support them. The Circles network is made of people who are volunteers and are committed to inclusive societies that aim at interdependence. They are concerned about that person's future, they support them through difficult times; they work to create opportunities and solve problems.

The study, "Bridging the Divide" concluded that there were five key elements in a good transition process, which they called the 'Five C's', summarised below.

- 1. Communication** – which is open, honest and respectful between agencies and families; and gives and an independent voice for young people.
- 2. Coordination** – between all the agencies so that they work together effectively and plan a consistent approach to service provision.
- 3. Comprehensiveness** – an effective transition plan for all young people that considers appropriate race and disability equality training for all staff; that has expectation that young people with learning difficulties will be able to access the same opportunities to realise their dreams as their peers do.
- 4. Continuity** – key workers to support individual youngsters and their families throughout the transition process so that there is a seamless transition from children's to adult services and a range of options for young people to move into and between.
- 5. Choice** – more and better involvement of young people and their families in the transition process with good access to appropriate information on potential options as well as a range of local post-school alternatives in housing and employment.  
I would add a sixth
- 6. Commitment** – from the schools and external agencies to have regard to the timing and implementation of the

Transition Plan; from parents and carers to drive forward the plan and demand the support needed to fulfil the plan.

I have included a list of useful web sites and contact details if you want further information. You will need to find out what's available in your area and contact those groups directly. The important thing to remember is, "Don't leave it until last moment!" You may feel that services for children with disabilities are not particularly good now but the evidence suggests it is even less satisfactory once they become adults. That is why it is vital that parents and carers take an interest early on to ensure they get the best for their child.

If you live in England then the Connexions Service is your first port of call. It has specific responsibilities for young people with learning difficulties and disabilities as described in the SEN code of Practice and the Learning and Skills Act 2000. It is their job to provide young people who have learning or physical disability with a Personal Advisor who will be the critical link that brings together all the support services. You can find your local Connexions service through your child's school, the LEA (Local Education Authority), or by contacting one of the 47 Local Partnerships. These can be found at [www.connexion.gov.uk/partnerships](http://www.connexion.gov.uk/partnerships) or you can write to Connexions Service National Unit, Department for Education and Skills, Moorfoot, Sheffield, S1 4PQ.

Connexions service is not available in Scotland, Wales or Northern Ireland but you can get information about transition services from:

**Northern Ireland:** MENCAP have published a guide for young people preparing to leave school called, "What next?" It can be viewed and downloaded from [www.mencap.org.uk/download/what\\_next\\_parents.pdf](http://www.mencap.org.uk/download/what_next_parents.pdf) or contact the Family Advisor Helpline 0845 763 6227. There is a Regional Office in Belfast: 028 9064 0121. If you don't have broadband then it will take a while to download, otherwise ring and ask them to send you a copy.

**Wales:** Youth Gateway uses a team of dedicated Personal Advisors to guide young people through transition. Contact through your local Careers Centre or Careers Wales Association, Suite 6, Block D, Van Court, Caerphilly Business Park, Van Road, Caerphilly CF83 3ED. Telephone: 02920 854880 Email: [enquiries@careerswales.com](mailto:enquiries@careerswales.com) Website Address: [www.careerswales.com](http://www.careerswales.com).

**Scotland:** Careers Scotland provides information, services and support. Telephone: 0845 8 502 502 or visit their web site: [www.careers-scotland.org.uk](http://www.careers-scotland.org.uk). Not a huge amount of information available at the moment. PAMIS (Promoting A More Inclusive Society) is a voluntary organisation in Scotland that works with young people with profound and multiple learning difficulties, their family, carers and professional who support them. Head Office, Springfield House, 15/16 Springfield, University of Dundee, Dundee, DD1 4JE, Tel: 01382 345 154, Email: [pamis@dundee.ac.uk](mailto:pamis@dundee.ac.uk). They have produced a pack, 'Life after School' that assists parents with many of the issues that arise during the transition from child to adult services. (Its free if you live in East Dunbartonshire but £18!! for everyone else. I would try to get your local library to order it for you)

**Other useful sources of information on transition** can be found at Trans-active a project where teenager with and without

learning disabilities work together. They have developed Communication Passports using multi-media. Contact by email: [trans-active@mencap.org.uk](mailto:trans-active@mencap.org.uk). Telephone: 0121-707-7877 or write to The Trans-active Project, 4 Swan Courtyard, Coventry Road, Birmingham.B26 1BU.

TransPlan is a practical interactive step-by-step guide to successful transition for young people age 13 – 19 with Statements of Special Educational Need. Available FREE from DfES Publications, PO Box 5050, Sherwood Park, Annesley, Nottinghamshire, NG15 0DJ. Telephone 0845 6022260 e-mail: [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com) I understand there are only a few copies left so hurry and put your order in!!

One of the 11 SEN Regional Partnerships, South West, has written an excellent guide to Transition Planning, which can be downloaded from the site at [www.sw-special.co.uk](http://www.sw-special.co.uk).

The DfES (Department of Education and Skills) sponsors 11 sites in England that cover all the local authorities. Each partnership brings together groups of LEAs, Health, Social Services and the private and voluntary sectors. They aim to improve the efficiency and effectiveness of SEN processes and services and inter-agency working. (We all have to live in hope!) Contact them for information on Transition Planning in your region. National Adviser for the SEN Regional Partnerships:

Claire Lazarus Tel 020 7925 6421 or email: [Claire.lazarus@dfes.gsi.gov.uk](mailto:Claire.lazarus@dfes.gsi.gov.uk). You can visit the website at [www.teachernet.gov.uk/wholeschool/sen/regional](http://www.teachernet.gov.uk/wholeschool/sen/regional)

The Valuing People Team, part of the Department of Health, has a website on Transition which can be found at [www.valuingpeople.gov.uk/Transition.htm](http://www.valuingpeople.gov.uk/Transition.htm).

MENCAP have set up help line and a website specifically to answer questions and provide information on anything to do with learning disability. It can be found at [www.askmencap.info](http://www.askmencap.info) or you can telephone 0808 808 1111 if you live in England, if you live in Northern Ireland then its 0845 763 6227 and the Welsh can call 0808 8000 300. If you live anywhere else I would still try these numbers to get help – just watch your accent!

If the thought of having to track down this information has put you into a cold sweat – DON'T PANIC! I would suggest that you start with the school first and ask what information they have available on transition. If that does not help then move onto Social Services, most of who will have someone dealing with transition. You can always ask them to get you copies of documents mentioned above. Don't forget you local voluntary groups such as Contact a Family who have also written about Transition.

**Lydia Dickie**

## Families in the News

Congratulations to Nicola Hughes, aged 20 who was awarded Prima Baby Nursery Worker of the Year – Nicola was nominated by The Wrigley family for her care and support in looking after their daughter Darcy who has Angelman Syndrome (you may have met Darcy at the recent conference). I believe Kathryn attended the presentation ceremony and was delighted when Nicola received the award. There were reports in the September 2004 Baby Prima Magazine and also the 22 July edition of Nursery World. It's great when there are champions out there who have a special relationship with our children and enable them to maximise their opportunities. Nicola has now been promoted to the role of Special Needs Co-coordinator at the nursery in Northampton where she works and won a hotel break in London including a spa day and tickets to a West End show. Well done!

## The Pioneer Centre

If you live in the Kidderminster area you may know about this new centre – ASSERT received information at the beginning of the year about an open day. This has passed but you may like to find out more. It is essentially a residential centre providing Development Training, Outdoor Activities, Arts and Crafts etc for young people with disabilities . Website [www.actioncentres.co.uk](http://www.actioncentres.co.uk) Tel: 01299 271217 NAYC Pioneer Centre Cleobury Mortimer, Kidderminster DY14 8JG

## Medical News

For those interested, the recent Prader Willi News reported that a woman in New Zealand with Prader Willi (as a result of deletion of Paternal Chromosome 15) syndrome has given birth to a baby (this is the second case we are aware of) – normally fertility is low in the syndrome and this is an unusual occurrence. As we know the maternal chromosome 15 is responsible for AS, so this mother with Prader Willi has given birth to an Angelman child.

## All Terrain Buggies

These seem to be all the rage at the moment so much so that the following supplier is currently experiencing shortages of stock. However, you may be interested in their product which costs around £800, a lot less than some on the market. Additional bits like hoods, aprons and footplates can be at an additional cost but we think you will find it good value. We did ask them to the conference to display but they were unable to attend. For more information contact Delichon at [www.delichon.co.uk](http://www.delichon.co.uk) or tel: 01725 519405 – they are based a Kings Yard, Martin, Fordingbridge, Hampshire, SP6 3LB. They also supply some supportive car seats.

## Fledglings

If you need help with a disabled product or toy or clothing and don't know where to turn for help, give Fledglings a call – they have lots of ideas and solutions either at their fingertips or they may know where to point you if they don't. The telephone number is 0845 458 1124, there isn't a website but you can email them at [enquiries@fledglings.org.uk](mailto:enquiries@fledglings.org.uk)

# ASSERT – The Future

*The following letter was given to all the delegates at the conference about the current situation with ASSERT – a few families have put themselves forward to help with the organisation in the future – but we need a good team – ASSERT is growing and moving forward and it is important the parents and carers are involved in the process. Please contact Sally Walburn as soon as possible in order to find out more. As you know Sally has not written a newsletter since February, and this one has only been produced as all the work she did for the conference is over and it is important that those of you who couldn't attend, know what happened over the weekend.*

## **To all ASSERT Members**

ASSERT is a thriving, growing organisation and we need your help...for some years now the trustees have been providing support and information to many family members, carers and professionals especially in the first few traumatic weeks after diagnosis. There is a wealth of expertise at ASSERT as many of you have found on the support line, and at meetings and other conferences. However, we desperately need YOUR help.

Bernie and Jackie Silver and Ken and Sally Walburn will be stepping down from ASSERT at the end of the year and this will inevitably result in changes for ASSERT and limit the support it can provide.

As you know Sally's role within the charity has increased since Jim Brennan's departure last year, and therefore the service both she and Jim shared will be under threat – these include the newsletter, the support line, the conference,

regional meetings and general information. Sally would point out that when she joined ASSERT eight years ago, she had no experience or expertise in Angelman Syndrome other than being a parent of a five year old AS son.

Perhaps you can help? We need help with mailing out to families, newsletter, support line, regional meetings and future conferences. We do need new trustees as well – there will only be 5 left at the end of the year and this is the minimum we can have under our constitution. We need fresh enthusiasm and ideas, which can be used to support the new generation of Angelman parents and carers. We want to make a video on Angelman Syndrome – this is so important as there is nothing current available for new families and professionals. We are being asked to be at training events for professionals. Plus there is the valuable support we provide to families like you, which needs to be ongoing.

If you want to be part of the future direction for ASSERT and build on the successful foundations already in place, please contact us. There are serious implications for ASSERT if we cannot get some new trustees and more support from you the families, and there will be the inevitable compromising of our services.

The conference was oversubscribed and there was a waiting list...this demonstrates the need to continue just one of the important services we give to Angelman families...it would be a shame if we are unable to put on such events as this in the future...please think about how ASSERT has helped you and how you can help us.

The next Trustees meeting is on 21st November 2004 – if you are interested, please give Sally Walburn a call.

## Contact Register

An updated Contact Register is included with this newsletter if you are a family on the list or have requested one in the past. The register is for families only and is to be used to contact other families either in your area or when you visit another part of the country or overseas. Please do not use the Register as a means of support, if you require any help with a particular problem you have, please use the support line, likewise none of the information is to be passed to any professionals, without prior consent from ASSERT. If for some reason you have not received your copy and you are a family member, please let us know.

## Information from GIG (Genetic Interest Group)

### **Media opportunity**

A production company called 'Films of Record' (<http://www.filmsofrecord.com>) have contacted us looking for people interested in being in a programme about disabled teenagers and education. They are looking for teenagers with any disability who in 2005 will be:

- starting at a new (mainstream) school
- starting their first year of university
- moving out of home for the first time to live independently

The idea of the programme is to introduce the world to teenagers who are starting start school /new education setting when they haven't necessarily got all the equipment or support that they need. She wants to follow someone's journey – filming will take from 2 to 6 weeks. If this might be of interest to you or to members of your group please get in touch with Kate Boyd direct on mob: 07944 980594.

## Greater Manchester Run

Earlier on in the year Lee Atkinson and his team raised money for ASSERT and this is from Lee.

The run was a great success and we're all busy collecting the sponsorship money, which I am hoping to send to you in June.

It was a thoroughly enjoyable day and if Leah had not fallen asleep just after I had finished the run I'm sure she would have enjoyed it too!! We had had plenty of support from friends and family on the day and as a result we now have several other people that would like to join TEAM ASSERT when we make our next outing.

Please find attached picture of all the runners that took part in the Great Manchester Run, they are (from left to right); David Daniel, Antony Clements, Lee & Leah Atkinson, James Mee, Craig Woods, Dario Marchiano.

Kind regards **Lee & Leah Atkinson**



Team ASSERT!

## London Marathon – Golden Bond Places

ASSERT has been on the waiting list for several years and finally we now have 5 Golden Bond Places for next year's London Marathon on 17th April. We did announce this at the conference and 3 people have put their names forward, however, as suggested to them, if you are interested the London Marathon, the organisers have advised us that in the first instance you apply through the normal ballot route (entry forms can be found in the Marathon magazine which you can pick up in any sports shop outlet). If you are unsuccessful, then ASSERT will be pleased to offer you a place. The places are subject to you agreeing to raise a minimum of £800 per place for ASSERT.

For more details contact Sally and Ken Walburn 01268 415940 or [sallywalburn@aol.com](mailto:sallywalburn@aol.com)

**Since going to print the ballot for places has closed - you will need to apply to ASSERT as soon as possible after the 6th December 2004, forms have to be sent back to the Marathon office in January at the latest - so there's not much time.**

## Can you help?

This is where we need the benefit of your experiences and expertise to support other families – please reply directly to them if you can.

*Question from Rachel Simon 01772 600378*

Ralph is waiting to have corrective surgery for a divergent squint – we want to know whether this is a common problem in AS and what the rate of success is – if you have any info or advice we would be grateful to hear from you. (Rachel did write this some time ago so Ralph may have had the surgery but, we are sure she would still like to hear from you).

*Question from Sandra West wesjhn7@aol.com –*

Are there any other families going through surgery for Scoliosis – if there are she would like to hear from you – *same goes for Sally Walburn 01268 415940.*

*Question from Karen Evans knotsoberrd@bt.openworld.com*

Is there any evidence that the bowel can be underdeveloped, twisted or simply does not work properly? We are having problems with constipation and have tried many forms of medication over the last 3 years and nothing has worked – any suggestions?

*Question from Elizabeth Hawkins HAWKINS760@aol.com*

My son Richard (29) has a few problems at present. Firstly, he is very shaky, more than usual. His epilim has been reduced (he is undergoing EEG etc.) He has become very sleepy during the day (most unlike Richard. Secondly, his two front teeth have eroded to almost gum level. He has had root canal treatment in the past. The dental dept. want to remove the teeth thus leaving a gap. Has any parent any advice on alternative cosmetic treatment without causing Richard too much distress.

Thank you.

*If you need contact phone numbers for the email people, please telephone Sally and she will put you in touch.*

# North West Regional Meeting

In between the snowy and windy weekends back at the beginning of March, we managed to sandwich in a calm sunny Saturday on which Rachel Edgar and Rachel Simon had organised a meeting up in Mawdesley Lancashire. The meeting began at 11.00 a.m. with families being welcomed by Ken and Sally Walburn and the "Rachels" – they had roped in family and friends to help with a day full of tea/coffee and it seemed endless treats, including Shepherds Pie and good old Lancashire Hot Pot! Our 21 families who attended were well looked after. Nothing had been left to chance, they had organised Indian Head Massage, Reikki healing, reflexology and acupuncture for the parents, music therapy, face painting and balloons for the children, as well as speakers on aromatherapy, and speech therapy. Jill Clayton Smith put in appearance at the end, which was welcomed by all, as she knew the event was planned and was unsure whether she could make it. This gave old families a chance to catch up with her and new ones were able to get the benefit of her invaluable advice. There was a raffle with superb prizes including a mountain bike, which was won by one of our new families, Mike Wall proudly dismantled it to get it in the car on the way back to Liverpool. Pennine Industries Ltd donated all the prizes, so many thanks to them.

Thanks go to all concerned, it was a really good day and we thoroughly enjoyed it.

If you would like to organise a meeting in your region, please get in touch.

*Rachel Simon wrote the following about the day:*

At the beginning of March an event was held at Mawdesley Village Hall (near Chorley, Lancashire) for family and friends of ASSERT in the North West. Over 100 people attended including several "new" families and enjoyed the various activities that had been arranged. Trustees Ken and Sally Walburn travelled from Essex to be present and to represent ASSERT. Their time, effort and support was very much appreciated in the planning of the event and on the day itself. It was also a great privilege to have Dr Jill Clayton Smith Consultant Clinical Geneticist to join us.



Sally and the Rachels

The village hall proved to be an ideal venue as the separate rooms allowed different activities to take place during the day. Bolton Toy Library kindly hired out soft play and special needs equipment and Surprise, Surprise Balloons of Croston supported the event too. There was an entertainer for the children and face painting. Sue Ridyard who runs local music activities for children of all ages organised a music workshop for the youngsters and their parents and carers.

Speakers on the day were Susan Barber a speech and language therapist who spoke on using Hanen techniques for non verbal communication and Susan McFarlane who after an interesting presentation on aromatherapy and reflexology invited everyone in attendance to have a "taster" of these and other therapies in a room specifically set up as a treatment room. She was helped by colleagues Irene and Frances and this was a particularly popular part of the event.

There was a raffle; Pennine Ltd Bolton donated the prizes of a mountain bike, a fish tank and a skateboard.

Many thanks to Tesco, Chorley; Asda, Clayton Green, Warburtons; Park Cakes; and Parkinson's of Leyland for their donations and support, and to all the helpers on the day.

## Government SEN Programme

In February the government launched a new strategy for special educational needs. "Removing Barriers to Achievement" is the government's plan for meeting the needs of children with special educational needs and disabilities. It sets out a programme over the next few years and builds on other recent government initiatives aimed at improving the way services for children and their families are organised. You can order the full report (DfES/0117/2004) or a summary (DfES/0118/2004) from the DfES publication centre on 0845 602 2260. You can view it online at: [www.teachernet.gov.uk/senstrategy](http://www.teachernet.gov.uk/senstrategy)

## Disability Rights Bulletin

We have a copy of the latest Bulletin from Disability Rights, so if you have any questions on the latest benefit news etc or want us to check something for you, please contact Sally Walburn

# HFT

We were pleased to invite Robina Mallett to present at the conference back in September, this is some information about the organisation she works for, if you need any help with any of their projects or want further information please contact them on the numbers given.

HFT's Carer Support Service (CSS) was established in 1996 after 3 years work researching the needs of family carers and piloting possible support systems with them. Anyone is welcome to contact us.

We believe family members are expert at supporting their relatives, creating person centred opportunities and advocating for them to have fulfilling lives. Yet they are frequently unaware of their rights, have difficulties finding the information they need and achieving the partnership working they wish for. In addition they often feel isolated and unsupported themselves.

Our service is committed to empowering family carers so that they and their learning disabled relatives can live full, well supported lives. Person Centred Approaches, Direct Payments, Supported Living and Employment can offer new opportunities for this. The challenge is to take these, and other initiatives, forward in ways that are family carer aware. We will continue to work at individual, local and national levels to help achieve this!

We provide information and support to family carers through

- Personal contact by telephone, letter or email
- Workshop courses in which we share knowledge, skills and mutual support; these are either tailored to particular circumstance (such as preparing for the transition into adulthood/preparing for the future as an Older Carer) or designed for mixed groups of family carers
- Occasional conferences and seminars for family carers and/or professionals
- Family Carer News Digests about Government policy and carers issues
- Developing other family carer focused materials, events and networks

We work with other carer and disability organisations to influence policy, provision and practice. Partners include universities, the British Institute of Learning Disability, The Foundation for People with Learning Disability, Carers UK, The Princess Royal Trust for Carers, the Transition Information

Network/Action 19+, plus other disability and learning disability specific groups. We are family carers ourselves and have experience of training staff from residential and day services about working with families. We are interested in helping Learning Disability Partnership Boards in their work with family carers, staff and policy makers whilst implementing the Valuing People agenda and beyond!

## Funding

Our services are free to carers. In the past we have had support from Lloyds TSB and The Rank Foundation. We have been awarded a three year Strategic Grant from the Community Fund (2004-7) so we can expand our services in response to the increasing demand for information and support. We also undertake commissioned work.

HFT is a national organisation, delivering a range of opportunities with and for people who have learning disabilities and their families. It was set up by parents in 1962 and now has an extensive network of services providing:

- Housing and support for over 650 people (over 120 in Supported Living)
- Day services – employment, learning and leisure – to a further 200 people and a range of other services including supported employment, advocacy, carer support, specifically designed IT programmes and an ICT centre for staff and family carers working with people with a learning disability.

We have one full time Carer Support Officer (Robina Mallett) and a part time Assistant Carer Support Officer (Margaret Power). As family carers we have experience of mainstream & special school education, transition, support into employment, supported living, medical interventions, national SEN/Parent Partnership and the mental health and learning disability interface. A second Assistant Carer Support Officer will join us this summer. When necessary we recruit and manage further staff to undertake particular projects. You can contact us at HFT, Merchants House, Wapping Road, Bristol B51 4RW tel: 0117 930 2608 e-mail: [Robina.Mallett@hft.org.uk](mailto:Robina.Mallett@hft.org.uk) or [MargaretPower@hft.org.uk](mailto:MargaretPower@hft.org.uk) Or through the HFTs Website: [www.hft.org.uk/CarerSupport](http://www.hft.org.uk/CarerSupport)

## Can you help the German AS Support Group?

Melanie Barton (President of the IASO and also Vice President of German Association) wrote to me in September appealing for information from parents of Angelman Syndrome adults, this is what she said:

The German AS group is planning to dedicate its next issue of the newsletter to older people with AS. We have 2 persons in Germany and Fred Windbeck has approved that I publish his report on David.

I know that you also have parents with older kids in your group. Do you think, we could get a report and photos from them also? That would be a way also for you to get some new reports for your newsletter and also we could integrate them (if they agree) on the IASO website.

*Would you like to write an article? If so please contact Sally Walburn and she will liaise with Melanie.*

Great news for parents of disabled children in Ireland! The Irish Government has abolished means testing for parents of disabled children who apply for a Disabled Facilities Grant to help with the costs of adapting their homes. The decision followed the establishment of a working group in April 2003 by the Department for Social Development.

# Product Alert! The Dangers of Aspartame

*This information was received from Mike Booth one of our parents and he would like to bring to your attention the following:*

Some time ago I sent you information on the dangers of aspartame. Herewith some more startling information. So many of our children experience seizure activity. Anything that changes the brain's chemical activity has to be dangerous. Especially as it depletes serotonin. Something like this has to be properly investigated. I shall be passing this information on to Jill Clayton-Smith.

<http://www.earthways.co.uk/aspartame.html>

Aspartame is marketed in The U.S. and Australia under the trade names of "Equal" and "Nutrasweet". Elsewhere as "Spoonful" and "Equal Measure". Reports indicate that it is consumed by more people than any other synthetic product in history<sup>1</sup>. In 1992, 14 million pounds (6.4 million kilograms) were consumed.

**Contained in:** Antibiotic syrups, chewable and effervescent vitamins, foods of all description, diet drinks, lipsticks and many unlabelled products. There are no restrictions on its use in foodstuffs.

**Composition:** Methyl alcohol (10% by weight), aspartate and phenylalanine.

**Decomposes to:** Formaldehyde and formic acid.

**Relatives:** Monosodium glutamate. Aspartates and glutamates

differ by one methyl group and have similar undesirable effects.<sup>2</sup>

**Toxic Effects:** Aspartates and glutamates are both excitatory amino acids. When excessive amounts of these are present in the brain they act as a neurotoxin destroying brain cells. The phenylalanine component when combined with the aspartic acid from the aspartate and the methyl alcohol can deplete serotonin from the brain. High levels of phenylalanine are associated with abnormal brain function and brain damage. Levels may reach 30-40 times normal in certain susceptible individuals producing PKU even in adults. Medium to high doses in monkeys produced grand mal seizures in all test animals within 218 days.

**Symptomatology:** Memory loss, depression and irritability, tinnitis, flicker vertigo<sup>3</sup>, flicker induced epileptic activity, seizures, gradual loss of vision, dizziness, increased appetite<sup>4</sup>. Possibly also peripheral neuropathy, joint pain, fatigue, liver damage but these are unconfirmed.

In extreme cases it may induce suicidal tendencies. Brain cell damage may result in the symptoms of Alzheimer's and Huntington's Chorea.

1 Mullarky, B.A & Newman, A.V "The hidden Effects of Aspartame" *Informed Consent* Sept/Oct 1994 3539

2 Letter to Barbara Mullarky from Ralph Dawson Jnr, PhD, Assistant professor, University of Florida Dept. of Pharmacodynamics (29 Jan, 88)

3 *Flying Safety- a publication of the US Air force*

4 *Increased appetite by producing chemical changes in the brain. Leeds (England) University study.*

## Fundraising/ Donations

*Thanks to all who have given to us so generously since January of this year – we have received some quite significant amounts so thanks very much.*

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## House Adaptations

If other parents have made modifications and extensions to their homes in order to make looking after their children easier, I would love to hear from you.

We are planning to build a downstairs bathroom for our ten-year-old son, George and to build a new kitchen extension in which we can all eat as a family.

Thankfully, the bathroom plans don't seem to be in jeopardy, but it is debatable whether our district council will allow us to extend our kitchen without justifiable reason. My feeling is that George needs a significant amount of 'free' space around him when we're sitting down to eat, to prevent our having to leap from our chairs to rescue whatever he might decide to reach for! Have other parents found this to be true? Anything anyone can send me about their own experiences would be truly appreciated!

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