

# Link ~ Up

No. 94 September 2006

## Chair's Report

Welcome to another packed edition of Link-Up. We aim to keep you up to date with what we at the LAS are up to, bring you information about new developments in the field of autism and give you information about other support services you may find helpful. Tina Bale's article on XXYY is particularly fascinating - don't miss it.

Please take the time to complete the enclosed questionnaire from ASPIRE - see page 2 for full details.

I had hoped to include my Chair's report to the AGM in this issue, but it has been squeezed out by so many interesting items-please contact me if you would like a copy.

This is a crucial time for the education of autistic children as Leicester City is reviewing its autism provision and Leicestershire is reorganising SEN provision based on area special schools. We welcome these reviews and we are taking every opportunity to promote the interests of ASD children. We are very concerned that both City and County authorities significantly underestimate the numbers of autistic children in the school population. This is partly due to under-diagnosis and partly to the way children on the SEN register are classified. We believe many autistic children are "hidden" under the headings of learning difficulties, speech and language, behavioural difficulties etc. We are pressing both authorities to

compile accurate figures of the number of ASD children in schools so that they can plan for and resource sufficient provision.

We are also making the case for more autistic specific provision. We hear from many parents who feel that mainstream, particularly at secondary, cannot meet their children's needs. Another major issue is the lack of support for families of school age children.

We have prepared a manifesto, based on national guidance about provision for autistic children, and supported by evidence for the parental survey we conducted last year. If you would like to see a copy, have your views represented in the LAS response to the current reviews of education services, or discuss any of these issues, please contact Lindy (see Contacts).

Next Education sub committee meeting 5th October - all members welcome - call me for details.

Lindy Hardcastle (Chair)

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## 100 Club

Thanks to all the new members of the 100 Club who have joined in the last three months. The total membership now stands at 140 giving monthly prize money from August at £70. Proceeds help to fund the production of Link-Up.

Recent prize-winners are for June, Kevin Lint No.77, for July, Shakila Sheikh No.45 and for August, Caroline Stevens No 42.

Shakila very kindly donated her prize money back to the LAS.

If you would like to join the 100 Club, please complete the enclosed form – just £7 will pay for your membership from September 06 to March 07.

## **ASPIRE (Autism-Specific Programmes In Real-life Environments)**

ASPIRE is a small, independent team of dedicated professionals, highly experienced in and committed to supporting young people with an autistic spectrum disorder (ASD). We are writing to investigate the need and level of interest in a new ASD-specific provision that we intend to offer across Leicestershire.

The ASD-specific provision ASPIRE intends to deliver, focuses on individualised, life-skill-based programmes that are implemented within the individual's home and local community. The range of programmes (known as Home and Community Life-skills Programmes), are all designed to not only increase an individual's level of independence, but to also incorporate the newly-acquired daily living skills into their everyday routines.

Whilst ASPIRE is targeting a Post-16 age group, the team is extremely confident that its range of programmes can be adapted for younger children with autism, who would benefit from early intervention with social and communication skills.

Some examples of Home and Community Life-skills Programmes ASPIRE intends to offer are:

- Domestic skills
- Personal hygiene
- Planning and cooking a meal (hot or cold)
- Shopping skills
- Accessing community amenities
- DIY skills

One or any number of Home and Community Life-skills Programmes can be selected at any time, each being tailor-made to the necessary

level of support and timescales required for the individual. After initial Observation and Assessment days, the programme is devised, approved by the parent/carer, and then delivered in the home or community, either by ASPIRE, or the parent/carer themselves, who will have been fully trained by a member of the ASPIRE team.

Research conducted with the Leicestershire Autistic Society and Leicestershire Social Services proved extremely supportive, with each expressing a great interest in this new service. More importantly, each recognised the potential of ASPIRE's Home and Community Life-skills Programmes as they bridge a huge gap in current provision for individuals with autism within the East Midlands.

As a parent/carer of a son or daughter with autism, your opinions and feedback are invaluable to ASPIRE. With your knowledge and experience, you fully understand how this highly complex disorder affects your son/daughter, and the impact it can have not only on an individual's ability to live as independently as possible, but also on family life in general.

ASPIRE is acutely aware that you want your son/daughter to live a full and rewarding life, where all opportunities are maximised. We believe an essential part of this is to gain and incorporate the necessary daily living skills that enable your son or daughter to live their life as independently as possible. Learning life-skills within their own home and local community ensures that all learning is concrete, achievable, and, most importantly, relevant.

With our Home and Community Life-skills Programmes, ASPIRE will ensure that these essential life-skills are

taught and incorporated directly into each individual's daily/weekly home routines. This addresses and therefore helps overcome the difficulty that the majority of all individuals with autism experience in transferring skills and routines learnt in one environment (such as school or college, which is out of context), into another, such as the home.

ASPIRE's Home and Community Life-skills Programmes represent a truly exciting provision for all individuals with autism and their families. The ASPIRE team believes it would be an extremely beneficial service to all individuals on the autistic spectrum, as it provides each person with the opportunities and skills that allow them to lead their life as independently as possible where it really matters - in their own homes and communities.

In order to ascertain the level of interest in ASPIRE's Home and Community Life-skills Programmes, the team would greatly appreciate you – the real experts on your son/daughter's autism - completing the enclosed, confidential questionnaire at your earliest convenience, and returning it in the envelope provided. Please complete the questionnaire whatever the age of your child as we need to measure future as well as current demand. If you have any queries please e-mail [fj.autism@virgin.net](mailto:fj.autism@virgin.net), or write to ASPIRE (Autism-Specific Programmes In Real-life Environments) 178 Maplewell Road Woodhouse Eaves Leicestershire LE12 8RA

Many thanks for taking the time to read this letter and questionnaire – we cannot overestimate the importance of your feedback to ASPIRE; the confidential information we gather and analyse will be invaluable when we submit our bid for Big Lottery funding.

# IPSEA's Advice Line – volunteers needed

## Volunteering to advise parents/carers of children with Special Educational Needs.

We at the LAS see this as a really exciting opportunity for our members to acquire really high quality training and advice to enable them to support other families both through IPSEA's Advice Line and most importantly through our own helpline and local groups. We have already had several expressions of interest so there is a good chance that we could put together a group of IPSEA trainees. Please contact Lindy ASAP if you would like to discuss this.

Independent Panel for Special Education Advice (IPSEA) is a registered charity which provides free and independent advice and support services to parents of children with special educational needs, including a Freephone Advice Line.

Parents contact the Advice Line with a wide range of queries/problems, and volunteers are trained to give information and advice on:

The School based stages, including reviews of Individual Education Plans;

Assessments: including how to ask for a statutory assessment of a child's needs;

Advice on the assessment procedure and on writing the parental contribution;

Proposed Statements: in particular, how a statement should be written to ensure that a child's needs are appropriately met;

Finalised Statements: including help with referring parents to our Tribunal Support Service, when necessary;

Problems with Statement Implementation, including possible negotiation with LEAs and referrals to solicitors when legal action is necessary;

Advice on how parents can influence the outcome of Annual Reviews;

Issues relating to disability discrimination in schools;

Procedures relating to the exclusion of SEN children.

Most of the volunteers on our Freephone Advice Line are parents of children with special educational needs, and we need to recruit more volunteers to our Advice Line. In particular we are keen to recruit parents who are members of locally-based parents' groups. The value of this development is that it would both enable IPSEA to expand its telephone advice service, and also enhance the parent advice and support functions of local groups.

### What we are offering:

Free and comprehensive training in SEN law and procedures, with IPSEA certification on satisfactory completion;

Free ongoing support, which includes access to IPSEA's Internet discussion group, mailed legal updates on SEN and Disability Discrimination Law; invitations to any up-dating training organised by IPSEA for its volunteers (at least one weekend session a year);

Legal and strategic advice to help with case work for individual families for the parents who ring you via IPSEA's Line, and also for parents who approach you in your capacity as a member of your local parent support group.

### Training for the Advice Line consists of:

- (i) 15 to 20 hours of home study (depending on prior knowledge/experience);
- (ii) attending a 2 day course to consolidate the home study and introduce practical advice giving;
- (iii) practical training 'On-line' under the supervision of an experienced volunteer/worker;
- (iv) final assessment and certification by IPSEA's Trainer.

Volunteers do not need any previous legal experience or qualifications to take part in IPSEA training.

Advice Line volunteers work from their home phones diverting the Freephone number to their own line via BT's Call Diversion service.

We ask volunteers to cover one 3 hour daytime session or one 2 hour evening session, each week, for a three month block in any one year (although many volunteers do more than this).

All expenses would be met by IPSEA. There would be no cost your local group, or the individuals who volunteered for training.

Interested? Call Lindy now – we need you!

# XXYY - Do you know this guy?

We have many children/adults going undiagnosed with a chromosome anomaly simply because they have a first diagnosis, e.g. Autism, Asperger Syndrome, ADD, ADHD, PDD and others, or they just don't have a diagnosis because they are looked on as a disruptive or undisciplined. These behaviors are due to the disorders within them and if no understanding to their struggles is being shown then these behaviors can escalate. To the child's down fall because their needs are not getting met within the school system.

The blood test needed is a karyotype, which takes a few months to process in the genetics dept, and as this is a lengthy process it's costly too, but most doctors don't automatically detect a chromosome anomaly and that's when they get first diagnosis of the autism spectrum or other disorders. It can also be detected in pregnancy by an alpha feta protein test.

My son's diagnosis came at age 14 when he was re-assessed after being wrongly diagnosed with Epilepsy by Dr Andrew Holton.

I shudder to think of how many children have gone through his care with the possibility of a chromosome anomaly as I remember he would ask my son to write his name on a piece of paper, where he could see the hand tremor was present.

After getting the diagnosis first of autism, I asked for a deep down blood test, just to make sure autism was all I was dealing with. I trusted my gut instinct, then to my shock, XXYY syndrome results came back. I joined a world-wide network for parents of children/adults with XXYY and started to

learn all about how extra chromosomes can affect the body.

Since then I have built up a web site for information and awareness from all I have learnt being part of this group of parents.

[www.xxydoyouknowthisguy.co.uk](http://www.xxydoyouknowthisguy.co.uk)

Then I started on the task of getting all the UK families together and meeting up for the first time. 23 families all with their guys came along, some traveling from as far as St Ives UK, Spain and Denmark to meet our speaker, Dr Tartaglia primary researcher at the MIND Institute California USA

It was the most emotional gathering and the guys got along immediately as if long lost brothers. It was so successful that I am organizing another get together this year here in Leicester in October. This year Dr Tartaglia will be updating us on all her research into Chromosome Anomalies and we also have Endocrinologists coming from London who have been given a grant to start research into the effects of testosterone deficiency in the boys.

Because of last year's successful get together I decided a support group was needed for UK families. If you find your child has a chromosome anomaly and would like to share your calm and chaos moments with others who have probably been in a similar situation as yourself, please contact

Tina on 0116 2259953 email [xxyymum90@yahoo.co.uk](mailto:xxyymum90@yahoo.co.uk) or [xxyysupportgroup-owner@yahoogroups.co.uk](http://xxyysupportgroup-owner@yahoogroups.co.uk)

## What is XXYY?

Every person has 46 chromosomes and they are paired off to make 23 pairs of chromosomes, it's the last pair that decides if we are male or female: XX, for female and XY for males.

Boys and men with XXYY share certain characteristics with other chromosome anomalies, however the features are not obvious in every guy and do not affect every guy to the same extent, this is due to the extra x/y chromosome being dormant and then it's down to the gene expression as to how it affects the guys individually.

Minor anomalies of the skeleton are common including curved little pinky finger, prominent elbows that look like they are dislocated, this is due to two bones fused together in the forearm, flat feet, long limbs, tall stature with long arms and legs, speech delay, hand tremors, especially when given motor tasks, like writing; and may even refuse to write because of this.

Undeveloped/undecended testicles, penis may not grow in length. This is due to lack of natural testosterone produced by their body.

Dental problems can be significant in xxyy syndrome with obvious signs of dental eruption, missing or extra teeth (especially adult molars) severely decayed teeth, or Taurodontism (a condition in which the teeth have very large pulp chambers and long roots and teeth appear very large)also poor enamel, wide set eyes, pear shaped nose, lack of facial/body hair, heart and circulation problems, exceptional long term memory, always remembers a face from years ago or will find a destination even after just one visit, but has difficulty with short term memory.

**continued**

Cannot find the words he wants to speak, which is the main cause for behavior outbursts, communication and lack off is the biggest cause of frustration in our guys, this is caused by Central Auditory Processing Disorder, speech, word finding, word processing are also a cause of frustration outbursts for children with a chromosome anomaly.

The extra X and Y do balance out some of the imbalances which other chromosome anomalies may have. XXYY heightens the senses so they often hide under school desks, behind bushes, climb obstacles of great height to get themselves away from a stressful situation; it feels for them to be on defense against the world from an early age. This is due to visual/hearing sensory overload; imagine being in a playground all those children flying around playing and all those noises together can be frightening for a child.

The guy's body sometimes does not produce its natural testosterone that's needed to develop the male body, so testosterone injections are needed, to help develop muscle mass and strengthen bones. This too assists in giving them a sense of well being and helps with confidence in social situations as all they want to do is belong and have friends.

They also have sleeping issues, and have often runaway from home, because they have a very active mind, in the evening and early hours of the morning there is less noisy traffic, less movement of people and dimmer lighting. These guys need close supervision as they may not understand the full impact of dangers around them. And can be easily duped by people with devious intentions. They are often half their chronological age men-

tally and can mix with any age of child.

Each XXYY guy is different with their own behavioral strengths and weaknesses, just like typical XY guys have differences in their behavior. The difference is XY guys are in control of their behavior, children with a chromosome anomaly are not.

As a group they are affectionate, friendly and non-judgmental and can be generous with their time, making them selves available to help others in need, they can also be very thoughtful, caring and considerate, particularly to other people with special needs.

Thank to the LAS for helping me get awareness out to the Leicestershire parents about children/adults with chromosome anomalies. Most of our guys have the Autism or ASD diagnosis, you just never know what's going on, deep down.

Tina Bale

### **News from ASPECT (Castle Donington group)**

SPACE (Support and Play for Autistic Children with Energy!) continues to go from strength to strength. As well as local families, we now welcome those from further afield, partly due to Link-up and partly word of mouth! Some of us have gone to the Whitwick activity session on a Monday evening, and most of this group have joined us in Castle Donington during the summer sessions of SPACE. The children have been able to use the swimming pool during the last hour, and although some parents have gone in too, it is not a requirement. As well as the bouncy castle, trampoline and balls, etc. in the gym, there is also a quiet session offered.

Parents/carers still meet in the community lounge, where tea and coffee are available - and everyone has found this a very useful session to swap experiences and get to know other families in the area.

SPACE meets at Castle Donington Community College on the first Saturday of every month, 10am - 12noon and costs £2.50 (£2 with Leisure Link card) and £1.50 for siblings.

Once again, we would like to say a big "thank you" to Amanda Baines - she has co-ordinated the scheme brilliantly. She welcomes any comments and suggestions from the parents, and her enthusiasm has been fantastic.

Jane Sherwood (see contacts)

## **The jury is still out on MMR**

An article in the Sunday Express in May claims that the controversial research by Dr Andrew Wakefield into the MMR jab has been replicated. Dr Wakefield says "The Department of Health was able to discredit our research by saying no-one else had found similar results to our but no-one else had looked. In the light of these results which are strikingly similar to ours, the government is obliged to act. At this stage it would be prudent and in the best interests of vaccine uptake to make single vaccines available."

We at the LAS feel that the MMR controversy remains unresolved and we welcome any research. If you are concerned about this issue, consult your GP or visit the Jabs website [www.jabs.org](http://www.jabs.org).

# Another great playscheme week - but only just!

Touch and go on this year's play scheme and activity week.

This was the 5th year of the play scheme and activity week at Quorn Rawlins College for youngsters with an ASD. It so nearly wasn't to be!

The week had been organised and we were expecting over 70 youngsters. The Friday before the end of term I discovered that the main facility we use, the youth centre was being renovated over the summer and had been put out of use.

Like many of our children this level of change created immense anxiety for me, a cloud of panic descended on me and I fought to suppress an almighty scream as I stood in the rubble that was once the youth centre.

Colleagues at the Specialist Teaching Service successfully used calming techniques to enable me to make the decision that 'The Show Must Go On'.

We relocated to 2 other working areas and crossed our fingers (a little known strategy that eminent writers on autism have yet to discover but parents use all the time)

With some trepidation (from staff) the youngsters arrived on the first morning. They adapted amazingly well. We had posted pictures of the youth centre for them to see to explain our change of venue and the week began.

It was a hard and demanding week for the staff mainly due to the change of environment but the youngsters seemed to have a great time. Our trip

day was to the Snowdome at Tamworth. The youngest children did sledging and the older groups took on the challenge of 'tubing'. This involves sitting in a rubber ring and throwing yourself off a steep slope. The biggest challenge was to do it without pulling a gurney face, the children achieved this, and the staff most certainly did not!

Jane Mansfield along with Jo Pickering and Julie Spradbury from the Specialist Teaching Service organised a pre-school play scheme this year alongside our activities. They catered for 15 children and everyone seemed to have a wonderful week. Seeing the children engage with the music session, on the trampoline and in the swimming pool was very moving.

This year for the first time we created a youth group for youngsters aged 12 – 16. We had 15 in the group and they had an amazing week together. They had trips out to the river Soar on pedalos and also went into Leicester for ten pin bowling. At the end of the week it was decided by the group that they would all like to meet up again over the coming year. I am hoping to organise this and letters will be going out soon.

The week would not be possible without the expertise and commitment of 25 staff. Each year they continue to amaze me with their energy and enthusiasm.

I would like to thank Jigsaw and Astra Zenica for helping to fund the week. and The Specialist Teaching Service, especially Sarah, for their help on administration. Also thanks to Mr and Mrs Makvana who provided all our refreshments over the week and 'The Depot' in Leicester who donated a football table when we lost ours in the

forced move.

Last but not least a word about the children / youth group this year. I think I can speak for all the staff when I say they were so rewarding and delightful to be with over the week. They have made us smile, laugh and cry a few times.

I'm sure that this reflects an immense amount of hard work from parents and also (in some cases) good provision and support in schools. Over the 5 years that the scheme has been running we have seen some children move from 1:1 support to being able to be part of a group and be relaxed enough to enjoy themselves. It is a real privilege to witness such changes and gives further hope for the future of all children with an ASD.

Lynda Lowe

If anyone has any news, views or comments to make about their own experiences, good or bad, we will do our best to include them in the newsletter,

As a general rule, items are published in the next newsletter unless space does not permit, in which case, timebound or urgent items take priority. No items are edited for content unless space does not permit or the contents are potentially litigious. Other changes are made only with the permission of the author.

The views expressed in any article are solely those of the author and not necessarily those of the editor, committee or any other part of the Leicestershire Autistic Society.

Deadline for next edition: 31st November 2006. Items to Lindy Hardcastle see contacts list) – by e-mail if at all possible.

# Jigsaw playscheme

This year's scheme was held between 24th July and the 4th August, as usual at Guthlaxton College, Wigston. Over 20 children aged between 5 and 11 years and who have severe autism enjoyed between 3 and 5 days of the scheme. Unusually we had less demand for places this year so children were able to be offered extra days if they wanted them. Activities enjoyed by the children were: swimming, horse riding, outings to Twin Lakes, water and sand play, outdoor play, a gym was used for dance and running around, construction toys, painting, puzzles, soft play, ballpool, music and dressing up! Certainly plenty to keep the children occupied. There was a quiet room for those who didn't want to be busy too!

Staffing was 1:1 and all the staff were very experienced, many working in special schools as either teachers or support staff.

I hope all children who attended the scheme enjoyed themselves and that parents felt they were well catered for, and that they managed to have some time to spend with their other children. Please contact Gillian Wisdish if there are any matters you would like to raise over the scheme. Please telephone: 0116 28 6747. Thank you.

## Database and Information Service

The Database and Information Service is a multi funded multi agency service that offers advice, information and sign posting to parents/carers of children and young people with special needs or disabilities aged 0-19 living in Leicester, Leicestershire and Rutland.

The service has been operational since October 2002 and to date has over 2500 parents/carers who have joined the service.

Parents/carers joining the service receive:

Advice, Information Support and Signposting on to services that are relevant to them

A tailored Information Pack when they first join

A regular newsletter – 3 times a year, with one of them being the playschemes special

Parents/carers can refer themselves or be referred by a professional. You can join the service either by giving your details over the phone (in which case you will be called back at a time that suits you) or by completing a data collection form returnable in the freepost.

More information is also available on the service website at [www.infoxchange.org.uk](http://www.infoxchange.org.uk) that has a number of direct links to useful local and national websites.

### Free Carer's Pass and a Free Family Swim Voucher

Leicester City Council Leisure Centres are now offering a Free Family Swim Voucher for any parents/carers joining the service. As well as the free family voucher you can also apply for a free carer's pass, which entitles any carer to go in free when accompanying the child or young person with special needs or a disability taking part in leisure activities at Leicester City Council Leisure Centres. The child/young person would pay half price.

For more details about the service or about the Free Carer's Pass please contact Bhanu Mistry – Database and Information Manager

Tel: 0116 223 2294/5 Email: [data.inf@leicester.gov.uk](mailto:data.inf@leicester.gov.uk)

## Sponsored walk 2006

This year's annual 'Leicester and Leicestershire Combined Children's Charities' sponsored walk took place on the 30th April. 42 people walked for the LA S which was well up on last year.

The monies are still coming in but to date about £3,300.00 has been raised for the Society, which again is a marked improvement on last year.

There are going to be some changes to next year's walk route, I will keep you informed in future Link-Ups as to what they will be when things are finalised.

Lastly, but not least may I say a big THANK YOU to all those who walked, sponsored someone or helped in any way at all. Your contribution is much appreciated and essential to the success of the walk.

Gillian Wisdish

# ASSG

The Asperger Syndrome Support Group continues to meet on the second Monday of the month at the Baptist Church Hall in Buckminster Road Leicester. Meetings start at 7.15pm and the cost is £1.00 per family which covers the cost of the hire of the hall as well as tea and coffee and soft drinks when we break for informal discussions.

In August we had two new members join us and were able to have a lively discussion on some of their issues. Items that we have identified as needing further work are information on benefits for those who may only work part-time, funding for education courses once a student has done three years at the same level and relatives of carers not being funded for providing respite for a family member, although the person with AS will not have dealings with someone they do not know. Some parents only manage to get 24 hours away during the year and siblings suffer because they cannot get a holiday with their parents because of the difficulties in finding a suitable person to provide respite.

Meetings sometime incorporate a speaker and I list those that are provisionally booked for this rest of this year. Our speakers are on a range of topics and are designed to give us background on the different ways we are parents and carers can get support for our children or for ourselves. You are very welcome to suggest topics that are of particular interest to you by giving me a call on 0116 270 1074.

The rest of the meetings are about sharing information between ourselves about our own circumstances. This enables parents to off-load their worries and concerns and sometimes

find strategies for dealing with the sometimes impossible behaviour of our children. One of the major factors in sharing our concerns in this way is that we learn that we are not alone and that there are others out there with the same kinds of problems. By making a list of our concerns we can press for changes in the system(s). You will generally find that someone in the group has been through the same frustrations as you and may be able to give you ideas as to how to handle the problem.

We would be very interested in hearing from anyone who would be willing to act as secretary for the group. This will not be too onerous and involves taking notes of discussions during our monthly meetings so we have a record of our concerns to be raised with outside agencies; and taking the minutes at our quarterly committee meetings.

## September 2006 – December 2006

- 11 September 2006  
Advance Housing – Joseph Mailer  
His presentation may start at 8.00pm
- 9 October 2006  
Christopher Bush, Service Manager  
for Children's Services
- 13 November 2006  
Person Centred Planning +  
Launch of Art Exhibition and Christmas  
Card competition 2007
- 11 December 2006  
Christmas "Get together" and Anne  
Lewis will give some input on Sibling  
Groups

## HELP!

I have spoken to Lorraine McAllister of the NAS who ran the HELP! Programme earlier this year for parents with a recent diagnosis of AS for their

child. Children should be aged 14+. She has pencilled in a new course for January 2007 but will need to have the numbers to run it. If you are interested in attending this course – and you will learn a lot about the condition and how to deal with it – please contact Lorraine McAllister on Lorraine.McAlister@nas.org.uk or on 0115 847 3530. Her postal address is:

The help! Team, The National Autistic Society, Castle Heights, 72 Maid Marian Way, Nottingham NG1 6BJ

We look forward to meeting you.

Shelagh Wilson (Chair)

## Special Needs Childminder

I have had some experience with Downs Syndrome, autistic children and epileptics. I am more than happy to do some more training to improve my knowledge and to help more people.

I work Monday to Sunday hours are negotiable because not everyone has a 9 to 5 job Monday to Friday. I am registered with Menphys and with social services. I am on the childminding plus scheme which again is a link with social services where I might have children whilst both parents need treatment through hospital etc. I have been a childminder since Christmas Eve 2005 but have had experience for 8 years.

Katherine Wilson 25 Dunton Road Broughton Astley Leicestershire LE9 6NA (01455) 284199 07790306339

*Editor's note: we have no personal knowledge of Katherine and cannot therefore recommend her.*

# Support for students in Leicestershire

Vernon Beauchamp, Chief Executive of The National Autistic Society (NAS), the UK's leading charity for people with autism, visited De Montfort University on Friday 30 June to discuss the NAS's unique 'University and College Support Scheme'.

He met John Gough, Director of Student Services, and Tina Sharpe, Team Leader at the Disabilities Unit of the University. They discussed the success of the scheme, which has just completed its first year at the university.

Tony Sunner has Asperger syndrome and has just completed his first year of Humanities Studies at De Montfort. He receives 20 hours of support from the NAS. He said:

"I am so grateful for the support I receive. It is paramount. Without it I would not be able to go to university or study."

The scheme will now continue into the next year, with plans to provide support for up to 20 students.

The level of support is wide-ranging, from full one-to-one support across the timetable to single-session support or out of class support. Students first have their needs assessed by a college link worker and a level of support is agreed. Funding comes from the student's local education authority or the Learning and Skills Council.

Winston Kimber is the Further Education Co-ordinator for The National Autistic Society's Leicestershire Service. He said:

"People with Asperger syndrome can have difficulties with social interaction and communication. They may be totally competent as far as their studies are concerned but may experience problems with the social and logistic aspects of being a student.

"NAS link workers and support staff are trained to help people with issues such as organisation, timetabling, time-keeping and generally aim to make students feel secure and have structure in an environment that some people with autism might find challenging. We want to make sure any feelings of anxiety are reduced and they finish their studies successfully."

Vernon Beauchamp added:

"Everyone should have the same opportunities to access education, and it is a shame that this is not always the case. The NAS has been campaigning to ensure that everyone with autism is provided with an education that is appropriate to their needs. The NAS is keen to develop the scheme further so that we can provide support to as many people as possible."

The scheme was set up six years ago in Leicestershire to provide autism-specific support to students within their classes and during break and lunch-times.

The scheme has now grown to provide a term-time service to around 30 students at Leicestershire universities and colleges. These are:

- Leicester University
- De Montfort University
- Leicester College
- BrooksbyMelton College
- South Leicester College.

Advice and support is also available to teaching staff to help them work with people with autistic spectrum disorders.

In addition to the support offered to students, the NAS holds two-hour advice and guidance surgeries each day during term-time, on the campus for students, lecturers and university staff to drop in with any queries or concerns they wish to raise relating to autism and Asperger syndrome. There are also plans to set up a group on campus in the new academic year specifically targeted at students with Asperger syndrome who attend De Montfort University.

For more information and the booklet Leicestershire service university and college support scheme handbook 2006, please contact the College Support Team at: NAS Leicestershire Service, Grovebrook House, Brook Street, Whetstone, Leicestershire LE8 6LA. Telephone: 0116 286 6956.

## Driving lessons

Debbie Hudson tells me there is a female driving instructor who teaches people with special needs, including Asperger Syndrome, to drive. Her name is Julia Malkin and her telephone numbers are: 0116 2235652 Mobile: 07761 064 694.

We had a lovely response to Debbie's article in the last Link-Up – Advice to Professionals. It says:

"Absolutely Brilliant - perfect concise list of tips - it will even help Aspies understand what carers might have to think about!"

Thanks again, Debbie!

# Menphys SOS

## Mission Statement

Menphys SOS is looking to a future full of choice and opportunity for all disabled children, young people and their families

We help Children and Families by: -

- Checking that families know about and are referred to the appropriate and relevant services available to them
- Helping families access flexible day care for their children with registered childminders
- Facilitating the inclusion of children and young people into sport, play and leisure activities
- Providing fun & social opportunities at our clubs and family centred events
- Providing support in claiming disability related benefits
- Running parent/carer support groups across Leicestershire and Leicester with the Parent and Carers Council and Parent Partnership.

This support is given through home visits and telephone contact

We help Childminders and other Early Years Childcare Providers by providing free training on disability awareness and including disabled children and young people. We currently run two courses: -

'Choice Opportunity and Inclusion' – this is a 12-hour 'taster' course, which aims to raise the providers' awareness about disability and the barriers children and their families face. A certificate of attendance is provided at the end of the course

'Menphys Disabled Children and Young People' – this 30-hour course aims to help providers include disabled children into their settings/ homes. This course is accredited through the National Open College Network (NOCN) for which we are supported by Loughborough College. Participants have course work so their competence can be evaluated. This is internally and externally verified. If successful a certificate with their accreditation is provided through Loughborough College.

Further support we give to Childminders

Individual support from Menphys SOS Field workers when including a child.

We run Childminding Network Support groups for all Childminders who are caring for disabled children.

We have specialist multi sensory equipment, which we loan to Childminders to help with the inclusion of children. For example bubble tubes, fiber optic lights, musical instruments & disability relevant toys.

Contact: Lyn Edwards/Christine Ward/Nicola Hampton 01455 899111 Email [lynbloor@menphys.org](mailto:lynbloor@menphys.org)

### **Birchwood Support Group**

The Melton & District Autism support group meets Monthly on a Tuesday 9:45 until about 11:30 at Birchwood special school in Melton Mowbray.

The first one after the summer holidays is on the 19th Sept, with guest speaker Anne Lewis (LAS Family support worker).

From then on; Tuesday 17th October, Tuesday 21st. November, Tuesday 12th December: speakers to be arranged .

Lesley Herbert (see contact list)

# Reality

Reality holds monthly support group meetings on Thursday mornings from 11:00am to 1:00 pm at the Parkfield School on Pindar Road, New Parks. The dates for the remaining meetings for 2006 are; September 7th, October 5th, November 2nd and December 7th. No formal diagnosis of ASD is required to attend and anyone is welcome. The meetings are always well attended and everyone is encouraged to participate. Parents can share their concerns or address any issues they may have, with each other, or with any of the guest speakers or visitors from within the ASD community who regularly attend Reality's meetings. Childcare workers are available to entertain your children and members will have access to the toy and book library.

Each year, as a group, Reality provides opportunities for various outings throughout the school holidays as part of its 'pro active' approach to introducing ASD children to social settings. This year included day trips to Drayton Manor, Alton Towers, Sundown Park and a day trip to Skegness. Other activities for this year and early 2007 are to be confirmed.

Members of the group will be advised as to the dates and particulars of these outings in due course.

Reality completed a highly successful 12 week course of events at the Outdoor Pursuits Centre near Red Hill Circle prior to the summer holidays, which involved a large number of the children and their siblings from Reality's database accessing Archery, Wall Climbing, Quad biking and various water sports.

These events have been enormously well received by the children and parents at Reality who have all benefited from the activities. It was really quite amazing to see how quickly most of the children developed their confidence, with the help of parents and the highly praiseworthy and patient centre staff, at what many would regard as quite challenging activities.

Plans are in progress to continue and to expand the course again next year, as there is already a great interest from many parents about accessing future courses.

Should you require any further information about Reality, or wish to be added to the group's database please contact Leisa Smith on 07879428553 or via e-mail at [leisa\\_smith3@hotmail.com](mailto:leisa_smith3@hotmail.com)

## **Jigsaw coffee mornings.**

Our regular monthly meetings start again from this month. We meet on the 3rd Wednesday of the month DURING TERM TIME ONLY. The dates up until Christmas are: 20th September, 18th October, 15th November.

We meet from 10 am until 12 noon at the Red Cross Special Needs Family Support Centre, Kenilworth Drive, Oadby. Please contact the centre if you intend to visit for the first time, they need to know for staffing purposes. Tel: 0116 271 0359. They may also be able to provide transport for people who live in the CITY. Otherwise contact Gillian who may be able to help. We have a speaker in September - Elaine Cummins will be tell-

ing us about Person Centred Planning. We hope to arrange for speakers in October and possibly November also.

We have a fund raising coffee morning in November, so please come along and meet with other parents, chat over a drink, browse through the books and resources and borrow some toys! Look forward to seeing you there.

## **Jigsaw library books and resources.**

Jigsaw own a vast quantity of books, resources, information about colleges and residential homes for people with learning disabilities, as well as leaflets about benefits, and other subjects related to people with an ASD Some

are for reference only, but are marked if that is the case. These are kept at the Red Cross Special Needs Family Support Centre, Kenilworth Drive, Oadby, where the coffee mornings are held. Please do feel free to browse through them either at one of the coffee mornings or at other times when the centre is open. Their telephone number is: 0116 271 0359. There is a booking in system for the library books, please use this and ensure books are returned within 1 month if possible. I am in the process of updating the list of books we have, so if there is a particular book you would like to borrow please contact me first and I should be able to tell you if Jigsaw have it or not. Please telephone Gillian Wisdich on: 0116 287 6747.

# **SPECTRUM Market Harborough**

The past few months have seen a lot of activity in our group.

Over the summer we have run a series of enjoyable and well attended play sessions for the children and their siblings. The children and carers tried their hands at a variety of arts and crafts projects as well as had a gymbobs session, physical activity session and music and tactile/sensory session. These were made possible by the help of St Nicholas Church, Tracey Kew and The Mobile Toy Library who lent us a lot of their toys and resources. Many thanks to everyone. Who can forget Ricky's Biscuits, Morgan and his parachute and the mothers who discovered untapped card making skills!

These sessions were so successful that we have received a plea from a child to make these available on a more regular basis.....watch this space!

We had our first Swim Session at Market Harborough Leisure Centre which was a huge success attended by 25 children and their carers. A good time was had by all and I feel that greater understanding was achieved between us and the Leisure Centre as to how important accessing this leisure facility on a regular basis would be to us.

Amanda Bradfield took her life in her hands and strapped to a gorgeous instructor(!!!!) jumped from a plane over Peterborough with a smile and a prayer. She has raised approx £900 to be divided between us and Early Birds. Well done! She does have a DVD to prove it and will do so given any encouragement.

The Ball preparations are in full swing for Oct 13th Friday at The Shearsby Baths and tickets will soon be available from Ali Lehman 01858-445886. Please help support us and come together to celebrate THE SPECTRUM OF LIFE. We are looking for donations/prizes so if you have any connections or want to help contact Yasmin on 0116 279 24 19.

The Next Meeting is on Sept 27th. Join us to work together for our families and have a laugh. Not at us you understand! But with.....

Jenny Cornwell 01858-469401

Yasmin Delargy 0116 279 24 19

## **COMMUNICATION SKILLS WORKSHOPS**

Over the summer we ran a series of play sessions in Market Harborough which were very successful. We got a "feel" for the children in the surrounding area and on chatting to them and carers some areas for possible development came to the forefront.

Some of the children wanted more regular contact with others in a supervised and structured form to involve games, arts and crafts, sports etc. So we are looking into regular sessions. Others wanted a "Youth Group" with the focus on communication skills, life skills, confidence building etc. For them to realise and vocalise this need themselves was astounding.

Bearing this in mind we are looking for people, professionals, carers etc who feel they could help us set up a Workshop running over a week next summer. Of course this does raise funding issues so get your thinking hats on and feedback to Yasmin on 0116 279 24 19.

## **THE SPECTRUM OF LIFE BALL**

**Please support the  
SPECTRUM OF LIFE  
BALL**

**Fundraising for  
Spectrum MH and the  
LAS.**

**OCT 13 th 2006 Friday**

**SHEARSBY BATHS nr  
Husbands Bosworth**

## **BLACK TIE**

**SPARKLING WINE , 3  
COURSE MEAL , LIVE  
BAND/DISCO , RAFFLE  
AND COMPETITIONS.....**

**TICKETS £35.00 EACH**

**Tables of 10**

**PHONE ALI LEHMAN re  
tickets on 01858-  
445886 > sept 1st**

**LETS CELEBRATE THE  
SPECTRUM AND DANCE  
THE NIGHT AWAY!**



# Useful Contacts

## Leicestershire Autistic Society

Treasurer: Carole Heubeck, 5 Grey Crescent, Newtown Linford, Leics. LE6 0AA Tel: 01530 244790

Chair/ Helpline: Lindy Hardcastle, 31 Flaxfield Close, Groby, Leics. Tel: (0116) 291 6958 e-mail [lindy@flaxfield.demon.co.uk](mailto:lindy@flaxfield.demon.co.uk)

Directory of Children's Services - call Lindy

LAS Education Support Worker: Anne Lewis Tel 07958 235015

PDA Contact: Alison Mann  
Home Telephone 01455 271060

Jigsaw Contacts: Chair: Gillian Wisdish, 82 Lime Avenue, Groby, Leics. LE6 0EN Tel: 0116 287 6747

Asperger Syndrome Support Group:

Chair: Shelagh Wilson 0116 2701074 email

[shelagh.m.h.wilson@btopenworld.com](mailto:shelagh.m.h.wilson@btopenworld.com)

Website: [aspergerleics.org.uk](http://aspergerleics.org.uk)

Monday Club Project Manager: email [themondayclub@hotmail.co.uk](mailto:themondayclub@hotmail.co.uk)

Chair: Mrs. Jenny Fisher email – [jenfisher@btinternet.com](mailto:jenfisher@btinternet.com) 0116 2595351

Oakham/Melton SAC Club : contact: Mo Potter on 01664 500688

Loughborough ASD Group : contact: Carole Heubeck, 5 Grey Crescent, Newtown Linford, Leics. LE6 0AA 01530 244790

Rutland and Melton Support Group: contact Carole Gamble 01664 434502

Castle Donington Support Group: contact Jane Sherwood 01332 850709.

Birchwood Support group: Contact Lesley Herbert 01664 565155

Market Harborough Support Group: contact Jenny Cornwell 01858 469 401, mobile: 07775 777524

Yasmin Delargy home 0116 279 2419, mobile: 07763 823282

Reality Support and activities for children and families, Contact Leisa Smith 078794 28553

Activity Club Contact: Jane Hall 07870 688973

Saturday Swimming Sessions at Bosworth Community College: Josh Wilson 07950 379447 email [Josh@boscol.globalnet.co.uk](mailto:Josh@boscol.globalnet.co.uk)

## Children's Services

Leicestershire Educational Psychology Service: 0116 2845100.

Leicester City Educational Psychology Service: 0116 221 1200

Leicestershire Autism Outreach Team: Contact George Thomas 01530 513600

Leicestershire Pre-school Support Worker: Jane Mansfield, 01530 513600

Leicester City Learning and Autism Support Team: Tel: 0116 225 4800

Rutland Autism Outreach: 01572 758496

Parent and Carers' Council: Tel. 07786 626564 e-mail [enquiries@parentcarercouncil.co.uk](mailto:enquiries@parentcarercouncil.co.uk).

Red Cross Family Support Centre: Anne Payne, Tel: 0116 271 0359

Red Cross Advocacy and Family Support: Anne Lewis 0116 2710359 / 07921 492431

## Services for Adults with Autism

Fosse Autism Service: Chris Howell, Leicester Frith Hospital, Groby Road, Leicester. Tel: (0116) 225 5335

NAS, Grovebrook House Resource Centre: Brook Street, Whetstone, Leics. LE8 6LA Tel: (0116) 286 6956

National Autistic Society (NAS): Helpline: 0845 070 4004 email [autismhelpline@nas.org.uk](mailto:autismhelpline@nas.org.uk)

NAS Regional Office: Ester Vickers, Regional Coordinator, Central Region Kim Higgins, Regional Officer, Central Region Castle Heights, 4th floor, 72 Maid Marian Way, Nottingham NG1 6BJ Tel: 0115 911 3360

Befriending Scheme: Gillian Keeling email [Gillian.Keeling@nas.org.uk](mailto:Gillian.Keeling@nas.org.uk) Tel. 0116 236 7524.

Directory of Adult Services - call Lindy

## Local Education Authority-run Schools with Autism Units:

West Gate School, Glenfield Road, Leicester Tel: 0116 285 6181  
Maplewell Hall School, Maplewell Road, Woodhouse Eaves, Leics. Tel: 01509 890237

Newbold Verdon County Primary School, Dragon Lane, Newbold Verdon, Leics. Tel: 01455 82236  
Birch Wood School (Melton Area Special School) Grange Drive, Melton, LE13 1HA Tel. 01664 483340

Netherhall School, Netherhall Road, Leicester LE 1 5TS Tel. 0116 2417258

Vale of Catmose College, Cold Overton Road, LE15 6ND Tel

