

Parent & Carer Council Newsletter

September 2006



c/o
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face2face

Parent supporting Parents of Disabled Children

As a parent of a 7 year old boy with cerebral palsy, I can remember so clearly the feelings of isolation and grief that I felt when we were given the diagnosis at 18 months. I didn't know any other parents who had children with the condition, so I felt really cut off from my friends and didn't feel that I had anyone that I could share my fears and negative feelings with.

How I wish I had known about Face 2 Face then. This is an organisation of trained volunteer befrienders (all parents of disabled children themselves) who offer emotional support to other parents whose children have been recognised as having a special need or disability.

I felt that this was such a worthwhile service, so last year I decided to look into becoming a befriender. I found out that there was a network of local schemes, but unfortunately not one in Leicestershire. However, I was offered the chance to take part in the next training session for online befrienders, a rapidly expanding service, which comprised of three residential weekends in Bromsgrove with seven other volunteers who didn't have local schemes.

Most of us have already received at least one referral and the Face 2 Face coordinator tries to match befrienders as much as possible to parents in similar circumstances.

The need for emotional support is something that can all too easily be overlooked, but the lack of it can have such a negative impact on the family as a whole.

Anyone who feels they could benefit from the service, or parents who are interested in becoming befrienders themselves, can find out more by visiting the website www.face2facenetwork.org.uk or

Tel: 01432 370860

Fiona Burton P.C.C. Volunteer

Leicestershire Employment Action Today (LEAT)

LEAT is a registered charity providing training and supported employment services to individuals with Aspergers syndrome/ high functioning autism. Having identified a lack of specialist employment services for people with autism spectrum disorders (ASD) LEAT are now concentrating in developing a service to bridge this gap.

Steps In to work 16/17

Is a new project funded by The Big Lottery. The structure of the group is based on that of the 18 + age group with necessary adaptations for younger students. LEAT has an open and flexible referral system, enabling prospective service users/families/carers to self refer. Referrals also come from a range of professionals. The programme is based on three modules:

- A college based ten-week 'Steps into Work' course in Personal Development and Preparation for Work – the 'Steps into Work' course is specially designed for adults with Asperger syndrome and consist of one three-hour sessions, held once a week. The course covers a variety of topics including communication and social skills, assertiveness, stress and time management, interview skills and CVs. The focus of the course is on building the student's confidence and self-esteem whilst preparing individuals for work. The learning group has between six and eight learners who are supported by the tutor and training specialists respectively.
- Work experience placements across the city and country. Following on from the course will be work experience placements in positions that are relevant to the individual's choice of career; LEAT prides itself on offering a person-centred service to its students. The work experience is designed to gain an understanding of a person's employment aspirations and capabilities, as well as their strengths and limitations whilst supported by the training specialists. The duration of the placement will depend on the needs of the individual and can last up to a maximum of twenty-six weeks.
- After the work experience placement, it is envisaged that students will be ready to access paid employment. The training specialist will offer one-to-one support with the job search, application forms and the interview process itself as well as job coaching, support and mentoring once the student is within the workplace.

LEAT is also actively engaged in forming effective partnerships with a wide range of local employers in both the private and public sectors. These employers provide opportunities for work experience and paid employment for service users. This focus on partnership working is utmost importance to LEAT, as it is felt that in working this way, LEAT is able to offer a multi-faceted, holistic approach for the people of Leicestershire who require the organisation's services. This can only be beneficial to service users and employers through the provision of individualised support, and the raising of autism awareness issues to employers.

For further details please contact Carol Hunt on (0116) 254 1664



All Dependent And Pre Term Babies & Children Charity Number : 1080112

In-B-Tweenies Parent, Baby & Toddler Group

If your baby was on a Neonatal Unit because he/she was premature or poorly, then come along to our parent, baby & toddler group at:

The Pavilion, Ravenstone, Coalville
Thursdays 10am – 12.00pm
(including school holidays)

Meet other families with similar experiences and have fun in a safe play environment.
For further details, ring
Lisa on (01530) 454046 or feel free to come along to the group.

Special Needs Awards Group (S.N.A.G)

An Integrated Youth Group

This is a new group for young people 9 Years upwards in the Lutterworth and surrounding district.

The group meets at Lutterworth Youth Centre, Lutterworth Grammar School, Bitteswell Rd on Thursday evenings from 7.00pm - 9.00pm. It costs just 50p to attend.

Our group most benefits those young people who would gain from being part of a social youth club but also from gaining awards in activities they both help to plan, deliver and participate in.

At present we offer the following awards:

- Duke of Edinburgh Access Awards
- Youth Achievement Awards
- Youth Work Awards

If you are interested in finding out more please contact:
Lee Kramer 01455 205 140

Funding News

DAYTRIPPERS

Daytrippers was founded in 2003 to help children with, life limiting and terminal illnesses. They provide funding for group daytrips including visits to theme parks, the seaside and wildlife parks. If your group is interested in applying for funding for a group day trip we would really like to hear from you.

For more information please visit our website at: www.daytrippers.org.uk or call Jude Saffron on 020 7758 0030

The Autism Alert Card

Developed by the National Autistic Society, this card informs people about people with autism and their condition, enabling them to identify their needs in situations where they might find communication difficult. The card comprises a credit card style wallet which contains a leaflet of key facts about autism which is printed in a variety of languages. The NAS also produces cards explaining Autism & Aspergers Syndrome.

For more information contact the NAS helpline on 0845 070 4004 Monday- Friday 10am-4pm

Good Practice Awards

Many thanks for all the recent nominations submitted for this editions good practice award. Due to the recent holiday period a final decision has yet to be reached and therefore will be included in our next newsletter.

Please continue to submit your Good Practice Award nominations by contacting Caroline on: 07786 626564 or via email: caroline@parentcarercouncil.co.uk

When did you last update your details with us?

If you are moving please do not forget to tell us, so that you continue to receive our newsletter.

We would also like to receive any updates that you have on your child's change of school, diagnosis, up to date email addresses and telephone numbers from you etc. This information helps us to provide you with the most up to date information regarding services and issues that may concern you.

Please ring Caroline on: 07786 626564 Or Email: enquiries@parentcarercouncil.co.uk

N.B. Due to Data Protection you will need to update your details with the Parent & Carer Council and the Database & Information Service separately, unless you give us specific permission to forward the information on your behalf.

National Deaf Children's Society

Parenting a DEAF CHILD is currently developing a range of support, ideas and advice for parents. The NDCS have received help from many parents & professionals and are currently developing a wide range of new resources:

10 week parenting a deaf child classes:

SUBJECT

- Daily communication
- Behavior management
- Dealing with feelings
- Self esteem
- Describing behavior and praise
- Play
- Siblings and the wider family
- Piloting the parenting classes by phone
- Range of publications
- Free activities planner

If you are interested in any of the above resources please contact:

Carmel Bartley, Parenting Co-ordinator, The National Deaf Children's Society
15 Duffin Street, London, EC1 8UR

Tel: 02070145912 Email: carmel.bartley@ndcs.org.uk
Web: www.ndcs.org.uk/parenting

Unlock the Allowances



Is a campaign to help more people in the North West Leicestershire District to find out about allowances and benefits they could be entitled to & how to get help claiming these.

SELF HELP CHECKLIST

What you need to know about Disability Living Allowance (For people under 65 - including disabled children- living in the NWLD for at least 6 months in the last year)

Keys to getting help if these benefits are not already being claimed.

DID YOU KNOW?

1. Disability Living Allowance and Attendance Allowance are paid on top of other benefits.
2. DLA is payable to people who are working.
3. If your partner works it doesn't affect the claim for these benefits.
4. Any savings you have does not affect the claim for these benefits.
5. You don't even have to consider yourself disabled – the benefits are for people with long term health problems or impairments which affect their everyday activities.

6. You will get the benefit if you fit the legal criteria- it is not because of anyone's opinion – not even your doctor.
7. If you have someone caring for you already this does not affect the claim for these benefits.
8. If you have applied before and been turned down this doesn't affect the claim for these benefits.
9. If you are awarded the money, you can spend the money as you choose- it is paid to you and you don not need to show how you spend it.

Do you know someone (Adult or Child) who is:

- Physically disabled?
- Visually Impaired?
- Needs supervision out of doors or in unfamiliar places?
- Learning Disabled?
- Has a chronic condition that limits what they can do?
- Has a mental health problem?
- Unable to be safe and independent because of mental, physical or behavioral problems.

If the answer is yes to ANY of these questions and you would like to know more or need help with filling in the forms to apply for either these benefits or about any other concerns or issues please contact

**North West Leicestershire
Citizens Advice Bureau
87 Belvoir Road
Coalville
LE67 3PH**

TEL: [01530 454751](tel:01530454751)

If you do not live in the NWLD then please call the Parent & Carer Council who will be happy to answer your questions.

EXTRAORDINARY GENERAL MEETING NOTICE

PARENT & CARERS COUNCIL

Fosse Neighbourhood Centr, Mantle Road, Leicester LE3 5HG

NOTICE is hereby given that an Extraordinary meeting of the Parent & Carers Council will be held at Syston Community Centre on Friday 24th November 2006 between 10.00am & 1.00pm, for the purpose of considering and, if thought fit, passing the following resolution (parts 1-4 below) (1) with or without modification as a

Special Resolution:

1. That 2 new companies will be created namely the Parent & Carer Council (Leicester, Leicestershire & Rutland) & the National Federation of Parent & Carer Councils, both will be registered as Companies Limited by Guarantee and Registered Charities.
2. That the current assets, liabilities and contracts of the Parent & Carers Council be transferred to the new Parent & Carer Council (Leicester, Leicestershire & Rutland).
3. That once the transfer process has been completed the Parent & Carers Council (unincorporated association) be dissolved.
4. Election of Directors & Trustees designate. Nominations are:

Mrs Carole Gamble Tel: 01664 434502 or 07786 626696 (PCC & NFPCC)

Mr William Dodd Tel: 01509 813655 or 07886 473394 (PCC & NFPCC)

Mr Paul Harrison Tel: 01509 550450 or 07960 751778 (PCC & NFPCC)

Mrs Julie Marriott Tel: 01530 245468 or 07736 874923 (NFPCC only)

Chief Executive
25th September 2006

Notes

- (1) Only members of the Parent & Carer Council registered at the 1st October 2006 are eligible to vote at the meeting
- (2) For further information about this process please contact one of the proposed Directors (trustees designate) as detailed above.

Please confirm your attendance at the meeting in advance and by the **17th November 2006 at the latest** (to allow us to supply numbers for catering and confirm your eligibility to vote) by telephoning/emailing Carole Gamble (numbers above) or email: carole@parentcarercouncil.co.uk

Useful Websites

Contact a Family Rare Eye Conditions Directory

Contact a Family is shortly to publish the Contact a Family Rare Eye Conditions Directory. Available from late March, the Directory will cover specific eye conditions and disorders that include visual impairment among their features. Entries will also carry details of support groups. All 20 descriptions of conditions are written or checked by a recognised expert in the field. There will be information about benefits and concessions for people with visual impairment, dictionaries and glossaries, inheritance patterns and extensive details of organisations offering support and services. Aimed at social work and education professionals as well as non-specialist health professionals to help individuals and families, the directory will cost fifteen pounds including post and package.

To order your copy either telephone **020 7608 8700** and ask for Contact:
Family Rare Eye Conditions Directory sales
Or email:
<mailto:info@cafamilly.org.uk>

Translating medical records

A new service has been launched called the Transmedi system. This Service can translate medical information into other languages producing a passport style document which can provide vital information for those with specific medical needs when abroad. In addition, users also receive an internet pass to a secure web page containing their details. The service covers 107 languages.

For further information and prices telephone **08709 509331**
Or visit:
<http://www.transmedi.com>.

PAMIS

PAMIS reported in their October 2005 newsletter that they have joined forces with MENCAP and other organisations to form the Changing Places Consortium. Through this they hope to reach a wider audience in the UK. This Consortium aims to develop a web site for advice and information, raise awareness of the need for fully accessible 'away from home' toilets, produce publicity material and distribute a PAMIS' video.

For further information visit:
<http://www.dundee.ac.uk/pamis> .

Useful Websites

Well Child children's site

This is a really fun site which provides a range of information for children including medical descriptions and stories from other children affected by a range of conditions. Visit: <http://www.childrenshealth.org.uk>.

The National Autistic Society Befriending Scheme

As you may be aware the National Autistic Society recruits and trains volunteer befrienders to support people with Autism or Asperger Syndrome and their families. We ask our befrienders to commit for at least one year and to visit for approximately two hours a week.

Our volunteers are all ages and come from all walks of life; some have experience of working with people with Autism others don't, some spend time in the home others go out and about.

When it comes to matching volunteers to families, in order to ensure that both the volunteer and the family have the best possible experience we operate a 'best match' system. If volunteers are available at a time to suit the family, have common interests, are a suitable age, don't have to travel too far and we are confident they can cope with the situation, the befriending relationship is far more likely to last a long time and be a success in the eyes of all concerned.

All our volunteers undergo a full induction and training, attend regular, informal volunteers support meetings and have support from a Regional Co-ordinator and a local Volunteers Support Officer.

If you are interested in finding out more about either having a befriender or volunteering as a befriender please contact:
Leicester Volunteer Support Officer
Gill Keeling on [0116 2367524](tel:01162367524)
Or email her at: gill.keeling@nas.org.uk.

Travel Insurance Surgery

The Insurance Surgery is a UK website specifically to help those with pre-existing medical conditions find competitive life insurance, travel insurance and other financial services. There is a list of conditions covered on the site although there are not many rare conditions listed. Visit their site at: <http://www.the-insurance-surgery.co.uk>.

Useful Websites

Sleeping or not sleeping that is the question

The Handsel Trust is collecting information about the effects of sleep deprivation on families. Are you regularly suffering from disturbed nights, how is this affecting your child, siblings, the whole family unit generally? Exhausted children find it harder to learn and a lack of sleep can put a strain on the whole family.

They are also keen to hear from families who used to suffer from disturbed nights. How did you manage? What made the situation easier for you?

To share your sleep experiences contact:

Peter Limbrick
The Handsel Trust,
9 Pitt Avenue,
Worcester
WR4 0PL

Telephone: [01905 23255](tel:0190523255)
Or email: <mailto:p.limbrick@virgin.net>.

Cerebra Sleep Nurse Service

An electronic bulletin, Children with Disabilities/SEN, recently reported on a service available to families of children with brain-related disorders. A registered nurse can give advice on sleep issues to both professionals and parents and this service is free.

For further information write to:

Cerebra Northants,
PO Box 7107,
Higham Ferrers,
Rushden
NN10 8WY

Telephone the Cerebra Parent Support helpline on
Freephone [0800 32 81 159](tel:08003281159)
Or email: <mailto:patriciaE@cebra.org.uk>.

Support Group info TBC

Countywide Parent Drop in Support Groups

Parent & Carer Council 07968 857598
 Menphys SOS 01455 894880
 Parent Partnership 01162 714137



The Leicestershire Parent Partnership Service

SEPTEMBER

Monday	4	11	18	25
Tuesday	5	CD 12	19	26
Wednesday	6	Syston 13	Hinckley 20	Syston 27
Thursday	7	Wigston 14	21	Coalville 28
Friday	Melton 1	15	Lboro 22	29

NOVEMBER

Monday	6	13	20	27
Tuesday	7	CD 14	MH 21	28
Wednesday	1	Syston 8	Hinckley 15	Syston 22
Thursday	2	Wigston 9	16	Coalville 23
Friday	Melton 3	17	Lboro 24	

OCTOBER

Monday	2	9	16	23	30
Tuesday	3	CD 10	MH 17	24	31
Wednesday	4	Syston 11	Hinckley 18	25	
Thursday	5	Wigston 12	19	26	
Friday	Melton 6	13	20	27	

DECEMBER

Monday		4	11	18	25
Tuesday		5	CD 12	19	26
Wednesday		6	Syston 13	20	27
Thursday		7	Wigston 14	21	28
Friday		Melton 1	15	22	29

CD = CASTLE DONNINGTON

Village Hall
 Moira Dale, Castle Donnington, Ashby
 2nd Tuesday of month (term time)
 1.00pm - 3.00pm

C = COALVILLE

Warren Hills Children's Centre
 Stamford Drive, Coalville
 4th Thursday of month (term time)
 1.00pm - 3.00pm

H = HINCKLEY

Hinckley Baptist Church
 Baptist Walk, Hinckley
 3rd Wednesday of month (term time)
 10.00 am - 12 noon

L = LOUGHBOROUGH

Shelthorpe Children's Centre
 Woodthorpe Road, Loughborough
 4th Friday of month (term time)
 12.00 - 2.00 pm (including light lunch)

MH = MARKET HARBOROUGH

Congregational Church Centre
 Bowden Lane, Market Harborough
 3rd Tuesday of month (term time)
 10.00 am - 12 noon

M = MELTON MOWBRAY

Venture House, Ashfordby Road
 Melton Mowbray (next to Brooksby Melton Col)
 1st Friday of month (term time)
 12.00 - 2.00 pm (including light lunch)

S = SYSTON

Syston Community Centre
 School Street, Syston
 2nd/4th Wednesday of month
 10.00 am - 12 noon (all year round)

W = WIGSTON

Memphys Centre
 Launceston Road, Wigston
 2nd Friday of month (TBC)
 11.00 am - 1.00 pm (inc. light lunch)

HOLIDAY

AUTUMN TERM 2006

CITY PARENT CARER SUPPORT WORKER POST

The Parent & Carer Council will be advertising this post within the next few weeks, via our website, the Leicester Mercury and other available networks.

We will be looking to employ a person/persons to work for the equivalent of 3 days per week (21 hours) in the City of Leicester, supporting parents and carers and working with others to improve and maintain services.

Hours and days worked will be flexible to meet the needs of any carers, or others who wish to be considered for the post.

Job share/ term time only work and other forms of flexible contract will be considered.

Life skills and an understanding of parent/carer needs will be an important part of our selection process.

Training & support relevant to the post will be available if required.

For an informal discussion about your suitability for this post, or to register for an application pack please contact:

Mrs Sue Harrison on 07968 857598
Or email enquiries@parentcarercouncil.co.uk
(Please leave a message with your name & telephone number if Sue is not available)



c/o Fosse Neighbourhood Centre, Mantle Road, Leicester LE3 5HG

Phone: 07786 626564

Email: caroline@parentcarercouncil.co.uk

Website: www.parentcarercouncil.co.uk