

# Parent & Carers' Council

## Newsletter

Volume 3 Issue 3 April 2005

### Moving Forward

In the last 6 years, under the leadership of Kathy Pearson, the Parent & Carers' Council has grown from a few people wanting to see services change and take notice of their families needs to, as Christine Lenahan from the Council for Disabled children put it at the recent NSF conference in Nottingham, " A totally unique and very effective way of working, which many local authorities around the country should aspire to".

Growth means not only change, but also a continuing busy workload for all the PCC workers and volunteers. As many of you will know Kathy has been suffering with her health recently and has made the very difficult decision to step down as Chair of the PCC under the re-structuring process and will now be known as the Non-Executive Director, still in control of the overall function, still as a volunteer but not the day to day workload.

Overseeing the day to day workload of the PCC initially will be Julie Marriott, who has taken on the temporary post of Chief Executive. Julie will oversee the local work but also continue the national planning focus too, which she has been working on for the last 12 months. We continue to receive many requests from groups around the UK for help in setting up their own PCC and Julie is working towards pulling all of this together under the banner of a 'National Federation of Parent & Carer Councils'.

In the last 12 months alone the PCC has taken on a new part time family support worker, joined in partnership with Menphys SOS and the Parent

Partnership team in the County to deliver support groups around the County (modelled on the successful MSIG at Syston), commissioned the Early Support Audit of service and numerous other local and National initiatives. Conference work has also become a mainstay for many within the PCC, as guest speakers, workshop leaders and joint hosts.

One of the highlights of 2004 was a trip to London to launch the Parent Participation packs with Contact a Family (see separate article).

2005/6 will be just as busy and we hope just as successful as the last 12 months, as we continue to highlight the needs of families and their children in Leicester, Leicestershire & Rutland.

Julie Marriott

### Thank you from Sue Harrison

I would like to give a BIG THANK YOU to all the parent volunteers and our Parent Representatives who give up their valuable time to help us within County, City & Rutland.

To all the professionals who have referred parents to us and who have worked with us over the past year plus our gratitude to Chris Bush and his team at the Database & Information Service for their support.

A HUGE Thank You to Kathy Pearson - for her support to all the PCC workers and volunteers and for her guidance as well as her vision for the PCC.

## A Parent's Story: Katie Thomas

I first heard of Parent and Carers' Council through the Database & Information service. But it was one leaflet amongst many in an A4 envelope. As I was totally overwhelmed at the time, I didn't register with the PCC for about a year. Even then, when I got the newsletter it went into a pile for reading along with loads of other literature (I'm a bit too investigative for my own good!). It wasn't till Nirmala came to the Red Cross centre, to interview some parents for the Early Support Project, that I made real contact with them.

Nirmala came to my house and after the interview she told me that other people could benefit from my experience and knowledge, and invited me to join PCC.

Working with them has provided me with an arena in which to be heard and taken seriously, channels through which I can make a real difference, a sense of purpose, drive and direction, and last but not least, a focus, that is productive instead of destructive.

As a parent, the Parent and Carers' Council has given me understanding, support and strength to fight when everything seems too much, advice and encouragement, knowledge and information, friendship, motivation..... I could go on, but I think you get the picture. My only regret is that I didn't get involved with them sooner as I suffered for so long without help.

So many services operate with criteria such as age, diagnosis, city/county divides, benefits, social workers, severity of difficulties, and many more. If you don't fit those criteria then to you they're just another person walking away. You're back where you started but just a little more desperate than before.

This is where PCC has an unprecedented and invaluable role. I hope that all agencies and services will support us in this - we can only help.

I hope to continue working for PCC for years to come and, if my son's disabilities permit me, to forge a career pathway in this or a related field. My key area of interest is early intervention/prevention.

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# An introduction to the people who work for the Parent & Carers' Council

**Kathy Pearson** – Kathy is now our Non – Executive Director. Kathy is a volunteer for the PCC and sits on the following steering groups:

- SEN/disability Sub-Group in the County
- Database & Information Steering Group (Chair)
- Early Support Steering Group in County
- CAMHS National Steering group (Child & Adolescent Mental Health Service)

Kathy can be contacted at  
kathy@parentcarercouncil.co.uk

**Julie Marriott** – Julie is our Chief Executive. Julie is working on a short term contract to work on the National Strategy of the PCC. She is also our Access & Inclusion Officer. She represents the PCC at:

- User Forum - (Chair) Specialist Child Community Health Services (SCCHS)
- "Right from the Start" group – SCCHS
- Children's Therapy Joint Strategy Group SCCHS
- Children's Model of Care Board - SCCHS & UHL Trust (University Hospitals Leicester)
- Child Health Strategy – SCCHS
- CAMHS National Steering group (with KP)
- Early Support (Training Implementation National)
- VISTA - Service user forum and fundraising group
- Parent Governor - Ashmount Special school
- Virtual Parents Reference Group - SCOPE (National)
- Direct Payments & Playschemes service user groups (City & County Children's Social services)

You can contact Julie at:  
julie@parentcarercouncil.co.uk

In her spare time Julie has her own consulting business in playground equipment for children with physical disabilities and for more info go to <http://tockconsulting.mysite.wanadoo-members.co.uk>

**Sue Harrison** Project Development Manager – Sue supports the volunteers within the PCC, She also

supports some families in the City but her role is more strategic and she represents the PCC in the City at:

- Leicester Children's Strategic Partnership Board
- CAMHS Joint Steering Group (joint City /County)
- LCLDPB (Leicester City Learning Disabilities Partnership Board) transitions
- CBII (Child Behaviour Intervention Initiative)
- Psychology Service Reference Group
- Early Years SEN/Inclusion Task Group /Early Support

In the County Sue represents the PCC:

- Autism Forum (Chair)
- Sure Start Partnership Board
- Early Years Forum
- SEN Disability Sub Group (when Kathy can't go)

Sue is also involved with Jane on a study with Social Policy & Research Unit at York University on "Outcomes for Families affected by Autism" (update can be found later in the newsletter). Sue runs the Support Group in Loughborough for Parents & Professionals dealing with ASD under the banner of the Leicestershire Autistic Society

Sue can be contacted on  
sue@parentcarercouncil.co.uk  
or 07968 857598

**Jane Hall** - Family Support Worker. Jane supports families in the County and represents the PCC in the County at:

- Portage Management Group
- Autism Forum
- Inclusion Sub-group
- East Midlands Mediation Steering Group
- Leicester Epilepsy Concern Group
- Children's Model of Care (When Julie can't make it)

Jane has been in post since August and has supported many families within the County and a few in the City. Jane can be contacted at [jane@parentcarercouncil.co.uk](mailto:jane@parentcarercouncil.co.uk) or 0787 0688973

**Nirmala Mistry** – Nirmala has been commissioned by the PCC to undertake the audit for Early Support in both City & County. Her report will be available

by April 2005. She also is a patient advisor at University Hospitals in Leicester (UHL).  
Nirmala can be contacted at  
nirmala@parentcarercouncil.co.uk

## Our Volunteers

**Kerry Stafford** – Kerry helps us out at our support groups at Syston and represents the PCC at our Market Harborough Group. She is also a fully trained parent partnership volunteer for the Leicestershire Education Authority.

**Bill Dodd** – Bill comes to our support groups at Syston and has done some consultation work for CAMHS (Child & Adolescent Mental Health Service) His support and his input has been really appreciated by both the PCC and by the professionals he has been in contact with.

**Isis Barker** – Isis comes to our regular meetings in Syston, she is also a trained Parent Partnership Volunteer. Isis will be taking a rest as she awaits the birth of her baby in April (actually we are all eagerly waiting the new arrival!)

**Katie Thomas** – Katie, helps Sue in the City and she represents the PCC at

- Youth Offending Services - Parenting Forum  
A new group of around 15 agencies aiming to work together from pre-school to teens, to combat the slippery path from 'difficulties' - behavioral problems - exclusion - offending.
- Admissions Forum A thrice-yearly meeting to discuss school admissions criteria / planning school admissions policies for the coming year.
- Children's Therapy Joint Strategy Group  
Again a multi-disciplinary group aiming to share - information, good practice, training and understanding. Also to ensure efficient, thorough and timely delivery of therapies, early identification, and preventative support for children/parents.

Our purpose is to 'develop a framework in which more effective health, educational and social outcomes for children can be achieved by co-ordination of the local agencies...'

Katie also represents to PCC at Syston and at the Hinckley Group and she can be contacted at  
katie@parentcarercouncil.co.uk

**Carole Gamble** – Carole is our treasurer and keeps a tight rein on the budgets! She also runs the support group at the Birchwood Autism Group.

**Linda Wright** – Linda represents the PCC at both the City and the County's Anti-Bullying Strategy Steering groups within both the psychology services.

**Thomasina Phillips** – Thomasina is one of our new volunteers and is one of the parents who has helped to re- form the new Children's Therapy Strategy Group within Specialist Child Community Health Service. She also represents the PCC at the County Support groups in Loughborough.

**Julie Hajat** – Julie is also a new volunteer and she is a contact point if people can't get hold of Sue or Jane. Her number is 07791 809791

**Caroline Coxon** – Caroline is our wonderful play leader at the Syston Groups. She has a wealth of experience in early years childcare and she keeps all the under school age children occupied with her imaginative activities (even the Mums join in!) but often she gives Mums a well earned rest.  
Thank you Caroline!

**Phil Pearson** and **Paul Harrison** help us out on the odd occasion as Parent Carer Council volunteers, they both actively promote the PCC through their day jobs!

## Parent & Carers Council dates for diaries

### PCC Annual General Meeting for 2005

11th April 11-30 am at The Maurice Bailey Resource Centre, Leicester Quaker Housing Association, George Hythe House, Croft Road, Beaumont Leys (light lunch included). This is an open meeting which any parent/carer may attend.

PCC Non-Executive Committee meetings for 2005/06, these meetings are for our volunteers and parent reps only.

June 24th 05

October 14th 05

March 3rd 06

All meetings to commence at 11-30am until approx 1-30pm

## Relationship fact sheet

In our last newsletter we referred to work that Contact a Family were involved in seeking views and producing a survey on how caring for a disabled child impacts on a partnership. 2,000 parents of disabled children were asked for their views.

Contact a Family received a grant from the DfES Marriage & Relationships Support Programme to produce a fact sheet. The fact sheet gives a brief overview of the results of the survey and, using the comments and views from parents themselves, along with some practical information about services and entitlements, it is intended as a useful guide for all parents of disabled children struggling with relationship issues. To order a copy of this fact sheet call Contact a Family helpline Tel: 0808 808 3555

The PCC are hoping to work with University of York with the Social Policy & Research Unit (SPRU) building on the work we are already involved in on "Parental Well Being".

The next piece of work the PCC may be involved in is looking to research into the effects on children with disabilities after a breakdown in their parents' relationship and what barriers need to be overcome to sustain the relationship between the child and the estranged partner.

We are looking for parents who would be able to help us with this piece of work. At this stage, we are looking for advice on the sorts of issues we need to be aware of and the best sort of methods to use.

If anyone is interested in taking part in this research please contact  
[sue@parentcarercouncil.co.uk](mailto:sue@parentcarercouncil.co.uk)  
Or 07968 857598

## Take a Break Scheme

We shall be administering the Take A Break Scheme on behalf of Leicestershire County Council Social Services to carers who are not receiving a service from Social Services. We envisage that we will be up and running with this at the end of April. To qualify you must be a carer in Leicestershire and your child must be receiving middle or higher rate "care component" of Disability Living Allowance or the higher rate "mobility component". If social services are funding a place in nursery or providing home care or any form of respite then Take A Break will not be granted.

This year we will be able to take applications at a location near you (see item for County Support Groups).

We will have a PCC representative at each support group in the County and the forms will be available at each location. Please bring with you proof of your Disability Living Allowance and our PCC reps will help you fill out the forms.

For parents who cannot make the meetings then please phone our office on 0116 2232290 giving Jenny your name, address and a contact telephone number and one of our workers will call you back.

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## Small grants from the PCC

One of the ways in which the PCC can help families further is to ensure that they have access to any relevant information/courses/books etc that they might need to further understanding of their child's needs or condition.

We are always willing to consider requests from parents for a grant to purchase such materials, or fees for courses that are appropriate to their needs.

If you would like further information, or would like to make a request, please contact one of our family support workers, email the PCC, or telephone us. If your request is for large amount it may have to be agreed by the Management Team, but we will consider all requests carefully before making a decision.

## Parents' Participation Packs

Contact a Family and the Council for Disabled Children have produced a pack which consists of two documents. The professionals' guide covers the key principles involved in successful participation. It is a very practical approach, detailing methods of good practice, all illustrated by many real life examples. The parents' guide addresses parents who are already involved or wish to be involved, in influencing services and gives ideas to help them make good use of their time and energies.

Both guides draw on work carried out by Contact a Family & the Council for Disabled Children with hundreds of parents and professionals workshops and a variety of forums. In the process, evidence was gathered on the principles that underlie effective participation and the good practice that results. Both documents pull together the knowledge that has been developed through the workshops. Both are underpinned by the experience of willing parents and professionals who work hard to make participation a reality.

Kathy Pearson was asked by Contact a Family to help from the very beginning of this project. Having worked with Contact a Family for many years it became clear that national guidelines were required for both parents and professionals. The PCC as a team have been involved in supporting other areas who have parents' forums and areas who wish to set up a parents' forum by sharing our good practice. We have been invited to work towards a national federation of PCCs where individual areas gain accreditation.

In the interim we continue to support and advise other areas but are not able to fulfil more commitment until substantial funding has been secured in partnership with Contact a Family.

The launch of these packs took place in early October and the PCC committee were invited to attend the event at the House of Lords. We met with Margaret Hodge the Children's Minister who launched the Participation Packs for Contact a Family (see photo below).

The parents' guide is free for individual parents and the whole pack including the professionals' guide is £15. To order please e-mail: [Debbie.bunyan@cafamily.org.uk](mailto:Debbie.bunyan@cafamily.org.uk)





## Supporting Parents throughout Leicestershire

The Parent & Carers' Council, Menphys and the Leicestershire County Council's Parent Partnership Service are all working together to help support families across Leicestershire.

At each group there will be a representative from each of the three agencies plus a specialist health visitor on hand to give advice to parents and carers. We are also there to provide a listening ear and to answer any queries you may have. You may have questions around education, inclusion, access to leisure facilities, specialist child-minding or just need another parent to talk to. We are on hand to help you.

We are all really excited about the development of this group and hope that you will be able to join the group nearest to you.

Come along for a cuppa, and a chat plus you will have the opportunity to meet other parents. We look forward to seeing you!

We meet in:-

Loughborough (Shelthorpe Children's Centre) – the 2nd Tuesday of the month 10am until 12 noon

Syston (Syston Community Centre) 2nd & 4th Wednesday of the month 10am until 12noon

Ashby (Hood Park Leisure Centre) 4th Thursday of the month 12-30pm until 2-30pm

Coalville ( Marlene Reid Centre) 1st Monday of the month 10am until 12noon

Market Harborough (Congregational Church Hall) 10am until 12noon

Hinckley (Hinckley Baptist Church) 3rd Wednesday of the month 10am until 12noon

Melton (Birchwood Area Special School) 1st Tuesday of the month 9-45 until 12 noon

## Easy Guide to Being Held Safely

This booklet, costing £5 & p&p from BILD (British Institute of Learning Disabilities), provides guidance for children and young people with learning difficulties and/or autism, their parents and teachers.

It has been developed in consultation with children with learning difficulties and their teachers and is based on the Department of Health/department for Education and Skills guidance. Using plain English and clear illustrations, the guide encourages good practice in this difficult area by explaining

- About being held
- Why teachers may hold a child
- The child's rights.

To order a copy of this publication contact BILD Publications BookSource, 32 Finlas Street Cowlairst Estate Glasgow G22 5DU Tel 08702 402 182

## Loughborough Support Group Autistic Spectrum Disorders

On the 25th April 2005 The Loughborough Parent & Professionals group will be holding an information event on Pathological Demand Avoidance Syndrome. This will be held at John Storer House in Loughborough at 7-30pm.

Lynda Lowe from Leicestershire's Autism Outreach team will be joining us to talk about her work with some of the children and families affected by PDA. For more information contact Alison Walker on 01509 557639.

Dates of future meetings: 23/05/05

BBQ 27/06/05 venue to be arranged

## Have -A -Go Day of Sport

Shepshed Disabled Swimming Group are hosting a fun day out for people with disabilities with their families and carers.

Sunday 12th June 2005  
Hind Leys Campus, Shepshed Leicestershire  
10am until 5pm

There will be over 30 different sport and leisure activities plus a snack bar and bar and lunch will be available. There is also a BBQ and picnic area. Note: This is a non-competitive event and it's free.

For more details please contact Nina & John Walker 01509 506392

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## The Autism Epidemic

In the last ten years, the number of children being diagnosed with autism has increased tenfold. Most schools in Leicester City, Leicestershire and Rutland will have at least one autistic child and the demand for specialist provision and expert support for children in mainstream schools continues to grow. We believe the education authorities underestimate the number of children with autistic spectrum disorders and the provision they plan is therefore likely to be inadequate.

The Leicestershire Autistic Society is conducting a survey of families with one or more autistic child to establish both how many children are affected and what difficulties they are encountering obtaining a diagnosis and accessing appropriate support at school. We will use this information to continue to press for expanded and improved services for children on the autistic spectrum.

Questionnaires have been sent to the 600 families with children who belong to the Leicestershire Autistic Society and the Reality support group. If you do not belong to either group but do have a child aged 2-19 on the autistic spectrum, it would be very helpful if you could fill in and return the enclosed questionnaire to The Leicestershire Autistic Society, 31 Flaxfield Close, Groby, Leics LE6 OEZ. We welcome responses from families struggling to obtain a formal diagnosis, those with dual or multiple diagnoses, and those whose children are being educated outside the county or in independent schools.

For more information, further copies of the questionnaire or to join the Leicestershire Autistic Society and receive our regular newsletter, please phone 0116 2916958

Lindy Hardcastle

# Connexions

Connexions is a service for 13-19 year olds. The service can be accessed by young people aged up to 25 years if they have a learning disability and/or disabilities (LDD).

The service is designed to help young people to reach their full potential and to make a successful transition into adult life.

Connexions Personal Advisors (PAs) will work directly with young people and will have a pivotal role co-ordinating services with other agencies to meet the needs of young people.

There are 8 key principles of the Connexions service and these are

- Raising aspirations of young people
- Meeting individual need
- Taking account of the views of young people
- Inclusion
- Partnership working
- Community involvement
- Extending opportunity and equality of opportunity
- Evidence based practice

## APIR

When working with young people PAs will use, along with other assessment methods, the connexions framework for Assessment, Planning, Implementation and Review (APIR)

APIR, rather than being an assessment, is a process involving the engagement of young people and others in identifying areas of concern for individual young people, action planning and the reviewing of action plans.

There are 18 factors that can be assessed within the process of APIR and these are broken down into 4 categories as follows:-

- 1 Education and Employment  
Participation, Achievement, Basic skills, Key skills, Life skills, Aspirations
- 2 Personal Health factors  
Physical Health, Emotional Well Being, Substance Use Issues
- 3 Social & Behavioural Development

Identity and Self image, Attitudes and motivation, Relationship within the family & Society Risk of (re) offending

- 4 Family and Environmental Factors  
Capacity of Parent/Carers Family History & Functioning Social & community factors, Housing, Income

In the process of using APIR information is gathered on the factors, although not all of the categories within the 18 factors will be relevant to all young people and therefore all 18 will not need to be explored with every individual young person. The whole process is very much young person centred and only those factors relevant to the young person need be used.

## Connexions Locally

Connexions Leicester Shire is split into two areas, Leicester City & Leicestershire County. Each area has a Local Management Committee, which is made up of Connexions staff and partners from the statutory and voluntary sectors and young people.

A PA can be either an Education PA based in schools and colleges, or a community PA. Some Community PAs also work within schools, generally with young people who have multiple barriers and considered to be in the "harder to help group". Most schools will have at least 2 PAs assigned to them dependant on the number on the school role etc.

There are also a number of PA's who deal specifically with young people with Learning Disabilities and or/disabilities(LDD) Each special school will have its own LDD PA

The LDD PA's are seconded to teams within the city and the county offices to offer advice and support to colleagues on LDD matters. LDD PAs will also deal with those young people in mainstream schools who need specialist support, although not all stated young people in mainstream education will have a LDD PA.

There is a duty placed upon Connexions around attendance at Annual Reviews of young people who have a statement of Special Needs, Transition Planning and the submission of Section 140 (Learning Skills Act) Assessments.

A Connexions PA must attend year 9 reviews, should attend year 11 and where appropriate years 10, 12, 13 and 14.

A S140 assessment in last year of education and should outline what is required to meet the young persons needs in future Learning Skills Council Provision.

Phil Pearson (Connexions LDD Manager)

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## E-bay and special needs!

Internet surfers who are looking for useful toys or resources should log onto [www.ebay.co.uk](http://www.ebay.co.uk).

I typed in words such as autism, special needs, disability and came up with 4 to 5 pages of items which were useful for all children with special needs.

For example there are "good behaviour bracelets" in brightly coloured and in florescent colours with "I was caught being good" written on them, or "fidget boxes" containing little items that will occupy your little one on tedious car journeys. Items for sale such as sequence cards, reward coins with positive messages written on them – singing straws which sing as the child sucks all at reasonable cost.

Happy surfing  
Sue Harrison



## BOOK REVIEW

### What is a disability?

A guide for children by Heidi Argent. Published by the British Association for Adoption and Fostering (2004) BAAF Publications Skyline House 200, Union Street London SE1 0LX Tel: 0207 593 2072 [www.baaf.org.uk](http://www.baaf.org.uk) price £3-50 + £1 pnp ISBN 1903699576

This is a new guide for children that explains what disabilities are, and what it can mean for children who have them. This guide may be useful for children who are disabled themselves, children who know someone who is disabled or where a disabled child is about to join the family.

There are stories of children, and a range of disabilities are explained with straightforward definitions. It explains how lack of provision for their needs can "disable" people and includes short descriptions of how famous people, both real and fictional, have achieved in spite of their disability.

Simply written and colourfully illustrated, this guide makes the point that whatever a child can or can't do and however a child looks or acts, each child is special.

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## Leicester City - Integrated Services

Web users go to <http://www.everychildmatters.gov.uk> Pathfinder Sites - Leicester

Leicester City Council, Leicester City West Primary Care Trust and Eastern Leicester Primary Care Trust have been selected by the Government to establish one of the first Children's Trusts in the country. The new Trust will commission and provide a wide range of services for vulnerable children in Leicester. Teams of staff from a range of professional backgrounds will work with children and their families at neighbourhood level, focusing on the best ways to meet their individual needs. Children, young people and their families will be consulted on the way the Trust develops services in the future. Children's Trusts bring together all services for children and young people in an area to focus on improving outcomes for all children and young people.

# Change for Parents

The Every Child Matters: Change for Children programme is a new approach to the welfare of all children and young people. It is focused around the five Every Child Matters outcomes but is also intended to deliver better information and support to parents and carers who need help, from maternity right through the teenage years.

This long-term national programme will be led by Local Authorities and is underpinned by new legislation, the Children Act 2004, which requires all agencies working with children and young people to cooperate in delivering services in a way that is truly centred on individual children and young people and those that care for them.



Each local authority will be expected to put in place a children's trust, to enable all of the bodies which have a role in looking after children in a particular part of the country to work together. Partners in children's trusts will include schools, Local Authorities, the police, health and probation services, the voluntary sector and community sector, as well as children and parents themselves.

Each Local Authority will also have to put in place a Children and Young People's Plan to show how they intend to implement the Change for Children programme for all 0–19-year-olds in their area. They will have to appoint a Director of Children's Services, and organise a local children's database, so that agencies can share information relating to children's welfare. Nationally, there'll be a Children's Commissioner, who will be a voice for children – especially the most vulnerable – in the public arena.

When it comes to dealing with individuals with specialised needs, the programme is designed to put children and young people first, providing services that are systematically joined rather than joined up by the child or family themselves. The result will be services that deal with multiple needs without subjecting children and families to unnecessarily repetitive and complex processes; and without creating obstacles in the form of boundaries between areas of service provision. Where a child has complex needs, a lead professional will link them to multi-agency support.

Locating services together in children's centres, extended schools and health settings, will mean more professionals working closely together, with a stress on early intervention and prevention.

The five outcomes of Every Child Matters:

- Be healthy - enjoying good physical and mental health and living a healthy lifestyle
- Stay safe – being protected from harm and neglect and growing up able to look after themselves
- Enjoy and achieve- getting the most out of life and developing broad skills for adulthood
- Make a positive contribution- to the community and to society and not engaging in anti-social or offending behaviour
- Achieve economic well-being

## Bereavement

Child Death Helpline 0800 282983  
Every evening 7pm - 10pm  
Monday to Friday 10 am - 1pm  
Wednesday 1pm - 4pm

It is unrealistic to expect families to return to normal when it seems their lives have been shattered. They have lost the future and the past. Their hopes and dreams have been snatched from them; the thought of never seeing, holding or talking to their child again is almost unbearable.

There is help available through the volunteers who run the child death helpline. It's run by parents who have experienced the pain and torment, guilt and remorse plus all the other emotions that surface when coping with the loss of a child as they too are bereaved parents. They understand.

A helpline call is a very intimate sharing of feelings and experiences. It's a powerful; and hopefully beneficial experience for the two people involved. Kinds of help available:

### Books and videos

- The Child Bereavement Trust – supplies resources which may help families and professionals supporting them  
[www.childbereavement.org.uk](http://www.childbereavement.org.uk)
- Winston's Wish [www.winstonswish.org.uk](http://www.winstonswish.org.uk)

### National Support groups

- Child Bereavement Network [www.ncb.org.uk/cbn](http://www.ncb.org.uk/cbn)
- The Compassionate Friends Tel 08451 23 23 04
- Cruse Tel 0870 167 167
- SANDS (Still Birth and Neonatal Death Society)  
Tel 0207 436 5881

### Counselling and Psychotherapy

The opportunity to explore and express emotions with someone else outside the home environment – who is there solely for one person's benefit and guarantees confidentiality- can be a lifeline when bereaved. You should be able to access this service through your GP.

## Multi-activity Group

A great opportunity for the family to enjoy an evening at: Hermitage Leisure Centre

Every Monday evening 5-30pm until 6-30pm  
Open to ALL families of children with special needs plus family and friends welcome too.  
Cost £1-40  
For more information contact  
Jane Hall on 07870 688973

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## Improving the Life Chances of Disabled People

The Prime Minister's Strategy Unit has published a radical strategy for transforming the life chances of disabled people. One of the key areas covered is 'Early years and family support'.

The strategy specifically refers to this feasibility study, saying,  
"This report welcomes the DfES funded feasibility study into a National Centre for Early Intervention. If implemented, such a centre could be an important hub of training and evaluation of early interventions to help guide service provision for young disabled children and those with special educational needs"

You can read more about this report on the News page of our website at <http://www.earlyintervention.org.uk/default.aspx?page=2298>

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## Early Support Audit

Nirmala Mistry would like to thank ALL the willing parents who gave up some of their valuable time to take part in the Early Support Audit interviews. Their individual contributions were really appreciated and we will be able to report back on the audit in the next newsletter or publish and publish the report on our website. If there are any mums who have had recent experience of maternity services whether good or bad ones she would love to hear from you.

Contact Nirmala on  
[nirmala@parentcarercouncil.co.uk](mailto:nirmala@parentcarercouncil.co.uk) or on her mobile 0794 6546472.

# Extended Schools Childcare and Childcare taster pilots

In February 2004 the Department for Work and Pensions and the Department for Education and Skills, announced a package of measures designed to support lone parents into the labour market. Research findings have repeatedly found that non-working lone parents cite lack of affordable, accessible childcare as a significant barrier to work for them. Many lone parents have no experience of childcare in formal settings and these two pilots are designed to enable them to explore the benefits of it for themselves and their family.

## **Extended schools childcare pilot**

The extended schools childcare pilot aims to provide enough affordable childcare for lone parents, most of who will be on income support and have school age children, to enable them to enter employment. The project will work with local schools to increase the number of childcare places available after school, before school and in holiday periods to wrap around the school day, thus enabling parents to work.

## **Childcare taster pilot**

The childcare taster pilot scheme will run until April 2006 and is open to all parents either unemployed or working less than 16 hours per week. The pilot is designed to help parents build trust and confidence in using childcare. By providing this service, parents are offered an opportunity to discuss childcare issues and concerns with an adviser. If they meet the criteria, a pre-visit to providers will be arranged, followed by an opportunity to experience up to 10 free childcare sessions.

If you are interested in joining the scheme, need more information, or would like to refer individuals to the pilots please contact: Krysha Catterall or Kate Gregg on 0116 265 8363 or email at [childcare@leics.gov.uk](mailto:childcare@leics.gov.uk)

Ed Harris (Early years & Childcare Inclusion Officer)

*Ed has asked the PCC to discuss with him this pilot for families whose child/children have additional needs. Sue, Julie and Jane will be meeting Ed in April so if you are a lone parent of a child who needs extra care and you would like to get back into work then contact the PCC.*

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## **Bullying**

I am a practising psychologist, speaker and author. I treat victims of school bullying of all ages and have over 30 years working with children, parents and schools. I am on the Board of the National Coalition Against Bullying in Australia.

I noticed that you have a website on school bullying. I would like to introduce you to my website, [www.bullying.com.au](http://www.bullying.com.au). It is full of practical hints and simple but solid ethical ideas. I am hoping you can link it to yours.

I would also like to suggest that you also consider my book, *Bully Busting* (Finch 1999) now available in the UK, which is a self-help book for parents, students and teachers. Although schools can do a lot to reduce bullying, parents and students must also learn basic social survival skills to cope with it themselves. I see this book as a replacement for obtaining help in my office.

Thankyou

Evelyn Field MAPS

## Physiotherapy groups

Julie Harvey (Technical Instructor, Physiotherapy) is currently running groups for pre-school children.

Originally these groups were held in the Child Development Centre at Leicester Royal Infirmary however they have now moved to the Fosse Neighbourhood Centre, Mantle Road and Loughborough. We plan to hold further groups in Healthy Living Centres.

Parents and carers have reported that they like the new venue and for once they are able to park with ease!

Julie runs a morning and an afternoon group. Parents, staff and children embark in a number of fun activities, which they can then continue at home.

Parents have reported that they enjoy the informal, relaxed atmosphere and value this pre-school opportunity, as facilities for some of these children can be very limited.

The parents also engage in an informal support network. They have also reported that their child enjoys the company of the other children and the group activities often encourage them to try things they might not have done at home.

More information is available from Julie Harvey on 0116 2232492.

## Rapid Response Team

City-wide service for families in crisis or nearing crisis due to emotional, behavioural or relationship difficulties

This service is a joint initiative between the Family Support Unit (FSU) and the Centre for Fun & Families. It's intended to provide a swift response where the family are not receiving (or entitled to receive) a service from either Social Care & Health or Child & Adolescent Mental Health Service (CAMHS) or not able (or considered appropriate) to receive an immediate service from the Child Behaviour Intervention Initiative (CBII).

The FSU team's target is to have contact with families within 3 days of referral, who will work with them for a short period, linking to the Centre for Fun & Families when group work is a suitable method of intervention. Contact will then be maintained with the family until they have completed one of the group work programmes.

Referrals: families can refer themselves to the service. They can also be made by agencies, provided consent has been obtained.

·Jessie Farrell (Project Leader), Leicester FSU, 26 Severn Street, Leicester, LE2 0NN. Tel 0116 254 3352

·David Neville (Co Manager), Centre for Fun & Families, 177-179 Narborough Road, Leicester, LE3 0PE. Tel 0116 223 4254

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## Annual Carers' Week

The annual Carers Week carers survey is now being carried out. The purpose of the survey is to update our knowledge, in advance of Carers Week (13-19 June), about carers' experiences of juggling work and care, what support carers receive, how they view that support, and what changes might make a difference to their quality of life.

We have designed the survey so that it should only take a few minutes to complete; it is available online at: <http://www.carersuk.org/Newsandcampaigns/CarersWeek/2005survey>  
Copies can also be ordered from this office (maximum 250).

For further information about the survey, or any aspect of Carers Week. contact Paul Matz-Carers Week Manager 20/25 Glasshouse Yard London EC1A 4JT  
[www.carersweek.org](http://www.carersweek.org) tel 020 7566 7608  
mobile 07850 920899 fax 020 7253 9831 email [paul.matz@carersuk.org](mailto:paul.matz@carersuk.org)

## The Cinema Exhibitors' Association Card

This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema.

To apply for the card, you will need to meet one or more of the following criteria

A) Be in receipt of the disability living allowance or attendance allowance.

B) Be a registered blind person.

C) Be a holder of a disabled person's rail card.

The card is valid for 3 years from the date of issue and is valid throughout the UK,

Application forms are available from cinemas across the UK supporting this card.

If you have any difficulty, please contact us at the address below.

A processing fee of five pounds is chargeable per card. This is to be sent along with the completed application.

Tel: 0151 348 8020 Fax: 0151 348 8021  
The Card Centre The Technology Centre  
Rossmore Business Park  
Ellesmere Port, Cheshire. CH65 3EN  
Minicom / Text phone: 0151 356 7113  
Email: [info@ceacard.co.uk](mailto:info@ceacard.co.uk)

## Update on the Weather Lottery

We launched the weather lottery in November and to date we have 38 lines playing on a regular daily basis.

In the first few weeks we had our first £200 winner, Mrs Brown from Thurmaston and quite a few members have been winning small £2 & £20 cheques too.

For those of you with your applications forms sitting in a pile of 'things to do', make sure you dust them off and fill them in, so that you can start being added to our winners lists too. At £1 per week and far better odds than the Big Lottery it has to be worth supporting our respite holidays fund.

If you have lost your application form, let me know or phone 07736 874923 and I can arrange to get a new one to you.

Please remember that anyone can be a player - it is not restricted to PCC members, the more people play the quicker we can buy our holiday caravan for respite breaks.

Julie Marriott  
[julie@parentcarercouncil.co.uk](mailto:julie@parentcarercouncil.co.uk)

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## Sleep problems in families of children with disabilities/SEN

The Handsel Trust is trying to raise awareness about sleep issues. This follows the workshop by Sleep Scotland at the Interconnections conference in June 2004. Research has shown that in other parts of the UK:

- Many families keep their problems to themselves because they do not imagine help could be available
- Many professionals, having limited awareness of the problems families might be facing, do not ask parents about how much sleep they are getting or include sleep issues in their assessment processes.

The Handsel Trust is collecting information about the scale and nature of the problem, about the effects on families of disturbed sleep and would like to hear from families and professionals about what sort of help is available and how effective it is.

If you can help please contact Peter Limbrick on 01905 23255 or e-mail [p.limbrick@virgin.net](mailto:p.limbrick@virgin.net)

# The National Service Framework

The Children's National Service framework (NSF) for England was launched on September 15th by John Reid, secretary for Health and former Education Minister Charles Clarke.

After three years of work we now have a set of national standards for children's health & social care.

The standard for disabled children needs to be read in conjunction with the wider standards, specifically those for children who are ill and children with mental health difficulties. It is a blueprint for change. The Parent & Carers Council will be actively working towards the following standards:

- Disabled children being included fully in mainstream services wherever possible
- Disabled children and families should get early support and intervention from point of diagnosis and identification of needs
- Families who have a high level of need should be able to access a key-worker service
- Parents should be involved in shaping services
- Transition services for young people need to be based on their needs, hopes and aspirations for the future

The big challenge now is to ensure that service providers and commissioners move forward and embrace the key principles and practice markers in the NSF.

The most important driver will be parents, parents groups and voluntary organisations who will be vital to ensuring that local services implement the NSF.

The Children's NSF is available from the Dept of Health, Tel 08701 555 455 or e-mail [doh@prolog.uk.com](mailto:doh@prolog.uk.com) or from the web <http://tinyurl.com/2ljke>

## The National Service Framework (England) and its implications for parents and support groups: parents' conference

Saturday 14 May 2005, 10am-4pm, Leeds

The National Service Framework for Children sets vital transforming standards for the health and social care of children. Contact a Family is hosting a conference for parents on the implications of the NSF for parents of children with disabilities and special needs.

- What will the NSF mean for your child?
- What will the NSF mean for parents' involvement in shaping service provision?
- What are the implications for your local area parents' forum/group?

There will be a variety of speakers including Christine Lenehan, Director of the Council for Disabled Children and Francine Bates, Chief Executive of Contact a Family and Chair of the NSF disabled children's working group. The day will include workshops on different aspects of the implications of the NSF and parents' involvement. It will also provide an ideal opportunity for parents to meet and talk with other parents from around England and share their experiences.

If you are interested in finding out more about the NSF and opportunities for you to become more involved in shaping health and other services for disabled children, please do come. The conference will be free, with a returnable booking fee of £30 securing a place.

We can even throw in a free night's accommodation for early booking parents who need to stay over, or possibly contribute towards travel or child care costs, but places are limited.

More details of the conference programme will be available shortly but for further general information, or to register your interest, contact Louise Derbyshire on 020 7608 8776 or <mailto:louise.derbyshire@cafamily.org.uk>.

A number of our PCC members will be going/hosting workshops etc, if you would like to go and require support they will be happy to assist. Please contact Sue Harrison on 07968 857598 for further information.

# Early Support

Helping every child succeed

Early Support (ES) is a programme that is being led by the Department for Education and Skills (DfES) which aims to:

- Improve co-ordination and communication between professionals and families of disabled children aged 0 – 3 years
- Keep the needs of the child and their family central at all times
- Introduce a standard set of materials across the country so that families in different places get the same sort of support

A range of materials has been published for both professionals and families. These materials are intended to support the aims of the Early Support, in partnership with parents and many other public/voluntary bodies have developed the free Family Pack, which is available to any family with a child 0-3 with an additional need or professionals working with these families.

The Early Support Family Pack contains background information about the services the family may need, the help they are entitled to and a family file, which is designed to help co-ordinate the support being provided for the family.

The following booklets are available free of charge from Early Support:

- |                                      |             |
|--------------------------------------|-------------|
| • Autistic Spectrum Disorders        | ref ESPP12  |
| • Cerebral Palsy                     | ref ESPP 10 |
| • Deafness                           | ref ESPP 11 |
| • Learning Disabilities              | ref ESPP 15 |
| • If your child has a rare condition | ref ESPP 18 |
| • Multi-sensory Impairment           | ref ESPP 9  |
| • Visual Impairment                  | ref ESPP 8  |
| • When your child has no diagnosis   | ref ESPP16  |

Work has now started to find ways of effectively using these materials locally to the benefit of the children, their families and the professionals who are working with the family.

To obtain your free Family Pack contact the DfES or Danni. For more information on the work to de-

velop Keyworking and coordination locally, contact Paul. For information on designated Key Working in the City contact Lyn.

DfES Publications  
PO BOX 5050  
Sherwood Park  
Annesley  
Nottingham  
0845 6022260  
0845 6033360  
Email: [dfes@prolog.uk.com](mailto:dfes@prolog.uk.com)  
Website: [www.espp.org.uk](http://www.espp.org.uk)

Danni Donovan  
ESP  
C/O Specialist Community  
Child Health Services  
Bridge Park Plaza  
Bridge Park Road  
Thurmaston  
Leicester  
LE4 8PQ  
Phone: 0116 2232427  
Fax: 0116 2232427  
Email: [danni.donovan@lcwpct.nhs.uk](mailto:danni.donovan@lcwpct.nhs.uk)

Paul Harrison  
Early Support Project  
Coordinator  
C/O Specialist Teaching  
Service  
Rothley House  
Coalville Business Park  
Jackson Street  
Coalville  
LE67 3NR  
Phone 01530 513600  
Email: [pharrison@leics.gov.uk](mailto:pharrison@leics.gov.uk)

Lyn Edwards  
Coordination Plus  
Menphys SOS  
C/O Fosse Neighbourhood Centre  
Mantle Road  
Leicester  
LE3 5HG  
Tel: 0116 2252060  
Email: [lyn.edwards@menphys.org](mailto:lyn.edwards@menphys.org)

# Right From The Start

## Introduction

There is a body of considerable evidence (formal research and anecdotal) that suggests that the quality of diagnosis can and does impact on the emotional well being of the parents. Scope leads the national initiative – Right From The Start (RFTS) in recognition that the unique experience of parents at the time news is shared with them varies considerably and impacts on:

- Future relationships with key professionals supporting the child and family.
- Parents' ability to respond to what is often an unexpected situation.
- Parents' relationship with their child
- How parents share news with other family members and friends.

A Multidisciplinary and User group was established within Specialist Community Child Health Services to audit current practice in relation to how information about a child's additional needs, diagnosis (or in the absence of a diagnosis the prognosis), and the likely present and future needs of the child is shared with parents and carers.

Phase One of this audit involved establishing the professionals' perceptions:

- of their practice of sharing news of a child's additional needs with the family.
- of their training needs.

This summary relates to the first phase only.

## What did the group do?

Postal questionnaires were sent to members of staff working within Specialist Community Child Health Services, (a total of 267). These were staff from the following services and departments; Admin and Clerical, Audiology, The Diana Service, Medical (Doctors), Occupational Therapy, Physiotherapy, Service Co-ordination, Specialist Health Visiting and Speech and Language Therapy.

A total of 161 questionnaires were returned (60% response), therefore it was considered that a representative return was achieved. The informa-

tion from the questionnaires was collected and analysed to determine a base line of current practice and knowledge.

Some of the recommendations included:

1. Specialist Community Child Health Services commission a task & finish group incorporating the support of parents and users, to draw up a policy.
2. The policy should incorporate guidance and standards for the process of sharing initial or subsequent news (Phase 2 will explore this further).
3. The policy should record the intention surrounding training staff support.
4. The policy should include recommendations for review.

A copy of the report was submitted to the Child Health Executive Committee for future action within SCCHS.

In addition copies of the report were sent to:

- The Parent & Carer Council Newsletter for consideration of publication of an Executive Summary.
- The Right From The Start working Group.
- The Early Support Pilot Projects locally for information.

Phase Two of this audit will identify current practice from both user and professional perspectives regarding the sharing of news of a child's additional needs with the family. Some of you as parents and carers may have been approached to complete questionnaires to inform this. Phase two will be published in the same way as Phase One.

If you would like more information regarding Phase One of this audit you can contact either

Julie Marriott (Parent & Carers Council) Tel: 01530 245468 Email: [julie@parentcarercouncil.co.uk](mailto:julie@parentcarercouncil.co.uk)

Katie Willetts (Modern Matron) Tel: 01162 225 5484. E mail: [Katie.willetts@lcwpct.nhs.uk](mailto:Katie.willetts@lcwpct.nhs.uk)

## The Doctor Andrew Holton Scandal continues

The General Medical Council (GMC), that oversees the guidance and control of Doctors in the UK, has at last fixed the dates for the disciplinary hearing. They are 18th to 29th April, and 3rd and 4th May. There is no guarantee that their decision will be made on the last date – going by past experience, there will be a lot more delay.

The GMC astounded parents with their latest announcement that, despite some of the complainants being on fixed incomes or benefit, they have decided not to pay any travelling expenses to get to the hearing in London. They don't think that any of the parents need to be there. They would be more than happy if none of us went. Presumably any evidence given on behalf of Dr. Holton would not be challenged. My request for the hearing to be transferred to Leicester, where most of the complainants live, was treated with disdain. So, a huge "thank you" to the PCC for their latest grant of £500 towards the travelling expenses of the 18 strong contingent. We all believe that less weight will be given to our evidence if we do not attend the hearing to be cross-examined on what we have said.

LECPG's Solicitor, Richard Follis of Alexander Harris, is giving of his time free of charge to attend with the complainants and help them through their evidence. Another big "thank you" to him. The complainants all wonder why they are being treated like people who have committed some awful misdemeanour, rather than trying to help the GMC get to the truth of the matter. So much for the GMC's motto: "Protecting Patients"!!! Of course, it could be that the GMC does not really want the truth to come out! Am I being too cynical?

However, the LECPG has not given up the fight on behalf of parents and carers. We went to see Patricia Hewitt, Secretary of State for Trade and Industry, and a local MP, to present a series of briefings to her, and our problems. We are aware that she has written letters on our behalf, and we anticipate that action will result – we have seen the strength of her feelings as expressed in her letters.

So we have not given up hope, even though we are now into the fifth year of the Scandal. And the litigation by over 450 patients against the NHS is also continuing.

Trevor Parr, LEPCPG Committee Member and affected parent.

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## 'Service Coordination Plus' is part of the Menphys Special Outreach Service

In the City of Leicester Menphys SOS has a team of \*'Designated Key Workers' who are able to support and help families/carers by making sure that:

- Families have all the information and emotional support they need
- Appointments, assessments and joint planning sessions are coordinated where ever possible
- Everyone knows who is doing what
- Information is shared efficiently with families and between everyone who is working with them
- Family Service Plan meetings are arranged when required, which the Key Worker will Chair
- At these meetings the family and professionals develop and write up the Family Service Plan
- Parents/Carers receive support to fill in and use the Family Held Record Packs

\* 'Designated Key Workers' are also known as Service Coordinators

Please contact us on 0116 2252060 for further information

the Leicestershire Parent								
	Partnership service							
<b>APRIL</b>							<b>Coalville</b>	
Mon	4	11	18	25			Marlene Reid Centre, Belvoir Road, Coalville	
Tues	5	12	19	26			1st Monday of month 10am-12pm term time	
Wed	6	13	20	27				
Thurs	7	14	21	28			<b>Loughborough</b>	
Fri	8		22	29			Children's Centre, Woodthorpe Road, Loughborough	
Sat	9	16	23	30			2nd Tuesday of month 10am-12pm term time	
Sun	10	17	24					
<b>MAY</b>					Bank Hol		Half term	
Mon	2	9	16	23	30		<b>Syston</b>	
Tues	3	10	17	24	31		Syston Community Centre, School Street	
Wed	4	11	18	25			Syston	
Thurs	5	12	19	26			2nd/4th Wednesday of month 10am-12pm all year	
Fri	6	13	20	27			<b>Market Harborough</b>	
Sat	7	14	21	28			Congregational Church Hall, Bowden Lane	
Sun	8	15	22	29			Market Harborough 3rd Tuesday of month 10am-12pm term time	
<b>JUNE</b>					Half term			
Mon		6	13	20	27		<b>Hinckley</b>	
Tues		7	14	21	28		Hinckley Baptist Church, Baptist Walk	
Wed	1	8	15	22	29		Hinckley	
Thurs	2	9	16	23	30		3rd Wednesday of month 10am-12pm term time	
Fri	3	10	17	24			<b>Melton Mowbray</b>	
Sat	4	11	18	25			Birch Wood, Grange Drive	
Sun	5	12	19	26			Melton Mowbray 1st Tuesday of month 9.45am-11.30am term time	
<b>JULY</b>					Summer break		<b>Ashby</b>	
Mon		4	11	18	25		Hood Park Leisure Centre, North Street	
Tues		5	12	19	26		Ashby	
Wed		6	13	20	27		4th Thursday of month 12.30pm-2.30pm term time	
Thurs		7	14	21	28		<b>Oakham</b>	
Fri	1	8	15	22	29		The Parks Nursery, Barleythorpe Road	
Sat	2	9	16	23	30		Oakham	
Sun	3	10	17	24	31		2nd Friday each month 10am-12pm term time	