

# Parent & Carers' Council Newsletter

Volume 3 Issue 1 Spring 2004

## A Challenging Year - Chair's Report

The last twelve months have been probably the most challenging and difficult since the beginning of the PCC. We have seen our membership soar and towards the end of the summer during 2003 had to make the decision not to promote ourselves further in order to not "overstretch" our limited resources. We have supported a record number of parents around SEN tribunals, DLA. Appeal/tribunals and other difficult meetings at school or elsewhere. We continue to ensure that appropriate representation is ensured at planning and commissioning groups at every level, across every district.

Responding to demand in May, we started a twice monthly meeting in Syston where families could meet for information support and a chance to meet other carers. Due to having a trained play leader at every meeting, this has meant that a cup of tea has often been drunk in relative peace .....not a common event for most carers. We were careful to choose our venue as we did not want to be pushed into a "grotty" hall – we are actually in bright, clean and modern surroundings and we hope this makes us appear more welcoming.

At a national level we have been just as busy, we had a parents' representative on a government group looking at Play & Leisure with Frank Dobson. Due to our success in working and advising on the N.S.F (National Service Framework) guidelines, we have become much more in demand to advise nationally on our model of consultation and support. We also have a parent representative who has been advising the length and breadth of the country on Inclusive Playgrounds. Several of our volunteers have spoken at both national and regional conferences and are assisting in forthcoming national workshops.

One of our main achievements this year has been our links with the Database and Information Service. As many of you are aware, the PCC provided an enormous amount of consultation and advice around the formation of this service. All of our views were not only listened to, but were incorporated into the structure and workings of the service. As a committee we were so impressed that, after consultation, we decided to work as closely as possible to provide an even more efficient service for carers. We now actively promote joint membership of the two databases.

We have representatives who sit on the Database and Information Service multi-agency planning group around information sharing (through their newsletters etc), and I myself am Chair of the multi-agency management Board who provide the ultimate 'steer' for the service.

The employment of workers will ultimately serve to strengthen us and enable the PCC to grow. I have deliberately not intimated that we will become more 'professional' as I do not think any of our volunteers have ever been perceived as anything other. I am immensely proud when I hear of the respect and esteem in which they are held. We work at all levels and I feel that we are treated as equal partners and our policy is such that 'tokenistic' representation is not tolerated. The introduction of the £20 honorarium to cover expenses has not only simplified the accounting system, but has helped to make our volunteers feel valued and supported.

As usual at this time of year I thank all of the parents and representatives who have given up some of their valuable time to help and support others. No two work the same way, we all have

different skills yet each one is crucial to maintaining our work across the City, County and Rutland, and I thank them all on behalf of the committee. Any amount of time that can be spared is always gratefully accepted and the committee will do all it can to support regarding childcare, expenses etc.

This year I also wish to thank the many statutory agencies that we have worked with over the past 12 months. There have been many individuals who have supported us as parents and collectively as the PCC. We have forged excellent links with most agencies and have always managed to maintain a dialogue even at times under difficult circumstances. We have a few parents who now chair important multi-agency groups and are treated fairly, respected for their views and made to feel welcome. I personally feel that the PCC has been responsible to some degree in breaking down the barriers between agencies and parents, thus enabling a more useful dialogue - long may it continue

Kathy Pearson

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## Constitution changes

The management committee has spent the past year consulting at meetings and with other members and feel that the constitution is now ready to be adopted with some minimal changes.

We do not have the funding to send a copy by post to all of our members, however any member is welcome to examine a copy either preferably on our website [www.parentcarercouncil.co.uk](http://www.parentcarercouncil.co.uk) or by sending a stamped addressed A4 envelope to our main address.

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## PCC Newsletter Online

We would like to be able to keep our costs down and keep our members regularly informed electronically

Parents and carers who have e-mail addresses please would you send an e-mail to [parentsc@aol.com](mailto:parentsc@aol.com) and type in the subject line "subscribe". We will then add you to the electronic e-mail system

## This PCC Newsletter



Is sent out to a thousand families and professionals concerned with the care and support of individuals with any special need and their families

We are inviting letters, articles, notices, features and suggestions for our next issue.

You might want to raise awareness of a particular association or support group.

Professionals: perhaps you would like the opinion of parents of special needs children on a particular area. Or you may just want to inform a target group of parents about your service or a change to provision.

Is there a new initiative or resource that families coping with special need could benefit from?

Do you have information, knowledge or experience with a particular diet, behavioural, communication or mobility aid that you would like to share with the rest of us?

Carers: do you want to get a message to professionals regarding the support of the child in your care? An insight into the parental perspective has proven very valuable for agencies and service providers in shaping their future provision.

Perhaps you would like to promote an event or service?

Whatever you want to say, share it with us!

Contact the PCC on 07968 857598 or e-mail [Parentsc@aol.com](mailto:Parentsc@aol.com)

Deadline for contributions to the next newsletter: July 31st 2004

The newsletter is the voice of parents and carers. Any item welcome for inclusion, please forward to Sue Harrison, preferably by e-mail. The views expressed in any article are solely those of the author and not necessarily those of the committee.

## Where we are at now

The Parent & Carers' Council was set up just under 5 years ago. We came into being as a result of difficulties and frustrations that parents felt when accessing services for their children with SEN and disability. We were able to express those frustrations in a document that became known as P.A.C.T (Parent And Carer's Testimonies). We have been so successful in working alongside service providers and other agencies that our model of working is being now being used across other counties.

There are now Parent & Carers' Councils in Calderdale, Rochdale, Kirklees, Sheffield and Leeds and we are working with them to help extend what we do across the country.

All our parent representatives are voluntary and when we receive a referral from either parents themselves or from a professional we can usually match one of our volunteers who has had similar experiences to the family. We find that parents sometimes just need someone to talk to and it's so refreshing to be able to talk to someone who has been through the same situation.

Do you want to make a difference?

All our parent reps are voluntary workers as well as all being carers themselves, and we recognise that there are times when it's not possible for all of our parent reps to be able to fit in the volunteering work for the Parent & Carers' Council around their own family life. Life can get really hectic with juggling meetings and visits combined with the practical issues around caring for our families.

We are always looking for more volunteers to become parent reps to help spread the load. We also appreciate that every parent is an expert in their own child's experience, so why not share it with others and use that expertise and experience to help make a difference to other families who could benefit from your support?

The work that we do in supporting families on the ground has been recognised by the statutory agencies and in recognition of the work we put in with families we now have funds available to aid our work to benefit parents/carers. We are in the fortunate position of being able to pay a fixed honorarium to every parent representative for each meeting they attend or each visit they make to a family when on PCC business. This helps to cover expenses or can cover child care costs if the need arises.

There are parents out there who DO NOT know what is available to them. Some don't know what services are out there and some parents just need a friendly supportive person who will listen to them and have an understanding as to how they feel.

As parental volunteers we play a vital part in filling the gap where parents are most vulnerable. We can identify with the isolation and the concerns that parent share when bringing up a disabled youngster.

Call Sue: 07968 857598

### Contact the PCC

If you would like to join the PCC; for spoken copy of the newsletter on tape; or for access to advice and support, please contact:

Sue Harrison  
Parent and Carers' Council  
c/o Fosse Neighbourhood Centre  
Mantle Road  
Leicester  
LE3 6ZJ  
Telephone 0116 2232290  
PCC mobile 07968 857598  
e- mail ParentsC@aol.com  
website  
[www.parentcarercouncil.co.uk](http://www.parentcarercouncil.co.uk)

When Sue is not available, call  
Jane Hall 07870 688973  
Fatima Abdulla 07814 119165

## Changes within the Parent & Carers' Council

The start of 2004 brought in a few changes within the PCC. We managed to secure funding for a part time worker within Leicester City. We are now working in partnership with the Database & Information Service for children and young people with special needs or disabilities.

Kathy Pearson due to health reasons is now taking a less active role; although she is still attending some of the meetings across Leicestershire and Rutland as well as managing the overall work of the PCC.

Sue Harrison has been appointed on a temporary part time casual basis to work for the Parent & Carers' Council supporting families. Sue also attends the Leicester Children's Strategic Partnership steering group and will be attending the Learning Disability Partnership Meeting. Both Kathy Pearson and Sue represent parental views on the Child & Adolescent Mental Health steering group for City & County.

Sue has already made contact with some of our City families and if you haven't already you should be receiving a phone call from Sue (that is if we have your phone number on our system) as she will be in touch with our City parents to introduce herself and to check out how things are going for families within the City. If you are experiencing any difficulties with any of the services you receive or if you have any positive experiences to share then just call: we would love to hear good news.

Parents as always, are able to contact us on 07968 857598 during office hours. If the answer phone cuts in this is because Sue will either be in a meeting or it's her day off or it is out of office hours. The phone is always off at the weekend but messages are checked regularly so please do leave a message and Sue will get back to you.

Whilst we are delighted that we are about to receive funding we would like to make it clear that we have insisted and will always retain our impartiality working alongside the statutory agencies. Please be assured that our work will always be in the interests of parent /carers and represent them on their behalf, and that we will never be controlled by the statutory agencies. We have always and will continue to remain independent.



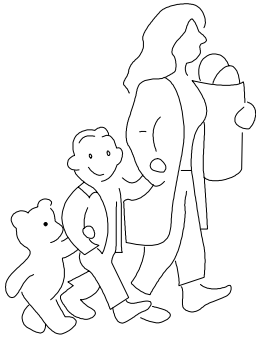
Leicestershire Parent Partnership Service is based at the British Red Cross Special Needs Family Support Centre, 54 Kenilworth Drive, Oadby. The Parent Partnership Officers are Jo Wagstaff and Helga Gardiner and can be contacted on 0116 2714137. The Service offers support to parents of children with special educational needs. It provides:

- ◆ support and information over the telephone
- ◆ keeping a register of Independent Parental Supporters
- ◆ providing parents with an Independent Parental Supporter on request
- ◆ training for Independent Parental Supporters
- ◆ written information for parents about special educational needs
- ◆ assistance for parent support groups
- ◆ maintenance of a list of local helpful addresses and groups
- ◆ providing interpreters
- ◆ signers for the hearing impaired
- ◆ arranging independent mediation between parents and the LEA or schools

For support and information: contact Jo or Helga on 0116 2714137.

### New PCC leaflets

New leaflets are available if any one wants copies, then contact Sue on 07968 857598.



## TAKE A BREAK SCHEME ( CHILDREN )

The Scheme provides a one off payment to parent/carers living in Leicestershire who:

- ◆ Have a child with severe or moderate disabilities
- ◆ Receive DLA (high or middle rate) or High Rate Mobility component
- ◆ Are eligible for services from Leicestershire Social Services Dept (SSD ) but have not received any other service provided or funded by the SSD in the past 12 months.

The payments can be used flexibly to pay or contribute towards a service with constitutes a break for you from caring. This year it is possible for payments to be used towards the costs of a family holiday.

### How to apply

All applications will be processed by the Parent & Carers' Council who will:

- ◆ Check and confirm your details and see proof of your DLA (High rate DLA / Mobility component would qualify for a £150 grant ; middle rate DLA would qualify for a £100 grant );
- ◆ Confirm how you would be using the payment;
- ◆ Confirm that only one application is being made per child;
- ◆ Pass on your details to Social Services Finance Section to confirm you have not received other services over the previous 12 months and for a cheque to be sent to you.

### Payment Process

- ◆ It is important that you do not purchase a service until you have received your grant.
- ◆ Keep proof of the service purchased as Social Services will be asking a random sample of carers to provide evidence of the service purchased.

Because last year's scheme was heavily oversubscribed, we have reduced the payment levels in consultation with the Parent & Carers Council. We will

also stagger payments throughout the year so that grants are paid out at least 12 months after a previous grant was made.

### Parent & Carers' Council

The Parent & Carers' Council is a support network run by Parents and Carers specifically for Parents and Carers.

- ◆ We all have children who are affected by disability or Special Educational Needs.
- ◆ We work alongside Social Services, Education and Health.
- ◆ We voice parent/carer views through the various working groups that our parent representatives attend throughout the County.
- ◆ We are all committed to improving the quality and range of services for all our disabled children and families.
- ◆ We provide information and support through home visits and information sessions.
- ◆ We want to hear what works well for you.
- ◆ We want to hear what you think should change.
- ◆ Service providers consult with our group on issues that have an impact on disability and Special Educational Needs.
- ◆ TOGETHER WE CAN MAKE A DIFFERENCE

We have an excellent working relationship with Leicestershire County Council's Social Services Department and this year we will be administering the Take a Break Scheme for Children on Social Services behalf.

For further details on whether you are eligible and how to apply for the grant you can contact the Parent and Carer's Council on 07968 857598

### Breakaway scheme for City Parents

Please contact Bena Blankley at Beaumont Way Social Services, tel. 0116 2995799 to apply for the City Breakaway scheme.

## Update on Epilepsy and Dr Holton

Dr Holton has been allowed to practice again by the GMC. He is working in the field of Clinical Neurophysiology. This includes reading EEGs, the GMC claim this is "an area of unrelated Practice" !!!! We are in continual contact with the GMC to make our concerns known.

The independent report by the Trent has been published and many recommendations have been made.

The chair of the LECPCG and a member of the PCC are now sitting on the steering group looking at the recommendations made by the Bamford report and those that should have been made. Hopefully changes will be implemented that should alter practice to ensure this doesn't happen again. It is a long, slow process and there is lack of confidence on the parents' side as they have been let down so badly time and time again.

It is also coming to the time when legal action must be taken if you are considering doing so. You only have until May 2004, after that it could be too late. If you are unsure please call our help line, view our web site or seek a solicitor that deals with medical negligence for help. This is for the benefit of your child.

For those out there that are still concerned about their child, remember : "It is your right to have a second opinion"

You do not have to accept a second opinion from inside the Leicester Trust. If you still have doubts, ask.

If there is anything else parents would like to know you can :

1 Call 0797 4481688

2 View web site [www.lecpcg.org.uk](http://www.lecpcg.org.uk).

3 Email [enquiries@lecpcg.org.uk](mailto:enquiries@lecpcg.org.uk)

4 Write The Orchard, 1 Blaby Road, Enderby, Leicester, LE19 4AR

The LECPCG have been very grateful for the continuing support they have received from the Parent & Carers' Council, it has made a difference.

## SEN STRATEGY Access to play and leisure services



'Removing Barriers to Achievement, the Government strategy for SEN, was launched by Charles Clarke on 11th February. Its aim, as promised in the Green Paper on the reform of children's services Every Child Matters, is to achieve a vision where ALL children and young people have the opportunity to achieve their full potential through good quality care, play and leisure services and school.

The strategy aims to personalise learning for those with SEN or disabilities by making education more innovative and responsive to the diverse needs of children. It covers all aspects of school life and also incorporates actions that the Sure Start Unit will take to improve access to care, play and inclusive facilities for children and young people aged 0-16 who have special needs or disabilities. This aspect of the strategy will be taken forward by the Sure Start Unit over the coming months and years in collaboration with local authorities, the voluntary sector, schools, Connexions and other Departments/agencies.

The main features relating to out of school activity for the Connexions age group include action on

- ◆ Improving information for parents
- ◆ Promoting inclusive and affordable care, social and leisure facilities
- ◆ Collecting and spreading good practice through work with Connexions and local authorities
- ◆ Promoting inclusive care and leisure facilities as a priority within the extended schools programme; and
- ◆ Improving access to training for the teaching and children's services workforce.

The full "removing Barriers to Achievement Strategy" can be viewed on the internet at :

[www.teachernet.gov.uk/strategy](http://www.teachernet.gov.uk/strategy)

## Relationships survey

The impact on parents of having a disabled child has now been quantified in a comprehensive new survey, *No Time for Us*, conducted by Contact a Family.

Key findings show that:

- nearly half (44%) of the respondents felt that having a disabled child had caused problems in their relationships and nearly one in ten (9%) felt that it had led to separation
- over one in six (17%) were bringing up their disabled child alone
- nearly one in four (24%) had received professional relationship counselling. Seven out of ten had found it helpful. Thirty-eight per cent would have liked to have had counselling.
- of the 76 per cent who suffered stress or depression, 88 per cent linked it to having a disabled child. Similarly, of the 72 per cent who cited tiredness and lack of sleep, 84 per cent attributed this to their child's disability.
- over half (51%) of parents had financial difficulties with 66 per cent linking this to having a disabled child. A third (32%) had problems at work with 71 per cent of these parents linking it to their caring duties.

When asked what helps relationships the most important factors were:

- time to be away from the child to be with their partner
- the ability to communicate openly
- sharing the care of the child between the parents

The views of over 2,000 parents with disabled children were collected through a postal survey, a web-based survey, a conference and a workshop during 2003.

The in-depth report gives detailed conclusions and recommendations, suggesting a number of practical steps which could be taken now by central and local government, other service providers and the voluntary sector. The areas pinpointed for targeted action include:

- the provision of better services
- supporting parents in work
- tackling family poverty
- addressing housing problems
- addressing the emotional needs of parents and wider family

The executive summary can be found at Web: <http://www.cafamily.org.uk/relationships.html> or call the Helpline for a copy. For the full report send a cheque for £5 payable to Contact a Family, to Debbie Bunyan at our UK office.



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## Mobility

If you want to avoid paying the toll on the new stretch of the M6 you can apply for a pass from Mobility Exemption Pass, Midland Expressway Ltd. Freepost NAT 9069 Lichfield WS14 0BR or phone 0870 850 6262

You can also apply if you are in receipt of Higher Mobility Allowance or DLA 404 form. Further information regarding this DLA form can be obtained from the same address.

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## National Deafblind Friendly Award

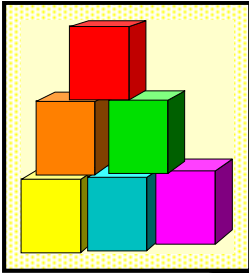
Deafblind charities, Sense and Deafblind UK, are inviting businesses and services to nominate themselves to receive a National Deafblind Friendly Award. All businesses and services commended through this award scheme will be entitled to display the Deafblind friendly symbol in their outlets to show that they positively welcome Deafblind customers

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## The Database and Information service

is holding an information evening on 28th April 2004 6pm until 8pm at Halford House Leicestershire where Connexions are based.

This will focus on Transition for Young People with Disabilities. For more details contact Bhanu on 0116 223225



# Service Coordination Scheme

## *Children with Complex Needs*

Leicester - Leicestershire - Rutland

C/o Specialist Community Child Health Services, Bridge Park Plaza, Bridge Park Road Thurmaston, Leicester, LE4 8PQ  
Tel. & Fax. 0116 2232 427 E-mail: [Service.Coordination@lcpwct.nhs.uk](mailto:Service.Coordination@lcpwct.nhs.uk)

### First things first

The service coordination scheme started in 1999, and since then over 120 families have decided to take part. It began as a small pilot in Leicester City East, Rutland and the Coalville area, initially catering only for the under 8 age group. Now the scheme has expanded the age group to 0 – 19, and the areas now cover the whole of Leicester, Leicestershire and Rutland.

### Who is the scheme for?

The criteria remain the same, that is families with children, who have a significant health related condition, which means that they need specialist services from more than one agency.

### What is the scheme all about?

The scheme is about helping the children and their families by ensuring everyone involved, whether from statutory agencies or voluntary sector organisations, is working together. We find that this also helps the professionals in their role and we try to encourage a spirit of teamwork and mutual support.

### Who runs the scheme?

The scheme does not represent any one agency. We are funded by The Health and Local Authorities in Leicester, Leicestershire and Rutland and are managed and monitored by a multi-agency steering group, comprising of parents, health, education, social and voluntary services.

The Service Coordination Scheme is a member of an umbrella organisation, Care Co-ordination Network UK ([www.york.ac.uk/inst/spru/ccnuk](http://www.york.ac.uk/inst/spru/ccnuk)), which was created in 2001 to increase interest in care coordination on a UK-wide basis

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### What does the scheme aim to achieve?

1. Ensure that professional roles are clearly defined for parents and professionals
2. Reduce the number of times parents have to 'tell their tale' to different professionals
3. Increase the level of information supplied to parents and increase family participation in decisions that are made about their child's care provision
4. Appoint a named person as the first point of contact for parents and professionals
5. Reduce duplication and gaps in service provision

### How do we try to achieve this?

1. The parents consent to all professionals sharing relevant information by signing a registration form
2. Regular family service planning meetings enable the family and the professionals to have a united view of the child's and family's situation and to create a shared service plan
3. A service coordinator, which can be anyone involved with the child, including the family themselves, coordinates the care of the child and supports and advises the family
4. The family hold multi-agency records and service plans

## What do other people think of the scheme?

In 2001, De Montfort University completed an 18-month long study, which found that all of the scheme aims were being met. 67% of parents were very satisfied, 22% satisfied, and 11% not satisfied.

The steering group members are currently participating in a comprehensive study, carried out by the Social Policy Research Unit at the University of York. The study will compare 'costs and outcomes' between a number of very different coordination schemes in the UK.

In the past few years, our scheme has attained national recognition, and is mentioned as an example of good practice in the National Service Framework for Disabled Children ([www.doh.gov.uk/nsf](http://www.doh.gov.uk/nsf)) and also in several local Social Services Inspectorate reports.

In September 2003, the scheme was highlighted as an example of good practice in a handbook for managers and staff working with disabled children and their families, which was produced as part of a major report by the Audit Commission ([www.audit-commission.gov.uk](http://www.audit-commission.gov.uk)). In addition it has achieved publicity in the Journal of Interprofessional Care, Community Care, Nursing Times Research and Disability Now. A couple of years ago, a local parent recommended it to a 'Valued Support Services' database, held by the Social Policy Research Unit at the University of York.

A parent from the steering group was commissioned to compile a unified service directory 'SIGNPOST' for disabled children. It is great that 'SIGNPOST' can now be accessed through [www.infoxchange.org.uk](http://www.infoxchange.org.uk)

## Who can contact the scheme and how?

Anyone can contact us using the phone number and e-mail address above. If you would like any further detail about the scheme or any of the information provided above, members of the Service Coordination Scheme, Sunny Ahmed, Paul Harrison or Anette Beattie will be very pleased to hear from you.

## Growing up, Sex and the Disabled Teenager.

Contact a Family, the national charity for families with disabled children, has joined with the Arthrogryposis Group to produce a free information pack on growing up, sex and the disabled teenager.

Entitled "Growing up, Sexuality and the Young Disabled Person" this comprehensive pack contains a series of publications offering a wealth of information and advice for the teenager, the parent, the teacher and other professionals involved in the development of teenagers.

Appropriately worded for its intended audience, this user-friendly, cartoon illustrated pack comprises a folder with separate booklets. Areas covered include self esteem, making and keeping friends, personal relationships, body image, puberty, sex education and sexual relationships.

In the booklet aimed specifically at young people, young disabled teenagers pass on their tips about dealing with some of the toughest parts of growing up. Also included in the pack is a useful list of organisations and further resources.

A free pack can be obtained from Contact a Family 0808 808 3555 or e-mail on [cafamily.org.uk](mailto:cafamily.org.uk)

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## Leicester Charity Link

Do you need help with transport costs for children's activities?

- ◆ Cubs scouts guides youth clubs or local church groups
- ◆ Leisure trips
- ◆ After school activities
- ◆ School residential trips

Ring Alison for more details

0116 2222212

## Database Launch

28<sup>th</sup> June 2004 9-30am – 12-30pm. Leicester Tigers Bar at Leicester Tigers ground

Come along to find out what's going on with the database and information service and have your chance to speak with professionals.

Open to Parents & Carers. This event is by invitation only, look out for yours as numbers are limited to the first 50 parents/carers. For booking your place telephone Bhanu on 0116 2232295

## Do Children Need Statements?

The money previously held centrally by Local Educational Authorities to fund the provision for children with Special Educational Needs is now largely delegated to schools by a formula based on social deprivation and attainment of pupils.

The LEAs hope that having the money in schools' budgets will reduce the need to issue statements. Unfortunately, there is no way of ensuring that the children with special needs will fit neatly into the catchment areas of schools with most funding.

Previously, schools had a financial interest in supporting parents in applying for statements; they knew they would be given extra money to meet the child's needs. Now they know that they will have to meet the identified needs out of their existing budgets, they are much less likely to alert parents to their rights.

Parents need to know that their rights under SEN law have not changed.

Parents still have the right to apply for a statutory assessment of their child's needs if they feel the child has significant difficulties which are not being catered for by the school. Without a statement, a child with special educational needs is at the mercy of the goodwill, expertise and resources of the school, which are variable. The Statement is the child's legally enforceable guarantee of a whole range of support: specialist teaching, LSA support, speech therapy, occupational therapy, behaviour management support etc.

The PCC can offer advice and support to parents going through the statementing process. Make sure your children get the education they deserve.

Lindy Hardcastle ( Leicestershire Autistic Society)

## Loughborough ASD Group

We meet on the 4th Monday of the month at John Storer House in Loughborough. For further details, phone Paul or Sue on 01509 550451. An advance notice for all those families who are connected with the Loughborough group: we are holding summer BBQ. Children will be more than welcome too! June 28th at 6pm at Paul & Sue's home. Phone for details.

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## Syston Community Centre Meeting, Support and Information Group

### Dates and Children's Activities

April 28 <sup>th</sup>	Free Play
May 12 <sup>th</sup>	Spring
May 26 <sup>th</sup>	Animal Activities
June 9 <sup>th</sup>	Fathers' Day
June 23 <sup>rd</sup>	Bubbles
July 28 <sup>th</sup>	Cake Decorating
August 11 <sup>th</sup>	Circus Day
September 8 <sup>th</sup>	Transport
September 29 <sup>th</sup>	Autumn
October 13 <sup>th</sup>	Free Play
October 27 <sup>th</sup>	Halloween
November 10 <sup>th</sup>	Bonfire Night
November 24 <sup>th</sup>	Snowy Days
December 8 <sup>th</sup>	Christmas Party

See back page for more information



## Medical Students

All medical students have to interview parents on the statementing process as part of their medical training.

The PCC are asked to find parents who are willing to take part in assisting students. As an incentive we at the PCC offer High Street vouchers for their time. If anyone is able to give an hour of their time, contact Sue Harrison, telephone 07968 857598

# TOCK INCLUSIVE PLAYGROUND PROJECT UPDATE

Many of you will already know about this project, but for those of you new to the Newsletter I will outline what the project is about and then bring you up to date with what I have been doing in the last 12 months.

The TOCK project was set up in 2001 by myself and Nicky Ashby, following our concerns about the lack of Inclusive outdoor parks in the UK. In the main this was triggered by 2 events, a trip by Nicky to the USA, where she saw just how different some of their parks were and my realisation that parks were not for families who have a child in a wheelchair.

We set about trying to change all of that by setting up the project. The name of the project may seem quite strange to some of you, but it is really an amalgamation of the names of our respective sons with special needs, Toby and Jack.

The aims of the project were first and foremost to build an Inclusive park in Leicester for all of our children to benefit from and use that as a 'flagship' to inspire other Local Authorities to replicate and thereby build a National Network of TOCK sites. After many false starts we approached Leicester City Council and have over the past 2 years been working on a scheme to build a 3 ½ acre Inclusive park in the city. Approval of the full Cabinet of the Council has been achieved and we have spent a considerable amount of time over the past 2 years working on new equipment designs with manufacturers and preparing the draft design.

Once planning permission is granted in 2004, we can then launch the draft design to the public for consultation, prior to finalising the design and preparing to build. Much liaison has also been going on with the major National Children's Charities in the background; as if we have to fundraise we will need their backing too. The concept is supported 100% by Contact a Family, Scope, Mencap and the Council for Disabled Children.

Alongside the local project, I have been working on the National strategy for TOCK, which has meant lots of speaking at conferences and many meetings up and down the Country with Local Authorities who wish to be involved too. This culminated in being invited last March to become an 'Expert Advisor' to the Children's Play Review, chaired by Frank Dobson MP. This review is part of the process prior to release of £200million of National Lottery Funding for Children's play. We hope that the impact we have achieved so far will stand us in good stead when we put in our application for the Leicester site, as we need approx. £400,000 if we are to achieve all our aims.

In tandem with the Children's Play Review has been another Government lead initiative to produce a guide for Local Authorities on 'Developing Accessible Play Space'. Again, I was invited to have input into that document. Whilst it does not go anywhere near far enough for a 'seasoned expert' like me, it does provide a valuable starting point for anyone to begin an evaluation on; and, as it was pointed out to me the other day, I am the only individual mentioned specifically in the guide!

Following on from the work done for the guide, I have been pestered, badgered and bullied by various others (and no one from the PCC for a change!) into setting up in business as a Consultant to advise on how existing playgrounds can be made more inclusive and to advise on area strategies for Local Authorities to follow. I have so far received one commission from a large Metropolitan Authority and am currently tendering for a second.

So the question is just how life changing and rewarding can having a disabled child be? For me the change has been dramatic, from Banker to Inclusive Play Consultant is not a logical step, but a very rewarding one and one that I could not have made without a little help from Toby.

If you would like to know any more about the project then please feel free to contact me:-

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**Parent & Carers' Council**  
**Meeting, Support**  
**&**  
**Information Group**



**Come Along and Relax**

The PCC is a well-established and very active group of parents and carers of disabled or special needs children. Our membership extends throughout Leicestershire.

It's held on 2nd and 4th Wednesday of every month from 10am –12.30pm

We meet at  
Syston Community Centre,  
School Street, Syston, Leicester.

Whilst the group is primarily for carers (parents, grand parents, childminders etc.) of any aged child with a special need or disability, you are welcome to bring along any child in your care on that day. We are investing in some great new toy and play equipment to keep them amused.

We will also be offering juice, biscuits, crisps or fruit for the children as well as tea, coffee and biscuits for the carers

Ample car parking space with ramp accesses to and from our room.  
We have an experienced play therapist on hand to supervise the children  
There is also a large side room for anyone wanting a more quiet chat or meeting.  
Kitchen facilities are available with a serving hatch for refreshments.  
Full and separate toilet facilities also on site, including a disabled toilet.  
Cost will be just £1 per family to cover food and refreshments.

There will always be skilled volunteers on hand to help with any children, so you should be able to relax, meet other carers, chat to representatives of the Parent & Carers' Council and get the opportunity to learn and share the latest information about issues affecting all our families; Benefits, Carers grants, DLA, Statements, Health issues, leisure facilities etc.

We are able to offer free transport for families with particular difficulties and therefore enable parent/carers to attend who are particularly isolated or who themselves have special needs.

For further information or directions, or to volunteer your time to help, call the Parents & Carers' Council on 07968 857598 or email us at ParentsC@aol.com Or just drop in!

Come and join us on the 2nd or 4th Wednesday each month

We will also have regular speakers and representatives from agencies and other support organisations to talk to our group as well as one-to-one with carers about individual issues.