

# Great News for the PCC!!

The past few weeks have been really exciting for the Parent & Carers' Council. We now have our workers in post one in the City and one in the County. Jane Hall is now the Family Support Worker within the County and she will support Sue Harrison, who is City based as our Project Development Manager. Sue works 3 days in the City and will join Jane for one day in the County working on an exciting project for which the PCC has been commissioned.

Jane and Sue are both based at home with an office base at Fosse Neighbourhood Centre, Mantle Road, Leicester. You can contact them on their mobiles or leave a message and your call will be returned within 2 working days. The answer phones are always on outside normal working hours and during the day when they are in meetings or visiting parents. If you leave a message at weekends, your call will be returned the next working day.

**Sue Harrison: 07968 857598**  
**Jane Hall: 07870 688973**

Kathy Pearson, our Chair, and Sue Harrison have been working at a national level as other counties and local authorities are interested in our model of working. Kathy has been to various parts of the country with Contact a Family and we are in the process of developing an affiliation pack for other Parent & Carers' Councils nationally.

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## Early Support Pilot Programme (ESPP)

ESPP is a UK government funded programme to support the development of effective well co-ordinated, multi-agency support services for disabled children and their families. The programme is aimed at 0-3 years of age.

The aim of the ESPP is to explore how education services, working in partnership with other agen-

cies, can translate some of the principles set out in the guidance into effective practice and how best to promote partnership between parents and professionals in planning the delivery of these services. (Baroness Catherine Ashton)

The programme will learn from and build on existing good practice, allow participants a networking opportunity to exchange details of good practice, and support the improvements of services where they are not well developed. The aim is to work with service providers and service users:

- To improve the quality and consistency of services available at local level
- To develop robust quality assurance mechanisms
- To ensure that families get the right support at the right time


Leicestershire County Council and Leicester City Council are national pathfinders for the ESPP and a partnership (of Education, Health Social Services /Social Care & Health, voluntary organisations and



# Parent & Carers' Council

## Newsletter

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parents) is taking work forward on the key aims of the project.

For more information visit [www.espp.org.uk/pilot2/index.html](http://www.espp.org.uk/pilot2/index.html)

The Parent and Carers' Council have been invited to lead the audit part of this project and we will be auditing all the services to evaluate the quality of these service provision for disabled children under three and their families.

We are really excited that Nirmala Mistry has accepted the role of Lead Consultant and we have commissioned her to undertake this on behalf of the PCC. Her work will be supported by both Sue Harrison & Jane Hall and we are looking for families who have children with special needs/disabilities up to the age of seven to hear of your experiences during those early years of your child's life.

We will be arranging focus groups and consultations shortly, so if you as a parent/carer would like to take part in this project, Nirmala will be very pleased to hear from you. You can contact her directly on 07946546472. This is a really exciting project and will give parents/carers a chance to tell us what they have found helpful as well as unhelpful, what they want that they don't get and so on. This is a real opportunity to help shape services for our children and their families in those early years.

### Meeting Support & Information Group dates

**September 8th**  
**Sept 29th**  
**Oct 13**  
**October 27th**  
**November 10th**  
**November 24th**  
**December 8th**

**Activities are provided for the children on all the dates. See separate flier for details.**

**Disclaimer** The views expressed in this newsletter are those of the contributors and do not represent the views of the PCC.



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## What a Week!

Carers Week always falls on the second week of June, and this year was no exception. This week celebrates and highlights the work done by families and friends for no pay in looking after a loved one, a friend or neighbour. It's always a busy week for organisations supporting carers because there are events all over the City, County and Rutland, all aimed at attracting, informing and offering a break for carers. This year was no different.

In all, over 20 events took place, starting with a Multicultural Family Fun Day at Age Concern, Evington. A mixture of entertainment and alternative therapies was offered – and, of course, lunch! Around 150 attended this event, and it is a shame that more people from the white community didn't come. Some of the other highlights were:

On the Monday evening, an art exhibition was opened by the Lord Mayor of Leicester, Cllr. Piara Singh Clair, but I have no doubt that this is reported on elsewhere in the newsletter! I would be surprised if fewer than 200 visited the exhibition over the whole week it was on.

Nottingham Oddfellows Working Mens Club laid on an evening of entertainment in support of CLASP on Thursday 17th. Some 120 people came, of all ages from about four to eighty-five(!) to see five top local club acts give their all for no fee. £734.50 was raised for CLASP on the night, which ended just after midnight. I know it was after midnight because my head felt like a pumpkin all the next day!

The rest of the events were dotted all over the City, County and Rutland, and by and large concentrated on the theme of Carers' Health. Activities included the use of gym equipment and swimming pools, gentle aerobics, dance, alternative therapies (always popular) and the rather less healthy cream teas and pub lunches or other meals out that are always popular. Of course, these events are relaxing and offer a real break from caring – so they're healthy for carers in that way. That's my excuse, anyway!

These events help to highlight carers' needs, but cannot hope to reach every carer. In all, no more than 600 carers will have taken part in all of the events, and we can always stand to meet more. The good news is that, every year, carers' workers come across some new faces and are able to offer more long-term support to those who want it.

Charles Huddleston  
CLASP Development and Support Worker

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## Summer Play schemes 2004

The Parent & Carers Council would like to hear from any parent whose child either

- Did not get on a play scheme this summer
- Lost their place on a play scheme
- Had a successful experience

We have had a number of phone calls from some of our parents who were naturally quite distressed and upset and we will be taking this matter forward as a cause for concern. If this was your experience then please phone Julie Marriott on 0773 6874923

However, if you had a successful summer and your play scheme worked for you and your child then tell us about it so we can spread the word. We want to hear of good experiences too. Again ring Julie on the above number.

### Free Advice

Thanks to funding by the Legal Services Commission, The Children's Legal Centre is now offering parents and guardians 30 minutes free advice over the phone. The number is 0845 345 4345. Monday to Friday 9am-5pm.

Topics that the centre expects to cover include SEN, school exclusions, transport and "local education authorities" failure to find suitable education. It could just give a bit of extra help.

## Flexible working

Contact a family received funding from the Department of Trade and Industry to research the knowledge and use of flexible employment rights amongst parents of disabled children. The new legislation, which was introduced a year ago, gives parents a right, subject to certain conditions, to ask their employer to allow them to work flexibly. Their employer does not have to agree, but he/she must consider the request seriously.

The views of 930 parents with disabled children were collected through a postal survey and web-based survey plus a workshop in Wales.

The Executive Summary is available from the web: <http://www.cafamily.org.uk/flexiblesurvey.html>  
The full report can be downloaded or a paper copy costs £5 Tel 020 760 88700.

Only around half the parents surveyed were aware of their new rights and very few had actually used the new law. If you are a parent and would like to know more about your rights Contact a family provide a free factsheet "Working and caring for a disabled child" which is available on the Web <http://www.cafamily.org.uk/employment.html>.

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## Support Pack for Health Professionals

Sharing difficult news with parents about their child is a challenging task requiring skill and sensitivity. This support pack aims to provide health professionals with practical suggestions on how best to communicate information and offer appropriate support to parents at significant times from pregnancy to pre-school. The support pack has ten inserts on topics covering :

- Prenatal diagnosis
- Options following a prenatal diagnosis
- Death in utero
- Information sharing in neonatal units
- Care and support at home
- Referral to a genetics clinic
- Support for fathers, siblings and grandparents

At the end of each insert there is a list of "Useful

Organisations and resources. The support pack is intended for ultrasonographers, obstetricians, midwives, neonatal nurses paediatricians, health visitors and counsellors. The support pack has been funded by the Department of Health and produced by Contact a family. Call Contact a family's helpline on 0808 808 3555.

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## Education Maintenance Allowance

16 year olds who are staying on at school in the United Kingdom may be entitled to extra financial help from September.

From September 2004 those who are 16 between 1st September 2003 and 31st August 2004 (i.e who become 17 this coming academic year) and whose household income is less than £30,000 may claim between £10 and £30 a week. This is called the Education Maintenance Allowance and about half of all 16 year olds who are studying are expected to be eligible.

Disabled students are equally entitled to apply and claims can be made now. A claim will not affect any other benefits a family receives. For more details log onto <http://www.dfes.gov.uk> or phone your local Connexions for details on how to apply.

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## All Together Better

This is a guide which has been produced for families who have a child with complex health care needs.

"All Together Better" aims to help families get the best possible support for all aspects of family life. It also aims to make sure that at review and assessment meetings families get professionals to consider the needs of the whole family not just the medical needs of the disabled child. The booklet covers issues including accessible living social and emotional well being and standing up for the rights of a disabled child.

Copies can be obtained from the Family Fund by sending a SAE to Family Fund PO Box 50 York YO1 ZX

[http://www.bris.ac.uk/Depts/NorahFry/adobe\\_files/all\\_together\\_better.pdf](http://www.bris.ac.uk/Depts/NorahFry/adobe_files/all_together_better.pdf)

## Supporting Siblings

"Sibs" is for people who grow up with a brother or sister with special needs, disability or chronic illness. Certain issues are particularly relevant for siblings at different stages in their lives. These will vary from one child to another and will be affected by each family's own circumstances.

They have produced a really useful fact sheet for parents addressing some issues which some siblings find it difficult to deal with.

### Pre school children 0-5

- Less time attention and from parents
- Imitating an older child
- Feeling jealous of the child with additional needs
- Anxiety through not understanding a brother's or sister's condition
- Frequent absence of parent and child with additional needs due to hospital stays or visits.

### School age children 5-12

- Talking to friends and others about their brother or sister
- Dealing with teasing and embarrassment
- Being involved in caring for the child with additional needs
- Not having enough time together as a family
- Wanting their brother or sister to have his or her own friends

### Adolescents

- Dealing with embarrassment
- Concern about being like their brother or sister with additional needs
- Influence of disability on their future career
- Having space and opportunity to develop their own life
- Concern about their brother's or sister's future

Sibs produces an excellent information sheet with helpful tips on parenting the siblings of the disabled child and Sibs work with younger siblings, the parents and adult siblings as well as the professionals who work alongside siblings.

You can subscribe to a free weekly "parent tip" and there is support on 01904 550029

The web details are [www.sibs.org.uk](http://www.sibs.org.uk)

## How to avoid Meltdown with Autism

Anyone with a relative on the autistic spectrum will be familiar with the perils of health and social care consultations. These situations can cause complete "meltdown" for the affected child leaving the parent helpless. The problem with autism is that it tends to be an invisible disability. It covers a spectrum from the mute, withdrawn child with a severe learning disability to one with high functioning autism who may have an above average IQ but limitations in communication and social interaction and rigidity in thought.

Having autism is likened to finding yourself stranded in a foreign land with no knowledge of the language, culture, customs or traditions without a map or guide book. Alison Morton-Cooper has written a book "Health care and the Autistic Spectrum to raise awareness of autism among health & social care professionals. She explains how ASD has the potential to affect an individual's care and how consultations can be made autism-sensitive

Her aim is to emphasise that those on the spectrum require special understanding if they are to make the best use of health & social care provision. The book covers GP consultations and hospital care consent to treatment, medication, nursing care issues, social support and bereavement.

Key strategies for effective consultations include providing a safe environment paying close attention to sensory problems, maintaining a sense of structure and an appreciation of family situation and history.

Published by Jessica Kingsley Publishers  
Written by Alison Morton-Cooper ISBN 1853029637  
£13-95

## Leicestershire Autistic Society

The LAS produces a quarterly newsletter of particular interest to people of all ages with autistic spectrum disorders and their families.

To join our mailing list, or for help and advice, please call Lindy Hardcastle on 0116 2915958 or e-mail [lindy@flaxfield.demon.co.uk](mailto:lindy@flaxfield.demon.co.uk)

## Air Travel with a disabled child

I hope this is of some benefit to the families who receive your newsletter, if it saves one person £100 I will feel that my crusade has been worth it!!

I am a parent of a child with severe disabilities, and I am currently in the process of taking him on our first holiday abroad.

I wanted to write to let you all know firstly the problems that I have encountered with British Airways, and secondly the outcome at present. My child cannot sit up unaided, and after BA confirmed that they had seating available for my son, I booked my holiday. On further investigations I was then told by BA that I would have to hire a Skychair at the cost of £100.

After speaking to Dawson Engineering, who hire the chairs, I was made aware that Monarch, JMC and Virgin all supply these chairs free of charge (key learning- travel with these if they fly to where you want to go - unfortunately for me they don't fly to Nice). I was also told that the chair would be delivered to my house, and it was my responsibility, therefore would have to accompany me on holiday.

What with luggage, wheelchairs, car seats and now an airline seat I think you can imagine how I felt! After numerous conversations and letters to BA, they have now agreed to review their policy, and, whilst legally at present they are not responsible, I have pointed out that morally they should have these seats available. They have also agreed to reimburse all passengers for the hire of these chairs whilst the review is taking place.

Whilst it takes considerable time and energy, which believe me I know is in short supply when you have a child with complex needs, I just want to say to other parents who feel that they are banging their heads against a brick wall - DON'T GIVE UP!!!

**Nicola Golding**

## Information on holidays

Holiday Cars Ltd is a car rental company based in the UK arranging car rental for those visiting Florida. They are able to supply specially adapted minivans for wheelchair users and can also arrange for the hire of equipment such as hoists and IV stands. Visit: <http://www.floridacarhire.com/disabledcarhire/index.htm>

- Enable Holidays offers package holidays for disabled people. All the accommodation is personally audited and there is a wide range of resorts. Visit: <http://www.enableholidays.com>
- Grooms Holidays is a national charity that offer affordable and accessible holidays around the UK. They offer both hotel and self-catering accommodation. Visit: <http://www.groomsholidays.org.uk>
- The Family Fund produces an information sheet listing organisations and books that provide information on holidays and leisure activities for disabled people. Visit: <http://www.familyfund.org.uk>
- The Wheelyboat Trust offers opportunities for wheelchair users to take to the water mainly to go fishing, however in some areas for pleasure boating. They are available at a number of rivers, lakes and reservoirs around the UK. For more information visit: <http://www.wheelyboats.org>
- Access Travel is a holiday company specialising in accessible holidays abroad. Visit: <http://www.access-travel.co.uk>
- The Calvert Trust aims to provide the best possible facilities for disabled people to participate in adventurous outdoor activities in the countryside. They are located in Keswick and Keilder in the Lake District and Exmoor in Devon. For more information visit: <http://www.calvert-trust.org.uk>
- Holiday Care is the UK's central source of holiday and travel information for disabled people. Visit: <http://www.tourismforall.info/>



Menphys SOS offers support to families of disabled children and young people aged 0-19, through home visiting, outreach, advocacy, and access to information on resources, childcare, play, leisure and youth opportunities.

We aim to fulfill our mission by developing relationships, providing opportunities, and helping to break down the barriers of isolation and discrimination felt by so many.

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

### **Stop Press....**

The Menphys SOS access to play, leisure and sports scheme for 5 - 13 yr olds (County Children's Fund)



We are delighted to announce that we were successful in a bid to the Leicestershire County Council Children's Fund. This has enabled us to: -

- Recruit 2 further inclusion field workers, Claire Marsden and Nicola Hampton.
- Recruit another clerical assistant for the Melton office.
- Put aside a budget to enable children/young people with additional needs aged 5-13 to attend 'taster' activity sessions
- Start to recruit a team of 'Inclusion supporters' to attend the 'activities' when the child/young person is there to support the provision and child/young person.

Please call us if you are interested in finding out more about any of the above. We look forward to hearing from you.

Main Office Contact Details : Menphys SOS, 27 Upper Bond Street Hinckley Leicestershire LE10 1RH Tel. 01455 894880, E-mail [lyn.bloor@menphys.org](mailto:lyn.bloor@menphys.org) [www.menphys.org/sos](http://www.menphys.org/sos)

## **Social Policy and Research unit (SPRU) York**

Members of the Parent and Carers' Council are taking part in developing a tool for measuring outcomes for families who are affected by a child with an Autistic Spectrum Disorder. We are working together with representatives from Health, Social Services and Education to develop a tool that can be used across all agencies. We are focussing on "Parental Well-Being. This work is currently developing and ongoing and we hope to be able to feedback more on this work in our next newsletter.

## **All Join in**

A new video/DVD has been produced called "All Join In". The video is made with and for young children and looks at friendship, play and difference.

More information is available at:  
<http://www.triangle-services.co.uk/publications.htm>

## **Katie Willetts, Modern Matron for Specialist Community Child Health Services, Hosted by Leicester City West Primary Care Trust.**

I am a Registered Sick Children's Nurse; my first years as a children's nurse were spent in the Children's Hospital at the Leicester Royal Infirmary. I began working in the community in 1996 for the Children's Outreach Service that is now the Continuing Care Team within the Diana Service. I was appointed as Modern Matron in September 2003, this was a new post for SCCHS but one that has been adopted nationally following the NHS Plan 2000. The post has 10 key responsibilities which were driven by responses from the public, not all of these are relevant to my post as originally Modern Matron posts were established within hospitals.

Within Specialist Community Child Health Services I have developed objectives for the year that encompass:

### **User involvement**

I have lead responsibility for developing a user involvement strategy within SCCHS and sit on the User Forum; this group meets quarterly to :

- Establish a two-way dialogue with parents, carers, paediatricians and staff involved in the care of children.
- To disseminate information regarding developments in Specialist Community Child Health Services.
- To receive feedback from "the field" and to work collaboratively to suggest new ways of working or improving services.

I would welcome any feedback (e.g suggestions for improvements, areas providing good service etc) from parents / carers / children / young people to take to this group and can be contacted on: Tel 0116 225 5484 : E-mail [Katie.Willetts@lcwpct.nhs.uk](mailto:Katie.Willetts@lcwpct.nhs.uk)

### **Care delivery**

I have also developed an action plan for using the "Essence of Care" benchmarking tool that was developed following consultation with users by the NHS Modernisation Agency, its emphasis is on getting the basics right and includes topics such as Privacy and Dignity, Record Keeping and Pressure Ulcers.

SCCHS have identified Champions within each staff group to coordinate this activity and over the next year I will be ensuring that all staff know its existence and how to use it, SCCHS will then begin benchmarking activities in April 2005.

I also contribute to the working group that is conducting the Right From The Start project within SCCHS, this is looking at the views of parents and professionals about breaking news of a child's additional needs, some of you may receive questionnaires in the Autumn regarding this. As a result of the questionnaires SCCHS will provide training to staff to ensure this activity is always addressed sensitively and appropriately in the future.

### **Leadership**

This objective links very closely with the other two above and will address areas such as service reviews, development of policy and guidelines and ensuring that nursing practice is up to date and evidence based.

Thank you for taking the time to read this and I look forward to speaking to any of you who wish to contact me.

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## **Specialist Health Visitor Service**

The Specialist Health Visitors offer advice about your children's special needs and how this may affect the whole family. They can provide information on both local and national support and resources for families and children. Working with Family Health Visitors they are able to offer advice and support about the extra help needed in caring for a child with special needs.

To access a Specialist Health Visitor (SHV) their Help Line is manned by an SHV at Bridge Park Plaza from 12 noon until 2.00pm Monday to Friday.

The telephone number is 0116 225 6560

Families who are not currently receiving input and need additional advice and support will get an immediate response by using the Helpline.

# Specialist Community Child Health Services (SCCHS) - Audits

Audit is 'the systematic and critical analysis of the quality of clinical care' (DoH 1993) Within SCCHS audits form part of the examination and improvement processes known as Clinical Governance. Clinical Governance ensures that the right person does the right thing in the right way at the right time. It includes elements such as making sure that clinicians' practice is up to date and based on the latest research evidence; ensuring that clinical records are properly maintained; that the lessons learned from complaints and incidents are shared and acted upon and that services take their users' views into account.

SCCHS would like to make parents/carers aware of the range of audits we have undertaken and of our continued efforts to improve services. Below is a list of audits recently completed and those planned for later on this year.

Audits completed include: - ADHD Baseline Audit, Botox-A Team Communication, Equipment provision for children with life threatening illness, Inhaler devices in asthma (5-15 years children), User Experience Survey, Medical Staff Attendance at Multidisciplinary Meetings, Referral Review – Diana Children's Community Service, School Entrant Health Interview, Telephone follow-up clinics, Time required to complete assessment of special educational needs.

Audits planned include: - Audiology partnership, Children's Respite Care – response time to new referrals, Consultant Clinical Supervision, Investigations offered to children under 5 with identified learning difficulties, Multidisciplinary working and Response times to referrals by the Speech and Language Dysphagia Link Therapist in children with eating and drinking difficulties, On call provision within Continuing Care Team, Outpatient clinics – patient experience, Quality of service provided and received by parents when news of their child's additional needs is shared with them, Review of referrals made into the National Autistic Society EarlyBird Programme (Leicester County), Review of Specialist Health Visitor helpline

The findings and action plans from SCCHS audits are shared in a variety of ways including twice yearly events The next sharing event is on Friday 19th November 2004

If you would like to know more about any of these audits or if you would like to come to the sharing event in November please contact Mandie Bland (Clinical Governance Manager) on 0116- 2236534.

## Patient and Public Involvement in Health

As a government agenda each NHS organisation has an obligation to involve and consult with patients and the public when planning or changing their services. There are many ways of involving the patient and the public.

At the University Hospital Leicester (UHL) Patient Advisors have been appointed to each clinical directorate. There are 12 such advisors. We are all from different walks of life, who give a public's point of view on any issue that need, an input. However, this is solely a voluntary role.

I have been involved with UHL as a patient advisor since 2002. I have been asked to sit on infection control, clinical benchmarking, information forum meetings to name but a few. I have also been asked to sit on an interview panel as a member of the public. Currently, I work with the Women and Peri-natal directorate. The work with UHL can be very interesting and the professional are listening and taking on board the comments Patient Advisors make.

Another service all NHS hospitals have is a Patient Advice and Liaison Service (PALS). UHL has a PALS service at each of its 3 hospitals. They provide on the spot information, support and advice to patients, carers and their families. PALS offers a confidential listening service and try to resolve any concerns on the spot. They also encourage hospital users to give suggestions and participate in group forums. This information is then passed on to department and directorate levels.

So if people are looking to having an influence in how your local hospital delivers patient care then why not get involved in patient support groups or forums. If interested contact the PALS office at any of the UHL hospitals.

**Nirmala Mistry**

## Access & Inclusion Officer

As Access & Inclusion Officer for the Parent & Carer Council I try to take a very broad look at all the areas we cover. Access & Inclusion is not just about physical access for the disabled, or inclusive schooling, it is making sure that we all have access to opportunities and are included in planning for those services.

I tend to lean towards leisure access, mainly through my passion for outdoor play areas, wearing my other hat, as the TOCK Inclusive Playground Project. I do also sit with Phil Pearson on the Leicester, Leicestershire & Rutland Disability Sports Forum, representing the PCC and its members.

I would encourage anyone who experiences problems re access & inclusion to let me know about them. If however your query is better dealt with by another member of the PCC (because they have greater experience in that area) then I will pass your details on to the relevant person.

I am currently also looking at training opportunities, both for the PCC Management Committee, paid staff and parents too. Access to good quality training is something I would like us all to have, to aid our roles as Parents/Carers and as volunteers/workers.

I have recently attended as a guest speaker the SCOPE 'Play Talks' conference in Northampton, which launched Scope's new information pack on communication and play. This was a very informative day, which covered how children communicate, communication passports, play and communication and the TOCK project too. If you wish to know more about their communication pack, then you can log on to the website [www.scope.org.uk](http://www.scope.org.uk) and access information via the Early Years section.

Taking off my Access & Inclusion Officer hat and as a Parent Representative I do also work on a few Committees in the Health field too.

I took over last year from Kathy Pearson representation on the User Forum at Specialist Community Child Health Services (SCCHS). I now Chair the User forum, which meets approx. termly and discusses issues around all of the Therapy Services and anything else to do with Community Paediatrics where there are either new developments, or issues that

need to be resolved. Currently we are looking at Triage clinics and the Single Point of Access service, which are both fairly new and feedback so far is good on both from both the clinicians and users viewpoints. Sue Harrison also sits on the User Forum to represent the PCC members' views too.

If anyone has unresolved problems with SCCHS then I would like to know about them, as we may be able to resolve them through the Forum, or indeed they may relate to an area which is already under review.

As the Chair of the User Forum I am also representing parents on the Right from the Start initiative which SCCHS were chosen as one of the pilot areas for. Please see the separate article on this initiative.

If you need to contact me you can use any of the following methods:-

- Telephone me at home on 01530 245468, or my mobile 07736 874923.
- Email me at [Julie.Marriott@care4free.net](mailto:Julie.Marriott@care4free.net)
- Or snail mail letters to Wisteria Cottage, Ratby Lane, Markfield, Leicester. LE67 9RJ

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## Take A Break

Have you applied for yours yet? Please apply quickly as funding is limited.

Parents/Carers of children 0-19 and living in Leicestershire can apply for a grant of either £100 or £150 dependant on the level of Disability Living Allowance you are in receipt of.

To qualify you must not be receiving any other service from Social Services such as Respite or HomeCare or if Social Services are contributing towards nursery fees for the disabled child to then you don't qualify.

The Take a Break Grant is for Parents/Carers who are not using Social Services at all.

To apply you can e-mail your details to [parentsc@aol.com](mailto:parentsc@aol.com) or phone 07968 857598 for more details.

## Review of training Course: Verbal Reasoning & Thinking in Children - Karen Ferguson

I attended a training course on behalf of the Parent & Carers' Council and promised to produce a short write up, so here goes.

The Course was presented by Terry Gilligan , Independent Speech and Language Therapist. The course was held in a school in Oadby, though Terry is seeking a new venue for future courses.

The course was in the evening and was well attended, 80 or so people sat in groups around tables ready to have a whistle top tour of 40 games. There was a mixture of parents and professionals most people had some connection with special needs.

The topic was 'Verbal Reasoning'. Terry explained that prisons are full of people who cannot express themselves and struggle with communication. He went on to explain that we can help our children to develop better communication through playing simple games. We tested a variety of games which challenged our verbal reasoning.

Since attending the course I have practiced one of the games where you have to name as many words as possible on a topic beginning with a certain letter for one minute. For example, name as many girls names as you can beginning with the letter A, April, Anna, Abigail etc, etc . The first time I tried could do about 20 after a couple of games I am reaching 40. Amazing how a little practice can help with word finding difficulties, I will try and adapt some of these ideas and try them with my children.

Terry also gave us some games using pictures and mime. I think the course was useful, I learnt some new games and remembered some old ones.

Terry talked about teaching your child 'think it, say it' as a strategy in the playground. He said often children run away because they cannot explain themselves, a problem that I have personal experience of. Terry talked about exercises of playground scenarios where you ask a child 'what should you do'. Not quite sure how the exercises will work with children on the Autistic Spectrum.

He also mentioned teaching 'stop, think, act' which be may be a useful tool in the playground for social problem solving.

I enjoyed the evening and came away with information pack and list of resources, though many of the games did not require materials. Terry has said that he will return to Leicester in a couple of years or before if a large group wishes to book him. He also runs courses on ADHD, ASD and other topics. His web site is [www.talkingmatters.org](http://www.talkingmatters.org)

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## Orthoscotics

Orthoscotics is a new way of looking at visual (and other secondary sensory) perceptual responses to stimulus. It developed from the realisation that corrupt visual input causes a number of effects varying from the merely inconvenient through to those which are life altering.

These include headaches and migraine, visual field problems, balance and postural difficulties, touch sensitivity (or lack of), hearing sensitivity and filtering problems, short term sequential memory access, eye muscle anomalies, dyslexia, and dyspraxia.

The system has already won a number of awards, was partially government funded and will eventually be available nationally. It often produces results in unexpected ways and is of immediate effect: either it works instantly or it is not proceeded with.

Unfortunately, it is not available through the NHS at present but your consultant may be able to refer. For unusual cases it is probably better to attend the Cambridge clinic. Private costs at the Cambridge clinic are £50 if not successful with a maximum cost of about £400 (except in very unusual circumstances).

Tel: 01223 843200 (you will be asked to leave your name and number and will usually be phoned back within a week or so).

For further information visit the website: [www.orthoscotics.com](http://www.orthoscotics.com).

## Disability Living Allowance Success Stories

Hi, I'm Sally, my son Simon is 8 years old and has cerebral palsy. He was assessed at 5 years old to need the middle rate of DLA. During a cup of tea and very nice biscuit at the Parent and Carers' Council drop in, I said in passing that I thought Simon should be on the Higher Rate. Yes, I knew it would be more money but I could feel myself getting stressed just at the thought of applying.

I was encouraged by Mums at the P & CC and told to bring the forms along. I phoned the DLA service for the forms and took them into the P & CC partly filled in. I was told I had been sent the wrong forms. I phoned the DLA service and they sent me the correct forms. I photocopied a blank of them, and drafted my answers (whilst feeling the need to eat a lot of sweets!).

It took me ages to fill in and made me miserable! I took it to the P & CC to be read. It appears that all the information was there, but not on enough pages and very, very vague. When you have to write all the negative things down about your own child it is so hard to do.

This was May last year, the summer holidays then arrived - no time for form filling. September arrived, ok, just got to write out the original answers with the alterations included (more sweets!). I then sent the forms to the DLA service with a note stating that I had originally applied for the forms in May and had been sent the wrong form out by them, this had then meant that I did not have time to complete them over the Summer as I was doing all the things detailed in my form every day as well as every night! They accepted my application as being from May instead of September and I got the higher rate.

Self analysis - I am ok with my child's long list of professionals, good at dealing with my child's special needs, and a good mum. BUT I am absolutely rubbish at analysing every single thing I help my child with and how many times a day / night I do them!! Well, who wouldn't be!!

If you think this description fits you as well, don't despair, help is at hand - go to or phone the P & C.C. and just ask!

## And another success.....

Mandy applied for Disability Living Allowance for her daughter Katie who suffers with narcolepsy. Mandy attends our fortnightly support meetings and she had been turned down twice for DLA. We were able to help her add more information when her claim was turned down after the second attempt. We helped her gather her evidence and Rachel (our brilliant benefits advisor!) visited Mandy and wrote a letter on our behalf explaining just how the disability affected Katie. Within a few weeks Mandy was granted DLA for Katie and awarded over £2000 back dated benefit.

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## Brilliant website!!!!!!!!!!!!!!

Here is a website which is highly recommended. There are some brilliant books focussing in various issues such as disability, interventions, art therapies, fostering, bereavement, health & social care, parenting and education

### About Jessica Kingsley Publishers [www.jkp.com](http://www.jkp.com)

Jessica Kingsley Publishers is a wholly independent company, committed to publishing books that make a difference.

The company was founded in 1987 by Jessica Kingsley and has grown since then to the point where we now publish over 100 books a year, which are available throughout the world. In 2004 we opened our US office, in Philadelphia.

We publish books for professional and general readers in a range of subjects. We are well known for our long established lists on the autism spectrum, on social work, and on the arts therapies. More recently we have published extensively in the fields of mental health, counselling, palliative care, and practical theology. [www.jkp.com](http://www.jkp.com)

For parents who haven't got access to the web here are the contact details and they will send out their catalogue of publications if you request one :  
Jessica Kingsley Publishers, 116 Pentonville Road  
London N1 9JB Tel: +44 (0)20 7833 2307  
Fax: +44 (0)20 7837 2917  
Email: [post@jkp.com](mailto:post@jkp.com)

## Right From The Start

Way back in 1994 SCOPE first published a report called 'Right from the Start', which highlighted the experiences of parents at the time that they were given a diagnosis for their child of a disability, or special need. The report highlighted both good and bad practice in delivering diagnosis news to families and carers and encouraged partnership working with parents/carers.

Following on from the report a working group was established by SCOPE to take the work forward. The working group are involved with both the statutory and voluntary agencies, paediatricians and parents to achieve increased levels of 'best practice' across the UK.

Specialist Child Community Health Services (SCCHS) for Leicester, Leicestershire & Rutland are now one of the pilot areas for taking the project forward and as Chair of the User Forum I am sitting on the group tasked with implementing the strategy. It means that I can give input both as a representative of the PCC and as a parent who has direct input with the services provided by SCCHS on a regular basis.

The services parents receive from SCCHS include community paediatricians, physiotherapy, occupational therapy, speech therapy and the Diana service as well as things like specialist health visitors etc.

As a starting point, we need to look at the way in which diagnosis information is given and the experiences around that meeting, from both the point of view of the health staff involved and the parents/carers receiving that news.

A questionnaire has been devised and sent out to all relevant health professionals about their experiences and training needs recently and information from those questionnaires is currently being assessed.

More importantly, after the Summer Holidays, some of you may receive a letter advising you about the project, followed by a questionnaire asking you about your experiences, good and bad, relating to diagnosis given about your child.

I must stress, that whilst we would like as many people as possible to complete the questionnaire, so

that we obtain a good sample of the true situation and your feelings, you must not feel pressurised into completing it.

What I would say is that if you are approached to complete the questionnaire please complete it if you can. It is very important that we give a true and honest opinion as parents and carers of how we felt we were treated at the time a diagnosis was given. That information will help to focus the training health staff receive to improve things for all of us in the future.

Julie Marriott

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## Muscular Dystrophy Campaign

The Muscular Dystrophy Campaign has issued new guidelines on the inclusion of children with muscular dystrophy in mainstream schools. The report can be obtained from the organisation by emailing: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)

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## Websites

**Parentline Plus** has launched an email helpline to increase the way it offers support and help to parents. They promise a 72-hour response. For more information visit: <http://www.parentlineplus.org.uk>

**The Child Death Helpline** is a service offering emotional support to all those affected by the death of a child. For more information visit their website at: <http://www.childdeathhelpline.org.uk>. Helpline number: 0800 282 986

**The Office of National Statistics (ONS)** has published a new report giving statistics on the Health of Children and Young People. This includes a chapter examining the prevalence rates of disability in the UK. You can read the report at: <http://www.statistics.gov.uk/Children/downloads/disability.pdf>

## New service to help with adapting homes

If you need to adapt your home to enable your child to live more safely, conveniently and independently because of a disability, then a new service the House Adaptations Advisory Service (HAAS) will help you source a local professional with experience in designing for disabled and older people.

If you, or someone you know, is applying for a Disabled Facilities Grant (DFG) to adapt your home and need to employ professional designers to plan and oversee the work HAAS can help put you in touch with the right people.

HAAS is the only UK wide register of health care professionals, architects, surveyors and other related professionals who have a demonstrable knowledge of the housing needs of disabled and older people. The HAAS data-base also contains details of members' experience of other small scale projects such as local churches, village halls, community and day centres. Users of the service are sent a list of all members in their region with their details free of charge.

For further information on HAAS and to find a professional designer in your area contact Paul Highman, Principal Information Officer, Centre for Accessible Environments Nutmeg House, 60 Gainsford Street, London SE1 2NY Tel 020 73578182 or e-mail paul.highman@cae.org.uk

## Wheel Chair Skills Training

The Association of Wheelchair Children is the only national UK charity, which specialises in the free training of children and young adults who use wheelchairs.

If you have a child who needs to use a wheelchair, you can contact the Association. There are three main groups of children who use a manual wheelchair:

- uses a wheelchair as their sole means of mobility
- uses a wheelchair for outdoor mobility
- uses a wheelchair for sport

Ideally, training should begin as early as possible to ensure that these children reach their full potential. The basic training for manual wheelchair users involves the teaching of back wheel balancing. Being able to tip the chair and balance the back wheels will enable the child to negotiate steps, kerbs rough ground and steep slopes independently. Road safety also plays a large part of the training.

For the child who uses an electric wheelchair, in addition to teaching techniques for safe control outdoors, time needs to be spent with the child looking at the maintenance of the chair and discussing what happens if the chair breaks down.

For further details

<http://www.wheelchairchildren.org.uk>

Or contact Phil Rossall on 0870 121 0051

e-mail [marketing@wheelchairchildren.org.uk](mailto:marketing@wheelchairchildren.org.uk)

## Proposal for an Early Intervention Centre

The Parent And Carers' Council were approached by Mencap to get together a group of parents for consultation on setting up a centre for early intervention to give children the best possible start in life. We held our consultation day on the 24th June and our parents were treated to a buffet lunch as a thank you for taking part in the study. The survey is part of a feasibility study co-ordinated by Mencap and commissioned by the Department for Education and Skills. This will look at the viability of a centre that could act as a one-stop shop for information, advice, research and training related to early intervention for babies and pre-fives with a disability.

The results of the consultations and the findings will be published and completed by March 2005.

## Celebrating the achievements

The Database and Information Service held its official launch on Monday 28th June at Leicester Tigers.

The launch was an opportunity for all the stakeholders to come together, celebrate the achievements of working in partnership, and look at the future implications of the service.

It was made possible thanks to the support from the Co-operative Bank and Parent and Carers' Council. The event was very successful and well attended both by professionals and parents/carers.

The event was hosted by Kathy Pearson (Chair of the Database and Information Service) and Chris Bush (Service Manager of the Disabled Children's Project). There were speakers from each of the funding authorities and the high light of the morning was a parent who talked about how the service had been very helpful to her since she joined up. She thanked the Database and Information Service and other organisations for their support.

The database service has been operational since October 2002 and to date there are over 1300 parents/cares who have joined this service. The feed back from these parents has been very positive with comments like:

"Thank you very much for all the information, it's a very good idea – this service"

"Excellent – Keep up the good work"

The service is available to parents/carers of children and young people with special needs or disabilities, living in Leicester, Leicestershire and Rutland. It provides advice, information and sign posting to parents/carers about services relevant to them.

Parents/carers need to join the service in order to receive an information pack and regular newsletters.

The service has a website with links to a lot of useful organisations both local and national and is accessible on [www.infoxchange.org.uk](http://www.infoxchange.org.uk)

If you have not already joined this service.....

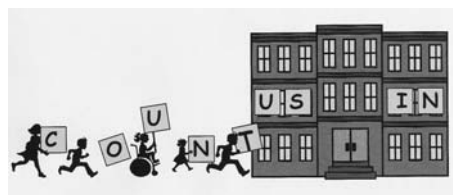
Then all you need to do is to contact us on 0116 223

2294/5 and we will send you a data collection form to complete and send back in the freepost or take your details over the phone, which ever suits you better.

You will receive an information pack and regular newsletters. Although there are over 1300 parents/carers who have joined we need your support in greater numbers to contribute to useful planning and developing information for service providers. So join up if you haven't and make that difference.

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## Count Us In



Count Us In is a new project that has come from a successful idea run by Parents For Inclusion in London. Count Us In's three inclusion workers will be helping to empower parents of children who have additional needs and are attending mainstream school, or parents who may need support trying to get their child into a mainstream school.

The inclusion workers are currently setting up meetings in the schools in and around the SRB6 area (Merrydale, Rowlett's, Northfield house, Humberstone, Thurnby Lodge, Scraftoft Valley, Hamilton Community College) and will be covering the whole of Leicester over the next couple of years.

The project is funded by Leicester City Council's Education Department.

If you want any more information, please contact:

Count Us In

LCIL

5-9 Upper Brown Street

Leicester. LE1 5TE

Tel: 0116 2225005 : Fax: 0116 2225008

Minicom:0116 2225007 : Email:[admin@lcil.org.uk](mailto:admin@lcil.org.uk)



# Update and Background on Dr Holton

Dr Andrew Holton was appointed Consultant Paediatrician at Leicester Royal Infirmary in 1990. He worked from that hospital as well as from other clinics both within and outside of Leicester. He developed a special interest in children's neurology and ran what his hospital called a "paediatric neurology clinic" even though he was not qualified to the specialist level of paediatric neurologist.

Dr Holton is now known to have wrongly diagnosed many children as having epilepsy when they did not suffer that condition at all. He also went on to prescribe powerful antiepileptic drugs to children who did not suffer the condition. Many other children, who did in fact have epilepsy, were given more antiepileptic drugs than they should have been. Sometimes the quantity prescribed was too high. Frequently he used multiple drugs in combination in a way that no other responsible doctor would have done.

Many children suffered side effects from the drugs. On occasion these effects were severe. Parents and carers had the unenviable task of giving the medication to their children on doctor's orders and then trying to cope with the often distressing side effects. More than one parent was even threatened by his or her own child with a knife. Other parents watched their children live in a twilight world where the drugs left them barely able to function normally. For many their schooling suffered.

In May 2001 Dr Holton was suspended from his duties by the Trust because of concerns about his work. Numerous complaints have been made against Dr Holton to the General Medical Council (who regulate doctors) who are going through a long and slow procedure to assess whether his performance was adequate or not. In the meantime he is free to work. He left the hospital in Leicester voluntarily and is now believed to be working in the field of neurophysiology somewhere in the Midlands. It is not known exactly where he is working or whether he is concerned with children or with diagnosing epilepsy.

Meanwhile investigations are being made to dis-

cover whether the drugs that Dr Holton gave out so freely have or can cause any long term side effects. One of them, Vigabatrin, is known to cause a subtle but important loss of peripheral eyesight in some people. The loss can be enough to prevent the person from holding a driving licence but may not be noticed by the sufferer without special testing. Even then it is very difficult to test children who have a developmental age of less than 9 or so.

The lawyers representing the hospital in Leicester have arranged for special testing to be carried out on children given Vigabatrin by Dr Holton and who are bringing claims for compensation. So far as we know testing is not being routinely done on children who were given Vigabatrin but whose parents are not bringing a claim for compensation. This seems very unfair on those children.

The process of seeking compensation for children harmed by Dr Holton, both in Leicester and elsewhere, is being organised in a way that avoids so far as possible going to court. Lawyers for both sides working together have set up special panels of experts. These panels examine all of the medical records and detailed statements from a parent or carer before deciding what harm was done by Dr Holton's treatment. Even though the process is one of cooperation, it is still long and drawn out. There are time limits applicable to bringing claims even through this panel process. Meanwhile research by an independent expert who is checking for side effects is still ongoing.

We urge any parent or carer whose child has been affected by treatment under Dr Holton to seek expert legal advice sooner rather than later.

The GMC are not meeting until the new year and even this will not give a decision!!

If you need any advice or information

Call 0797 4481688

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

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

Write to

1 Blaby Road, Enderby Leicester.LE19 4AR



**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.