



Leicester, Leicestershire and Rutland

## Database and Information Service

for children and young people with special needs or disabilities

Issue 2  
WINTER 2004

# InfoXchange

Database and Information Service Newsletter

## Happy New Year and Welcome

Welcome to the issue 2 of our newsletter. We have called the newsletter "InfoXchange" after the Database and Information Service website which is now up and running. The address is [www.infoxchange.org.uk](http://www.infoxchange.org.uk) and over time the website will grow.

### The website has a lot of useful information such as:

- Details of our service and contact us section
- Updates on our service and news
- Publications
- Experiences
- Welfare Benefits
- Leisure Activities
- Transitions
- Standard Reports
- Links to other relevant local and national websites

### Inside this issue we have:

- News about some of the national issues
- Stories from parents
- A page for young people
- Information on more services
- News on events or meetings that have taken place

### Update on Database

Since our last issue we have more than doubled the number of parents/carers who have joined and we now have over 900 people on our database. We want more parents and carers to benefit from our service and give us their views on other services, so if you know of anybody who is eligible to join, please tell them about us.

We hope you enjoy reading our newsletter. If you have any interesting stories or information you would like to share, why not contact us and we will be glad to include that in our future issues.

You can contact us on:

Tel: 0116 223 2295. Minicom: 0116 223 2299. email:[data.inf@leicester.gov.uk](mailto:data.inf@leicester.gov.uk)  
Database and Information Service, FREEPOST MID30929, LEICESTER LE3 6ZJ

The views expressed in this newsletter are not necessarily the views of the management committee.

## Let Me Be Me



### Research that will make a difference

“**Let Me Be Me**” is the title of an important National research report published recently by the Audit Commission. It looked at a successful service in Leicestershire.

The views of disabled children and their parents are at the heart of the study. Children spoke about what matters to them, about being respected and included. Parents told the study about their experience of services and gave practical ideas about improvements.

The study looked at services and found a “lottery” of provision, which depended on where they lived. Sometimes there were poor services and long waits whilst others had pockets of good practice. In the City, Leicestershire and Rutland the “Multi Agency Service Coordination Scheme” for children with complex needs was held up as an example of good practice.

The researchers identified that effective services must be based on:

- an understanding of locals needs
- helping families participate in everyday activities
- recognition of the impact of support or treatment
- staff who understand needs and work with users in respectful partnerships.

The study says that pockets of good practice must be mainstreamed. It says there must be a new attitude that sees the exclusion of disabled children as unacceptable.

To improve services the Audit Commission have issued a set of “tools” to support the change. There is a handbook and factsheets for parents and carers to get the best of services, as well as recommendations about what should be done to make a difference.

This information will be used to help plan improved services locally.

**More information is on the website at [www.audit-commission.gov.uk](http://www.audit-commission.gov.uk)**

### Changes at the Parents and Carers Council

The Parents and Carers Council (PCC) now have an office based in Leicester. **Sue Harrison** is based at Fosse Neighbourhood Centre, Mantle Road, and you can contact her on **07968 857598**. **Jane Hall** on **07870 688973**. **Fatima Abdullah** on **07814 119165**. The PCC hold their Meeting, Support and Information Group twice a month at Syston Community Centre for all parents of children with special needs and disabilities. We start at 10am and run through until 12 noon. Come along and meet others over a cuppa and a chat. If transport is a problem for you then ring Sue Harrison for more information.

## **So what are Children's Trusts?**

Children's Trusts are going to be a big part of the future of Children's Services. The government papers called "Every Child Matters" says that this will be a new way to give better services. They want all children to be healthy, safe, achieving their potential and enjoying life. They want children to develop the skills for adulthood.

Children's Trusts are one of the main suggestions about how to achieve this. They will bring together local authority, education and children's services, some children's health services and the Connexions service.

The Children's Trusts will develop as a partnership and will include working closely with parents/carers groups, young people and voluntary groups.

At the moment Children's Trusts are a proposal in "Every Child Matters". All agencies are expecting this to be the future arrangement because the government has set up 35 "Pathfinder" trusts.

Leicester City has a pilot Children's Trust. It is called "Federation" of services working together in partnership.

It is important locally because it has been accepted that "disabled children's" and "transition to adulthood" themes will be the key priorities for the trust in the city.

Parents and carers, agencies and the voluntary groups in the Rutland and Leicestershire are watching closely the developments in the City to see what service improvements they will bring.

## **Where "Every Child Matters"**

"Every Child Matters" (as mentioned earlier) is an adventurous new report that has recently been published by the Government. It will lead to improvements in services for disabled children and their families.

It has four main aims:

1. To increase the focus on supporting families and their carers.
2. To avoid children reaching crisis point and prevent them falling through the net.
3. To improve the integration and accountability of services.
4. To improve the training and professionalism of people working with children.

To do this services will be reformed across professional boundaries and new arrangements will aim at improving the experience of those who use the services.

The Database and Information Service is involved locally in discussions about how to improve services for disabled children and those with special needs.

If you have comments please contact us and we will feed them into agencies.

## **Meeting for families with children with a disability living in Rutland**

A meeting was recently held for families and workers in Rutland, to explore the opportunities and issues for local families around the leisure needs for their children with a disability.

Issues identified as priorities for these families were:

- The absence of a specialist health visitor for Rutland.
- The need for the training and recruitment of volunteers to help with activity groups.
- The need for easily obtained information on access to buildings in Rutland.
- The need for support for groups to include children with special needs into mainstream activities.

**Roger Beggy** (Leader of the Rutland County Council), introduced the morning. **Sarah Bysouth** (Early Years Rutland County Council) discussed the development of an integrated and inclusive playscheme to meet the needs of all children in Rutland.

**Steven Attwood** (Social Services Department Rutland County Council) informed parents about the support available from the Social Services Department.

**Chris Redmon** (Voluntary Action Rutland) introduced the work of Symbiotica a selfhelp/advocacy/information group.

**Tina Bailey** (Sports Development Rutland County Council) discussed the assistance she could offer and talked about opportunities for funding through the Awards for All Programme.

The Have a Go day was introduced by Tina Bailey and Marg Burke (Rutland Children's Fund) as an opportunity for children and their families to try various leisure activities. This day will be held in the summer months.

A free training session was offered to parents of children with a learning disability on managing challenging behaviour at home. This training will be run locally over a period of 5 to 10 weeks.

Contact **Sarah Bysouth** if you are interested in obtaining further information on **01572 758 490**.

## End of Year Celebrations

The City's Disabled Children's Inclusion service celebrated the end of the year with a disco held at Rack N' Roll Club and snooker hall.

It was held on Saturday the 6th of December, between 2 and 4.30pm. We invited all our referrals and almost all of our Families made an effort to come and join in the fun. All the staff from the Multi Agency Disabled Children's Project, were dressed as fairies and our Service Manager did us a huge favour by being Santa.

There were lots of activities going on, such as dancing, party games, food and drinks, presents, face painting and henna patterns.

We started off with people coming in, putting their coats away and registering while there was music playing in the background. Children warmed up with dancing, we then played party games, followed by dancing competitions. Snacks were then served. Children enjoyed having their hands decorated with henna patterns and loved having their faces painted.

Santa gave out presents to all children who were there, for some children seeing Santa made their day. We finished off with a raffle and all winners came away with a prize they liked.

Parents and Children all thanked us, for a very enjoyable time they had. We have had lots of positive feedback from parents saying how much they enjoyed the disco and how well it was organised.

## Open Day - 6th April 2004

### At British Red Cross Special Needs Family Support Centre

Bradbury House, 54 Kenilworth Drive, Oadby, Leicester. Tel: 0116 271 0359

### GUEST APPEARANCE - MATT ELLIOTT LEICESTER CITY FOOTBALL CLUB

The Family Support Centre is organising an Open Day that will be open to Professionals, parents/carers and children. Tuesday 6th April has purposely been picked, as this is a date when the schools are closed therefore allowing families to be involved.

Matt Elliott will be the special guest of the Cerebral Palsy Parents and Children's Support Group: this support group being his designated charity this year. Also a signed football shirt has been given to the group and it is proposed to auction this.

Exact timings are to be finalised, however it is envisaged that the Open Day will be from 10.30am to 3.00pm with Matt Elliott making his guest appearance in the afternoon. The day should be fun and informative. Database team will be there to give information.

## Why not come and meet us!

You are invited to an information event that is being held on **Thursday 22nd April, from 6pm to 8pm** at Connexions Leicestershire, Halford House, Charles Street, Leicester.

The event is for children with special needs or disability up to 19 years of age, and their families.

This is your chance to come and talk to us about various service providers to:

- Get advice, information and support
- Discuss specific issues regarding your son/daughter.
- Plan ahead for your son/daughter
- Discuss short break services.

A wide range of service providers, both from voluntary and statutory organisations have been invited on the day.

Make sure you book this date in your diary and don't miss this opportunity to come and talk to the service providers. If you have transport problems, please contact us.

Creche and childcare facilities will be provided. For further information contact Database and Information Service on 0116 223 2295.

## Scamp (Student community action mobility playgroup)

Scamp is a free playgroup run by Leicester University students for all ages of special needs children. It has been set up since 1998 and has been very popular with volunteers.

SCAMP accommodates for children with a variety of behavioural and learning difficulties and the volunteers are fully trained. Parents often stay and watch.

SCAMP takes place each week on a Sunday from 1:45 - 3:15pm. It is held on the University of Leicester campus in the Charles Wilson Sports Hall.

If anyone is interested in attending, or if they wish to request more information, they can either e-mail Contact (student run association) on [contact@le.ac.uk](mailto:contact@le.ac.uk) or phone on 0116 223 1141. One of the members of the Contact executive or our Volunteer Co-ordinator, Birgit Lewis, will then inform SCAMP that a new member will be attending.

## **New Opportunities Grant**

### **For children, young people and families with palliative care needs**

Leicester, Leicestershire and Rutland were successful in securing a large grant from the New Opportunities Fund to support children, young people and their families with life limiting, life threatening conditions and palliative care needs. For the purposes of this grant, we are using the ACT definition of life limiting conditions, which is: *“those children for which there is no reasonable hope of cure and from which children will die. Many of those conditions cause progressive deterioration, rendering the child increasingly dependent on parents and carers.”* The grant will run from July 2003 to July 2006, and therefore is time limited.

One of the projects to be funded by the New Opportunities Grant was the development of a bank of volunteers to enable families to take part in and enjoy social and community activities. Hence the opportunity to apply for this grant.

The grant can be applied for by parents on behalf of a child or young person to enable them to take part in some social activity, group or event.

In most cases you should hear whether your grant application has been successful within 6 weeks. If you do require the assistance of a volunteer the arrangement of this could take a little while, therefore, it is suggested that your application is submitted at least 3 months in advance of the date assistance is required. This is especially so at busy times of the year such as the school holidays, when demands on volunteers are at their peak.

Each child, young person and family are allowed to apply for up to a maximum of £200:00 per year. This could be one off grant of £200:00 or a number of smaller grants within the year. Applicants need to specify what activity they require the money for and be prepared to submit receipts.

For inquiries or further information please contact either Dorothy Gillespie, Diana Children's Community Service Manager on 0116 2255484 or Anne Payne, Manager of British Red Cross Leicester on 0116 2710359.

## **Service Development Worker - Palliative Care**

Donna Mitchinson is the Service Development Worker for children and their families with Palliative care needs in Leicester, Leicestershire and Rutland. The post is funded by the New Opportunities Fund.

The aims of the Service Development Worker over the next year are to establish what the Practical and Welfare support needs are of families with Palliative care needs.

Over the next year Donna will be working closely with families to identify their individual practical difficulties. If the family's needs cannot be met within the existing services, Donna will record this as a gap in current service provision. The objective of collecting this information is to inform and support the potential development of a service that will meet the identified needs.

The Service Development Worker role incorporates working in partnership with

families and professionals to develop information on palliative care issues, raise awareness and develop strategies to meet the identified needs.

Please do not hesitate to contact Donna Mitchinson for further information, on (0116) 225 5484.

## **Country Parks Service for Blue Badge Holders. Car Park Season Tickets**

In order to improve the collection of parking fees and improve security, pay on entry has now been installed in the Car Parks at Beacon Hill, Market Country Park and Watermead (North) Country Park. Blue Badge Holders have always had free parking. In order to ensure that this continues, a Season Ticket is available free of charge to those eligible to hold a Blue Badge.

### **Benefits of a Season Ticket**

- Valid for all Country Parks where charges are levied (except on Special Event Days, when special charges will apply).
- Valid for the life of the Blue Badge
- Saves paying for car parking on each visit

### **How will Scheme Operate?**

You can obtain a Season Ticket by completing a form which is available from: Country Parks Service, Community Services Department on **Direct Dial: 0116 265 6918.**

Details of how to operate the Pay on Entry system will be sent to you with the Season Ticket.

## **'Quids for Kids' campaign to reduce child poverty**

The Local Government Association (LGA) has now launched its "Quids for Kids" campaign, to promote benefits and tax credit take-up for children in England and Wales.

They have also published a good practice guide and accompanying electronic toolkit to coincide with the introduction of new child tax credits and working tax credits by the Inland Revenue.

The guide outlines good practice amongst councils and their partners in the community and voluntary sector to promote benefit take up amongst disabled children, low waged families.

The electronic toolkit enables councils and partners to run their own campaigns to raise awareness of the changes locally and is available at: **[www.lga.gov.uk](http://www.lga.gov.uk)**.

The next stage of the campaign will consist of a benefits take-up conference to be held at the Local Government House on 12 May in partnership with the Department for Work and Pensions.

A disturbing number of families have never received any advice in benefit entitlement. We therefore believe that the LGA's campaign will have a positive impact upon child poverty levels and will greatly improve the quality of life for disabled children and their parents/ carers.

## Good News

Planning the future with young people.

One of the things parents and young people worry about is their future. Young disabled people and those with special needs have access to an information pack.

The pack, called “**Transition Planning**” is available to year 9 students. It covers information like meetings, things to consider, colleges, benefits, social services and many other issues.

If you are a parent or a carer of year 9 student in this group, please contact the database and information for a copy.

If you are younger or older you can see a copy of the pack on the website.

You can get this via:

**[www.infoxchange.org.uk](http://www.infoxchange.org.uk)**

and then click on transitions and go to Connexions Leicestershire address.

People from Rutland: Please have a look at the pack or contact Rutland Connexions directly.

## Information Events

We have now completed 12 transition information events around the city and county.

Many parents and young people have attended. The comments we have received have been very positive. Over 90% of the responses have said the information was good or very good.

## Tell us what you would like

We are thinking about planning more information events and would like to hear your views on it e.g.

- Would they be useful to you?
- Where should they be held?
- What information would you like?
- When should they be held ie. morning, afternoon or evening?
- Any other things you would like to see at these events.

Let us know via our website or email to us on: [data.inf@leicester.gov.uk](mailto:data.inf@leicester.gov.uk)

## Thanks to Transitions Events

### Story from parent

I received a letter from Database and Information Service in February last year, inviting me to the transition events. I went to the event that was held at Belgrave Neighbourhood Centre. I was able to talk to a number of different service providers and gather a lot of information.

Bhanu from the Database and Information Service gave me the information about the Disability Living Allowance (something I was not aware of). I applied for it and have recently started receiving it for my daughter who is fourteen years old.

Had I known about this sooner, I would not have had to struggle as I did, especially being a single parent.

I found out a lot about other agencies that could help me. I have also been able to get more information about sorting out my daughter's transition plan.

Database Service and Transition events have proved very helpful to me.

I wanted to share this with other parents because I would not want any other parent to struggle as I did.

## A Wealth of Information

The second of our three children, Oliver, has a condition called congenital nystagmus. It's very complex, but in a nutshell, his eyes wobble uncontrollably from side to side resulting in him having impaired vision. There is not treatment for his condition.

I was made aware of the database service by Oliver's educational psychologist who we see, along with his hospital consultant, on a regular basis. I rang the service the day after his appointment. A member of staff rang me back straight away to gather the information needed to enter Oliver onto the database. The lady concerned was courteous and helpful and the information was collated sensitively and intelligently.

Following our telephone conversation a comprehensive information pack arrived very quickly in the post. It provided a wealth of information from specific help with disabilities to advice on benefits available. My husband is amazed at how efficient and thorough the service is.

With a relatively rare condition such as Oliver's, as parents you become accustomed to information being very difficult to find. The database service is a very rich source of relevant information which, for the parents of a child with a disability, could help to make a huge difference.

Marie Taylor, NW Leics.



## Help is at Hand

Mr and Mrs Jayes Cloth needed help to re-organise their home to make it safe for their children to live in. The Homecare course which, offers practical help and guidance and a certificate at the end if successful, was introduced by Lindy Mead of the Family Inclusion Service.

Mr and Mrs Jayes Cloth said, "We like the idea of being a student. It makes us feel important and we want to do the work to achieve the certificate and have a nice clean and safe home for the children to live in."

Mr and Mrs Jayes Cloth have been very successful and gained new skills. They say that they can now invite people into their home and feel proud that their home is organised. Mr and Mrs Jayes Cloth would recommend this course to others to help them to clean their homes.

If you are interested in more details about the course you can contact Lindy Mead of the City's Family Inclusion team on 0116 223 2293.



## 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.  
Telephone & Fax: (0116) 2232 427. Email: Service.Coordination@lcwpct.nhs.uk

The service coordination scheme started in 1998, and since then over 120 families have decided to take part. It began as a pilot in Leicester City East, Rutland and Coalville, initially catering only for the under 8 age group. Now the scheme has expanded the age group to 0 – 19, and the areas cover the whole of Leicester, Leicestershire and Rutland.

#### **Who is the scheme for?**

It is for 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.

#### **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.

#### **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.

A UK wide study is currently being carried out to compare costs and outcomes between a number of different coordination schemes including ours.

Our scheme has attained national recognition, and is mentioned as an example of good practice in e.g. the National Service Framework for Disabled Children ([www.doh.gov.uk/nsf](http://www.doh.gov.uk/nsf)) and 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)).

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)

If you would like any further information, members of the Service Coordination Scheme, Sunny Ahmed, Paul Harrison or Anette Beattie will be very pleased to hear from you.

## TELL US WHAT YOU THINK...

Your views are needed and welcomed.

Using the reply slip below, please tell us what you thought about the contents of this newsletter and what you would like to see in the future issues.

I would like .....

.....

I think the presentation of the newsletter is .....

Please send your replies in the FREEPOST to:

**Database and Information Service, FREEPOST MID 30929  
LEICESTER LE3 6ZJ. No stamp required.**



# 'Lets Talk'

## Consulting disabled children and young people about their views regarding services.

The consultation of disabled children/young people in Leicester was conducted between June 2002 and March 2004. The main purpose was to seek their views about services (education, social and health, and leisure services) to inform planning and delivery of disabled children's services.

Approximately 200 disabled children/young people, including young disabled adults, (non-disabled) siblings and young carers were consulted. Their views provided a snapshot of their experiences of service provision in Leicester.

Overall the disabled children/young people's experiences include both positive and negative experiences of service provision. Although some are positive experiences, aspects that could improve service provision include:

A communication strategy for disabled children/young people that is aimed at:

- improving communication between professionals and disabled young people
- using child/young people friendly approaches to communicate.
- consulting these children/young people about services and various aspects of their lives.
- involving disabled children/young people in decision-making processes.
- providing accessible and appropriate information regarding a range of issues pertinent to them through various access points.
- ensuring that their views are included in wider consultation processes and activities that take place within the authority and the city.

Youth provision that:

- meets disabled young people's needs for accessible information and discussions to empower them regarding issues such as sex and relationships, and advocacy for services that are appropriate and equitable.
- is staffed by trained and qualified youth workers, who are neutral and therefore can provide disabled young people with the opportunity to discuss issues that they might not with other members of staff such as teachers and support staff.

Inclusive services that are aimed at mainstreaming disabled children/young people in the long-term.

The above has informed the strategy for disabled children's services in Leicester, which should help to improve their quality of life.

Pratima Patel, Consultation and Information officer.

June 2002 - March 2004



Leicester, Leicestershire and Rutland

**Database and Information Service**

for children and young people with special needs or disabilities



Leicester City Council



Leicestershire County Council



**NHS**