



Leicester, Leicestershire and Rutland

Database and Information Service

for children and young people with special needs or disabilities

Issue 1

Newsletter

SUMMER 2003

Welcome

Welcome to the first newsletter of the Database and Information Service. This is a new and exciting service that has been around since October 2002 and is available in Leicester, Leicestershire and Rutland.

It is an independent service that is supported by Leicester City Council, Leicestershire and Rutland County Councils and the Primary Care Trusts.

It is managed in partnership with a number of agencies and voluntary organisations set up for children with special needs or disabilities.

You can contact us on:

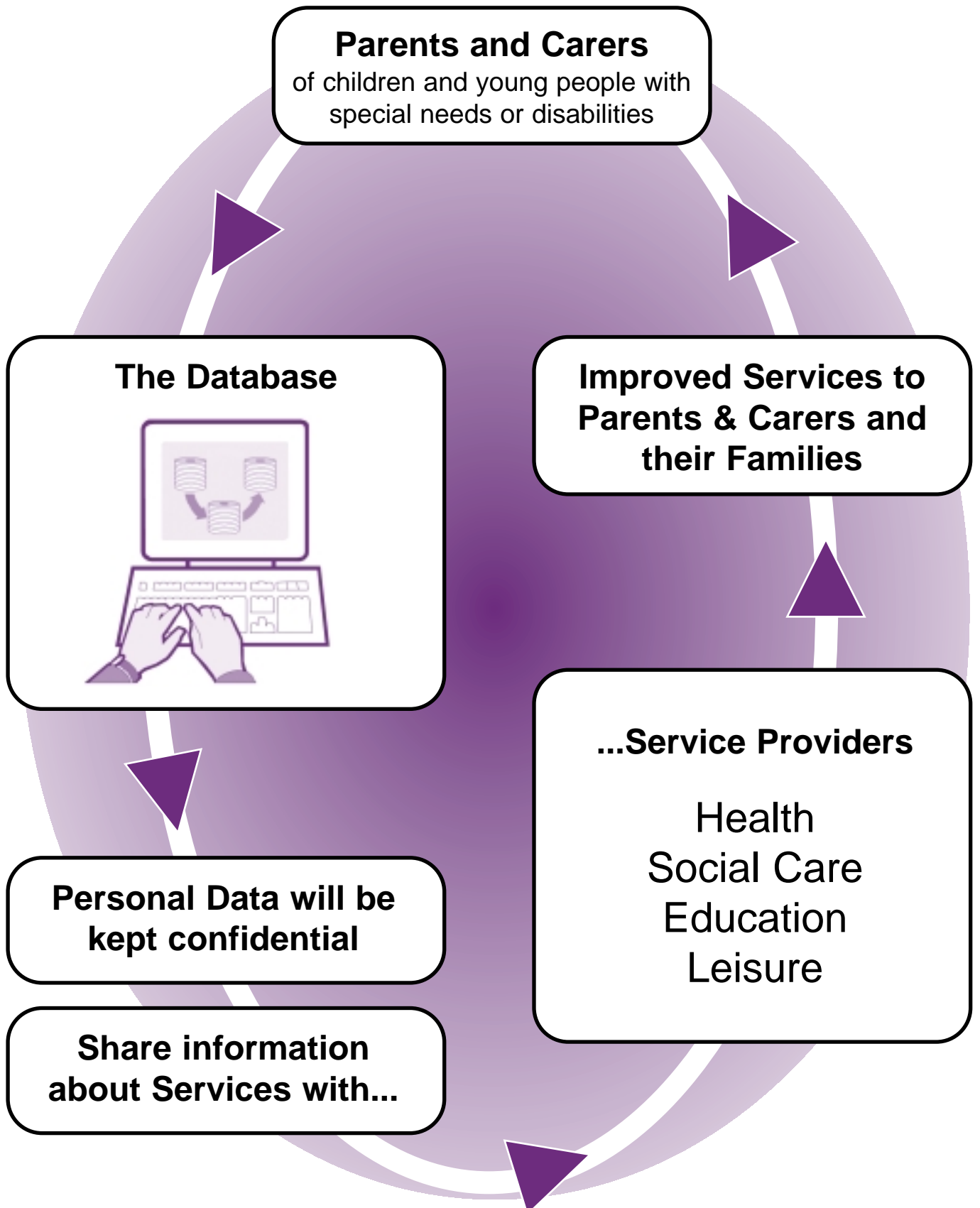
Tel: 0116 223 2295. Minicom: 0116 223 2299.

email: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.

How Does It All Work



You can contact us on 0116 223 2294 / 2295

So how did it all begin?



A Database and Information Service must be set up by law. The Children Act 1989 expects that there should be a list of disabled children who live in an area. The Health Service also have to collect information about needs.

In April 2001 the planning began to set up an independent database and information service. Large and small meetings were held with parents and carers, voluntary groups, and agencies. We asked ourselves some questions. What was the service going to be? What did we need to do to provide an acceptable service? What sort of services would encourage people to join?

We spoke to agencies and professionals but – most importantly – we spoke to parents and carers, and young people from a variety of backgrounds and cultures.

So, what did we find out? Families and young people were all very clear. They wanted:

- **Information that is easy to use**
- **Friendly people who give out the information**
- **A place to call or visit where they know they will get independent and useful help.**

And here we are to do just that and we are very pleased to send you our first newsletter!

If you receive more than one copy of this newsletter, please contact us and pass the spare copy to a friend or relative.

You can join the Database by contacting us on 0116 223 2294 / 2295

What is it all for?



- **The first aim is to give** parents and carers and young people relevant:
- **Advice**
- **Information and**
- **Signposting** about services relevant to them.

The second aim is to help organisations both private and public to:

- **Improve,**
- **Plan and**
- **Develop** services that meet your needs.

So, we would like you to join so that we can plan to meet needs. It is easy! Details on how to join are in this newsletter.

Please join the database, we will ask you some questions about your views of the services and what you think might improve them. That way we will be able to plan services for the future. That is the plan, we really need your help!

Thank you for your patience



A special Thank You to the parents who joined the database and had to wait for their printouts while we were sorting out some technical problems.

We have now sent out all the printouts that were waiting. Your feedback has helped us to sort out some of the teething problems.

We hope you enjoy reading this newsletter and would welcome any articles from you. This is your newsletter and we would like to give you the opportunity to share your experiences, with other parents and carers.

Details on how to join are on page 5, or contact us on 0116 223 2295.

Have you joined the Database yet?

News and Update... News and Update...

DATABASE UPDATE

Three hundred and fifty parents and carers (as of 25th June) have joined our database, but we need more, so we can have your support in greater numbers to make a difference to the services for you. If you know a friend or relative who is a parent or carer, please ask them to join us.

How to Join the Database

All you need to do is to send the reply slip below and let us know whether you would like to register over the phone, or send you a data collection form for you to complete and return in a freepost envelope.



REPLY SLIP

Your Name

Address

Postcode Telephone

Please tick the appropriate box:

Please ring me, I would like to register over the phone.

Please send a data collection form for me to complete and send back.

Send the completed slip to:

Database and Information Service, FREEPOST MID30929

LEICESTER LE3 6ZJ. *No stamp required.*

If not why not contact us now on 0116 223 2294 / 2295 or send the above reply slip.



OPTIONS EXHIBITION COMPETITION WINNERS

First Prize Winner

David Mayes of Ashfield School, Leicester.

Second Prize Winner

Leann Rettany of Ashmount School, Loughborough.

Third Prize Winner

Craig Stevens of Emily Fortey School, Leicester.



OUR LOGO



We hope you like our logo.

It was designed by the pupils of Western Park School and Church of England School Oakham. These were the schools that took part in the logo competition. We liked the designs from both the schools and incorporated the two to form our logo.

Both the schools have each received a £50.00 prize.



Presentation of the cheque by Bhanu Mistry (Database Manager) at Western Park School, Leicester.



Presentation of the cheque by Chris Bush (Project Leader) at Church of England School, Oakham.

Join the Database and be that number that makes a difference to the services.

PLAYSCHEMES - Story by a parent

Both my children, one of whom has ASD (Autistic Spectrum Disorder), attend a mainstream playscheme during Easter and summer holidays. This makes the holidays manageable. However this year I was told that due to lack of 1:1 funding my son could no longer go there.

On Kathy Pearson's (Parent Carer Council) advice I contacted Chris Bush at the Disabled Children's Service Co-ordination point. I am registered with the Database and Information Service, as they are trying to improve planning of services for disabled children.

Chris rang around and liaised with the playscheme manager, who has now managed to secure some 1:1 funding. This means that my son with ASD will not be excluded from the playscheme this year.

So if you want to ensure that your child is not excluded from a playscheme, my advice would be to contact one or more of the people below:

- Speak to Social Services if your child has been assessed
- Register with the Database and Information Service and speak to Chris Bush or Bhanu Mistry on 0116 223 2295
- Contact playscheme manager and ask them to look into funding
- Contact Mencap on 0116 2510011
- Contact Jigsaw about their playscheme for children with ASD on 0116 287 6747.

The 'What Matters?' Research Project

Parents in Leicestershire and Rutland are being invited to take part in a Department of Health research project. The 'What Matters?' project is about finding out the sorts of things disabled children and their families want to do and achieve, and to get their views on how services can best help them experience these things.

The project is working with two groups: families who have a child with a diagnosis within the autistic spectrum, and families whose child has 'life limiting', progressive condition.

If you would like to hear more about the project, please contact Bryony Beresford, who is a member of the project team, at:

Social Policy Research Unit, University of York, Heslington, York YO10 5DD. Telephone: 01904 433608. Email: bab3@york.ac.uk

You can join by ringing us on 0116 223 2294 / 2295 or by sending the reply slip.



Specialist Community Child Health Services



In the past the main way in which we could inform parents/carers of developments in therapy services was through the Therapy Update newsletter. We now welcome the opportunity to be able to contribute to this new venture of a Database and Information Service. This will enable us to share information about Specialist Community Child Health Services (SCCHS) as a whole. An introduction and overview of our service seems a good starting point for this first edition.

WHAT WE DO

We work with children and their parents/carers to maximise their development and health potential.

Children are seen as individuals within the context of their family and in their wider and diverse communities.

SCOPE OF THE SERVICE

We address the needs of the child as a whole, ranging from the general universal needs of all children to those with life-limiting conditions.

The universal services include Birth Registrations and Records, Child and Family Health Promotion, Immunisation, School Health, Looked After Children, Child Protection, Adoption and Fostering.

Support for children with more complex and special needs is met by a range of professionals including nursing and respite services via the Diana Team, medical services, specialist health visiting and therapy services including physiotherapy, occupational therapy and speech and language therapy.

Management and administrative staff support the teams.

WHO WE WORK WITH

We also work with our professional counterparts in hospitals, education, social services and the voluntary sector.

WHERE ARE WE GOING?

We are developing our service so that it is family centred – designed around the needs of children and families in order to ensure that:

Have you got a story or an experience you wish to share with others.

- Services are accessible and fair and provided in a timely way as locally as possible
- Services are co-ordinated both within health and with other agencies. This includes work with organisations such as Sure Start and Connexions, Health Action Zones, and the Service Co-ordination Scheme which works specifically across agencies.
- We are able to demonstrate good, effective and efficient outcomes for children and their families.

HOW ARE WE GOING TO GET THERE?

Some recent developments in how we manage complex health needs include:

- Since September 2002 we

have introduced a system initially for children under 5 years of age whereby all professionals work together locally.

- In February 2003 we introduced a process whereby a child can be referred to any aspect of our service via a single contact point. This will help improve the timeliness and efficiency of our interventions.
- Where appropriate on going staff education and training is provided in a multi disciplinary way to ensure that professionals have and share up to date skills and knowledge.

If you have any questions about our service please ask your community doctor, nurse or therapist.

SPECIALIST HEALTH VISITOR

Advice and Information for Children with Disabilities and their Families, Professionals and Voluntary Agencies.

Open Monday to Friday
12 noon to 2.00pm.

Telephone: 0116 225 6560

CONTACT DETAILS

Julie Cowie
Head of Service
Speciality Community Child
Health Services
Bridge Park Plaza
Bridge Park Road
Thurmaston
Leicester LE4 8PQ

Why not send that in for the next issue of the newsletter?



Working in Partnership with...

Parent & Carer's Council



This is a group of parents and carers of children with a wide range of special needs and disabilities, who have experienced difficulties in getting the support they need. They want to use the expertise they have gained to help others. They are committed to making services better for their children and others.

Landline: 0116 260 3934

Centre for Deaf People



Provides a range of services to all people with a hearing loss.

Telephone:

0116 257 4800 (voice)

0116 257 4850 (text)

0116 257 4856 (fax)

0116 257 4900 (videophone)

Connexions Service

Primary Care Trusts

Mosaic



mosaic: shaping disability services, offers a range of services to disabled people who live in Leicester, Leicestershire and Rutland.

Telephone: 0116 251 5565

Menphys



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.

Telephone: 01455 894880

CLASP



CLASP is committed to being a quality led organisation providing advocacy, information and support to carers across Leicester, Leicestershire & Rutland.

Telephone: 0116 251 0999

More details on the above when you join the database.



Working in Partnership with...

Leicester City Council

Leicester City Social Care and Health: **0116 253 1191**
 Leicester Education and Lifelong Learning: **0116 252 7807**
 Leicester City Parent Partnership Scheme: **0116 257 5027**
 Leicester City Childcare Information Service: **0116 225 4890**



Leicestershire County Council

Leicestershire County Social Services: **0116 265 7403/4**
 Leicestershire Local Education Authority: **0116 265 6631**
 Leicestershire Parent Partnership Officers: **0116 271 4137**
 Leicestershire Children's Information Service: **0116 265 6545**



Rutland County Council

Rutland Social Services and Housing: **01572 722 577**
 Rutland Local Education Authority: **01572 758 496**
 Rutland Children' Information Service: **01572 758 494**



Vista



"Vista"- Society for the Blind - Services for children and families. There is an extensive programme of activities for blind and partially sighted children and young people which runs throughout the year.

Contact:
Sue Hulatt
Telephone: 0116 233 2032



Red Cross (Special Needs) Family Support Team

Advocacy information and support for carers of children & young people with any special needs or disability.

Telephone: 0116 271 0359

Please keep this newsletter for future reference.



Working in Partnership with...

Mencap



Mencap - The Information Service for Leicester and Leicestershire was set up for people with learning disabilities, their families or carers. It aims to provide clear, accurate information and support about benefits, assessments, education, leisure, holidays and local services.

Telephone: 0116 251 0011

Disabled Children's Inclusion Service



The Disabled Children's Inclusion Service helps children who live in the city of Leicester, and are between the ages of 5-13, to be active members of the community.

Our aim is to enable disabled children and their families to access community facilities and be valued as individuals.

Telephone: 0116 223 2293

Lets Talk

Hello, my name is Pratima Patel, and I work at the Multi-agency Disabled Children's Project. My role is to ensure that the views of disabled children and those with Special Needs are included in planning services for children, who live in the city of Leicester.

I am meeting with disabled children and young people, and those with Special Needs to ask their views about education, health/social care and leisure, so that these could be improved.

I am working with other services such as the Leicester Children's Fund and the Disabled Children's Inclusion Service, to organise activities, for example a 'Big Brother' activity in which disabled children, their sisters and brothers were asked about what they liked and disliked about school, health and leisure services.

Please contact Pratima on 0116 223 2290, for more information.

Your comments are important to us ...

Tell us what you thought about the contents of this newsletter and what you would like to see in the future issues.

Send your reply to FREEPOST address on the front cover.

Replies received by 31st August 2003, will be entered into a prize draw to win £50 shopping vouchers.