

# “PARENT CARER VOICE”

*The Newsletter of the parent carer involvement team in Hertfordshire*

Issue 2/2010

This newsletter is published three times a year to update you on what is happening with parent carer involvement in Hertfordshire and to let you know how YOU can help to improve services for children with special educational needs and disabilities.

## STOP PRESS!

We have just launched the Parent Carer Involvement Network. It is great for parent carers who want to keep in touch but have very little time. Please do sign up to this free service which will help the Parent Carer Involvement Board listen to the parent carer voice and help influence service development. We will feedback through regular e-bulletins, focus groups and occasional events. To join please contact your local Parent Carer Involvement Worker.

### Involvement?

Involvement means people who use services being included in deciding what should be provided.

### New parent carer?

Speak to a Carer Support Worker at *Carers in Hertfordshire*:

Tel: 01992 586969  
[www.carersinherts.org.uk](http://www.carersinherts.org.uk)

### Write to:

Carers in Hertfordshire  
FREEPOST ANG50009,  
Hertford, SG14 1BR

### Or email

[contact@carersinherts.org.uk](mailto:contact@carersinherts.org.uk)

## Welcome to the summer edition of “Parent Carer Voice”, the newsletter of the parent carer involvement project supported by *Carers in Hertfordshire*.

We want parent carers and professionals to see how parent carers getting involved as a ‘critical friend’ in the development of services for children and young people with special educational needs and/or disabilities (SEND) will lead to better services and better use of the funding available. Take a look at the article “Parent Carer Representative – the Critical Friend role” and please do contact your local Parent Carer Involvement Worker if you want to get involved. Even if you have no time, you could join our new Parent Carer Involvement Network for regular updates.

The long summer holidays can be a particularly exhausting time for families of children with special educational needs and disabilities. I would urge you to register as a member of HAND (Hertfordshire Additional Needs Database) if you haven’t already. Children, Schools and Families (CSF) are producing a new HAND e-mag which will include information about holiday play schemes – intended to give the child or young person a positive experience and the rest of the family a short break. Go to the website for details: [www.hertsdirect/hand](http://www.hertsdirect/hand).

### One of the things we know from families, is how difficult it can be to access leisure activities and this is something we want to see improving. Aiming High money is funding 2 county wide training programmes which should help.

- Disability training is being offered to leisure providers to help improve access to mainstream or “universal” activities. The Parent Carer Involvement Board would like to see the introduction of a quality mark for leisure organisations which take up this training opportunity and include effectively children with special educational needs and disabilities
- For children with additional medical needs, the “Training High” programme has been set up as a joint health and social care initiative. Nurses offer training on, medical procedures, either to enable a particular child to access a service or to improve a range of clinical skills in a mainstream or specialist setting.

It takes time to achieve change and we don’t get a perfect outcome every time, but through the Parent Carer Involvement Board representing families of children with SEND, Hertfordshire parent carers are ‘having a say’ in how the additional funding under the Aiming High for Disabled Children initiative is being spent. We are hopeful that by next summer, a new adventure playground with indoor and outdoor space will be open to help SEND children and their siblings while away the holidays.

**Charlotte Elgar,**

*Chair of the Parent Carer Involvement Board*

# Parent Carer Representative - the "Critical Friend" role

Members of the Parent Carer Involvement Board are now acting as Parent Carer representatives at key meetings with Children, Schools and Families and NHS Hertfordshire, where decisions are made about services for children with special educational needs and disabilities.

The Parent Carer Involvement Board sees itself as a "critical friend".

## So what does the "critical friend" role mean?

- A parental view from someone who understands the needs of children and is representing the views and experiences of families across a wide range of disabilities.
- Insight into the impact a strategic decision would have on the family of a child with special educational needs and disabilities.
- The chance to question and raise issues that have not been considered.
- A viewpoint that is not influenced by budgets or working practices.
- A nominated and trained representative, to ensure an objective view is presented effectively.
- Representation that is linked into a clear framework of involvement with a clear method for gathering views and communicating back to other parent carers.

## Does it work?

- It is recognised that working with parents, helps professionals to understand what needs to happen to develop services that meet families' needs.
- Equally, working with professionals, helps parents understand the challenges faced by professionals in bringing about change.
- Working together and sharing knowledge enables parents and professionals to find solutions that work.
- Problems arise because professionals often lack experience in involving parents effectively and the bureaucratic processes and meeting times are not always parent friendly.
- Our view is that the more parent carer representatives are involved, the more notice professionals will give to the needs of the parent representatives and the more effective our participation will be.
- In this economic climate, it is particularly important that resources are not wasted on services that families do not value.

# Parent Carer Involvement Workers (PCIWs)

The Parent Carer Involvement Workers have been recruited by Carers in Hertfordshire to develop a robust and sustainable parent carer involvement structure linking support groups and individual parents into a county-wide network that underpins the work of the Parent Carer Involvement Board.



From left to right: Sara, Maria and Kay

If any parent carer wants to be involved, either in the Parent Carer Involvement Network or in the Parent Carer Involvement Board, or wants to find out more about parent carer participation, please contact your local Parent Carer Involvement Worker:

Name:	Area:	Contact Details:
Maria Kiely	Dacorum, St Albans, Three Rivers and Watford	Maria.kiely@carersinherts.org.uk 01442 253344
Sara Kent	East Hertfordshire and Broxbourne	Sara.kent@carersinherts.org.uk 01992 586969
Kay Lowney	North Hertfordshire, Stevenage, Hertsmere, Welwyn and Hatfield	Kay.lowney@carersinherts.org.uk 01992 586969

## Children, Schools and Families update "AIMING HIGH FOR DISABLED CHILDREN"

On the 15th February 2010 the County Council's Cabinet agreed proposals to transform short break services for children and young people with Learning Difficulties and or Disabilities (LDD).

Since then a huge amount of work has been undertaken to progress these proposals including work to;

- ensure that our overnight short break service is high quality and provided in modern fit for purpose buildings
- develop a safe, accessible and appropriately equipped adventure playground facility for all disabled children, including those with the most severe complex needs
- facilitate support for disabled children to use universal services such as play schemes, extended school activities and youth clubs
- increase the range of activities available in the local community

Please read the detailed update on Herts direct:  
<http://www.hertsdirect.org/caresupport/childfam/specialneeds/aimhigh/>

## We want to involve Dads too!



We are aware that the term "parent carers" is often taken to mean Mums. We are keen to involve any unpaid carer who has a view on the services received by families of children with special educational needs and disabilities in Hertfordshire.

We want as many parent carers as possible to sign up to our newly formed **Parent Carer Involvement Network**, this will enable parents to keep in touch and have their say. Parents will be invited to relevant focus groups and events and will receive a regular e-bulletin as well as a newsletter.

The **Parent Carer Involvement Board** is the steering group for the development of parent carer participation in Hertfordshire, and meets in the evening about eight times a year. Our aim is to represent the voice of the Parent Carer Involvement Network and to influence service improvement across health, education and social care.

**Training and support are available for parent carers interested in getting involved.**

## Parent Carer Event June 15th – Developing Involvement in Hertfordshire



*Carers cake made to celebrate the day*

On 15th June 2010, 50 parents took part in Developing Involvement in Hertfordshire, a conference held at the Bio Park in Welwyn Garden City.

The conference programme included updates on the national and local delivery of the Aiming High Programme, including the decision to develop an Adventure Playground at Aldenham Country Park in Radlett and to locate the residential respite care unit replacing Stairways and Adrian Road at West Hyde in Rickmansworth. There was also the opportunity for parents to have their say about a range of services including specialist Holiday Playschemes and to discuss the new Hub and Spoke service model.

At the end of the day, 19 parents signed up to join the Parent Carer Involvement Network, which brings the network membership to a healthy 60. More volunteers would be most welcome!

As this conference took place during Carers Week, we decided to combine work with pleasure and all enjoyed a special CARERS CAKE, made for the occasion by Bose Adegbola, the Administrator for *Carers in Hertfordshire* West Team. The day was rounded off with a free raffle when four lucky parents won the following prizes: £30.00 John Lewis vouchers, £25.00 McMullen Meal vouchers, tickets for the Hemel Hempstead Snow Dome and tickets for Roller City at Campus West.

# Developing Special Provision Locally (DSPL)

The Parent Carer Involvement Board presented its response to the "Developing Special Provision Locally" consultation to Jim Dalton, the lead officer and his colleagues at the end of May 2010. We liked some aspects of the proposals but did have some concerns and questions about other aspects. Our response can be accessed at [www.carersinherts.org.uk/PCIB.htm](http://www.carersinherts.org.uk/PCIB.htm).

Jim Dalton has analysed responses to the proposals and he has submitted a paper for County Council cabinet approval on 19th July 2010. The Parent Carer Involvement Board would welcome the opportunity to be involved further.

## Meet Carol Kelsey, Vice Chair of the Parent Carer Involvement Board



**I am Carol Kelsey and I am the current Vice-Chair of Hertfordshire's Parent Carer Involvement Board. Like all members of the Board I am a parent carer.**

I have two sons, my eldest is a teenager with autism and learning difficulties. In common with so many parent carers I have struggled to come to terms with his condition and at the same time negotiate our family's way through the maze of services that are education, health and social care. Some parents may

know me, as for many years I was a volunteer for harc (the Hertfordshire Branch of the National Autistic Society). At harc I helped to support parents through information, meetings and events. During that time I also occasionally represented the views of families affected by autistic spectrum disorders to officers and Councillors in Hertfordshire County Council.

I have felt for a long time that there needs to be a way for the views and skills of parent carers to be routinely involved in shaping how services for our children are developed. Therefore I welcomed the opportunity to get involved with the Parent Carer Involvement Board.

One thing that I have learnt over the years is that whatever disabilities and difficulties our children have the issues facing families are pretty much the same. In the current economic climate it is more important than ever that whatever money is available for disabled children is spent effectively.

I hope that some of you will be encouraged to come forward and get involved in some way with making a difference for our families.

**Any parent carers out there who want to make a difference?** Then please contact your local Parent Carer Involvement Worker.

## What are you talking about? – Understanding the Jargon

Do you sometimes talk to officers of Children Schools and Families and think that they are speaking a different language? Parent Carers often feel that service providers use too many acronyms or 'serviceland speak' which results in confusion and miscommunication.

**Here are some common acronyms translated:**

**CAF** – Common Assessment Framework, **TAC** – Team Around the Child, **CAB** – Citizens Advice Bureau,  
**BME** – Black and Minority Ethnic, **LDD** – Learning Difficulties and Disabilities, **LDPB** – Learning Disability Partnership Board,  
**PMLD** – Profound and Multiple Learning Disabilities, **BSF** – Building Schools for the Future,  
**SEND** – Special Educational Needs and Disabilities

## Send us your feedback and be entered into our prize draw to WIN a £10 M&S Voucher

We would welcome any feedback about this newsletter. Please let us have your views as to whether you find this information useful and we welcome any articles about involvement. Just send your name and address with your comments and articles and you will automatically be entered into a free prize draw competition to **WIN a £10 Marks and Spencer voucher.**

Please send any feedback to Carers in Hertfordshire, FREEPOST ANG50009, Hertford, SG14 1BR