



# Notes

Parent Carer Voice

Wednesday 9 September 2015

Kindle Centre

- Chair:** Nicky Symonds (NS): Chair, Herefordshire's Parent Carer Forum
- Note takers:** Michelle Baillon (MB), Helen Young (HY), Katherine Fellows (KF)
- Present:** Debbie Smith, Helen Young, Melanie Kay, Karen Childerley, Beverley Rodgerson (BR), Christine Yeomans, Rachael Noble, Katherine Fellows – Herefordshire Carers Support, Christine Price (CP) – Healthwatch Herefordshire,
- Apologies:** Sara Reid, Cathy Hayes, Jacqui Bremner, Janet Fleuchar, Lauren Keen.

## 1. WELCOME AND APOLOGIES

Everyone welcomed by NS and that it was good to see so many at the Voice today.

We went around the table and introduced ourselves.

Christine Price (CP) introduced herself and explained that she has been asked by Jacqui Bremner to pick up on issues, what works and what doesn't work within Health & Social Care. NS said that CP had been invited as there were issues raised when the health visitors attended meeting. Examples from parents would be very helpful and much needed.

Bev R (BR) explained her role with [SEND IAS](#) and [Independent Support](#).

Apologies, as above.

## 2. NOTES FROM THE LAST MEETING

NS and KF spoke of the difficulties of agency staff with Children's Social Care Team keep leaving work and assessments unfinished. It was said the Head of Safeguarding is leaving. Noted Social Workers get a rapport with a family – then leave. Families having to go through this process repeatedly. This will have a major (negative) impact on children. Parent Carer said that she received an email from her son's social worker to say that he was leaving and that case had gone to panel in July, nothing has happened since then.

Issues with Education, Health and Care (EHC) Plans for college students. The sudden closure of the Contact Course prior to the summer holidays had left several students who were expecting to go there shocked as were their parents. In one case, the proposed EHC Plan was then not completed, by the Social Worker (SW) for that student as the young person and Parent Carer were not able themselves to argue for a "similar/alternative educational option. Hereford College have problems with accepting pupils with EHC plans and appear to lack a grasp of statutory obligations. It was felt they didn't understand mental health and do not look at individual child. Also appear not to be reading EHC plans. It was

suggested Hereford College could advise if a course is unsuitable for a young person e.g. too complex. Again parents need to record examples.

Parent Carer said that she feels the college have not grasped that it is their statutory duty to follow the EHC Plan.

Parents need to catalogue issues they are having with regards to local college provisions and the suitability to meet needs. NS felt that parents might need to meet up before meeting with Ian Lancaster (**29 September, 7pm** at The bar of The Royal Hotel, Palace Pound, Ross-on-Wye HR9 5HZ and **6 October, 10am** at Herefordshire Carers Support, Berrows Business Centre, Bath Street, Hereford).

NS mentioned the free [training Herefordshire Carers Support are running](#) and encouraged Parent Carers to book on. Future training is in the pipeline and will be specifically for Parent Carers and asked parents to be make suggestions about what training they would like.

## **Direct Payments**

Extremes of scale either wonderful or too complicated.

## **Training**

### **a. Hospital Passports**

Hospital passports/ individual profile needed. Something that could be used in various situations e.g. GP Surgeries, Guides, EHCP. Workshops are being planned to support children/parents to pull passports together. RN said she is happy to support in this area as she has a proforma for using with EHCP that we can also consider. Copies of the Hospital Passports were handed out.

### **b. CAF 'To make GP practices more welcoming'**

It was brought up the importance of Parent Carer feedback with regard to GP practices – not just negative feedback. Positive feedback is very important because other practices can learn from the example. Parents need to be more involved and encouraged. Leaflets were handed out to all present.

CP said that this seems to be an issue in that GP's are needing to know that a child/young person has a disability and how the GP Surgery can or is making adjustments – no feedback as yet as to whether this has been addressed. NS said that Herefordshire Carers Support's GP Link Worker meets with Carers Leads – what works and what hasn't worked – to establish good practice. The interest and group has been very successful. Many surgeries have been very adaptive when an individual response is needed and discussed.

<http://www.helpineedhelp.com> recommended as a very useful.

Parent Carer asked if there was joining up between [Mencap](#) and Travel Trainers from the Council.

CP asked about action 6 and if they could details so that [Healthwatch Herefordshire](#) can follow this up.

Parent Carer said she visited A&E with her daughter and the staff were brilliant and now that they have a separate waiting area for children is less daunting. CP said that over the Summer a new Triage system has been put in place so that people are signposted to different streams to be seen according to health needs in the hope of cutting waiting time's issues. Experiences are varied. CP felt that making use of the [Hospital Passport](#) could

help. KF said that when she worked with children with disabilities that often it is due to lack of understanding of people in the waiting room and fear of the staff not knowing how to deal with children/yp with disabilities. Parent Carer said her two children struggled when they went for a hospital appointment and her one child was most anxious and it was a struggle and that unfortunately no one helped her.

### SEND IAS

BR wanted to clarify that SEND IAS is not with the Local Authority. Totally separate, the only connection being the Local Authority pay the service. She said that they are now based at Franlin House which has helped. Parent Carer said that she felt that the fact that the representative from SENDIAS and the Education Officer arrived together and she didn't feel that she was been helped. Bev hopes the reputation has not been tarnished. KF mentioned that there is going to be a meeting held in October to discuss working protocols for the Independent Support service.

### **National Autistic Society**

National Autistic Society (NAS) branch now in Hereford. Branch based at Hope City in Gaol Street. They have an email address [NAS.Herefordshire@nas.org.uk](mailto:NAS.Herefordshire@nas.org.uk) and will reply to questions within seven days that are posted via email.

### **Ross Parent Carers evening support group**

Ross Carers meet monthly, and is attended by parents and professionals. It is held on the third Wednesday of the month, 7.30pm – 9pm at the Royal hotel, Ross-on-Wye. Set up by Parent Carers who live in Ross-on-Wye and South Herefordshire. The group is looking at pulling together activities for families. They have a web page ([Parent Carer Network](#))

## **3. REVIEW OF SHORT BREAKS**

The database is available for parent carers to access information and holds a directory of activities and short breaks that are available nationally and are accessible to people with disabilities and special needs. Easy to use. Michelle demonstrated you can search by tabs or A-Z.

New features added including option for Parents to rate a place/organisation which will be vetted by Herefordshire Carers Support before being published onto the website. Feedback is useful for other Parents looking at venues to go on holiday.

To find the site you go to Herefordshire Carers Support's website [www.herefordshirecarerssupport.org](http://www.herefordshirecarerssupport.org) and click on the tab for 'Short Breaks'.

Very clear and easy to use. You can search destination wishing to go (international or national), disability type or age group.

Review of Short Breaks coming very soon. NS recommended that parents must complete the surveys regarding Short Breaks, make it clear that they are important to them and need them to continue. If parents do not voice their opinions and campaign to keep services it is more likely that these will be cut further.

Money needed for different activities ([RDA](#), [Marches Family Network](#), swimming etc). Parents need to voice how much they need services like these.

It was mentioned very strongly how much Ledbury Road is needed. There isn't anything else in place to replace No.1 Ledbury Road. Parents are extremely concerned.

Funding cuts is a big worry. Skills club at Westfield had had funding cut by 20%. Skills club in demand, waiting list to attend. More services need for our children. Need is high for social clubs.

Westfield, Brookfield, Blackmarston and Barr's Court Schools have all lost TA staffing which it is feared will have a knock on effect with students.

The holiday club at Blackmarston was pulled at the last minute having a significant impact on working parents and all arrangements made to cover holiday care with little notice.

It was raised that this could be seen as a 'significant change to service' which means that a formal 12 week consultation should have taken place? With all the cuts in education it was suggested that Jesse Norman/Bill Wiggin were contacted to create a 'Partnership with Parents'. NS suggested that ACE could be contacted for advice around this and how to move forward.

Bids have already gone in for grants. Noted, less money, more hours for higher needs. It was suggested to find out what the process involved is/time frames, budgets this year/ next year. 5,000 minimum and 20,000 maximum for bids. Daniel from the Ross Parent Carer Network group is putting together a bid to improve health for parents and children in Ross-on-Wye.

Concern that early intervention has gone. Crisis will cost more. Suggestion looking at broad needs of child then more inwards to Early Support Service needs.

Waiting lists for OT and other health professionals. Who independently assess schools?

Transport for post 16 is a major concern.

Meeting with Ed Edwards regarding EHC plans. Parent's feedback welcome.

Meetings scheduled for:

**Tuesday 22 September 2015**, 10am – 12noon at Plough Lane and

**Wednesday 21 October**, 10am – 12.30pm at Herefordshire Carers Support.

Meeting on 21 October will focus on two areas:

- i. Requesting Statutory Assessment/the Family Conversation including what information to provide
- ii. Annual Reviews including for those converting from a Statement of SEN to an EHC Plan. All Parent Carers welcome to attend.

#### **4. UPDATES**

##### **a. Herefordshire Council's Service Redesign Group**

Rita Scott not at the meeting. NS briefly recapped feedback notes from RS and stated CHIPP meetings have been stopped.

Ian Lancaster, Project Lead has been pulled in to Herefordshire and will be here until April. He is wanting to consult with families to see what works, what's not working on 8 October 2015, 10am – 1pm at Herefordshire Carers Support.

Pre-meetings on **29 September, 7pm** at The bar of The Royal Hotel, Palace Pound, Ross-on-Wye HR9 5HZ and **6 October, 10am** at Herefordshire Carers Support, Berrows Business Centre, Bath Street, Hereford.

## **b. Autism Strategy Group**

Parent Carer explained about [Safe Places](#). [More information](#) needed for people to know more about it and the public to be more aware. A sticker in Safe Places i.e. shop where someone can go into to get help and support. MK very positive about these meetings and as far as possible would like to continue with these meetings. MK will ask travel trainers if they will include highlighting 'Safe Places' in there working with Young People.

## **c. Independent Support**

Katherine Fellows, Independent Support (IS) Service Coordinator said that the (IS) staff are very busy.

## **d. Information sessions (Portage groups)**

To follow on from sessions at Blackmarston and Barrs Court Hub, The Voice arranged two sessions with Portage staff at Widemarsh Children's Centre (Hereford) and Westfield's Children's Centre (Leominster) for any families they had been working with. PCV arranged to attend taking and offering information on HCS, PCV and IS and EHC Plans KF, NS, CH. Three of the dates were attended and the parents who were unaware of our services were very keen to share their services and learn about registering.

One member of staff showed great interest in Herefordshire Carers Support and training. The Portage Staff also received further leaflets that they found useful, but felt at weekly Portage sessions they were often unable to share information such as ours because of normal daily routines and time constraints.

## **e. West Midlands Regional and National News**

NS confirmed how beneficial it is to go or join Facebook closed group of West Midlands Regional Parent Carer Forum to find out what is doing on in different parts of the country.

She has been attending West Midlands Forum in Birmingham. MK and LK have also attended. Ideas and training are shared between the areas - forums in regions or across the country are joining to be more proactive at strategic levels and share "practise" - BIGGER VOICE TOGETHER.

Any parents wanting to attend [NNPCF](#) meetings alongside NS, please let NS know. HCS will cover expenses, which will come out of the Parent Participation Grant.

Future date: 18 October in London for National Network of Parent Carers Form Annual Carers Meeting and Conference. Please let NS know if you would be interested in attending with her.