



Notes

Parent Carer Voice

Wednesday 12 January 2015

Kindle Centre

- Chair:** [Jacqui Bremner](#) (JB), Director of Herefordshire Carers Support
- Note taker:** [Katherine Fellows](#) (KF): Independent Support Co-ordinator, Herefordshire Carers Support
- Parents present:** Rita Scott (RS), Abi North (AN), Karen Childerley (KC) Vice Chair, Louise Walton (LW), Jo Lofting (JL), Max Bassett (MB), Laura Eacock (LE), Claire Justice (CL),
- In attendance:** [Christine Price](#) (CP): [Healthwatch Herefordshire](#)
- Apologies:** [Nicky Symonds](#) (NS): Chair, Herefordshire's Parent Carer Forum, Helen Young (HY) Parent Carer, Debbie Smith (DS) Parent Carer

1. WELCOME AND INTRODUCTIONS

KC has agreed to be the Vice Chair for the PCV and will stand in when NS is away.

JB has met with NS to set the agendas for the PCV for the year.

Every third meeting will be a business meeting where the work plan and other issues raised by parent carers will be discussed and progress monitored.

Actions will be identified and these will be checked again at the next business meeting to ensure that they have been followed up.

The implementation of the [Children and Families Act](#) and [SEND Reforms](#) will also be discussed and local issues will be identified.

We now have VOICE representation at the Service Redesign Group and Autism Partnership Board.

Parent Carers will be encouraged to get involved as much as possible with consultations such as Ed Edwards EHC review meetings.

When it is not a business meeting speakers will be invited to attend to cover issues pertinent to Carers. Speakers will be invited according to the VOICE work plan that will be revised for 2016/17.

Following the last meeting KC had offered to join the LA Post 16 group. BR was checking this out as she thought that currently this is just a professionals group, but they feel this may be a good idea and are currently considering a PC representative. KC said that BR will get back to her about whether or not she may be able to attend.

JB said the VOICE has always taken the approach of inviting service managers to the PCV so that they can hear direct from parents about their experiences and issues, they are also invited back to future meetings so that things can be followed up.

2. THE WAY WE WORK DOCUMENT

JB explained that there has been a change to this document to include how the minutes are ratified by the group. The minutes from the previous meeting will be sent out to all attendees for agreement and will then be ratified at the next meeting. Guest speakers will also be sent out copies of the minutes before they are approved to ensure that they are happy with what has been recorded about their presentation.

The changes to the [Way we Work Document](#) were signed off by the group.

The notes from December's meeting were agreed by the group as an accurate reflection of discussions.

CP spoke about the recent Healthwatch survey regarding autism. The outcome of this is that there will now be an Autism Lead within the [CCG](#). JB talked about some of the specific issues regarding autism and how some families are having to go outside of Herefordshire to gain diagnosis for adults particularly where there is a co-morbidity and other conditions mask the fact that there is an underlying diagnosis of autism.

Healthwatch Herefordshire is working to ensure that health services within Herefordshire are aware of these issues and to progress the training of health professionals to identify ASD as a clinical priority.

KC raised that there is an issue that even once you get a diagnosis of ASD, services can still be difficult to access. CP (from Healthwatch) stated that an increased number of people diagnosed with ASD will make a better case for the allocation of resources.

CP mentioned that it can be confusing for parents as lots of different agencies are using similar documents such as the Passport, single page profile, one page profile etc. the group discussed that it would be much easier to develop one document such as the passport which can be interchangeable to inform all of the different documents that may be required by health, education and social care services.

CP is going to look at the development of this document and will come back to the PCV to gain the views of the group as to what will be required and what will work.

JB reminded everyone that parent carers who attend the PCV can claim travel expenses and encouraged everyone to do so.

It was highlighted to everyone that future meeting dates and training dates are on the back of the December minutes. JB said that all parents can access all of the training on offer from HCS – the training programme is on the HCS website.

LW queried whether parents who are not registered with HCS can access the training, JB said that they can but we would also encourage them to be registered with HCS so that they can access the full range of information and services if they wish.

JL raised that there is other generic training also available that is not specific to parent carers but would also be useful such as the DoLS (Deprivation of Liberty Safeguards) & MCA (Mental Capacity Act) training which is available on the training programme on the HCS website.

RS gave an update on the situation with Ledbury Road. The LA have agreed that this setting will now stay open for another 12 months to offer respite to families whilst alternative provision is arranged for when the unit eventually closes next year. The plan is still to close

Ledbury Road but there is a consultation in the form of a survey which has gone out to those families affected. This will close on Friday (15 January).

The VOICE are inviting Richard Watson to come to a future PCV to discuss Short Breaks.

Jade Brookes (Lead commissioner for children from the CCG) wishing to attend the April PCV to discuss local health services. NS had written to her about the Continence Service which was discussed at the last meeting.

3. INTEGRATED PATHWAY ([Ian Lancaster, Project Lead](#))

Following up from the last presentation Ian reported that he has put forward a recommendation about the forum being included in the LA Governance. The hope is the LA would use the PCV as a reference group for consultation and discussions about issues, this would keep it simple for parent carers and would avoid the need for parents to attend lots of different meetings.

Ian explained his role to the group currently he is managing 3 projects: Direct payments, Integrated Pathway and Transitions.

Ian explained that Direct Payments are a way of delivering Personal Budgets. Ian explained that work was underway to develop a process for calculating Personal Budgets based upon assessed need.

Ian explained that there is a tool that the LA uses called the Resource Assessment Matrix which is used to assess children's eligibility for services. It had been proposed to use this matrix as a basis for calculating the Personal Budget. Three different ways of doing this had so far been tried ([handout attached](#)). He explained that one of the issues is that some of the funding is currently tied up in commissioned services meaning that direct payments cannot at present be offered for these services as effectively the LA would be paying for this service twice. KC asked if this is yet included in EHC plans. Ian said that currently it is only Social Care that they are looking at.

Ian explained the RAS (Resource Allocation System) and how this could be used to identify the resources required to meet a child's needs. LW asked how a family can access this and Ian confirmed that there would need to be a referral via Social Care.

KC raised the point that in that case there will be large numbers of children with ASD who are not in the social care system who although on paper are eligible will not be able to access direct payments. Ian confirmed that at the moment this is the case. Ian stated that one of the benefits of the RAS is that it is completed by the Social Worker and could avoid the need for cases funded within the Personal Budget going to panel, saving the council time and money and reducing the stress on families. However for more complex cases that do not fit in with normal trends these would still need to go to panel for discussion and approval.

AN raised the point that her son had been having a Family Support Worker working with him via the Children with Disabilities Team and was then assessed for a buddy via Crossroads. Abbi said that as soon as this was agreed in July the FSW was no longer allowed to work with her son and there was then a gap where he had no support at all until the Crossroads buddy was identified which has only just happened. AN stated that although they have just managed to cope it could result in a family breaking down under the stress. Ian said that he will feed this concern into the Children with Disabilities Team.

Ian is continuing to work on this project and will continue to consult with parent carers and will also widen the project to include children that are in transition to adulthood.

Ian shared the Draft Transitions Pathway ([please see attached document](#)) – Ian has been working on addressing how information is presented in a way that is easily understandable and grabs people’s attention. This is still in draft form and Ian is inviting comments and suggestions of people feel this can be improved upon. Jo mentioned that in her experience the Transition Reviews happened as they should have done and she was confident that her son’s transition to adult services and appropriate provision would be fairly smooth. However in reality this was the case and much of the work done at the Transition reviews was largely ignored and they had to start this from scratch.

KC asked about whether a Direct Payment can be used for transport as this stops when a child reaches 16 meaning there is a real barrier to accessing services. Ian stated that the direct payment could only be used for transport if this is specified as a need in the social care plan.

Ian talked about the Early Support Audit ([see attached](#)). The results of this will feed into the Integrated Pathway work.

Lunch and Close.

Date of next meeting: Wednesday 10 February 2016, 10am - 12.30pm at Kindle Centre, Asda, HEREFORD.
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