



# Notes

## Parent Carer Voice

Wednesday 8 June 2016

Kindle Centre

- Chair:** Karen Childerley (KC): Co-Chair of The Voice
- Note taker:** [Katherine Fellows](#) (KF), [Independent Support](#) Coordinator
- Parents present:** Nicky Symonds (NS): Co-Chair of The Voice, Melissa Boyle (MB), Max Bassett (MB), Sue Herrington (SH), Clare Hobbs (CH), Jaime Miles (JM), Rita Scott (RS) and Louise Walton (LW).
- In attendance:** Richard Watson (RW), Children's Commissioning Lead, Carol Williams (CW), Commissioning Support Officer and Gurinda Ryatt (GR), Service Manager for Children with Disabilities from Hereford Council
- Apologies:** Helen Young (HY)

### 1. WELCOME AND INTRODUCTIONS

See attendance list above.

### 2. COMMISSIONING OF SHORT BREAKS

RW, Children's Commissioning Lead and GR, Service Manager for Children with Disabilities attended to discuss Short Break Commissioning.

The [Parent Carer Voice](#) (PCV) asked for an update on the Short Breaks outcomes that were developed in 2013 to see how these are working and if they are still relevant.

RW is also looking to recruit Family Envoys in order to participate in the Short Breaks commissioning process. Current Short Breaks contracts expire on March 2017 after which they will need to put these contacts out to tender. Up until this date RW will be researching current Short Breaks provision and people's current experiences of the Short Breaks Service, they have had a phone survey recently and he wishes to get parental feedback.

Commissioning will have three phases, there will be a 6 week consultation period starting in July, the elements that we are going out for consultation are yet to be agreed. From mid-August RW will be collating and evaluating the feedback from the consultation and will take his findings and suggestions for services to Cabinet in September. Following this the contracts will go out to tender and RW hopes contracts will be in place by Christmas 2016. The contracts will then be ready to go from the 1 April to ensure continuity of service and effective planning/transition for children and young people.

KC asked if residential style Short Breaks appear to be being phased out and the feeling of PCV members is that these are the only settings that can meet some children's needs. RW said that all cases will be individually assessed for their needs by social workers from

Children's Services and if the assessment recommends residential Short Breaks then the LA must provide these.

KC raised concerns that there is a fear that all children will attempt to be fitted into foster respite services and that this may not always be suitable. RW stated that Short Breaks can also be delivered as a [Direct Payment](#) if parents would like to commission their own services. LW stated although this may look like an option it is very difficult if there are no services to purchase. GR stated that the LA are looking to commission additional services to bridge some of these gaps. J asked GR for the difference between buddying and Travel Teach as there seems to be confusion about these two elements and who pays for them. **ACTION: GR will clarify, how travel teach and buddying are funded.**

KC raised that there is a shortage of social workers to complete assessments meaning that families are missing out on the ability to access services. GR said that not all families will need a social worker and that referrals will be screened by MASH. GR stated that there is currently a compliment of 6 full time Social Workers, 3 family support workers and a manager covering approx. 190 cases and she feels that at present this is a stable team.

KC asked Autism Spectrum Disorder (ASD) children and young people as they routinely fall through the gaps in the service. GR responded that all cases are assessed on individual need. Members asked if GR would be staying in the LA for long as she is only interim, she said her contract has been extended for a further 3 months. PCV were informed Eve Schniederwind has now been appointed as a Team Manager.

RW stated that they have contacted 55 families, out of 190 to complete a phone survey so far and that this will be a pre-cursor to the main consultation in July. RW assured the group that there would be ongoing consultation. NS raised that with telephone surveys it's really important that calls are made at sensible times to take into account family needs; as with other services an appointment time for the call would be useful rather than "cold calling". CW said she had arranged to ring back on some occasions.

In 2013 a group from PCV worked with Maria Hardy to produce a set of outcomes for Short Breaks. RW read out some of the feedback from the telephone survey in response to these outcomes, \*please see attached. During the recommissioning the outcomes can be considered and improved.

Outcome; "getting to know other families in similar situations with similar experiences". RW stated that the feedback suggested that this particular outcome has not been met over the past three years, in relation to short term breaks and asked if the group feels that this is an appropriate outcome for short breaks. The general feeling of the group is that this should not be a function of Short Breaks as there are lots of opportunities for families to meet up if they wish such as support groups, PCV etc.

KC raised concerns about the transition to adult services for young people with a disability, particularly as technically under the [Children and Families Act 2014](#) they are classed as a child until the age of 25. GR explained that the LA acknowledge this area of the service needs to improve and feels that they assess too late, she is currently working on this. Parents talked about how some families have fallen off a cliff after the age of 18 and are left without any services or support and this is unacceptable. MB raised issues regarding individual cases that were no longer receiving respite care; ACTION: GR will look into this again. With regards individual cases. The forum is not a venue to discuss individual cases. Any queries need to be discussed with the allocate social worker.

GR stated that the Local Authority (LA) are developing a suitable service to support those young people within the 18-25 year age range. Housing provision is also an issue which is being looked at by the LA.

NS described a feeling of chaos with regard to Children with Disabilities (CWD) services with many of the "core" families who had been using Ledbury Road, not even having their

needs met. Not enough assessments were being done, or completed; apart from unmet needs, many were not even assessed. Also this would affect the number of Carers assessments being offered, known or completed and eligibility for other services.

Parents have surveys every year from the LA and the issues are always the same. It seems that the majority of issues are not resolved despite similar feedback each year and nationally. There is a fear amongst PCV members who are present that post March 2017 things won't have been sorted out and families will be left high and dry. RW explained that this is precisely what the consultation and commissioning is seeking to avoid.

A member at the last PCV meeting in May had suggested, as an alternative, a survey be sent to professionals of Herefordshire to review their opinions of services, roles, working together, process and needs of families etc.

NS reminded the group, that this meeting was primarily to consider the recommissioning and making suggestions for the future, with RW. Issues that were being raised regarding past and current issues whilst important, had been acknowledged and would be addressed at the 13 July meeting when GR and Elspeth Dixon, Health Improvement Practitioner were due to visit.

The question was asked if services other than those based in Herefordshire can be accessed or those that are not directly commissioned by the LA with Short Breaks? RW and GR explained that they are not able to answer all questions today but that they would like to build flexibility into the system however block funding of contracts will have an impact.

We talked about how some children are missing out on services as their requests for direct services with regard to OT, Physio, SALT as these are all block contracts that simply do not provide and sufficient level of service to meet the needs of all the children within the county.

One parent present gave the example of paying herself for a professional to see her son (reception - mainstream school), who has an [Education Health and Care plan](#), due to the waiting list. Again GR stated that the LA are looking at increasing service levels in this area and acknowledge there are issues. PCV members voiced that these issues are having very real, long term and negative effects on children's lives. If the need was assessed and unmet because the local service could not meet that need due to pressure, it would be "making it real" to use some direct/personal payments for a family to access a service at the appropriate time. GR and RW stated there are issues at present and would need looking at.

MB raised that communication between parents and the LA must improve and this also came out as part of the survey. She stated how this adds to stress and anxiety when you have to constantly provide the same information to multitudes of professionals and still the message does not get through.

JM asked how soon the funding should be agreed following an assessment by a social worker for buddying/direct payment for a PA? GR responded that it should take no longer than 3 weeks although this can be effected by waiting for [DBS](#) checks for staff.

KC checked who would like to be Family Envoys to work on the consultation with RW. LW and MB have put their names forward. [shortbreaks@herefordshire.gov.uk](mailto:shortbreaks@herefordshire.gov.uk) is the contact email for this piece of work. **ACTION: any parent carers who would like to take part in this should get in touch via email or speak with CW with questions or ideas.** These families would not necessarily be expected to meet regularly and RW does not expect it to involve a long commitment.

RW is keen to set up a set of ground rules with Family Envoys regarding how the piece of work will be conducted. NS suggested that we consider who become Family Envoys, and that we try to reflect different ages and needs. These families are reminded that you would be entitled to receive both travel and reimbursement for your time at these additional meetings/involvement.

RW would like to be invited to events with families so that he can be available to answer questions and get feedback from parents and will also do some online events etc. We suggested support groups, [NAS](#), support groups with Cathy Hayes, Parent Carer Support Worker, Marches Family Network and coffee mornings at Special Schools etc. NS will compile a list of dates and forward to RW. LW, said she would be welcome as invited in the past, to visit [Marches Family Network](#). RW explained who was currently working with him on the recommissioning; CW, GR and two members of Clinical Commissioning Group (CCG). which may affect if and when they would be available to attend groups.

MB asked if there would be an alternative to Ledbury Road post March 2017. RW said that [Aspire](#) have expressed an interest but that this will be dependent on the tendering process. Other organisations were mentioned. This is causing huge anxieties for families that fear they will be left with nothing as there will not be enough time to put things in place.

KC asked what the LA suggest families do that are left without services post 18? **ACTION: GR said that she will answer this question when she next attends the PCV in July.**

MB raised issues regarding individual cases that were no longer receiving respite care; **ACTION: GR will look into this again.**

The issue of how to maintain interest and feedback from families was a concern of the group. The time frame July - September, for this short term break review and recommissioning of Health Services for children is the same, although the initial written review was due out in March 2016 and delayed.

NS explained that we have still not heard back from Jade Brookes, Programme Manager Children and Mental Health Services at Herefordshire Clinical Commissioning Group reference the Review of Children's Health Services in Herefordshire and a letter has been drafted to Jade to follow this up.

The group agreed that it is really unhelpful to consult over the school holidays due to caring responsibilities.

JM raised that not all the families are having all of the hours that they are allocated, at Ledbury Road, for various reasons. RW said he was not aware of this and that these hours are already paid for by the LA. **ACTION: RW to look into it.**

NS spoke of attending the [Learning Disability Strategy Board](#) Meeting and that she had suggested the recommissioning of short term breaks and respite care may be relevant within their remit.

Many of those present were able to be with young people and adults up to twenty five years. John Gorman had understood this group to be for "adults" but the issue would now be discussed further. Parents, carers and service users at that group and the PCV felt the transition and Learning Disability issues were continuous and need to be addressed with flexibility and common sense across services.

RW said that he would talk to John Gorman about the Adult Learning Disability Team and how this can be more seamlessly integrated into the Children With Disabilities Team.

RW, GR and CW left the meeting at 11.20am.

### **3. MINUTES FROM THE PREVIOUS MEETING AND MATTERS ARISING**

JM asked if the PCV has written to The LA ref Ledbury Road following the meeting in May. NS explained that Jacqui Bremner, Director of Herefordshire Carers Support has met with RW who had agreed to use the PCV to consult over the planned changes to Short Breaks and Respite, including Ledbury Road. The planned letter to RW asking him to let us know his intentions was not required.

**ACTION: A letter will be sent from the PCV/HCS and/or meeting to be held to address the ongoing concerns that families raise regarding communication, lack of services, contact and outcomes with social workers.** MB had forwarded some suggestions and contribution. This letter is intended for Jo Davidson and GR. We will be working with Jacqui.

The group discussed how families that had used Ledbury Road could best be supported now. MB and JM felt the Ledbury Road group had become less involved with each other as children were individually moving on. People were tired and frustrated as time had passed. We spoke of HCS and it was suggested that it may be appropriate for Cathy Hayes to become involved as the Parent Carer Support Worker, with some families if known to her through HCS. KF will check whether this is possible as this may be a capacity issue for Cathy or the parent carers, may need to agree to be contacted by HCS/Cathy.

MB is also going to text to families that she knows that attend Ledbury Road and put a post on Facebook about issues at Ledbury Road and if they wish to request independent advice or support or to give feedback on services, to contact Herefordshire Carers Support.

**ACTION: MB will also put out on Facebook that Children's Wellbeing are looking for parents to take part in the consultation and for individual "family envoys".**

NS explained that both Blackmarston and Westfield Special schools had a newsletter that had the recommissioning of short term breaks in them. In the future we will consider whether school newsletters are a means of passing information on. Also cheaper than The Primary Times that we considered in the past.

**ACTION: JM will also ask Schools to sign post families to the Short Breaks Consultation.**

KF also found out about training for SENCO's and we had discussed this with Ed Edwards when NS and KF met to complete SEND survey. This is provided by the LA and some is bought in. **ACTION: KF to see if information can also go out via the SENCO network.**

Carol Soble is leaving her job, working with children attending main stream schools who have "autism"; she will not be replaced. Currently 2 teachers from the specialist unit at Hampton Dene are giving outreach across the county for Behavioural Support, this has been incorporated into their present roles.

**ACTION: KF also found out that in Training and apprenticeships settings there does have to be a person who is nominated to support SEN students but they do not have to be specialists in SEN.** This raises several issues - for future discussion.

Jacqui and RW have agreed that he will use the PCV to consult parents over various issues as well as wider consultation.

Jacqui, KF and NS have completed the [Parent Participation Grant](#) and this has now been submitted. RS asked if there could be a payment made to parents to encourage them to attend the PCV meetings, as we still need more members. Typically people come and go. RS also feels that we should spend the grant more creatively to encourage a wider attendance.

The group agreed to continue funding the lunch from the participation grant, at these meetings, despite the change of agreement and cost. It was agreed it was appreciated and appropriate for those attending. **ACTION: NS to discuss with Jacqui.**

Christine Price from [Healthwatch](#) asked **ACTION: NS and KC to write an piece about the PCV forum, which will be in their next Healthwatch Newsletter.**

KC asked it to be put on record that with regard to the Hate Crime training that was planned at the last meeting but not delivered, she would like to pass thanks from the group to Valerie Fitch, Trustee for Herefordshire Carers Support for all her hard work and to assure her that we have the training materials if anyone would like to access them.

KF found the SafePlaces List that is compiled by MENCAP and has distributed this to the group. "The Safe Places" list is attached to the minutes.

Questions were asked about advocacy services for children and young people. KC said that she will research this and feedback to the next meeting.

The WISH service is now in operation and is based in St Owen's Street. There is a feeling that this is under-utilised but this may improve when they are in the Library. It is intended to encourage the use of IT to find services. Staff at the shop are willing to look things up with you; when the Citizens Advice Bureaux shuts on 24 June 2016, they may become busier. The CAB had put in a bid to provide this service, but was declined.

It has been suggested, that the office opposite the Hereford "black and white house" will become a place of social and small event gatherings. Two more staff are also being taken on. WISH do outreach across Herefordshire.

[WISH](#) staff stated, their funding is for two years only and unlike the [Local Offer](#) is not required by legislation.

Parent carer asked if Valerie Fitch had raised with the PCV that there will be a GP conference to get carers experiences of accessing GP services taking place on the 20 July.

**ACTION: KF stated that she hadn't heard about this and would ask Valerie.**

## ACTION SUMMARY

ITEM	ACTION	UPDATE	STATUS
<b>JUNE 2016</b>			
2	<ul style="list-style-type: none"> <li>i. GR will clarify, how travel teach and buddying are funded.</li> <li>ii. GR to explain what the LA suggest families do that are left without services post 18.</li> <li>iii. GR to answer questions raised (at July meeting) on individual cases that were no longer receiving respite care.</li> </ul>		
2	<ul style="list-style-type: none"> <li>i. Any parent carers who would like to take part in Family Envoys should get in touch with RW/CW with questions or ideas.</li> <li>ii. MB will also put out on Facebook that Children's Wellbeing are looking for parents to take part in the consultation and for individual "family envoys".</li> </ul>		
2	JM raised that not all the families are having all hours that allocated at Ledbury Road. RW to look into.		
3	A letter will be sent from the PCV/HCS and/or meeting to be held to address the ongoing concerns that families raise regarding communication, lack of services, contact and outcomes with social workers.		
3	<ul style="list-style-type: none"> <li>i. JM will ask Schools to sign post families to the Short Breaks Consultation.</li> <li>ii. KF to see if information can also go out via the SENCO network.</li> </ul>		

3	NS to discuss continuing funding lunch at meetings with Jacqui.	Agreed to continue providing lunch at meetings.	COMPLETE
3	NS and KC to write a piece about the PCV forum, for next Healthwatch Newsletter.		
3	KF to get more information on GP conference on 20 July.		
<b>MAY 2016</b>			
2	NS to discuss further with JB and approach professionals in good time to discuss proposals for a co-production day with Parent Carers. Need someone to facilitate September's meeting. To be discussed at June's meeting.	NS and KC met with Jacqui on 4 July. Jacqui has agreed to organise a facilitation for the annual meeting in September.	AMBER
2	KF to look into who provides training for SENCOs.	KF has discussed this with Ed Edwards when NS and KF met to complete SEND survey. This is provided by the LA and some is bought in.	COMPLETE
2	PCV to have further discussions for 18 years plus education, apprenticeships and college support for adulthood within learning education.	To be raised with Gurinder Ryat, Service Manager for Children with Disabilities Team at July's meeting.	AMBER
2	i. NS to discuss with JB and find out when meetings are taking place and when the consultation dates are.		
	ii. Write to Jo Davidson, Director of Children's Wellbeing voicing our concerns of how the children/families were experiencing the closure of 1 Ledbury Road. Also invite to PCV.	JD has been invited to attend to speak at Carers Rights Day in November later this year. Depending on outcome may invite to PVC in March 2017.	COMPLETE
	iii. Write to Richard Watson, Children's Services Commissioning asking for clarity about the consultation. Also invite to PCV.	RW attended June's PCV. See minutes above for full details.	COMPLETE
	iv. Parents to attend which is a legal requirement.		

	v. MY will compose a letter, with examples and forward to NS		
5	Consider who and how this meeting will be facilitated. The action list on PCV minutes and monthly topics and visitors indicate current ongoing issues.		COMPLETE
<b>APRIL 2016</b>			
2	KF to send out the notes from last NNPCF meeting.	KF's personal notes have been emailed to KC and NS. When official minutes are circulated by NNPCF they will be shared with members of The Voice.	AMBER
2	Follow up with EE regarding Parent carers sitting on the EHC referral panel. EE had also said there would be training available for this role.		

## APPENDIX B

### Future meeting dates

DATE	TOPIC	SPEAKER
10 February 2016	Direct Payments and Transitions	
9 March 2016	Review of The Voice 2015-16 Work Plan	
<b>EASTER HOLIDAYS: 25 March – 10 April 2016</b>		
13 April 2016	Contenance service and Child Healthcare Review Healthwatch Hereford (incl. Hospital Passports)	Jade Brooks Christine Price
11 May 2016	Hate Crime with West Mercia Police	Adrian Symonds
<b>HALF TERM: 30 May – 5 June 2016</b>		
8 June 2016	Commissioning of Short Breaks	Richard Watson
13 July 2016	Children with Disabilities Team Manager Integrated Pathway	Gurinder Rayat Elspeth Dixon
<b>SUMMER HOLIDAYS: 21 July – 6 September 2016</b>		
14 September 2016	Annual business meeting	
12 October 2016	Procurement of short breaks	Richard Watson
<b>HALF TERM: 24 – 30 October 2016</b>		
9 November 2016		
14 December 2016	<i>Cabinet Member: Young People &amp; Children's Wellbeing</i>	<i>Cllr Lester TBC</i>
<b>HALF TERM: 19 December – 3 January 2017</b>		
January 2017	Healthwatch Hereford (incl. Hospital Passports)	Christine Price
February 2017	Business meeting	
March 2017	<i>Director of Children's Services TBC</i>	<i>Jo Davidson TBC</i>