



Notes

Parent Carer Voice

Wednesday 11 November 2015

Kindle Centre

- Chair:** Nicky Symonds (NS): Chair, Herefordshire's Parent Carer Forum
- Note taker:** Helen Young (HY), Parent Carer
- Parents present:** Melissa Boyle (MB), Karen Childerley (KC), Jaime Miles (JM), Hayley Milner (HM), Abi North (AN), Rita Scott (RS), Debbie Smith (DS) and Christine Yeomans (CY)
- In attendance:** Jacqui Bremner (JB): Herefordshire Carers Support, Katherine Fellows (KF): Herefordshire Carers Support and Christine Price (CP): Healthwatch Herefordshire
- Apologies:** Jo Lofting (JL)

1 WELCOME AND INTRODUCTIONS

NS explained how over the previous eight months new people (Parent Carers) have been attending Voice meetings.

A few parents that come to The Voice meetings are not only Parent Carers but have a professional role in the system. It was advised that said parent(s) should declare interests at the meeting if they are speaking as a parent or in their professional capacity.

2 NOTES OF PREVIOUS MEETING

NS proposed to distribute minutes earlier to The Voice members to check and make amendments to the draft. Feedback to the draft minutes can be given via email and [Facebook](#). Minutes would then be signed off at the following meeting before being published to the website.

This proposal was agreed.

Christine from Healthwatch, asked for her introduction at the last meeting, to include not only Health issues but Social care ones.

Following the last meeting, Ian Lancaster, Project Manager sent out an audit to Parent Carers and professionals to gauge how they differ. Easy tick box (happy, not happy, agree, disagree) Parents were asked to fill in as many as possible to get good feedback about current services.

National Autistic Society (NAS)

The representatives of the [National Autistic Society \(NAS\)](#) explained how the new Hereford branch has had a few teething problems which they are confident will be resolved. NAS Hereford are now at Aspire/Pen House, Canal Road. The best way to currently contact them is via [Facebook](#).

3 INDEPENDENT SUPPORT (IS) SERVICE FOR THE PROCESS OF THE EDUCATION HEALTH AND CARE (EHC) PLAN

The IS service is totally independent, it is funded by central government. The professionals who sit on the Local Authority panel making decisions about EHC plans will not know the child/young person at all, therefore it's important to send as much detailed information as possible.

IS can support parents and young people who are going through the EHC process. Schools often report that in turn they find that this also serves as a support for them as the IS worker can help with the completion of paperwork and gathering information.

Initial process of getting IS support would be a referral to IS from the school's SENCO, professionals involved with the family or parent's themselves.

IS would then have a discussion with parents to get an understanding of the situation i.e. child/young person, family, school etc and would then support them to put together a robust EHCP request.

Request for an EHC plan similar to the old statementing system however emphasis is out on this being a more holistic picture of the child and their needs. EHC plans should be carefully put together and streamlined with agencies working together. Parents can request a co-production meeting with the SENCO and SEN team so that they are fully involved and consulted in the writing of the EHCP

Transition plan for statement converting to EHCP's taking place in transition years (6, 11, 14) with the aim being for all statements to have transferred to EHC plans by 2018.

There is a cultural shift with a more holistic approach and more emphasis on the views of families.

Changes system and the SEND reforms were felt by the group to have happened too quickly, parents feel it is so quick that the Local Authority are struggling to implement the changes.

Some parents stated that they feel, in some cases, that corners are being cut by signing off final plans without parent consent and information is being missed out.

One parent had a productive meeting with their child's Social Worker and thought the Social Worker agreed with what she was saying only to find that what was written in the assessment was very different.

KF explained how IS can help Parents/children/young people through the whole EHC process but not if a case goes into mediation or appeal. If Parents are not happy and want to enter into mediation/appeal the IS service will hand over the case to [SEND IAS Hereford](#).

SEND IAS and IS are putting together a joint leaflet to give parents a choice about where to get IS support, whilst also limiting confusion and ensuring that the information is accessible

as possible. A new procedure has been developed for the smooth handover of cases from IS to SEND IAS, for families that wish to enter mediation or appeal regarding a LA decision that they are not happy with. There is also a handover of more complex cases between IS and SENDIAS and not just those regarding mediation. It is hoped that a smooth transition between services will reduce the stress on families.

Parents said how important honesty in the system was. Experiences have been of paperwork changing, professionals saying one thing, then doing something different. Parents want honesty and to be able to trust professionals and the system.

EHC plans pull together all the assessments from the different agencies into one document (Core Assessment, Physio, SALT etc) to make a very detailed plan.

It was discussed how Core Assessments have different timescales to EHC plan assessments, which can cause complications and result in statutory timescales being exceeded. Parents need to understand timescales.

KF explained how there have been teething problems with the new system taking time to bed in. EHC process is only 1 year old and there will be a review of the memorandum of understanding for referrals into the Independent Support Service.

There have been a series of focus groups reviewing paperwork i.e. one page profile/ family conversation with Ed Edwards (SEN Manager) and two of his team and Parent Carers. Paperwork has changed as a result. There is a revised Family Conversation form that is available to be downloaded from the Local Offer.

Local offer

If Parents don't find what they are looking for they can feedback to Herefordshire Carers Support or to the Local Authority via the feedback button on the [Local Offer](#) itself.

The SEN team decide how much money should be allocated to your child/young person, this doesn't always reflect what is needed in the opinion of some Parents.

The High Needs Funding Matrix the formula by which the LA makes its decisions regarding funding (How much money may be allocated to a child to support their SEN), is available on the Local Offer SEN Pages. It is advisable that where relevant parents may wish to familiarise themselves with this document.

One parent said she didn't realise the impact of the questions she was answering and how it would affect the amount of money her child would get. Staff at Marches Family Network can help Parents fill in DLA forms.

Parents discussed how they were worried to challenge professionals in case it made their already difficult life more difficult.

Healthwatch Herefordshire

Healthwatch with the Autism Board are doing a GP Autism survey to see how autism aware individual practices are across Herefordshire. GP autism should be a clinical priority.

The background to GPs and autism can be looked up at www.healthwatch.co.uk.

Parents said how they have had negative hospital experiences with their children:

- One Parent said how their child's arms were held because their child was flapping
- Parent said how people spoke could freak their child out, including one Parent saying her child took a lot of attempts to go into a room because of the word "loud" being used.
- Parents said there is very little understanding in hospitals of SEN.

- A Parent said there are two play therapists working at the Children's Unit. Many parents are not aware of this. Sessions to introduce the idea of some form of treatment or intervention, can be arranged very individually, to meet the child's needs.
- Good practice examples, photos to help with understanding, practising,, playing with "equipment" at home, contact in school time.
- Previously bought up at The Voice how unprepared hospital staff are.
- One Parent had previously spoken during The Voice of her experience with A&E when her son had glass in his foot – he came away from A&E with glass still in his foot.
- During this meeting a parent told how she was informed the hospital would not have the facilities to treat her child.
- One Parent stated that she has found the appointments to Hereford Hospital very stressful on numerous occasions.

Preparation for hospital, dental appointments would be beneficial. On parent said how play therapy helped their child understand a hospital appointment. Visual cues also suggested.

Parents talked about the difficulties in getting a GP to make a home visit.

Parents expressed how unless it was an emergency they wouldn't feel they could ask a GP for a home visit even though the general consensus was it would make it less stressful if Parent Carers could get their child/young person a home visit from their GP.

It would be good if individual issues flashed up on computer screens about child/young person to highlight agreements, that had been made, to reduce difficulties. Such as waiting in the car until the appointment.

All GP practices have a Carers Lead, you can find out more by contacting Hilary or Mandy at Herefordshire Carers Support. It was suggested that the individual children and family's needs are so different, that each case must be discussed with the surgery concerned

4 FUTURE DEVELOPMENT FOR THE VOICE

Work plan review and ideas for the future

Talked about parents taking part in:

1. Interviewing to any posts that may affect their lives (will need training)
2. Committees (Parent Carer representation)

RS went to a meeting and met with professionals. They found it beneficial RS being there and thanked her for attending. RS said she was doing to put video footage together to show professionals. RS is the Parent Care Voice representative for the Council's Service Re-design Group.

3. 'Tell your story' – Parents discussed how successful this has been previously. The developed by a parent carer to get funding for teenagers to tell their story in the same format.
4. Focus groups - regarding the reforms have been held over the last few months (EHC, Local Offer, Single Integrated CarePathway). Focus groups to either be one meeting or series of meetings. Change that have been made by Ed Edwards for EHC plans have been put on the [Herefordshire Council website](#).
5. Coffee/ information mornings in schools
6. Home education in Herefordshire – target this group as well as school educated children/young people.

7. Parent to share details about Herefordshire Carers Support on social media 'Save No.1 Ledbury Road' – 3,000 followers.
8. Look at Parent Carer section of the website to update and develop
9. Develop social media with Parent Carers
10. Shortbreak database, advertise it and make use of the reviewing facility.
11. Attend regional and national meetings – Voice members to put themselves forward to attend to help keep abreast of the national picture.

5 OPPORTUNITY FOR PARENT CARERS TO: RAISE ANY ISSUES, SHARE INFORMATION AND MAKE SUGGESTIONS FOR FUTURE AGENDA ITEMS/ VISITORS/ TRAINING

Spread the word about [Carers Rights Day 2015](#), 10am – 2.30pm at the Great Western Railway Staff Association club, Barton Yard (opposite Sainsbury's petrol station), Hereford HR4 0AZ. .

In April 2016, Ofsted will have to look at SEN separately. Parents have an opportunity to feed into the consultation.

Leaflets regarding current opportunities were distributed, and questionnaires regarding Autism/Healthwatch, Auditing children's' services under the Early Years principles, and regarding training. Please let HCS know training issues think would be beneficial and if you are interested in the March workshop around EHC plans, and becoming more confident.

Advertising

Parents talked about Herefordshire Carers Support putting an advert/information in the free papers that get widely spread e.g. Leominster Journal, Hereford Admag, Primary Times.

Too many children in mainstream, TA's are spread thinly and children are struggling to cope. Concern was expressed as to the reduction in funding generally; schools, colleges, short term breaks, and lack of family support workers and how this was affecting the children and families.

Concern rose regarding children disappearing once they have left education. They are still there; they need to stay in the system.

FUTURE MEETING DATES	
DATE	FOCUS
13 January 2016	Direct Payments and Transitions
10 February 2016	Education, Health and Care Plans
9 March 2016	Review of The Voice 2015-16 Work Plan