



Minutes of County Forum of Parent Carers' Voice For Families of Children with Special Needs

9 September 2009 at Fisherman's Cot, Bickleigh

Present:

Jeanette Kemlo	County Chair/Locality Chairperson for North Devon
Lois Markworth	Locality co Chairperson for East Devon
Ian Simmins	Locality co Chairperson for East Devon
Jo Woodcock	Locality Chairperson for South Hams
Margaret Ladbury	Locality Chairperson for Exeter
Cathy Wreford-Holden	Prospective Locality Chairperson for Teignbridge
Andrew Brent	Education Policy and Strategy Officer; Policy for School Admissions and Transport
Mark West	Children's Librarian, Devon Libraries
Julia Lock	Project Development Manager, TTVS
Sue Brealey	Parent Partnership Liaison Officer
Beryl Perrin	Commissioning Officer for Aiming High for Disabled Children
Abby Buckley	Inclusion Officer
Liz Carroll	Play Development/Play Builder Coordinator
Nicky Ruane	PCV Development Worker for Exeter and East Devon
Pam Hogan	PCV Development Worker for Mid and North Devon
Helen Phillips	PCV Development Worker for Teignbridge, South Hams and West Devon.

Apologies:

Julie Wilson, Donna Langmead, Lyn Davies, John Shaw, Gwen Pearson, Hazel Skinner, Cindy Stone, Jo Boydd, Penny Jerrard, Cathy Hill

Welcome and Introductions

JK welcomed everyone.

Minutes of previous meeting and matters arising

No matter arising

Action points

- JK unsure whether Miles has responded re lack of attendance by Locality Managers at County Forum as she has had computer problems and been unable to access her emails.
- Jeanette to arrange a Chairs meeting following this meeting when information on the contract is available.

Locality Meetings

Teignbridge South Hams and West Devon

4 locality meetings planned and a joint locality event - PCV Awareness & Sensory Workshop is being organised for 2nd October 2009

Main issues raised via phone since the summer break are:

- Concerns over John Parks Unit Closing and future respite care. A parent, representing 22 others who use the unit was concerned that parents had not been invited to a consultation meeting being held Friday 11th September. They intend to consult a barrister to challenge the legality of any closure. Though in Torbay this affects Devon children.

ACTION: JK to discuss with Gwen Pearson

- Claire Lloyd – Cerebra research – (See July minutes) would like parent carer input on 'Communication in Hospital' with a view to developing training for hospital staff. Please go to their website and share your experiences on the forum there. www.pcmd.ac.uk/cerebra/
- A parent was asked to sign a disclaimer for equipment just for the use in school and was told that this was policy – JK stated that there was no such policy, the school has to take responsibility.
- A parent raised the issue that if schools did not follow the advice of the Autism team what should she do? SB said that she should contact Parent Partnership

Good News – 2 years ago a lot of work was done on inclusive play in Teignbridge. There are 3 play schemes to pursue this year and Debbie Marshall will be visiting the Teignbridge locality meeting September 10th to update parents after their involvement / consultation on what they would like.

Exeter and East Devon

Held a joint informal catch up meeting with no specific issues to report.

North Devon

Last meeting Tuesday 21st July 2009 – Barnstaple. Topic - Parent Carers' Voice Contract Renewal. The group contributed thoughts on 'What's working well?' and 'what's not working well.'

Working well:

- Support, admin, someone at the end of the phone (Pam)
- Training/conferences/guest speakers
- Networking/shared experiences/mutual support
- Wide range of disabilities covered by group
- Representatives at other meetings who feedback regularly
- Opportunity to influence services/projects (professionals/agencies)

Not working well

- Like occasional longer meeting/social activity for more informal discussions
- Identifying (more) opportunities for parents to participate
- Some areas of PCT do not recognise importance of parent consultation

Issues raised:

Lack of neurology support in Devon

Lack of communication from/cancellation of, transitions group.

Information:

- CAMHS are running 12 week courses for parents of children with ADHD and a new diagnosis of ASD.
- Initial expression of interest for Play Builder funding was successful. The second round application now needs to be completed for October.

Date of next meeting - Tuesday 15th September

Mid Devon

Meeting held Tuesday 15th July 2009. Miriam Guard was to have delivered her 'Boobs and Black Tights' talk but this has now been postponed until November 25th.

Fortunately Hazel Skinner was present (confusion over County date) and summarized what was available for children with additional needs through the library service. Hazel particularly welcomed parent/carers ideas on how to make libraries more accessible.

Mark Saunders was sponsored by PCV to attend the NASEN conference on Children with ASD in mainstream Education. Following issues were raised in discussion:

- If children with additional needs are accepted into mainstream schools they should be making provision for life skills – e.g. money handling/management etc
- It's essential to widen the remit of IEP's to include, e.g.
 - Social behavior in the playground/playing games/coping with losing
 - Toileting
- There needs to be wider use PECS symbols and Makaton to control behavior and develop speech

Issues raised re residential placements:

- The worry about what happens after residential placements/How to support independence
- Specific concerns about the vulnerability of children with no speech. Will they get bullied?
- What needs to happen to ensure a smooth transition to adult services?

Thoughts on contract renewal:

- Would like more informal get-togethers to share – parents only
- Continue speakers at other meetings, very valuable
- PCV has vital role in conveying and sharing information with parents and professionals
- Suggest more co-chairs to spread the load/ Share roles around the group.
- Reach more parents through surgeries, nurseries/pre schools, children's centres
- occasional evenings to encourage dads. Mum's are getting a lot of information from the groups about how to cope/become more aware. Be great if dads could share in this. Mothers can feel have the sole responsibility for finding out the best options for the child. Should be shared.
- Like to see conferences continue. They're really informative, get professionals together
- Ask for commitment from speakers to stay and listen/answer questions/offer opportunity for quiet word individual issues
- Useful to be able to pick up information from stands
- Parent weekend great idea. No distractions, just relax and can reach dads buddy system – someone calling in advance who's in similar situation. Easier to walk in with someone

Contract Renewal – Beryl Perrin

Beryl informed the group that there had been no further progress on the contract renewal as they were still waiting for confirmation of PCT funding. PCV should be a 50:50 PCT/DCC contract. Last year DCC bailed the PCT out but cannot continue to do so this year. BP expressed her frustration and anger at the position this leaves PCV in. She stressed DCC support of PCV as a model of best practice and her concern that this breaks continuity and trust. However, although the specification is written and all ready to go, they cannot commission the service without knowing the money is available.

JK expressed her anger and concern, stressing that it was highly unacceptable that the organisation is in this position. It puts the future of the organisation in jeopardy as well as specific initiatives such as the 10k Aiming High funding that the group were successful in obtaining.

BP informed the group that they are looking at a proposal to extend the present contract for a period of time with DCC money given a suggestion that PCT money may be available from April 2010.

ACTION BP hoped to have an answer by the end of the week (September 11th) and would send a position statement round by email. IS requested that he be copied in to these emails.

JL emphasised that a commitment to the April funding needs to be obtained in writing as tendering needs to be in place almost immediately to be ready with a contract that begins on April 1st. Also nothing can be put in place for parent carers beyond the end of October so this confirmation is needed urgently.

BP anticipates that the tendering process could be completed within 3 months so theoretically the group could know by January who the contract will be awarded to but it wouldn't start until April. But this process cannot be started until the funding is in.

ACTION Jane Carroll's details to be passed to JK for her to follow this up with a meeting as a priority.

Parent Partnership Service Update - Sue Brealey

IPS

Interviews still taking place of those who have completed the 3 day initial training. Over 20 IPS volunteers will be in their probationary period around the county. Initial work will be shadowing Parent Partnership officers in each area with a range of PPS work. Confidentiality and impartiality of service is still paramount and will be maintained by careful selection of IPS and areas where they will work, robust and regular supervision.

Draft Policies

Confidentiality and Impartiality Policies are now ready in draft form. Could the forums please review these for accessibility for parents to understand. Will be placed on DPPS website -

www.devonparentpartnership.org.uk

On line Inset Training

Schools now have access to a course that has been developed to provide training for staff on working with parents. Entitled Working in Partnership with Parents. School staff who undertake the course receive credits towards FE qualifications. http://www.inset.org.uk/NPPN/introduction/nppn_intro_1.asp

Lamb enquiry feedback

Three main recommendations – OFSTED to include SEN which will include parental feedback and require additional training for inspectors.

Parents should be able to appeal refusal to amend decisions at review.

Statements should be made clearer

Combined assessment – New pilot in East Devon.

Parent Partnership Service have concerns about how parents will continue to be offered independent and impartial support in this process. Discussions taking place.

Request for parent feedback on letters to be sent to parents following request for assessment. Letters to be discussed on Monday 14th.

Children's Trust Update – Ian Simmins

The last meeting was in July and included:

- Participation exercise
- Verbal update on Ofsted from Anne Whitely
- Discussion on the Children & Young Persons Plan refresh

CYPS Update – Beryl Perrin

Beryl delivered a report prepared by John Shaw covering:

- Carers Strategy
- Tracker form – Cathy WH to look at this with Helen Issacs
- September 30th – interviews for commissioning officers
- Speech and Language interviews – Ian PCV representative
- Transitions Health Conference Cancelled – due to lack of take-up

BP clarified the situation regarding John Parks. The Friday meeting is not a consultation on the future of the unit but a meeting for Torbay parents to discuss preferences for provision. There has been considerable consultation with Devon parents about provision and it is now for Torbay to make their decisions. BP will be there Friday but to discuss with individuals out side of the meeting.

Mark West – Devon Libraries

Mark is one of 2 children's librarians who control stock, promote the library service and support libraries directly. Some of the points he covered included:

- Acknowledgment that access is a problem with some of the older buildings. They are looking at level access, space and lighting issues
- They provide book and CD sets – cassettes now being phased out
- Happy to put PCV leaflets out where space is available
- Every library has public computers offering free 30minute access
- Provide board books, picture books, beginner readers, stories, teenage stock and non-fiction. (Though acknowledge teenage stock is low)
- Central stock of Braille picture books.
- Purchase policy is now to buy books where words stand out clearly on the page
- Packs of CD's and large print books are available
- They purchase books printed on a yellow background from publisher Barrington Stoke for visually impaired/dyslexic. The comment was made that a stock of yellow, green or blue overlay sheets would mean that any book would be available
- Some high/low books are available – age appropriate content but with fewer words. (Marked with a gold star) The huge need for teenage/adult content but low ability reader books was stressed by the group. James Bond/football/ wrestling just some of the suggestions. Mark agreed there are not many non-fiction books for teenagers. He suggested all requests be fed back to local libraries as if there is a local demand they will try to respond.
- Some graphic novels are stocked – though a need to monitor for content

ACTION JK to email Hazel Skinner to set a meeting date to look at how parents can help library provide better services for children with special needs. LM, ML and CW-H to take part.

Andrew Brent – Transport

A new transport policy will be issued in September 2010 with a formal consultation taking place in January /February 2010. The aim is to achieve a clear policy that parents can access. Proposals will be sent out and views incorporated whenever possible within budget constraints.

The following questions were addressed and discussed.

How much training do escorts get?

All escorts (now contractor as well as DCC) have 4 days training covering:

- 1) Induction and Child protection,
- 2) Behaviour management and physical restraint (non),
- 3) Manual Handling
- 4) First Aid. After October the legislation with regards to First Aid training is changing and we will manage this by arranging two half days for this subject. Subsequently all escorts are retrained for Manual Handling and First Aid only. This is currently every three years. All DCC escorts also attend a yearly awareness training on Emergency medication. Contractor escorts are able to join this and often do since we started training them last year. TCS have also arranged training for some of their escorts in the past, possibly for more complex cases. DCC escorts will also have specific training for children with complex needs. We arrange for this to happen usually with School Nurses. But parents and carers can also be involved in this depending on the type of care. You need to be aware that since the 1st September this year, we only administer Buccaal (oral) doses of EM for epilepsy. Any requirement for rectal doses will be administered by Paramedics using the EM carried by the pupil.

It's sometimes appropriate for the parent to be the escort but they will have to be CRB checked in case the vehicle takes another child.

Why are different pieces of evidence required for post-16 transport as opposed to EMA and free school meals?

1. Post 16 students do not qualify for free school meals if they are attending a further education college so we would need to check benefit evidence for these students.

2. Some families who are entitled to claim free school meals do not do so but may well be in receipt of a benefit where we could waive the transport fee therefore, again we need to see the evidence.
3. If a family is in receipt of the **maximum** level of Working Tax Credit the transport fee can be waived but this is not an acceptable benefit for free school meals.
4. Currently the benefit evidence must be valid beyond September.- JK questioned this as the figures for September are estimated income taken from the April notice which is confirmed figures for income. In virtually all cases the estimated income is taken as the proven income from the April before. These are the award notices used by free school meals and EMA. JK felt that transport using the same evidence would cut down on the last minute work of getting direct debits etc set up where none was going to be required.

What are the transport rules on safe transport of medicines?

There is no specific regulation on the transport of medication apart from oxygen and other gases which come under rules governing the transportation of hazardous chemicals. Pupils normally carry EM on their person or in their bag (depending on the age / capability of the child) Thus it is parental responsibility to ensure the drug travels every day with their child. DCC escorts are NOT allowed to take any EM home, as there is usually a street value on the drug. I cannot report on what the general rules are, with regards to the transporting of drugs on a vehicle, other than where a DCC escort is involved.

Concerns were expressed about the safety of medicines carried on the back of chairs where they can be tampered with.

ACTION Andrew to speak with Pathfield re tamper proof boxes

What are the arrangements for safe storage of transport at night?

Medication should not be kept on a vehicle over night. Storage of vehicles is down to the individual contractor. There are limited storage facilities for DCC vehicles. There have been occasions where several white buses have been parked together and targeted because they were together. In the absence of high security storage facilities, all vehicles are vulnerable to vandalism and theft.

What safety checks are carried out in the mornings?

For DCC vehicle all drivers must undertake their daily checks as set out in the log book which must be completed before every journey. Checks for taxis and coaches/buses are governed by relevant legislation for each category.

Why do parents have an issue with transport when special needs children are going to a mainstream school assessed as meeting their needs rather than a local school?

Transport is provided to the nearest school appropriate for the child. If CSET have agreed a mainstream school is most appropriate and this is named on the statement then transport should be provided – **as long as the named school is not parental choice.**

What is considered to be the maximum travelling distance for a special needs pupil.

The policy says "The maximum journey should not exceed forty-five minutes for pupils of primary age and one hour and fifteen minutes for pupils of secondary age. There may be exceptions for attendance at a special school, attendance at a remote school or institution in order to avoid exclusion, or attendance at a remote school following a move in order to maintain educational continuity ". There is no maximum travelling distance for a special needs pupil as there are fewer special schools so the distance to them can be greater and vehicles have to pick up along the route. However, the journey would need to be "reasonable".

The issue of communication – between parents and DCC, escorts and drivers - was discussed. Points included:

- Concern re handover of information, e.g. where a different driver needs to know specific transport requirement of a child.
- Problems of using My Devon to find out what's happening if transport doesn't arrive
- Problem of being unable to phone own driver or escort to save them a journey if the child is not travelling at the last minute. No-one in at County early in the morning. Need the OK that if it's an urgent situation can call the escort/driver direct.

Good News - JK shared the results of a survey at Pathfield where 80 children all liked their journey to school. She also commended the drivers and escorts who all do their best to make journeys as enjoyable as possible for the children in their care. Many build up excellent relationships with their families which benefit the children enormously.

AOB

Liz Carroll reported on the Play Builder funding – there is update bulletin on the www.devon.gov.uk/play With regard to the Aiming High capital for 2010-2011, there has been a promising meeting with Beryl to access Aiming High Capital funding to enhance a minimum of 2 destination Play Sites in the County.

For information on an Employment Support Allowance for post 16 students with significant special needs in education call 08000 556688.

JK recommended the Challenging Behaviour Foundation, supporting children and adults with challenging behaviour. Lot of resources, fact sheets and advice available. See www.challengingbehaviour.org.uk or call 01634 838739.

Incontinence products JK to arrange to meet with Amanda Wells, nurse consultant for bladder and bowel care, to try to raise the concerns of parents re new contract and the failed consultation process that went with it. Any parent who has experienced difficulties or wants to comment should get these to JK by the end of the month.

Close

The next meeting – assuming a continuation of the Parent Carers' Voice contract - will be on Wednesday 11th November, 10am at the Fisherman's Cot, Bickleigh