

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE  
for Families of Children with Special Needs  
14<sup>th</sup> January 2009 at Fisherman's Cot, Bickleigh**

**Present:**

Jeanette Kemlo	County Chair/ Locality Chairperson –North Devon
Nicky Ruane	Development worker – Exeter and East Devon
Pam Hogan	Development worker –Mid and North Devon
Bronwyn Nott	Locality Chairperson – Mid Devon
Lois Markworth	Locality Co-Chair – East Devon
Ian Simmins	Locality Co-Chair – East Devon
Margaret Ladbury	Locality Chairperson -Exeter
Sue Brealey	Parent Partnership Liaison Officer
Liz Carroll	CYPS Early Years & Childcare Service
Julia Lock	Parent Carers' Voice Project Co-ordinator (DACVS)
Julie Wilson	New Locality Co-Chair –Mid Devon Locality
Beryl Perrin	Commissioning Officer for Aiming High for Disabled Children
Miles Hapgood	Assistant Director Integrated Children's Services
Penny Jerrard	County Development Officer, Devon Carers Link

**Apologies:**

Jo Woodcock	New Locality Chairperson –South Hams Locality
Lyn Davis	CAMHS Programme Manager
Cathy Hill	DISCplus Coordinator
Gwen Pearson	Children's Commissioner Devon PCT
Mary Kent-Smith	Parent – North Devon Locality
Cathie Wreford-Holden	Locality Chairperson –Teignbridge
John Shaw	Strategic Commissioner for Children with Additional Needs
Donna Langmead	Parent – North Devon Locality

**Welcome, Introductions and apologies**

JK welcomed everyone to the county; particularly all the new faces that were in attendance.

**Election of Chair, Vice-Chair and representatives:**

PCV County Chairperson

JL reported that there had been one self-nominations for the post of County Chair since the last forum in November in which JK expressed her interest to become county chair again for 2009, ML seconded this proposal with NR and LC in agreement. It was agreed that JK should take the position for another three years. JK proposed that Cathy W-H be nominated for the position of Vice Chair in South Devon. ML seconded. This election is subject to Cathy's agreement.

Children's Trust Board

There is a need to replace Nichola Winstanley on the Children's Trust Board since she left last year, IS has shown a particular interest in becoming the PCV representative. *IS was nominated by JK, BN seconded. It was agreed that IS should be the second representative on the Board*

**ACTION** JK to send date of next meeting to IS and inform the CT secretariat

Parenting Strategy Board

JK discussed with County several issues concerning the Parenting Strategy Board, many of whom expressed their individual concerns. ML attended the Parent Strategy network meeting in Exeter locality, and noticed that there was no mention of children with additional needs or the progress of the FACB scheme. BN said that this was also her experience in Mid Devon.

SB added that (to the best of her understanding) the Parenting Strategy networks are in their infancy, gathering the views of parents for the PS Board. These PS networks are for all parents of children, not just those with

additional needs. PH suggested that electing a PCV representative onto the PS Board will provide an important opportunity to raise the profile of PCV and the spectrum of problems faced by parents of children with additional needs. This will allow for the direction of views about inclusion, service provision etc straight to the professionals.

*JK nominated ML, who had previously expressed her interest in becoming the representative, BN seconded.*

**ACTION:** Invite Philippa Court and Liz Rafferty to next meeting, to discuss with them how PCV and the parenting networks can work together.

### **Minutes of previous meeting and matters arising**

#### Parent requests for training in restraint –how can they access this?

JK and other members of the Forum reiterated their feelings that individuals needed to be careful when using the expression ‘restraint training’ and what might be inferred from those words.

NR had previously been tasked with contacting Kate Sandel regarding the progress of the collation of restraint training contacts.

**UPDATE:** NR is currently speaking to a different group about training opportunities. It is all ‘marching on a bit slowly’, as it has been identified that parents would like something quite high level (exit strategies, positive intervention, advice etc), which is proving quite problematic.

BN would like to see training provided throughout the county. Whilst JK warned that PCV should make sure and highlight that what ever is provided does not absolve the statutory authorities of their responsibility to provide protection and their own sources of advice for parents and carers.

SB advised that it would be a good idea for the need for training identified above to be directed to the professionals on the Parenting Strategy Board, and highlight this as an important issue.

**ACTION:** ML to take the issues outlined above to the Parenting Strategy board.

#### The availability of communication and speech and language courses within Devon

This issue was raised at the November County Forum within the Teignbridge locality report. The action point tasked development workers to engage parents in each locality about what sort of communication training they might need – Makaton etc, whilst identifying what is available within training directories and other sources. On reporting back to the County Forum, it can then be identified what level of need there is for particular training in each district and the existing level of provision in related courses. If it is felt that the level of need is not being met, then PCV could arrange two training days with a focus on effective communication in the New Year –one in the north and one in the south.

**ACTION:** As there was only feedback from the parents in the North Devon locality (who identified Makaton and PECS), development workers are to bring the information to the next county meeting in March.

#### Children’s Trust Meetings Online

JK was pleased to announce that the online feed is now up and running on the Devon County Council website, which will allow all parent carers and professionals to watch the live proceedings of the Children’s Trust Board meetings remotely. Just follow the links.

#### Roles and Responsibilities

Development workers were asked at the last county meeting to survey what parent carers think the roles and responsibilities of a locality and county chair are and please forward these to JK.

**UPDATE:** JK has had some comments and ideas back from PH and NR; and would like to set a date for the drafting of the roles and responsibilities of a chairperson at the next PCV Chairs meeting.

**ACTION** JK to set date for chairs meeting and to arrange for this to be minuted

### Parent Partnership Service Update: IPS Information Days

Chairs and development workers were tasked with emailing JK with ideas for what information from the IPS Information Days might be useful for evaluation purposes (e.g. number of parents and carers raising issues about transport, statementing etc).

**UPDATE:** This is to be discussed in detail at the planned PCV Chairs meeting.

### **Locality Reports**

More detailed reports from each locality can be viewed on the PCV website at [www.parentcarersvoice.org](http://www.parentcarersvoice.org).

#### Mid Devon

There has been no forum since the last county meeting but Mid Devon held their Christmas lunch in December with 15 attendees. Fiona Burnett and Julie Wilson have been elected to become joint co-chairs and John Bennett will remain Vice Chair of the locality, when BN stands down sometime in the spring. The next forum is to take place on Wednesday 21<sup>st</sup> January and is an extended meeting on the theme of 'Meeting Your Child's Special Needs in Mainstream Education'. This is being delivered by Sue Brealey and Debbie Wheeler from Parent Partnership and Marion Argent from CSET.

#### Exeter

At the last locality meeting, Debbie Wheeler from Parent Partnership gave a talk on how to get the best out of meetings and left everyone with a very useful checklist.

One point that was raised concerned the difficulties faced when taking a young person with a learning disability to hospital. Doctors tend to address all their questions to the young person and may not get all the information they need. In one instance, a parent had been shushed when she had tried to answer the questions. She has now made a card that she carries with her saying 'my daughter has a learning disability so please address your questions to me'. This was felt to solve the problem where a parent did not wish to say that a young person has a disability in front of them.

*There then followed a discussion between Forum members about their experiences with consultants, paediatricians and within regional hospitals throughout the county. BP added that if any parents or carers had any particular issues, it would be a good idea to write to or email Gwen Pearson; whilst JK advised that individuals could also get in contact with the hospitals' PALS service.*

There was also a lunch before Christmas, as well as a mince pie and coffee drop-in, which encouraged a couple of parents who had not attended before to come along.

#### East Devon

At the last locality meeting, Debbie Wheeler from Parent Partnership gave a talk on how to get the best out of meetings and left everyone with a very useful checklist.

LM related the concerns raised by parents, who are still experiencing problems whereby their high functioning ASD children who cannot cope in mainstream schools, have nowhere to go. Although they may often be offered support through link education this can take some time to arrange and does not suit them all.

*With this in mind, SB suggested that it might be a good idea for her to take back these comments to Anne Porter at the next Strategic Inclusion Group meeting, to better inform the drafting of the Stepping Stones Continuum, which looks to provide an equitable service for all children within Devon.*

**ACTION:** Reports to and from the Strategic Inclusion Group to be made an agenda item for future PCV County Forums as part of the PPS update.

#### Teignbridge

Minutes on website, no one available to report. Helen Phillips has resigned and PCV Development Worker interviews will be taking place on Monday 26<sup>th</sup> January.

#### North Devon

Seventeen parents and seven professionals attended the last North Devon forum to hear Clare Cox speaking on the Mental Health Capacity Act and Laura Matthews on 14-19 provision at Pathfield School. Pete Squire

outlined his new role as Northern Manager for integrated services. James Skinner (CAHMS) summarised plans to offer group support for parents of children with a diagnosis of ADHD and/or ASD. The intention is that this will be a rolling programme.

Issues identified:

- Need for support at home where behaviour can be very different to that observed at school
- Concern over examples of nothing happening as a result of calls from desperate parent carers to social services

The next forum is on January 20<sup>th</sup> when managers from North Devon College will be presenting their plans for special need provision in the new build.

#### South Hams

Minutes on website, no one available to report.

#### West Devon

Minutes on website, no one available to report.

#### **Parent Partnership Service Update –Sue Brealey**

SB has reported back to the Strategic Inclusion group, about PCV's concerns that SEN children were being removed during Ofsted inspections. The group would be interested to know which schools in particular were practising this form of exclusion so that they might investigate further.

JK thought it would be useful if PPS, using the information they have, could produce a spider diagram for parent support groups throughout Devon, which also maps different development workers (and who they are responsible to), where they all fit in and what their roles are. *SB said that she would be happy to compile this.*

SB would be grateful if development workers could inform parents and carers in their localities, that there is a training and networking weekend in Dawlish coming up soon, with a focus on children with downs syndrome, aged between 0-17yrs. *Please contact PP for more information.*

Parent Partnership is due to move out of their current office soon, which will mean that they are no longer in the same building as CSET. A PP officer will inform the PCV county forum when they know where they are to relocate to. It is unfortunately going to affect their ability in the short-term to organise, to correspond and to carry out what they intend to.

#### **Contract Renewal – Julia Lock**

JL reported that the current contract runs out at the end of October 2009, and as yet there has been no conversation as to how to implement PCV after this date. BP announced that she has recently had a conversation with Brian Grady from Devon County Council, who is looking at parents running the tendering process, and there is a meeting planned for the February 5<sup>th</sup> to discuss the renewal of the PCV contract.

#### **Expenses**

JL reported that there had recently been an issue where an individual had sought a one-off cash payment for attending a PCT meeting. TTVS (who currently manage PCV accounts) are disinclined to make one-off cash payments (especially as on this occasion, the individual was *invited* to the meeting and so was not an out-of-pocket expense). There is also the side issue of locality and county chairperson's hours and whether it is essential for individuals to register for a P46, as this is at the centre of accountability issues with the tax office where the payments to members might be considered for work. Sally Piper (Finance Officer at TTVS) will happily answer any questions that anyone might have or she could attend the next county meeting to clear up any problems.

**ACTION** Email any questions to Julia and she can forward them on.

There followed a discussion between JL, BP, JK and MP concerning expenses, PCT meetings and the DCC. JK raised the issue that parents are often incurring expenses through the use of their mobile phones, the Internet, photocopiers, telephones, printers etc. BP said that she could raise these issues at the planned

meeting in February (see page 4), as both the PCV contract *and* budget are up for discussion in detail. They could look at whether these expenses should become encompassed within any new budget proposal and they will also examine whether it would be best for PCV accounts to be implemented by TTVS or DCC.

### **FACB Budget Update –Miles Hapgood**

The spend on carers breaks is increasing year on year causing the budget to spin out of control. A stringent audit process looking at the accuracy of FACB allocations on the database has confirmed the figures and the accuracy of the predicted shortfall. New commitments have had to be put on hold to get to grips with this situation. MH was aware that this has impacted on families.

MH distributed a report detailing the context, reasons for budget pressures, areas for savings recommendations for budget management in 2009/10 and details of banding within the FACB budget.

BP added that the new FACB Direct Payments Lead is due to start work on Monday 19<sup>th</sup> January, and will be tightening up the Direct Payments policy.

JK thought it would be useful to have the exact figures of how many parents are under-using or over-using the FACB scheme.

JK raised the issue of contingency budgets, as she would like to make sure that parents are not criticised for being prudent by putting some Direct Payments money to one side (e.g. monies for child care when parent in hospital, saving up for a longer break etc), as this might be seen as an under-spend. MH thought that this was a good issue to raise and will be looking to revise the outstanding DP policy further, with this in mind.

LM raised the issue of parents with children within the autistic spectrum, as many do not qualify for FACB despite their child (ren) being in a special school. MH stated that currently children within the autistic spectrum fall outside the FACB bandings, however, under the Aiming High for Disabled Children initiative, there will have to be a more overarching approach from FACB to encompass all types of additional needs.

JK and other county members thought it would be useful to have the figures of how many children fit into each individual FACB band and how many children do not qualify.

**ACTION** MH to forward figures of how many parents under or over using scheme, how many children fit into each band and how many do not qualify

*This was followed by a discussion involving many county members, expressing their individual concerns around the proposed Direct Payments policy.*

- ‘Can Direct Payments be used to employ a carer without a CRB check?’, the policy says that ‘in most cases no’, but ML and the county forum thought that all carers should have a CRB check before being allowed to work with children
- JK & NR were unhappy with the fact that Direct Payments in the revised policy can only be used to fund the cost of child going into attraction and not to contribute to travel expenses or the cost of refreshments etc
- LM saw fault in the fact that it is stated that Direct Payments cannot be used to make up in the shortfall in the provision of education etc
- Other issues that were discussed in relation the Direct Payments policy included school trips, arrangements for paid carers on holiday and the nature of carer expenses

*JK and BP agreed that it clear “principles of use” are required for parents and carers that they have to sign and agree to in order to access Direct Payments.*

JK, ML, LC and Julie Wilson agreed to attend a Direct Payments policy meeting.

**ACTION:** BP to set a date in early February for the meeting - avoiding the school half-term holiday.

### **Accessing Library Services with your Special Needs Child**

JK has recently been in contact with Devon library staff, and they have made a request to have some ideas and feedback from parents and carers, on how best to arrange books and sources when SEN children are visiting. For instance, should books be laid out on tables so wheelchair users can better access them? Or, should this be limited so as not to overly excite children with ADHD? Ideas proposed at county by ML, NR and BP included touchy-feely books, books on CD-ROM and longer loans.

**ACTION** Please forward ideas or comments to JK so she can pass these on to the library staff.

### **Parent Participation Bid**

PCV has successfully been granted £3,300 from 'Aiming High for Disabled Children'. This money has been allocated as follows: the East Devon, South Hams and West Devon localities are to be granted £1000 each to put on a workshop to encourage parent participation. Please note that this money needs to be spent in advance by March 2009.

PCV can now apply for a grant of £10,000 by May this year. JK would like ideas for what the money could be spent on in order to encourage parent participation. ML suggested the organisation of a conference focused on children with additional needs going through puberty, including issues such as protecting vulnerable young children and information on sexual health. JK reiterated that PCV would have to then demonstrate how active parent participation in this conference and other proposed events, influenced the ongoing work of professionals and the streamlining of services. In simplistic terms, PCV would need to evidence that the engagement of parents in these arenas led to documented actions.

SB suggested that some of the funds could be used to set up a PCV web forum, with the grant being used to buy computers, equipment and online consultations etc. IS proposed that a third party be paid instead to tag the forum onto the existing website, so someone from PCV is not tasked with maintaining the system.

ML informed the meeting that at Contact-a Family, PCV is considered a success story and Devon is their Beacon model of parent participation across the country.

### **AOB**

#### Conversation Events

BP reported that three new Conversation Events were to take place in Barnstaple, Dartington and Exeter, with actual venues to be confirmed at a later date. The focus of the events will be 'local commissioning' and what parents would like to see implemented across the county.

BP would like to actively encourage people to phone up, particularly new families, to book a place on any of these events. BP requested that a PCV representative be present at each of the venues, IS and JK nominated themselves for the Barnstaple event and BN nominated herself for the one in Exeter. JK and BP discussed maybe putting together reference material so that each representative presents the same information in a designated slot in the event programme, discussing the role of PCV etc.

**ACTION** BP would be grateful for any photographs - with relevant permissions - PCV can supply. JK to compile the info for the PCV slot and then pass on to BP for reproduction for each event

#### PCV Annual report

There has been a plea from Julia, (who is compiling the annual report) for some photographs from each locality to accompany each individual locality report. JK is also keen on the idea of having children design the front cover. There was general agreement that there is a need to get the annual report out earlier this year, as the last edition came out in May. JL hopes to have it printed and out by March. It was also proposed that the annual report could be sent out via BP's mailing list to Devon's special schools.

#### CAMHS Conference

This is taking place on Tuesday 3<sup>rd</sup> March at Tiverton Hotel, roughly within the school day, starting at 9.50am. This conference has a county-wide focus, CAMHS professionals will be there to respond to issues on the day, with a particular focus on the emotional health and wellbeing of children with additional needs. Any interested parties should contact NR in order to book a place. NR is also planning to send out leaflets advertising the conference.

### A new Parenting Strategy Board

LC reported that a new Parenting Strategy Board is being set up to look at Play Strategy under the direction of Dylan Hughes, which will be looking at the design and planning of 22 newly proposed inclusive play parks. This group really needs involvement from and the views of parents. LM expressed an interest in standing as the PCV representative, this nomination was supported by JK and other county members.

***The next meeting will be Wednesday 11<sup>th</sup> March 2009 10:00 am  
at the Fisherman's Cot, Bickleigh***