

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE
for Families of Children with Special Needs
11th March 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
Beryl Perrin	Commissioning Officer for Aiming High for Disabled Children
David Johnson	FACB/ Direct Payments Co-ordinator
Donna Langmead	Vic chair –North Devon locality
Kate Legum	Development worker –South Hams, Teignbridge & West Devon
Cathy Hill	DiscPlus Team Leader
Chris Wardle	Stepping Stones Head Officer
John Shaw	Strategic Commissioner for Children with Additional Needs

Apologies:

Cathie Wreford-Holden	Locality Chairperson –Teignbridge
Fiona Burnett	Locality Co-Chair –Mid Devon

Welcome, Introductions and apologies

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

Minutes of previous meeting and matters arising

Parenting Strategy Board

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

UPDATE: Liz will be attending the next PCV county meeting in May. Phillipa to be invited

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

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.

UPDATE: ML taking issues to the Parent Strategy meeting on March 23rd and will give feedback to PCV at the next forum in May.

FACB Budget Update –Miles Hapgood

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

UPDATE: JK to remind Miles to forward the figures.

Accessing Library Services with your Special Needs Child

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

UPDATE: JK is meeting with Devon library staff next week (16th-22nd March). She has received some interesting ideas and comments, concerning, in particular, the accessibility of resources for children in wheelchairs.

The Minutes of 14.01.2009

Liz Carroll would like to make the following amendments to January's minutes, within the 'A new Parenting Strategy Board' piece under AOB. *A new '0-19 Strategy Board' has been formed not another Parenting Strategy one, this board is being set up under the direction of **Dillon** Hughes not Dylan Hughes.*

A reminder that BP would be very grateful for any photographs –with relevant permissions, that PCV can supply.

Annual Report Cover

The number of designs for the annual report cover has been short-listed to three entries.

ACTION: JK to email copies of the three designs to everyone so that people can vote on what entry they believe would make the best report cover.

The number of annual reports to be printed was discussed as there was a shortage last year. Several county members expressed their wish that this year, the annual reports should go to special schools, county council workers etc. It was agreed that the extra cost incurred by this measure would be worthwhile and could be taken from the PCV County Initiative pot of money.

ACTION: BP to email JL a list of additional people to mail to and then a printing figure is to be agreed upon, maybe 200 copies.

Locality Reports

More detailed reports from each locality can be viewed on the PCV website at www.parentcarersvoice.org.

Mid Devon

The last meeting took place on 21st January, which was attended by 13 parent/carers and 6 professionals. This meeting took the form of a training day presented by Sue

Brealey and Debbie Wheeler (Parent Partnership), on the theme of 'Meeting your Child's Needs in Mainstream Education'. Concerns arising from the meeting included:

- the conflicting advice parents receive when completing a statement
- difficulties faced by parents whose route of appeal in a small school is the head teacher, who is being obstructive

The next Mid Devon locality meeting is planned for March 18th at Meldon Village Hall, Okehampton. The focus of this meeting will be 'Understanding the Joint Agency Service and the Keyworker's Role'. Representatives from the JAS will be in attendance to answer parents' questions. This will be BN's last meeting as Chair of the Mid Devon locality. Mid Devon are also in the process of planning a Transitions conference to take place on September 16th in Okehampton.

Exeter

The last meeting took place at the end of January. Issues raised included:

- The level of support that is provided when a child with additional needs has to stay in hospital –it was a common opinion amongst the parents in attendance that the support within the ward was insufficient, particularly where the child in question had communication difficulties
- Education –Southbrook special school in Exeter, concerns expressed by parents and carers with relation to Year 9 choices, there is very little option for students – eithercooking lessons or design and technology/ construction. Some of these courses within special schools are not accredited.

Steve West explained about CAPA (Choice and Partnership Approach) and answered questions from parents.

Chris West will be attending the next Exeter locality meeting, he will be talking about the OT Service and will be answering questions. This is in response to queries raised at a previous forum.

East Devon

The last meeting took place at the end of January, with approximately 15 parents in attendance. A wide range of issues were discussed:

- The negative and positive experiences of families with school transport systems

ACTION: School transport to be put on the agenda for July's PCV County Meeting.

County then discussed the recent leaflet that had been sent out regarding school transport, where the child (service-user) has to agree to a code of conduct. It was agreed that there would be a problem for some children to provide signatures, other issues raised with this leaflet included the lack of guidance notes and the fact that the leaflet applies a generalised code of conduct, that covers all types of students –mainstream and those with additional needs.

- Concerns surrounding the way in which schools record absences for children with additional needs

At this point in proceedings, Chris Wardle (the new Stepping Stones Head Officer), talked through the government initiative to highlight consistent absences with LM, who was worried that some children who consistently attend medical or CAMHS appointments, are recorded as below-average attendees. There are issues with some children not receiving entitlement because of their absences –despite these absences being authorised. It was agreed that:

- schools should improve the way in which they distinguish between authorised and unauthorised absences and track the progress of students on an individual basis
- schools should consider what could and should be done for a child during that absence, in particular, look at how children can receive a full education as they will be missing lessons. Parents have reported that there are currently no catch-up sessions for those children who are consistently absent for appointments. JS suggested that it would be a better idea to arrange for therapists to visit children on site at schools so that children do not have to miss so much of their education in order to attend their appointments.

The next East Devon locality meeting will be held on 25th March at the Heathfield Inn in Honiton. The focus of this meeting will be supporting a child with additional needs within education. Parent Partnership will be explaining about the different stages of support, how to work with schools and others involved with the child to get the best outcomes and what to do if things do not go according to plan. A representative from the Inclusion and Integration team will be explaining the rules surrounding exclusion and a member of CSET, it is hoped, will be on hand to talk about the process of statementing; who does what and the timescales involved.

Teignbridge, South Hams & West Devon

Kate Legum, the new Development Worker for this region introduced herself.

Twenty-seven locality meetings have been scheduled to take place between now and the end of December, with one meeting taking place each month in each individual district of the PCV locality (Teignbridge, South Hams and West Devon). This number has been discussed and agreed upon by Cathie Wreford-Holden.

ACTION: KL, JL and JK to arrange meeting in order to discuss these 27 meetings and their development further.

On consulting parents and carers, KL found that it was a common concern amongst those taking part in current meetings that the professionals seemed to be taking charge of the proceedings. Whether this is in the form of lecturing or talking at parents, or by talking in an obtuse way that prevents parents from being able to ask questions or challenge current strategies. This often leads to parents taking a back seat or worse, disengaging from PCV entirely. KL also reported that some parents feel that they are being encouraged to attend locality and county meetings in order to tick the boxes of professionals.

JS agreed that there seems to be a scattergun approach being applied by professionals, and that PCV need to make doubly sure that the views of parents are always presented at meetings. It is important to re-emphasise that these forums are parent-led.

KL aims to:

- concentrate on identifying and applying the skill sets of the parents themselves, these experiences and skills could be used to create a supportive and constructive meeting, where parents can help and advise one another, in order to self-support
- examine and identify what the expectations of the parents really are from the PCV forums, meetings and conferences
- develop channels of feedback from parents and carers
- develop more of an emphasis on constructive lobbying

North Devon

The last meeting took place on 20th January, which was attended by 16 parent/carers and 9 professionals. Donna Langmead was appointed Vice-Chair.

A presentation was given on the North Devon College New Build, David Collett aimed to take ideas back to his team and understand how they might best work with PCV to cater for students with additional needs on the new site. He proposed a smaller working group to look at the plans in more detail (accessibility, design elements, nursing and medical provision etc).

Concerns were raised re. transition:

- children who do not fall into the learning disabled category at 18, the loss of a key worker and vital support for both the child and parents
- children with CAMHS, no service available after 18th birthday, many adults with mental health difficulties end up on the streets or in prison
- the North Devon Group are looking to develop a Transition training package, initially from yr9 into adult services but later to cover all transitions

At this point in proceedings, SB also expressed an interest in developing specialised Parent Partnership training packages for parents encompassing the issues addressed above.

The next North Devon locality meeting will be taking place later this month and will be examining inclusive play. A Paediatric First Aid Course is planned to take place on 28th April and looking forward to this summer, there is a Carers Workshop planned to take place on 8th June, a joint day with the Generic Carers and Learning Disability Carers Forum focusing on the support you need to fulfil your responsibilities as carers.

Parent Partnership Service Update –Sue Brealey

The Parent Partnership team have moved to their new office at Greatmoor House, the website address and the telephone number will remain the same. PP are looking to develop the facilities and the reception areas where parents can come and visit Parent Partnership workers, with the effective deliverance of IPS courses particularly in mind.

Karen Horsnell has become the newest member of staff to join the Parent Partnership team. Karen will be taking over from Cath Butland, working throughout North Devon. She plans to attend both the North Devon and Mid Devon PCV locality meetings. Debbie Wheeler will be working throughout East Devon, Liz Batchelor in Exeter and Cath Butland will now be working in West Devon.

All PP workers continue to encourage parents to attend PCV locality meetings or to contact regional development workers; it is their commitment to look to improve parent confidence through joint-agency work.

IPS Information Days -Update

Parent Partnership will be running three information sessions across Devon for parents and carers, in order for them to find out what becoming an Independent Parental Supporter entails. The sessions will provide an opportunity to gain skills in providing impartial information and support to other parents and carers e.g. information about the rights and responsibilities of parents and schools etc. SB announced that these information days would be delivered in Bideford, Honiton and one in the Teignbridge area.

SB expressed her interest in examining how PCV evaluate the responses from those who have attended their conferences and training days, this will help PP officers make better use of the feedback that they will receive from the IPS Information Days. PH reported that she has forwarded comments and evaluation from PCV events to the Joint Agency Service.

SEN Strategy Group Report

SB reported that the last group meeting had addressed the development of Stepping Stones, actively looking at what is currently available and what is the best practice. SB raised the question 'how are parents going to be consulted?' The professionals in attendance agreed to set up consultation interviews, to feed the views of parents into the development of Stepping Stones. They all agreed that feedback from grass-root level was particularly important to highlight why parents choose some schools over others.

Contract Renewal

JL reiterated that the current contract comes to an end with DACVS at the end of October 2009. JS informed county that there will be a six month tendering process going ahead from the end of April. BP addressed the need for there to be some discussion about specifications within any new contract and what level parent carers would be involved in this process. Things to be discussed should include the possible realignment of PCV localities to fall in line with the current JAT areas and the identification of what is collectively considered to be important and the prioritisation of these elements. JS reported that the current DCC policy is to offer a year's contract, however, this will need to be addressed by PCV.

ACTION: Date for contract renewal discussions to be scheduled by the end of the meeting.

Expense Form

JK expressed her concern that the new PCV expense forms offered parents the opportunity to enter their BACS details, in order for their claim to be put straight into their bank account. JK understands that this is easier for the purposes of TTVS financial transactions, however, remains disheartened that this decision to amend the expense form did not go through PCV locality/county meetings for approval first and wondered whether TTVS are covered to protect the private bank details of the parents.

JL reported that TTVS thought it would be much easier for parents to have their money put straight into bank account. TTVS is definitely covered to hold that information. JL

reiterated that parents still have the choice to tick the box beside a cheque or BACS payment.

ACTION: TTVS to amend PCV expenses form –signature to be moved to the front.

ACTION: The date that an expense claim relates to is to be put on the TTVS compliment slip for county chairs ease of reference.

JL made available an email from Penny Mason (TTVS Joint CEO) concerning payments to county chairs, particularly, concerning the difficulties surrounding the classification of income. It is being proposed that there will be a one off payment made each year. This is to be agreed upon in a future county meeting.

ACTION: The issue of income classification for county chairs is to be considered in future PCV Contract Renewal discussions.

ACTION: JK to send a copy of her Westbank quarterly payment letter to JL.

Stepping Stones -Chris Wardle

Chris Wardle introduced himself as the new Stepping Stones Head Officer, responsible for the development and support of this project. CW outlined the key elements within the Stepping Stones Project:

- the process by which the end point is arrived at
- the project's consultation process
- how what works can be replicated
- examining services for children with additional needs
- a focus on the continuum of provision irrelative of geography
- a consideration of context –this will involve holding case-relative discussions with individual schools and key stakeholders (children, young people, parents and carers)

CW is looking to maintain a working partnership with SB at Parent Partnership, in order to bounce ideas off parents and receive valuable feedback. This consultation process is part of the formative, constructive nature of the project.

JS and/or CW hope to be able to update each PCV county forum meeting on the progress of the Stepping Stones Project. Equally, they hope that this will be a shared process, where PCV can update and keep the SS Project informed on the views of parents that they have come across throughout the region.

JK can give access to special schools, as are governors or know of governors. Can advertise project through development workers.

JK what engagement of SENCOs is there? CW looking to employ all groups of people in order to inform the SS Project, can not be specific yet as to whether yes or no.

Parent Participation Bid

After successfully being granted £3,300 from 'Aiming High for Disabled Children', PCV can now apply for £10,000 by the end of May this year. Any ideas for how this money could be spent must focus on the important element of parent consultation. JK is looking to do something of real substance with this money and really publicise the work that is

being done. BP to monitor what the emphasis on this bid will be so that there is no repetition in the tendering process for the PCV contract renewal going ahead.

The PCV County Chairs meeting is scheduled to take place on Friday 3rd April in Exeter.

Aiming High for Disabled Children Grant –John Shaw

Transitions Pathfinder –DCC £30,000 was granted, Transitions workers within Devon, including Kate Sandel and others, have helped to allocate how this money should be spent. Another £47,000 has been granted for next year to be spent on the Transitions services.

Mental Health Pathfinder - DCC have been invited to bid for £300,000 to be delivered over two years, in order to produce research to demonstrate how children and young people can benefit from accessing CAHMS services.

Devon have become 1 of 17 local authorities to achieve individual budget Pathfinder status, with £150,000 to be targeted to 30 families, this will make up for the money that can not be released from statutory budgets. JS is looking to map groups of families, in order to inform this process.

Stepping Stones –Oaklands School project is going ahead to rebuild two residential units, investigating a site for EBD provision at Roundswell in Barnstaple, looking to build two new pupil referral units which will be hubs of alternative curriculum services

Looking to re-commission multiple therapy services into a Single Devon Therapy service –which will encompass speech and language, OT and physiotherapy.

Carers Strategy –new positive links with Claire Cotter, Parenting Strategy, would like to make a joint strategy, looking to make a joint bid for parenting strategies

JS extended his thanks to BP, JS and to Miles Hapgood for all the sterling work that is being done.

Children's Trust

The Children's Trust have decided to split the current group into two, so that the Children Trust board and the new Stakeholders' Forum will meet separately. PCV are still waiting to hear when and where the Stakeholders forum meeting is to take place.

ACTION: JK and IS to update county on the progress of this new arrangement.

AOB

Staff vacancies in children's services

BN reported that one in eight of Devon County Council's social workers positions are currently unfilled. Would like to access information on how many of these vacancies are within Children's Services and how this is affecting the provision of regional services.

ACTION: Anne Whiteley is due to attend a future PCV county meeting. JK to email Anne to ask for these figures.

The abuse of children with additional needs

In her absence, Fiona, the Co-Chair of the Mid Devon locality would like to ask what role can PCV take to address the issue of abuse of children with additional needs (bullying, emotional, physical, sexual)? The abuse of children with additional needs is much more prevalent. PH and others agreed that maybe the best role for PCV to take would to actively raise awareness face-to-face with parents, carers and professionals.

Direct Payments from Devon Children & Young People's Services

Any feedback on the handout of draft guidance material for Direct Payments given out at the county meeting is to be forward by the 20th March to Louise or via JK if you do not have her email address.

'Together for Disabled Children' event taking place at Sandy Park in Exeter on the 24th March, PCV can offer one space to anyone interested. Julie Wilson looking to attend.

Thanks were extended to Bronwyn Nott for her participation within PCV as the chair of the Mid Devon locality.

***The next meeting will be Wednesday 13th May 2009 10:00 am
at the Fisherman's Cot, Bickleigh***