



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

13th May 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
Margaret Ladbury	Locality Chairperson for Exeter
Julie Wilson	Locality Chairperson for Mid Devon
Jo Woodcock	Locality Chairperson for South Hams
Jo Boydd	Locality Chairperson for North Devon
Anne Whiteley	Director of Children's and Young People's Services
Annie Moore	Parent Participation Officer
Liz Rafferty	Parenting Strategy Development Officer
Cathy Hill	DISCplus team leader
John Shaw	Strategic Commissioner for Children with Additional Needs
Sue Brealey	Parent Partnership Liaison Officer
Martin Spragg	Integrated Services Manager for South Devon JAT
Nicky Ruane	PCV Development Worker for Exeter and East Devon
Pam Hogan	PCV Development Worker for Mid and North Devon
Kate Legum	PCV Development Worker for Teignbridge, South Hams and West Devon.

Apologies:

Liz Carroll, Julia Lock, Cindy Stone, Donna Langmead, Beryl Perrin, Cathy Wreford-Holden

Welcome, Introductions and Apologies

JK welcomed everyone to county meetings: particularly new people who were in attendance.

- Cathy Wreford-Holden has resigned as Locality Chairperson for Teignbridge due to personal circumstances. Therefore, new vice-Chair for county is needed – if you are interested talk to JK.

Minutes of previous meeting and matters arising

Parenting Strategy Board

- Margaret Ladbury hasn't managed to attend the board yet but will be taking the matter of parents' requests for training in restraint to the next meeting.

FACB Budget Update

- No update from Miles Hapgood has yet been received.

Accessing Library Services for SN children

- JK met with Hazel Skinner. She is committed to putting into every library sections for special needs children and has been invited to the next county meeting. There will also be a specialist section which will be able to be ordered down from Exeter.

Other Matters

- Annual report cover is done. Annual reports disseminated to the attendees.
- School Transport will be put on to the next county forum agenda.

- Planned meetings in South Hams, Teignbridge and West Devon have been reduced following objections from the last county forum.
- There is a meeting next Monday re the renewal of the PCV contract
- Discussions re the Chairs payments will be included in the contractual renewal
- The Children's Trust meeting on May 22nd will feedback to the next county forum.

Correction to last month's minutes

Page 8

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 cannot be released from statutory budgets. JS is looking to map groups of families, in order to inform this process.

Should read

Devon hoping to become 1 of 17 authorities to achieve individual Pathfinder status.

Devon was not awarded Pathfinder status.

Locality Meetings

East Devon

Our last meeting took the form of an education day at Honiton just before the Easter holidays. It was a really good day with speakers taking parents through the stages of assessment from school action to statement. Speakers included Parent Partnership, Sue Meacham from the Inclusion and Reintegration team and Marion Argent from CSET, all of whom answered numerous questions from those attending. It was highlighted yet again that there are still schools who are excluding children without following the correct procedure. Some parents were really surprised to learn that what has been happening to their child is an illegal exclusion and hopefully they now have the knowledge to challenge such decisions in the future. The meeting again highlighted the need for parents to have time to talk to each other both for support and information.

Exeter

At our last meeting Chris West talked about what the OT Service does. During her talk the discussion moved on to sensory assessments. She explained about some of the things they look at and what they can do to help. She will be joining us again in June to talk further on this subject and especially about how some exercises may have a positive effect on either behaviour or on promoting a calming effect. At that same meeting CAMHS will be giving tips to parents on how to deal with their own stress, especially in light of the forthcoming summer holidays.

At our meeting next week we will be continuing to look at some of the local issues and what progress has been made on resolving them. One ongoing problem has been the continual lack of understanding parents have encountered at the RD and E, particularly with children who have little or no verbal communication. There also appears to be a widespread expectation that parents will stay with their child when they are admitted to Bramble Ward.

Teignbridge

At our last meeting we talked about local issues such as the demise of the enabling scheme, local consultation into inclusive play areas and the plans for the JAT. The group also decided that they would like Kate to look at organising training for Challenging Behaviour and Child Protection Awareness for parents with Special Needs children. They were also interested in Makaton training. The group decided that they wished the following issues be taken to the county meeting.

- Care Managers are fantastic
- Direct Payments make a big difference but there is a lot of paperwork
- Some health professionals lack training in special needs and have to be coached by parents
- There are few specialists in the South West. People have to travel to London for assessments

South Hams

Feedback on Cerebra research project was given.

There was a discussion about the location for county meetings.

Trainings budget to be spent on challenging behaviours training and child protection awareness.

These were some other issues that came up at the Kingsbridge Forum and the coffee morning in Dartmouth.

- Speech and Language services are few and far between. Services are crisis led. Children with known difficulties should be seen regularly rather than when they fall behind.
- Employment for young people with disabilities is a big problem.
- South Hams parents feel out of the loop and seem much more cut off from services especially those in Salcombe, Modbury, Kingsbridge, Dartmouth.
- Scouting can offer so much but parents don't seem to access this resource.
- Gaps: places where parents can leave their disabled children for a few hours.
- Inclusion policy will only work in schools if teachers and TA's are properly trained in SEN. Children in special schools receive so many holistic services which children in mainstream never receive or have to fight over. When does inclusion become exclusion!
- Bidwell Brook School is very much appreciated by the parents who use it.

North Devon

Last meeting was held on March 17th with 10 parents and 7 professionals
Donna Langmead was appointed vice chair.

George Holman, from North Devon Council, and Liz Carroll contributed to a discussion on Inclusive Play in Northern Devon.

Issue: Lack of accessibility of many parks across the area.

NDC conducted a Disability Discrimination assessment with access emerging as the main issue.
Spent £30,000 putting in new footpaths to link gates with equipment.
Wheelchair provision considered but problem with supervision meant was not included

Issue: Concern that total inclusion, with equipment available for everyone, not available in Northern Devon

Action: Sub-group formed to submit an expression of interest for 'Play Builder' funding. Priorities for this bid are that it is:

A demand led community initiative
In area of high deprivation
Targeting girls and ethnic minorities
Targeting Age range 8-13
For projects that can be finished by 2011

Issue: Current PCV contract ends October 31st

Action: Parent carers to consider what they want from PCV to inform the tendering process for a new contract.

The group welcomed the courses being set up by CAMHS supporting parents of children with a diagnosis of ADHD and for parents of children who've recently received a diagnosis of ASD.

Recommendations: That the ADHD course is run as a rolling programme across the area

That the ASD course is opened up to parents whose children were diagnosed longer than 6months ago.

Next meeting: 19th May looking at Direct Payments and Respite.

Also: Carers Workshop on June 8th. Joint day with the Generic Carers and Learning Disability Carers forum on the theme of Carers Health and Wellbeing.

Mid Devon

11 parents and 5 professionals were present at the meeting on March 18th

Bronwyn formally stood down as Chair of Mid Devon Parent Carer's Voice. Julie Wilson and Fiona Burnett were elected joint Mid-Devon Chairs although Julie is acting alone for the moment.

Jennie Waldron (Acting Complex Cases Team Manager) gave an overview of the Common Assessment Framework, Devon AXS pathway and Joint Agency thresholds for deciding

- whether or not a child's name goes on the Joint Agency Record
- whether or not a child receives help from the Joint Agency Service

The group highlighted the following issues:

- the long waiting list for an educational psychology consultation
- the lack of expert advice on strategies for children with high functioning Aspergers
- the lack of training and time for Special Educational Needs Coordinators (SENCO's)
- the situation where difficulties only manifest at home
- confusion over what direct payments can be used for.

Action: The new guidance on Direct Payments is the topic of the next Parent Carers' Voice meeting on May 20th at the Fisherman's Cot, Bickleigh.

Caroline Smith spoke on The Key Worker's role.

Trish Oliver spoke about CEDA (Community Equality Disability Action) is a Devon wide organisation supporting disabled people's development in artistic, IT and life skills. They have a new sports & activities leader and operate a holiday club, after school club and a Saturday club, although the holiday club and Saturday club are over subscribed.

Catherine Rees Stephan spoke about Face 2 Face,

a service where volunteer parent carers are trained to provide emotional support to parents

- training is free, funded by Brighter Tomorrows
- new course is starting after Easter running for 6 Tuesday's in school hours

Parent Partnership Service Update - Sue Brealey

1. Education events with PCV – really good working partnership
2. PP has been delivering training to schools governors on SN issues. More training needed in this area.
3. More funding is needed for inter-parental supporter staff training – JS - some money might be available from the stepping stones budget.
4. The recent parent weekend was very good
5. The annual report is in progress
6. The Lamb enquiry is very relevant to all of our work
7. PP is looking at how they will work with the parent support officers
8. PP is looking at the befriending role (face to face)

Parenting Networks

Liz Rafferty introduced parenting matters in Devon document and accompanying brochures Parenting Matters is a three year strategy to

- Support parents and practitioners
- Improve the way parents and practitioners work together
- Improve the resources available to support parents

There are five priorities:

1. Structures – establish a way to discuss parenting issues and put forward the recommendations for developing the priorities.
2. Services – help parents get the information, guidance and support they want and need.
3. Parents as partners – help parents get involved in services.
4. Qualified Workforce - continue to develop and improve our skills and knowledge so that parents feel confident that the services they get are effective and of good quality.
5. Making a difference – we will look at how the work we are doing is making a difference.

Annie Moore

Annie is the parenting participation /involvement officer for Devon County Council. She introduced the forum to some of her models and asked for volunteers to help design models further. Jeanette, Ian and Margaret volunteered.

Anne Whiteley

Thank you for inviting me to the meeting. It has been good to hear the details of what is going on.

The single largest objective is working PCT and Aiming High for Disabled Children budget. This has proved really challenging.

- There needs to be clarity about the base line of money and resources. A lot of historical investment has disappeared. New money will go into two areas
 1. AHDC where money is ring fenced and therefore manageable.
 2. PCT where DCC can't see where money is being spent.

PCV might usefully lobby PCT about where money is spent. DCC wants transparency to make sure all monies coming down are being spent on children with special needs.

PCV could ask what Health's strategy is, in particular in relation to the Way Forward agenda. Ask how Devon compares to other counties in the South West.

- There needs to be an integrated commissioning strategy between children's' services and the PCT in order that standards and expectations can be set for the JATs
- Within Children's Services, Stepping Stones is the key strategy for SN.
- Children's services will be taking on the commissioning of services and have got Beacon status in doing so. This means they will be working closely with government departments

Aiming High for Disabled Children Grant – Jeanette Kemlo

PCV has applied for a grant of £10,000.

1. £5,000 to be divided between the localities to engage parents in areas where PCV are not currently represented. The monies will also be used to engage harder to reach parents such as those in the mainstream education system, ethnic minorities with English as their second language, etc.
2. £5,000 to be spent on a Devon wide conference in October to celebrate the achievements of PCV.

CYPS Update – John Shaw

- Finance sheets from the PCT have been received but some of the figures are still vague about how monies earmarked for children with special needs was actually spent and what the outcomes were.
- A new commissioning officer about to come into post will speed up commissioning needs becoming reality.
- Feedback from Conversation Events:
 - Better information and joined up services,
 - Transport is still an issue,
 - Services are starting to radiate out from Exeter,
 - Parents and Carers are starting to feel heard.
- Overall, parent satisfaction with services was slightly below national average.
- Details will be on-line 10th June.

Aiming High for Disabled Grant

- £450,000 contract has been awarded to Robins to provide over night respite. Those with places at John Parks will be transferred to Robins.
- There is money to develop and firm up advocacy for transitional young people with special needs.

Beryl Perrin has requested a PCV representative to sit on the Aiming High reference group. Lois will volunteer.

The Stepping Stones project is developing a CAF centered integrated system. Chris is currently developing the paperwork for schools.

This year's goal is to prepare for a much larger budget expected next year.

The Conversation events will be happening again in June.

Martin Spragg – Integrated service manager, South and West Devon

Martin Spragg is interested in implementing a One Front Door for all Services Vision. The JAT to do all the work, not the parents or referral agencies. CSET will be joining and there will be some social care joined in as well. This makes the implementation more complicated in the short term. MS area needs new buildings and staff to catch up with other areas.

The strategy will be by the journey of the child fuelled by appropriate commissioning.

Children's Trust Meeting Feedback

At the last Children's Trust meeting in North Devon the following issues were discussed:

- Safeguarding
- Housing
- CYPP review process
- Plans for the future

Dates

PCV county forum dates for the next 12 months.

- 9th Sept 09
- 11th Nov 09
- 13th Jan 10
- 10th Mar 10
- 12th May 10
- 14th July 10

County Carers Forum

- 16th June 09
- 10th Sep 09
- 10th Dec 09
- 11th Mar 10

Close