

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE  
for Families of Children with Special Needs  
12<sup>th</sup> March 2008 at Fisherman's Cot, Bickleigh**

**Present:**

Jeanette Kemlo	County Chair/Locality Chairperson – North Devon
Nicky Ruane	Development worker – Exeter and East Devon
Julia Lock	Parent Carers' Voice Project Co-ordinator (DACVS)
Helen Phillips	Development worker – Teignbridge and South Hams & West Devon
John Shaw	Head of Children and Young People's Services (CYPS)
Beryl Perrin	County Carers Development Worker for CYPS
Margaret Ladbury	Exeter Chair PCV Forum
Bronwyn Nott	Locality Chair person – Mid Devon
Dennis Platt	DISCplus Co-ordinator
Lois Markworth	Locality Co-Chair – East Devon
Ian Simmins	Locality Co-Chair – East Devon
Anne Brand	Guest – Adult Learning Disability Forum (Dev)
Sue Pirrie	Minutes (TVS)

**Apologies:**

Pam Hogan	Development worker – Mid and North Devon
Liz Carroll	CYPS Early Years & Childcare Service
Cathie Wreford-Holden	Chair –Teignbridge PCV Locality
Nicola Winstanley	Chair- South Hams & West PCV Locality

**Minutes**

Error on page 2 under 'News on recent/future appointments' - Judith Johnson is not an OT.  
Parent Partnership new co-ordination has now been appointed – Sue Brady  
Minutes of previous meeting of 09.01.08 were agreed.

**Matters Arising**

**Pathfinder Status feedback *Update:*** John Shaw has submitted the application. It has only reached the second round; the reason for this is the fact there are too many authorities in the SW area.

**Equipment** - Bronwyn Nott had sent details of equipment to JK

**New funding in schools - ACTION:** Jeanette Kemlo to chase Ann Porter regarding 6<sup>th</sup> form provision.

**Feedback from Education Show**

Jeanette Kemlo attended the show which ran on 28/29 February at the NEC. She said it was worthwhile, had brought back many leaflets, but had not had a chance to read through them all. **ACTION** – to bring relevant information to next County meeting

**CAMHS** following a meeting with PCV to discuss the planning for future parent carers involvement in CAMHS development and delivery a programme for 2008 – 2009 has been proposed, Nick Preston, Lyn Davis, Julie Brough and Steve West will be attending County in May.

**Annual Report** One amendment was needed DISCplus should be added to the North Devon list of 'Networks Developed'. Numbers regarding circulation of the report have increased. Julia had prepared a small number with spiral binding but it was quite expensive. John Shaw said that additional financial support was available for printing & binding and offered to print copies for PCV.

**ACTION** – Annual Report to be printed & bound JS . CD Rom copies to be sent to Development Workers - JL

It was agreed that the new format looked good and thanks were given to Julia Lock for her hard work. Also thanks to the development workers for their locality reports and photographs.

### **Expenses and Funding for Workshops & Conferences**

North and Mid Devon have organised conferences through funding from their JAT Manager. All JAT managers need to be encouraged to offer this.

Carers Grant - nationally, 20% goes to Children's Services. Devon is to fall in line with this for 08/09 and therefore there is an increase of £200,000 to Children. In real terms it is an increase from £420,000 to £620,000.

John Shaw said that it was proposed that £100,000 should go to Young Carers. £80,000 will go to support Saturday / after school clubs and £20,000 has been allocated to PCV. There was a discussion as to who would hold/manage £20,000 and how it could be best used. Discussion on conferences and additional funding to be continued at a meeting between locality Chairs, Development Workers, John Shaw, Beryl Perrin and Julia – date to be set.

Julia Lock expressed concern that there had been a letter from Devon County Council saying that external contracts were being frozen (0% increase) in 08/09.

John Shaw explained that this was a blanket freeze on all external contracts.

Jeanette Kemlo mentioned that Pathfield School will be running a conference for parents (80) which will be free to attend. It will address the ongoing issue of SEN children in mainstream schools and will be held in June/early July, possibly at the Tiverton Hotel. School governors/head teachers will also be invited to attend. Jeanette requested a list of prospective parents to invite to the day. She will let everyone know the date once it is finalised.

Jeanette Kemlo queried the rules regarding payments for child minding. Julia Lock made it clear that the rules are there for auditing purposes. Cash-in-hand payments cause problems due to a lack of paper trail evidence – a proper invoice is required as there are tax implications. Julia explained that services must work under the National Guidelines i.e. childminder must provide invoice with clear evidence of the service provided and arrange their own tax payments. John Shaw agreed with this.

### **Locality Reports**

Brief updates from each locality were given. **Action plans for each locality are attached.**

#### **Exeter**

Only two parents attended the last meeting in Exeter, although apologies were received from 3 parents. June Marshall from Exeter Carers Focus came to talk about the benefits of joining the Carers Link. She discussed with the parents the possibility of linking into specific groups that are ordinarily hard to reach.

Issues in the area remain the difficulties of fully supporting children with additional needs in mainstream school.

Much of the meeting was given to providing support and advice to parents.

The next meeting will be the conference of Coping with Challenging Behaviour, held jointly with East and Mid Devon on 7<sup>th</sup> May at Exeter Racecourse

### **East Devon**

Attendance at the last meeting was disappointing and apologies were received from four parents for reasons of sickness and, in the case of two parents, due to a meeting with the Educational Psychologist (which is actually a result!) However, we are hopeful that numbers will be up for our next meeting next week.

Key issues in the area remain problems with inclusion in schools and the lack of out of school/holiday provision for children with additional needs. The initial report by the Joint Agency on the survey that parents completed about holiday/respite provision is out, and it is hoped that this will lead to improvements in the area.

A speech and language therapist for Exmouth is now in post

### **Mid Devon**

No meeting report.

### **Teignbridge**

A very busy start to the year. Three different meetings have been held a **locality meeting on 30/1/08 at Kingsteignton**, 6 parents attended along with Louise Smith Direct Payments, Beryl Perrin Fair Access to Carers Breaks and Cathy Hill from Displus. Site meeting at Decoy Park 18.2.08 with Debbie Marshall from Teignbridge Council, 4 parents and 6 children attended. An informal coffee morning 28.2.08 - 5 parents attended including 2 new parents, one who is also a Head teacher at a Primary School.

### **North Devon**

No meeting report.

### **South Hams and West Devon**

A very busy start to the year, two locality meetings have been held, one in Tavistock and one in Totnes with 13 parents attending, including 2 new parents in Tavistock.

### **JAR report – John Shaw**

JS outlined the structure of the Strategic Planning Framework (copy attached). Miles Hopgood will be Assistant Director for Integrated Services from 1<sup>st</sup> April and there will be three Area Managers immediately below him. He explained that there is to be a change in the management structure to a single management structure. JS's role is in Strategic Planning and Special Needs will involve working out strategies and monitoring delivery. He will have the power over a budget of £50million assigned to Mental Health and service specification will be formed following consultation.

Discussion around accountability of SEN funding in some schools – concern that there is little accountability as to how schools spend their SEN budgets.

BN asked if funding would be included in the strategy plan. JK mentioned Special School funding – some are funded at 74% and some at 64% and as a result Pathfield had a £130,000 deficit and that Bidwell Brook and Ellen Tinkham are also showing shortfalls. OFSTED had recommended that Pathfield employ 1 more teacher

but because of this deficit this would not be possible. JS explained that there is a bidding process and that was how funding is decided. There are 4 levels (1-4). Basically, residential schools are 74% funded currently and others will eventually rise to this level.

The Early Support programme was discussed and JS said that the national Joint Agency paperwork will not be used. Documents will be produced looking at current provision.

Over six months the Department of Children core offer is:

- Information
- Transparency
- Participation
- Local involvement network

JS said the terminology will have to be adopted. He ended by saying that the collective vision could achieve positive results over the three-year programme.

### **Childrens Trust**

There is no feedback as yet from the meeting.

### **Mission Statement**

**ACTION** HP/ JL will bring it to the next meeting.

### **Any Other Business**

Every Disabled Child Matters are campaigning to have fuel allowance for disabled children - please sign up on the website:

**<http://www.edcm.org.uk/Page.asp>**

Torquay free weekend for deserving parents 26/27<sup>th</sup> April Grand Hotel Torquay. Email BP or JK for details or with parent names.

**Conversation Events.** Beryl reported that they would look at encouraging new attendees to the events as opposed to the regulars. There was a positive response to what was being said and strong debate arising – 1) going to visit mainstream schools; 2) obtain views from children at mainstream schools

There was good feedback from parents generally. There were difficulties around timing – September/October and evening were suggested.

HP commented that they were often given too short notice for events, saying that two weeks is not enough time.

Future consultation events are planned over the year. JK said emails from parents were positive saying they felt they had been listened to.

It was agreed that it would be useful to record the website for the Devon County Council Children and Families in these minutes – see below:

**<http://www.devon.gov.uk/index/cyps.htm>**

Anne Brand thanked the group for allowing her to attend the meeting

**The next meeting will be 14<sup>th</sup> May 10:00am  
at Fisherman's Cot, Tiverton**

Parent Carers Voice  
Locality Work Plan- Teignbridge

Feedback to County 14<sup>th</sup> March 2008-03-03

A very busy start to the year. Three different 'meeting's have been held a locality meeting on 30/1/08 at Kingsteignton, 6 parents attended along with Louise Smith Direct Payments, Beryl Perrin Fair Access to Carers Breaks and Cathy Hill from Discplus. Site meeting at Decoy Park 18.2.08 with Debbie Marshall from Teignbridge Council, 4 parents and 6 children attended. An informal coffee morning

<b>Issues raised</b>	<b>Action Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
Concerns over inaccessible play equipment in local parks for wheelchair users. June 07	Write to local council and invite response (HP) HP to contact Liz Carroll HP to contact Mirrium Guard	June 07 - ongoing	Debbie Masrshall Project Officer for Play Areas Teignbridge Council attended locality Forum 27.11.07 Site meeting arranged for 18.2.08 at Decoy Park Debbie Marshal Requested full involvement of PCV in redesigning Trim Trail area of the Park. PCV meeting to be held to develop ideas following site meeting
SEN funding and children not receiving their entitlement outlined in their statements. Jan'08	Advice given on how to address issues within a school and writing to the chair of governors. You have a right to ask where the SEN is spent. SEN funding on County Agenda  Parent Partnership to deliver training at next Teignbridge Locality	Jan 08 - ongoing	
<b>Issues raised</b>	<b>Action Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
Direct Payments - difficulty finding carers to meet their children's needs	HP to raise at County and at Conversation event to be held 29.2.08 in Newton Abbot	Jan 08 -	

28.2.08 - 5 parents attended including 2 new parents, one who is also a Head teacher at a Primary School.

Parent Carers Voice  
Locality Work Plan- South Hams & West

Feedback to County 14<sup>th</sup> March 2008-03-03

A very busy start to the year, two locality meeting have been held, one in Tavistock and one in Totnes with 13 parents attending, including 2 new parents in Tavistock.

<b>Issues raised</b>	<b>Action Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
FLEXIBLE BREAK GRANTS - available Carers Link and Flexible Break Grants Nov. 07 & Jan,08	Leaflets and info given to parents Invite Carers link to attend future meeting Follow up next meeting	Nov 07 - Feb 08	Carerslink to speak at next SH & West forum on 25.2.08 Sue Hurley attended meeting on 25.2 Continue to promote through locality meetings
Lack of Inclusion in 6 <sup>th</sup> forms within Community Colleges require grade C GCSE'S Jan 08	Raise at County lack of 16 - 19 provision / inclusion	Jan 08 - ongoing	
Exclusion - children being excluded due to their disability Jan. 08	Contact Ernie Lloyd DCC Exclusions and request attending future meeting	Jan 08	Ernie Lloyd to attend Tavi. Meeting 6 <sup>th</sup> May to talk about exclusion
Transition from primary - senior school. Choosing the right school for your child.	Cathy Hill to forward information on Transition	Feb. 08 - ongoing	
<b>Issues raised</b>	<b>Action Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
SEN funding and	Advice given on how to address	Jan 08 - Feb 08	Nicola attended school meeting,

<p>children not receiving their entitlement outlined in their statements. Example give child's statement 11 1/2 hours entitlement only getting 4 hours</p> <p>Jan'08</p>	<p>issues within a school and writing to the chair of governors. You have a right to ask where the SEN is spent.</p> <p>SEN funding on County Agenda Nicola Winstanly to bring up at Children's Trust.</p>		<p>along with Cath Butland from Parent Partnership to support parent Feb. 08</p> <p>When new Parent Partnership Worker for area is appointed invite to locality meeting.</p>
<p>Lack of Youth Provision in Tavistock</p>	<p>Meeting held to establish Parent Group / committee along with Tavi. Youth Café Manager, Paul Dobbie Youth Worker, Jan Simpson CVS</p>	<p>Oct. 07 - ongoing</p>	<p>First Youth Café Plus session held on Monday 5<sup>th</sup> Nov. and is going from strength to strength. Meeting held 7.3.08 to develop further.</p>

**Parent Carers' Voice  
East Devon work plan**

<b>Issues raised</b>	<b>Action / Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
Nov 07 Concern over whether health professionals will be replaced when they leave or whether colleagues are being expected to pick up their caseloads	Parent to find out what is happening with Exmouth S and L therapist  Ask other localities if they have experienced problems.  Find specific examples to ask PCT	By locality Forum Feb 08  January 08  Feb 08	Speech and Language therapist has now been appointed for Exmouth
Nov/Dec 07 SEN/ Inclusion in schools	To be discussed at County Forum in January		Ongoing
Jan/Feb 07 Lack of out of school provision	In discussion with JAT over future developments		As a result of the survey that was sent to Exeter, East and Mid Devon families areas of lack of provision have been identified and plans are being developed to meet the identified needs of families
Ongoing Difficulties faced by parents/professionals in dealing with challenging behaviour	Organising conference on Challenging Behaviour with Exeter and Mid Devon	May 7th	

**Parent Carers' Voice  
Exeter work plan**

<b>Issues raised</b>	<b>Action / Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
Nov 07 Apparent inequality of service availability for some families, especially where children have 'hidden' disabilities	Continue to encourage families to ask for assessment. Raise awareness of what help is available	Ongoing	Fair Access to Carers Breaks is addressing this and so families are being encouraged to ask for an assessment of their needs and that of their child
Nov 07 SEN/ Inclusion issues	To be discussed at County Forum in January	Jan 08	Ongoing
Dec 07/Jan 08 TAs off sick and children left unsupported	Raise at County Forum in SEN discussion	Jan 08	Issue raised at County. Responsibility lies with school
Feb 08 Bullying of ASD children in mainstream school by other CSN	Speaking with the school	Ongoing	
Feb 08 Schools unable to deal with the inappropriate comments made by ASD children and the reactions those comments evoke	Speaking with the school and working with them to find a solution	Ongoing	
Feb 08 ASD children not being sufficiently supported which is leading to H&S situations such as child leaving school premises or hiding sharp objects in pockets	Parent in discussion with school. Has asked for higher level of support to be obtained from CSET.  Raise at County Forum for information	Ongoing	
Ongoing Difficulties faced by parents/professionals in dealing with challenging behaviour	Organising conference on Challenging Behaviour with East and Mid Devon	May 7th	

Parent Carers Voice  
Mid Devon Locality Work Plan

Date: March 5<sup>th</sup> 2008  
 Venue: Ockment Centre, Okehampton  
 Present: 5 parents, 5 professionals

<b>Issues raised</b>	<b>Action Responsibility</b>	<b>Time Scale</b>	<b>Outcome</b>
Information supplied on benefit entitlement	Jude Giddings from Devon Welfare Rights Project speaker at this meeting. Information disseminated through notes	Immediate	Parents have source of access to information
SENCO's minimising difficulties on DLA form	Challenge any rejection based on a school's report - parents Contact DWRU for advice - Parents/Jude Giddings	When occurs When required	
Advice required on completing DLA forms	Jude Giddings advised	Immediate	Clarified acceptable answers
Difficulty of coping alone when turned down by JAT	Re-contact JAT - Su O'Leary to assist with Help desk number Contact face2face - Parent Consider outreach/holiday clubs (details given at meeting) -parent	As soon as possible	

Parent Carers Voice  
Locality Work Plan

Date: January 22<sup>nd</sup> 2008

Venue: Cedars, Barnstaple

Present: 25 parents (3 apologies) and 6 professionals (2 apologies)

Issues raised	Action (Responsibility)	Time Scale	Outcome
Information required re practical techniques for coping with challenging behaviour	Presentation given/questions answered (Rod Conway & other professionals) Information distributed in the minutes (Pam)	Immediate  Within 2 weeks	Parents provided with practical strategies and techniques
Concerns expressed about support for children in mainstream	Clarify options (Jeannette)	Immediate	