

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE
for Families of Children with Special Needs
14th May 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)
Pam Hogan	Development worker –Mid and North Devon
Helen Phillips	Development worker – Teignbridge and South Hams & West Devon
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
Cathie Wreford-Holden	Chair –Teignbridge PCV Locality
Cindy Stone	Parent – North Devon
Philippa Braund	
Julie Brough	CAHMS
Liz Carroll	CYPS Early Years & Childcare Service
Nick Preston	CAHMS
Sue Brealey	Parent Partnership Liaison Officer
Lyn Davis	CAHMS Programme Manager
Nichola Winstanley	locality Chair –South Hams & West Devon

Apologies:

Gwen Pearson	Childrens Commissioner Devon PCT
John Shaw	Head of Children and Young People's Services (CYPS)
Frank O'Friel	Joint Agency Services Manager, Eastern Devon
Miles Hapgood	Director Children's Services, Devon PCT
Steve West	CAHMS

Minutes

Minutes of previous meeting of 12.03.08 were agreed.

Matters Arising

New funding in schools: Several meetings have been held with DCC. They acknowledge that they have possibly squeezed the 3 schools (Ellen Tinkham, Pathfield and Bidwell Brook) too far. The final outcome is not yet known.

Feedback from Education Show: Jeanette Kemlo attended the show which ran on 28/29 February at the NEC. Information displayed on back table, available for Forum members to read and take away.

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>

Feedback: Jeannette has been in contact, managed to get a response from an under secretary, who was very condescending.

CAMHS Update and Future Plans –Lyn Davis (Programme Manager)

Lyn met with Jeanette, Nicky and Pam on February 14th to discuss the planning for future parent/carer involvement in the CAHMS service development and delivery (minutes of the meeting were distributed).

By speaking with Miles and John, it has become apparent that there is a lack of consistency throughout the county e.g. Exeter and Mid Devon only take GP referrals, it has been identified that it is essential to build a consistent service. Within the next eight months, CAHMS will be beginning agency integration with JAT developing an emotional health and well being strategy.

There will be a new referral Pathway that enables parents, young people and professionals to access CAMHS. There will be a Referral co-ordinator in post with a clinician to support and screen referrals. Complex case teams will be assembled to be composed of Occupational Therapists, learning disability nurses, Mental Health workers etc.

CAHMS will be developing CAPA (Choice And Partnership Approach), the principles of which are to ensure that all referrals come through a single point/ entrance, it will be a much more supportive process and parents will be given a choice of appointments and will be sent an S&DQ (strengths and difficulties questionnaire) . There will be a shift in how CAHMS deliver services, working with children and parents, examining their strengths and looking to empower them. The initial session will talk through what services are available and what might be considered to be useful. After that it is envisaged that for many people a further four sessions will probably be all that is needed and probably only 20% will need further services.

An information and guidance pack will be distributed to all referrers that will include important guidance materials to explain assessment criteria.

CAHMS are also in the process of launching a new IT system (Care First); Julie Brough has attended steering groups across the county and hopes that it will be up and running by July 2008.

In the Programme there are three areas/proxies:

- 24/7 access to CAHMS
- CAHMS and learning disabilities (e.g. ADHD/AS and the development of multi-agency pathways)
- Working with over sixteen year olds

Young people from Barnstaple and Exeter have recently been involved in interview panels, JK found their feedback enlightening: She thought it was a great idea because some services have remained remote from young people and many other agencies have not been subject to parent's scrutiny.

JK suggested that NP and/or other CAHMS managers could attend PCV locality meetings in order to correspond about review panels in the local area and thus keep up a dialogue investigating the difficulties of policy, strategy etc. This would be one way of demonstrating the willingness of the CAHMS team to consult parent/carers.

LD would really like to see parent/carer involvement within the CAHMS disability steering group, and aims to visit each of the areas and hear opinions, concerns, suggestions etc. JK suggested that it would be good for CAHMS to deliver a remit for the project group and then PCV can then go out and find the best parent/carer to sit on the group. The forum agreed that it might be wise to find two parent\carers to sit in, so that they feel more confident in a room of professionals.

LD would like CAHMS information to go on the DISCPlus website lists, to be directly accessed by service users. The forum agreed that all promotional information needs to be clear as many parent carers do not know what CAHMS is; it is evident that the acronyms are not understood. LD and JB suggested the idea of producing a standard pack of guidance for parent carers with child-friendly leaflets etc. JK asserted that it would be good if the CAHMS team informed parent carers of the existence of PCV on their first meeting and that PCV leaflets and materials could go out with the guidance pack.

LM would like a leaflet for teachers to be included in the CAHMS information pack, as many schools and teachers do not know what CAHMS is and what their role is throughout the county. JK and NP agreed that communication with educational authorities should be heightened, in the hope of raising awareness of the role and work of CAHMS.

JB has been in the process of setting up some good audits in North Devon in order to see what parent /carers think about the CAHMS service from their first appointment.

The forum discussed some preliminary ideas for the CAHMS open discussion/ workshop on Wednesday 8th October (an all day event) at the Tiverton Hotel:

- updates
- CAHMS pathways
- information packs for parent carers
- CAHMS therapy demonstrations
- PH reported that parent carers at the Coping with Challenging Behaviour conference had identified that (1) access to CAHMS services should be made clearer and (2) their ability to help with the transition to adult services

It was agreed that CAHMS workers from different areas should attend the workshop so that they can meet and communicate with parent/ carers within each service district. LD will be inviting and updating all parent carers that attended last year's workshop. JK thinks that it would be a good idea for PCV development workers to disseminate information and start to publicise the date of the future program to parent/carers.

ACTION: PCV development workers to report back to LD the issues within their own area before date of workshop.

ACTION: Issues with CAHMS in each locality will also be fed back into the county meeting in September.

JB handed round a leaflet for the North Devon CAHMS Family Therapy Service in Barnstaple and Holsworthy.

Update from CYPs

JS and MH not in attendance to report. JK handed out a report from MH outlining his new role and his priorities within it.

BP is currently looking at the agenda for 'Aiming High for Disabled Children'. In the Exeter and East Devon area, a questionnaire is being sent out to all those registered with their JAS, this will ask parent carers what services they are currently using e.g. Direct Payments and what services they would like to see available. Having done two rounds of conversation events, BP has accumulated parent carers' priorities as well data which demonstrates the numbers of conditions, ages etc of service users within each district. At the end of June, BP will be inviting all service providers who want to be part of the process to a consultation day, where it can be examined whether services are currently providing the level of care that the parent carers need –with a particular focus on the standard of transition services.

Future 'Conversation Events' are to be renamed; they will cover such issues as:

- Are we commissioning in the right way?
- Palliative care (complex care needs), in conjunction with the Devon Hospice

ACTION: BP to update Forum on the progress of the events at the next meeting in July.

The provisional dates are as follows:

- Tuesday 23rd September in Exeter
- Thursday 25th September in Ivybridge (evening)
- Wednesday 1st October in Barnstaple/North Devon area

Please email Beryl if there are any issues with these dates beryl.perrin@devon.gov.uk

ACTION: The dates are to be posted onto the DISCPlus website, communicated to parent carers through locality meetings etc to avoid postal costs.

NW expressed her concerns over the long-term future of the Bidwell Brook School Holiday Club, who are experiencing difficulties due to lack of funding and practical support. The club would like to appoint a Treasurer. BP reported that other groups are experiencing similar problems, and that the committee could employ someone for two hours accounting work. The group may have to examine what is affordable and re-evaluate staffing costs and take account of these costs when deciding on the cost of the scheme.

CWH knows someone who if approached by four people, would be happy to do Payroll for groups on a self-employed basis.

DP added that groups are welcome to advertise any appeals within the DISCplus newsletter.

The Way Ahead booklet is to be made available, which contains information on Children and Young Peoples' services.

The Children's and Young People's Plan 2008 - 2011 was distributed.

Feedback proposals from May 1st meeting

Notes of the development meeting were distributed.

The purpose of the meeting was to look at the development needs of the PCV organisation in the light of the £20k sum of money awarded for use by parent/carers as announced at the March County Forum meeting.

A discussion followed regarding the Devon SEN conference on the 16th September:

BP reported that JS thinks that maybe the conference should have a PCV focus; promoting and celebrate the role.

JK is conscious that the workshops swallow up a lot of the time of development workers and puts a strain on finances due to expenses claimed. However, with regards to the suggested conference, PCV are to be working with Pathfield School in a joint initiative. The school can accommodate management and finance detail and the board of Governors have asserted that they will be lending support. JK hopes that the conference will attract a national speaker, in order to get a broader picture.

JL asked where the parent carers' expenses would be claimed from. JK recognised that the county needed to discuss and agree a source.

NW feels that PCV should be pushing educational authorities to converse with parents, that they should cover the costs and getting the two-way communication going, organising their own face-to-face discussions/conferences. JL added that education need to be following the lead of CAHMS, who have demonstrated that they are engaging with parents by running their workshop.

PH argued that a conference can demonstrate the benefits of communicating, with professionals and parents in the same room, it can help break down the mysteries and then professionals can see the need. PH reported that Frank O'Friel felt that the Exeter conference had encouraged professionals to take the lead and run their own. JL agreed but asserted that the core function of PCV is not the provision of conferences, but the consultation of parents about service development and delivery.

ACTION: JK to write to Anne Whiteley to report on the county discussion and the request that CYP Directorate fund the conference, leaving PCV to fulfil the important task of locating parent carers. JK feels that due to these developments the conference might not be in September now.

With regards to the allocation of monies outlined on the first page of the meeting notes, JL disagreed that £5k be set aside to pay for overtime and additional hours incurred by development workers in organising workshops/conferences which are outside the normal contract conditions. Arguing that the money will be needed to pay for rent, room hire etc.

ACTION: JL, JK and BP to set up a meeting to evaluate the budget as part of contract monitoring.

Locality Reports

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

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

Recruitment Panels and Processes

ACTION: LD to get a list of involvement opportunities to JK where parent carers can contribute to CAMHS development.

Any Other Business

- **ACTION:** Write as an organisation to Ofsted to make them aware that SEN children are being removed during Devon school inspections. Localities have identified that children are being taken on walks, being put in the corner and parents are being asked to remove them for the day. JK will draft letter and send round by email
- JK attended the Exclusions OSC Task Group in April, which examined environmental and education-based issues, the exclusion of statemented pupils and discussed the responsibilities of school governors. A report of her discussions was circulated.
- A request has been made by Becky Keeling to attend the next County Forum in July, in order to report about LINK which has taken over the work of CPPIH

- Kids South meeting in Reading on the 19th June –might be of interest to any parents with children that have special equipment needs
ACTION: JK to order more leaflets
- JK introduced the Forum to the Cooler Ruler –a specialised tool for SEN children (dyslexic etc), a leaflet is available on request
- PH to distribute OAASIS group information on special needs to development workers, which is also available on the DISCplus website
- BN shared her good experiences during a hospital visit with her daughter, would like county to put their voice to an application for a Learning Disability Nurse for children and young people
- There is a poster campaign going out to surgeries etc within Devon, to promote the work of Parent Carers Voice
- NR informed the group that Exeter CVS are hoping to undertake research project, which is looking for people to talk to who are actively involved in forums etc
- Miriam Guard has secured £125k for the Playground Park Scheme

The PCV Annual reports were distributed by Julia Lock.

Nanny Care

A presentation was given by a company that is currently developing a website and software application for families of children with additional needs. The aim is to incorporate a database that will help to locate CRB checked workers that can be employed to work with their children, as well as an interactive diary that can generate letters relating to appointments or childcare arrangements as well as keeping track of finances such as direct payments.

There were suggestions made as to what was felt would be useful to families and what other tools may be useful.

***The next meeting will be Wednesday 9th July 10:00 am
at Fisherman's Cot, Tiverton***

Parent Carers Voice
Locality Work Plan

Date: March 25th 2008

Venue: Cedars, Barnstaple

Present: 8 parents (4 apologies) and 3 professionals (3 apologies)

Issues raised	Action (Responsibility)	Time Scale	Outcome
Need for training and events for parents	Ideas requested on how the available money should be spent (all parents at locality level)	By County	Training for independent parental advisors & Education event requested
Concerns re procedures for children with additional needs in medical settings	Requests for issues to be covered on day to Pam (parents) Conference to be organised (Chair & development worker)	May 20th	
Clarification of referral process to the County Autism Team (CAT)	Information given at meeting (Rita Burgess CAT)	Immediate	Process clarified
Concerns over children being taken into care if parents admit they are not coping	Reassurance & support (all at the forum) Suggestions re support - face2face, Siblink, NCH Family breaks scheme etc (forum & Pat Herman)	Immediate Immediate	Parent reassured and went away with positive sources of support

**Parent Carers Voice
Locality Work Plan- South Hams & West**

Issues raised	Action Responsibility	Time Scale	Outcome
Lack of Inclusion in 6 th 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 th May to talk about exclusion – Newsletter with information from Ernie Lloyd sent to all on database
Transition from primary – senior school. Choosing the right school for your child.	Cathy Hill to forward information on Transition	Feb. 08 - ongoing	
SEN funding and children not receiving their entitlement outlined in their statements. Example give child's statement 11 1/2 hours entitlement only getting 4 hours 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 Nicola Winstanley to bring up at Children's Trust.	Jan 08 – ongoing	Nicola attended school meeting, along with Cath Butland from Parent Partnership to support parent Feb. 08 When new Parent Partnership Worker for area is appointed invite to locality meeting. Peter Holman to attend Kingsbridge meeting on 24 th June
Lack of Youth Provision in Tavistock	Meeting held to establish Parent Group / committee along with Tavi. Youth Café Manager, Paul Dobbie Youth Worker, Jan Simpson CVS	Oct. 07 - ongoing	First Youth Café Plus session held on Monday 5 th Nov. and is going from strength to strength. Meeting held 7.3.08 to develop further. Development meeting HP attended March.

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

Issues raised	Action / Responsibility	Time Scale	Outcome
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	Numbers attending conference had to be limited due to the level of demand. It is planned to repeat the day in July
April 08 Concern over the changes to the East Devon activities scheme and the increase in cost to families	Has been raised with the JAS. A letter is going out to parents to explain the plans. Will be discussed at locality forum	May 08	

**Parent Carers' Voice
Exeter work plan**

Issues raised	Action / Responsibility	Time Scale	Outcome
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 7 th	Numbers attending conference had to be limited due to the level of demand. It is planned to repeat the day in July
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Parent Carers Voice
Mid Devon Locality Work Plan

Date: May 7th 2008

Venue: Exeter Racecourse –joint event with Exeter & East

Present: 84 parents, 33 professionals

Issues raised	Action (Responsibility)	Time Scale	Outcome
Enormous demand for help with practical strategies for coping with challenging behaviour –over 90 parents waiting	Arrange further conference (Pam, Nicky, Frank O’Friel)	Provisionally July 8th	
Request for more frequent conferences, particularly on Challenging behaviour in puberty, managing anger and anxiety, transition from primary to secondary, help for siblings, food & mood, education & children’s rights, social skills and more	Discuss at next PCV locality and with Julia Lock and Frank O’Friel (Pam/Nicky)	Next locality (July 2 nd)/ PCV Team Meeting/ Joint PCV/JAS meeting (May 22 nd)	
Need for opportunity to share experiences with other parents & professionals	Forum & conferences (PCV/JAS)	May 7 th -ongoing	Positive feedback from parents on success of this at conference

Parent Carers Voice
Locality Work Plan- Teignbridge

Issues raised	Action Responsibility	Time Scale	Outcome
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 Miriam Guard	June 07 - ongoing	Debbie Marshall 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. ACTION Meeting held 29/4/08 Debbie Marshall had produced a document- Justification for Council to provide accessible play space (please see attached) Miriam Guard shared experience and knowledge re inclusive play ACTION 8/5/08 Locality group put together suggestions HP to write up and forward to Debbie Marshall.
EDUCATION 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	Training delivered 16 th March – well received feedback from parents that they found it very useful
EDUCATION – Inclusion school outings transport used is not inclusive parent either had to carry child on to coach or told to order taxi	HP /CWH Raise at County	May '08	
EDUCATION – OFSTED Drawn to our attention that during OFSTED inspection parents had been asked to keep SEN children at home or they had been taken out for the day by LSA's	HP /CWH Raise at County – suggest as an organisation we write to OFSTED to see if / how this is monitored during inspections	May - 08	

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 HP Contact NCH to find out the work they are doing to develop data base – leaflets distributed	Jan 08 - ongoing	Information received from NCH – HP to invite to future Locality meeting
SPLASH & Bidwell Brook Holiday Club – concerns over future as parents feel they are in danger of closing due to funding and the need for practical support	HP / CWH to raise at County	May ‘08	

Update by Miles Hapgood

My new role

I'm the Assistant Director responsible for the delivery of a range of integrated (Devon County Council and Devon Primary Care Trust) children's services, in particular:-

- a. the roll out of the AXS pathway Devon-wide.
- b. the Devon PCT's public health nursing services (health visiting and school nursing).
- c. child and adolescent mental health services.
- d. services for children with physical, sensory or learning disability, and long term health conditions.

My job is to ensure that these services are delivered to a high standard and that they link effectively with each other and with other areas of children's work, e.g. integrated youth support services and social care.

New Children's Trust Developments

There is a lot happening but the key development for me is the work being done to strengthen the work of the Trust at locality (district council area) level and at learning community level. It has been acknowledged that the work of the Trust has appeared too remote to those working in their local communities, and we are now putting into place some new arrangements to promote more effective local/centre working.

Next year's priorities

- a. to ensure that the practitioner toolkit for integrated working (common assessment framework, lead professional etc) supports effective day to day practice.
- b. to embed the AXS pathway within more areas of Devon.
- c. to deliver our new service specification for health visiting and school nursing services to the satisfaction of our PCT and GP commissioners.
- d. to reduce waiting times for child and adolescent mental health services.
- e. to meet the stretching targets set out by the Government in 'Aiming High for Disabled Children'.

How will the CYPP impact on children's lives?

The acid test is whether we can deliver measurable benefit for all 5 Every Child Matters outcomes. These benefits may be quantitative or qualitative, but we do need to be able to evidence that we are making a difference. I'll be making sure that we get more direct feedback from children, young people, parents, carers and staff on what is working and what isn't. I think we're getting better. The Joint Area Review was a challenging experience for all of the Children's Trust partners, and our collective response has led to a better understanding of how we are doing and more effective joint working. The CYPP describes the next stage of the journey.

How can we all contribute?

By making sure that we all do our core jobs to a high standard, by making the most of the opportunities for integrated working where the needs of the child and family require this approach, and by listening to what children and young people tell us about our services (and then doing something about it!).