

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE
for Families of Children with Special Needs
10th September 2008 at Fisherman's Cot, Bickleigh**

Present:

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
Bronwyn Nott	Locality Chair person – Mid Devon
Lois Markworth	Locality Co-Chair – East Devon
Ian Simmins	Locality Co-Chair – East Devon
Cathie Wreford-Holden	Chair –Teignbridge PCV Locality
Margaret Ladbury	Exeter Chair PCV Forum
John Shaw	Strategic Commissioner for Children with Additional Needs
Liz Carroll	CYPS Early Years & Childcare Service
Sue Brealey	Parent Partnership Liaison Officer
Sally Edgcombe	Parent – North Devon Locality
Kate Sandel	Young Devon
Steve West	CAMHS Manager, Eastern region
Marc Johnson	Advocacy Co-ordinator, Young Devon

Apologies:

Jeanette Kemlo	County Chair/Locality Chairperson – North Devon
Gwen Pearson	Children's Commissioner Devon PCT
Beryl Perrin	Commissioning Officer for Aiming High for Disabled Children
Frank O'Friel	JAS Manager, Eastern Devon
Dennis Platt	DISCplus Co-ordinator
Lyn Davis	CAHMS Programme Manager

Welcome, Introductions and apologies

Bronwyn explained that Jeanette was unable to attend as she had to deal with other matters in her role as Chair of Governors at Pathfield School due to the recent death of the Headteacher.

Minutes of previous meeting and matters arising

New Funding

An additional £1.5 million has been agreed for the special schools. This means that the schools should now all have about 75% of funding rather than the previous discrepancies. If Devon were funded at the level of other authorities this would mean that all the schools would have 100%.

Devon is now in the top 10% of special schools funding.

Education Conference

This is not going ahead at present.

Evaluation of PCV budget

Jeanette, Julia and Beryl have met, agreed a budget and all is on track.

Removal of SEN children during Ofsted inspections

It had previously been agreed to write to Ofsted to raise concerns that some schools were removing children from the school during Ofsted inspections.

ACTION: JK to draft a letter and send round by email.

Measuring and encouraging the involvement of parent carers

All PCV forum members had been asked to consider this; it would be discussed under AOB.

The minutes were agreed.

Locality Reports

Brief updates from each locality were given as this was the first County Forum of the academic year.

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

Mid Devon

No issues have been raised as we have not had a meeting yet but our next meeting is on Wednesday 17th September with Ernie Lloyd speaking on exclusions and a group discussion on issues concerning children in mainstream who had additional needs but are not statemented.

Exeter

No meetings have been held over the summer since the last County Forum.

There seems to be a growing concern amongst some families as to the lack of provision for children on the higher end of the autistic spectrum in schools, what is available for these children when their mainstream placement breaks down, particularly at secondary level? Are there any plans to create units within mainstream schools? Even for families whose child may not be in this position at present there is a growing concern that if things go wrong and their child cannot cope an 'out of county' placement may be the only option as there is currently no special school that meets their needs.

JS to answer this in his update.

There have been requests from parents for training in restraint – how can they access this?

There was a discussion as to the possible sources of training and several suggestions made. KS offered to collate the information if people send her what they have.

ACTION: All to send restraint training contacts to KS

East Devon

There has not been a meeting over the summer since the last County.

Next week we have Louise Edmonds returning to discuss how the East Devon Activity Scheme went over the holiday and to answer any questions/deal with any issues raised by those who used it.

We have been asked when the FACB assessment will be altered to better reflect the needs of children and young people with ASD, particularly those in mainstream schools, especially where they have mental health issues.

Teignbridge

In the South Hams a meeting was recently held in Kingsbridge. 12 parents attended and they were given lots of support and advice from Parent Partnership.

Helen has information about an online consultation on the new accredited training for SENCOs in schools. More information can be found at www.tda.gov.uk.

A parent has queried whether they have to have their child on medication in order to get behaviour therapy.

This was felt to be untrue.

There have been several issues with transport, including changes made at the last minute and the escort being withdrawn despite the child requiring 1:1 support.

It was queried whether there was a maximum journey time for children using school transport.

JS said that the county aspired to a 40 minute journey time, however, this was not always possible due to the geography of the county and the location of the schools.

It was felt that changes were a greater problem than the length of the journey. JS said that Pathfield had done a survey and found that the children enjoyed the time the spent on the bus, however he agreed we need a more consistent approach to transport.

There was considerable discussion around some of the problems experienced by families with school transport.

- *Delays in sending out details 'in case parents lost them'*
- *Children being forgotten/left off lists*
- *Code of conduct – insisting SEN children sign when they cannot read or write*
- *Code of conduct is generic – need one for SEN children*

JS suggested the forum invite the transport manager and co-ordinator to a discussion session.

A parent was asking whether they can approach the County Autism Team directly where either the school or the SENCO would not ask for help.

If parents have issues with individual schools they should contact John Shaw or Anne Porter.

Department of Health have been running a consultation on the National Dementia Strategy. Helen had attended a meeting that had looked at 'best practice' and one thing that came out of it was that in Dorset they do a baseline assessment on every young person with Downs Syndrome on transition to adult services, This provides the necessary information should an early of dementia be suspected.

North Devon

Concerns had been raised at the lack of OT provision for ASD children and at the low take up of early bird courses.

JS replied that Early Bird provision varies from area to area. The need to have 6 families with a diagnosis in order to secure the funding to run it may make running the courses difficult.

One parent who had done the course felt that it was excellent.

Pam commented on the sad death of Rod Conway, Headteacher of Pathfield School. Rod had had a profound impact on many parents during his time at the school. His practical, down to earth approach and his advice was greatly appreciated by the many parents he helped and he will be sorely missed.

A book of condolence is available at the school.

CAMHS Update – Steve West

Implementation of CAPA (Choice and Partnership Approach)

Point of referral



Form goes in and is checked against criteria. Family, young person and school are sent a strengths and difficulties questionnaire (SDQ).

Choice appointment



The aim of the choice appointment is to have a discussion about what help might be needed and what can be offered. These are block booked appointments in the clinician's diary. The secretary phones the parent/young person and arranges it. The clinician spends ¾ - 1 hour with the parent/young person and together they make the decision as to what can be offered and

what they think would be beneficial. About 80% of the cases are fairly straightforward and will require on average 6.9 sessions. 20% are more complex. The aim is to see someone and to get them sorted.

Partnership appointment

Having decided who they need to see their next step is to arrange a partnership slot. The information that is needed will be sent electronically to the new clinician. These sessions are limited to 6 after which the decision has to be made as to whether they are better.

There is the option to move to more specialist clinicians if necessary, but the service is limited and must be used wisely.

Steve will monitor where there is need for more services and take these findings to the commissioners to develop capacity in these areas.

CAMHS is part of a multi agency approach and will be able to signpost/refer clients to other agencies.

They know there will be some difficulties initially, but they need the flexibility to alter things/make changes to get it running.

At present different areas do things in a slightly different way, so the commissioners have set a date in December for the implementation of CAPA.

ASD Pathway

A meeting chaired by Hazel Curtis was held to look at this. There needs to be a lot more work done on this, but the right people are now talking. One of the key questions is 'how do you draw together all the treatment services'. Obviously there needs to be a consistent approach to ASD and ADHD and this model will have to fit in with JAS assessment. All clinicians need to be aware when they make either a diagnosis or a non-diagnosis there needs to be an assessment done of what support is needed for that child.

Parent Partnership

Sue Brealey updated the meeting on the recent developments within the service.

Staff Changes

We have new staff joining our team which will help us to build a prompt and equitable service across Devon. Georgina Cridland is our new administrative assistant who is based in our Exeter office, she is maintaining our central telephone enquiry service. Calls are taken centrally on 01392 383080 and then passed to the officer in the relevant area.

Debbie Wheeler is joining us in October as a Parent Partnership Officer. She will be covering East and mid Devon and part of Exeter.

Cath Butland is working in North Devon and Liz Batchelor in South Devon with part of Exeter. We are currently recruiting to cover West Devon. All enquiries for this area will be covered by the other officers until the new member of staff joins the team.

Parent Partnership officers are committed to regularly attending PCV Locality meetings, as required. They can provide individual and/or group information and support for any parents/carers attending who wish to access the service.

Training

Parent Partnership Service has a range of training sessions that can be delivered on request. Courses can be adapted and tailored to suit specific training needs as required.

Courses already arranged this term:-

Assertiveness training sessions- Kingsbridge PCV locality meeting 9th September
Tavistock PCV locality meeting 4th November

Independent Parental Supporters

During the autumn term Devon Parent Partnership Service will be running information sessions around the county for Parents and carers. Anyone who is interested to find out more about what becoming an Independent Parental Supporter entails is welcome to attend. Becoming an Independent Parental Supporter is an opportunity, through a comprehensive training and supervision package, to gain skills in providing impartial information and support to other parents and carers. This is an opportunity to effectively utilise knowledge already gained, enhance personal development and a beneficial addition to a c.v. Anyone who is interested in finding out more needs to either contact the Parent Partnership Service by phone or email or pass their details to the PCV Development workers. Dates and venues of the nearest information session will be sent in due course.

BREAK

Bronwyn welcomed Marc Johnson to the meeting. Marc would be talking later about Hear-Me-Now, an advocacy project for young people.

CYPS update – John Shaw

John apologised for not attending the previous couple of meetings.

He is now the strategic lead and co-ordinates all action and delivery plans. He no longer operationally manages any of the services.

Miles Hapgood is Assistant Director of Integrated Children's Services which is a joint funded post with the PCT, and Gwen Pearson is lead commissioner with the PCT. Together they are responsible for an £80 million pound budget of which £52 million sits within CYPS and the rest is within PCT services.

At present they are working through the budgets to find out how the money is being spent; by whom and on what.

John proceeded to explain the Integrated Strategy for Children With Additional Needs 'Aiming High for Devon Children' delivery plan 2008-2011.

Integrated Early years Services for CSN

Devon wants 3 specialist Devon based early years assessment centres (Child Development Centres). The intention is to provide an equitable service for all Devon Children.

Devon will implement the Early Support Programme through all relevant Children's Trust Partners.

Inclusion – Stepping Stones

They are doing an analysis of what is currently available and what is needed.

They are looking at how specialist services can be clustered around the special schools and how they can extend the outreach provision into mainstream schools.

Each Special School will have a pastoral support co-ordinator.

The hope is that in time JAS will have staff located in the Special Schools as this will be a better use of time and more efficient. The aim is to build networks and develop communication so parents do not have to speak to so many different professionals.

Concern was raised that if personal visits to the home ceased then the professionals dealing with the family be unlikely to have an understanding of the whole family if they only saw the child and the parent at school.

They are looking at the residential provision within the County and hope to increase capacity for respite for Children over 10 with a physical disability who attend mainstream schools.

Carers Breaks

They need to demonstrate to the Government that Devon is ready to receive the additional £590k.

The target date for the FACB assessment to recognise fully the needs of children with ASD or Mental Health issues is April. Currently those with an ASD and a Learning Disability are eligible under the current scheme and those with ASD and no LD are not, although many do receive services.

Tenders are going out in the South West for overnight carers' breaks. Longer term Devon is looking to increase capacity within the Special Schools for breaks

Emotional Health and Wellbeing Strategy

CAMHS Level 3 services for the South West area are being re-commissioned

Choice and Partnership Approach (CAPA) is being implemented.

Transitions and Young Carers Strategy

A strategy for Young Carers is currently being implemented.

Joint Agency Service Integration

Integration is now expected, it is no longer voluntary.

There is a need to look at where people are based and a review is underway.

Integrated equipment services

A single approach to equipment is needed in Devon in order to ensure equity across the county.

Special Needs Housing Project

This is looking at a support programme for families who have a child with a complex disability who need to access adapted housing.

Transition – Kate Sandel

A draft strategy has just been written which formalised the involvement of adult services in the process. The draft will go out for consultation. A service specification will be drawn up as a result of these consultations. This will mean that for the first time there will be quantitative data available that can be taken to the commissioners about the numbers of young people for whom there is currently no provision.

Person centred planning in schools

They have developed self-evaluation tools for schools.

By the end of the year all secondary SENCOs will have been on PCP training. It is proving harder for mainstream secondary schools to take PCP on board.

Schools should be offering advocacy for all young people in transition.

There is a lot of work being done at the moment with regular meetings with adult services and their commissioners. If parents are concerned that there are not the services available for their young people when they enter adult services then perhaps now is the time to identify what is needed and bring it to the attention of the commissioners. Things are moving at a slower pace than they would like, but the signs are hopeful that things are getting better.

Marc Johnson – Hear-Me-Now

Marc stressed that his service was keen to work hand in hand with parents and not take their place. The aim is to ensure that all young people have a voice and that their wants and needs are heard. It is not about taking the place of the parent.

It is taking a while for the service to become known and the take-up has been fairly slow however he is encouraging all schools to participate and use the service for transition.

He appreciated that many parents find it hard to let someone else speak on behalf of their child, but sometimes the parent and the child can want different things. It is about options and choice.

AOB

PCV Conversation Events

Beryl had asked that these be publicised across the areas.

Liz

The Devon Play Strategy is out in draft form. Could everyone look at it and feedback any comments they may have.

Inclusive Play Park

Building for this is about to start. For more information please go to www.theplaypark.co.uk.

Letter from Miles Hapgood.

FACB is facing a possible overspend. An audit is being conducted on every current commitment as the overspend may be due to what is not known or on projected commitments. Until the audit is complete no new commitments will be agreed. It is hoped that this audit will be complete by the end of October.

The letter can be viewed on the PCV website with these minutes.

This is part of the service commitment for 'Aiming High for Disabled Children' as they have to know what we are currently spending.

Inviting parents to attend meetings

Each area should encourage up to two additional parents to attend each county forum to find out more about what happens.

Vice Chair

With the resignation of Nichola a new vice-chair for the county forum is needed.

Locality budgets

There needs to be an agreed strategy for deciding how to spend the budgets in each locality and it was suggested that this be discussed at the next meeting.

Reductions in bills

It was flagged up that if a home is specially adapted for the needs of a disabled person that household may be eligible for a reduction in their council tax.

Similarly, certain medical conditions can give rise to access to a social tariff for water bills.

CAF Financial Survey

Contact a Family have published a survey detailing the financial hardship faced by many families in bringing up a disabled child.

***The next meeting will be Wednesday 12th November 10:00 am
at Fisherman's Cot, Tiverton***