

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE
for Families of Children with Special Needs
12th November 2008 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
Helen Phillips	Development worker – Teignbridge and South Hams & West Devon
Bronwyn Nott	Locality Chairperson – Mid Devon
Lois Markworth	Locality Co-Chair – East Devon
Ian Simmins	Locality Co-Chair – East Devon
Cathie Wreford-Holden	Locality Chairperson –Teignbridge
Margaret Ladbury	Locality Chairperson - Exeter
John Shaw	Strategic Commissioner for Children with Additional Needs
Sue Brealey	Parent Partnership Liaison Officer
Donna Langmead	Parent – North Devon Locality
Steve West	CAMHS Manager, Eastern region
Pete Squire	JAS Manager – North Devon
Kate Tapp	Parent – Teignbridge Locality
Tracey Adams	Parent - Exeter Locality
Jo Woodcock	Parent – South Hams Locality
Gillian Kurdziel	Parent - West Devon Locality
Dennis Platt	DISCplus Co-ordinator

Apologies:

Julia Lock	Parent Carers' Voice Project Co-ordinator (DACVS)
Julie Wilson	Parent - Mid Devon Locality
Liz Carroll	CYPS Early Years & Childcare Service

Welcome, Introductions and apologies

Jeanette extended her sincere gratitude for the support that she has been given following the sudden death of the Headteacher of Pathfield School, Rod Conway.

Minutes of previous meeting and matters arising

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.

UPDATE: Jeanette was recently able to speak to an Ofsted inspector in person, who deemed the removal of SEN children during Ofsted visits an illegal practice. However, those wishing to report these incidents need to provide evidence for the Ofsted inspectors in order for them to investigate. This was thought to be an important action plan as many parents have reported similar incidents within the locality forums.

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

At the County Forum in September, there had been a discussion as to possible sources of training and several suggestions were made. It was decided that all restraint training contacts were to be forwarded to Kate Sandel from Young Devon, who had offered to collate the information.

UPDATE: Nicky reported that Kate has yet to come back to her with the training information and contacts, and that she has recently sent round an email to remind individuals to forward any further details.

Jeanette felt that individuals needed to be careful when using the expression 'restraint training' and what might be inferred from those words.

ACTION: Nicky to contact Kate regarding the progress of the collation of contacts.

Fair Access to Carers Breaks Audit

JK and PS commented on the progress of the audit into Fair Access to Carers Breaks, implemented by Miles Hapgood. The audit is still ongoing and Miles is due to attend and report to the forum in the near future.

The Minutes of 10.09.2008

At a recent Teignbridge locality meeting (see p3), a parent asked whether they could approach the County Autism Team directly, in the event where either the school or the SENCO would not ask for help. SB would like it noted that if parents have issues with individual schools they should contact Parent Partnership as well as John Shaw or Anne Porter.

Locality Reports

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

Teignbridge

HP related that in the most recent Ofsted report for Bidwell Brook School, several parents had expressed their concern surrounding the lack of speech and language therapists, physiotherapists and occupational therapists at the school.

The availability of communication and speech and language courses within Devon was discussed.

ACTION: Development workers to engage parents in each locality about what sort of communication training they might need –Makaton etc, whilst identifying what is available within training directories and other sources. On reporting back to the County Forum, it can then be identified what level of need there is for particular training in each district and the existing level of provision in related courses. If it is felt that the level of need is not being met, then PCV could arrange two training days with a focus on effective communication in the New Year –one in the north and one in the south.

Becky Kelly has been appointed as the new Direct Payments Co-ordinator for the Teignbridge area.

The group has looked into the existing guidelines for the inclusion of children with physical disabilities in PE within mainstream schools. Have obtained a CD-Rom 'Success for All: An Inclusive Approach to PE and School Sport', that aims to provide teachers with the tools they need to include pupils with disabilities into all areas of the PE curriculum. Contact CWH or HP for details of how to obtain a copy.

A number of parents shared their experiences of the support networks put in place for siblings, including the STARS Scheme. Some parents felt that due to the nature of the service, which is mainly outings that their children lacked the confidence to go off for days with staff unknown to them. One parent carer related that their young son had been put on a bus of teenage girls to travel to an activity.

It was agreed that the introduction of new members should perhaps be taking place prior to journeys and trips.

Exeter

Clare Cox attended the last meeting and gave an excellent talk on the Mental Capacity Act and how it impacts on our young people. She answered many questions and left some really good handouts for future reference.

At our next meeting (next week) we will be joined by parent Partnership and will be looking at how to get the best out of meetings.

We have an informal lunch and a drop-in coffee morning organised in the run up to Christmas.

There is a new playgroup in Exeter for children with special needs which Nicky hopes to visit in the next couple of weeks. It is based in King William Street and is particularly aimed at children who have cerebral palsy and would benefit from a conductive education approach, although children with any form of need or disability are welcomed. DP has added their contact details and information on the DISCplus website, for anyone who is interested.

East Devon

The last meeting was a follow-on from the one in July where Louise Edmonds came back to discuss how the Activity Scheme had worked over the summer and to answer any questions or concerns raised by the families who had used it. We had a long discussion about possible future improvements, as well as a discussion around the suitability of various venues.

We were also joined by Ali Grew from the JAS who talked about some of the recent changes in East Devon and who did what. Ali then answered questions from parents and went away to find out further information for some families.

Currently there is an issue in East Devon where some families find that their children are not meeting the criteria under FACB as they have either Asperger's Syndrome or mental health issues.

We are meeting before Christmas for lunch.

Mid Devon

Bronwyn is due to retire as Chair of the Mid Devon locality on December 3rd 2008.

On September 17th, a locality meeting was held, attended by 17 parent carers and 6 professionals. The guest speaker was Ernie Lloyd, who talked about exclusions and the range of difficulties faced in communicating effectively with schools. BN noted that since the meeting, a parent had obtained an immediate response from their child's school when Ernie was mentioned.

On November 5th, another locality meeting was held, attended by 10 parent carers and 5 professionals. The guest speaker was Steve West, who detailed how to refer to CAHMS under the new system of CAPA (Choice and Partnership Approach). Richard Adams (Solicitor) also attended to give advice to the group on the planning of Discretionary Trusts for children, as some parents had expressed their concern that any money that they might leave would be swallowed up by Social Services.

South Hams

Issues raised at the last locality meeting included:

- The lack of six form provision in local community colleges
- The lack of services in general in Dartmouth
- The need for early intervention of support i.e. not waiting until families are at crisis point
- Currently there is no Primary Mental Health Worker in Dartmouth. Nick Preston (CAHMS) has given a time scale of twelve months for someone to be in post

West Devon

Issues raised at the last locality meeting included:

- The lack of support from SENCO and Headteacher within primary schools
- The lack of Speech and Language training
- Inclusion for children with Autism
- Post-adoption support for families who have adopted a child with additional needs
- Support for siblings

Gillian related her own and her child's experiences of Tavistock Primary School and highlighted in particular, the lack of training for its teaching assistants. Parents often feel isolated in the Tavistock area, which has a poor level of service provision and support groups.

The information that is sent to schools and SENCOs regarding training opportunities for staff members and teaching assistants was then discussed. JK informed the group that if anyone is interested in what course details are being sent to schools/SENCOs, please email John Fowler who will send you an e-update. Please contact JK for John's contact details.

A website has been set up to promote Tavistock Youth Café www.tycp.org.uk

North Devon

The last locality meeting was held on September 23rd, attended by 15 parent carers and 9 professionals, including staff members from supported learning at North Devon College. Issues raised included:

- Concerns over the provision of opportunities for post 19 students
- The lack of parent input in the supported learning department at the college (particularly with the new build). A letter was sent to Dr Dodds on September 25th, suggesting PCV involvement in the development of the new department, which was followed by a very constructive meeting between Dr Dodds and Jeanette. College staff are scheduled to attend the next locality meeting in January to discuss the new build
- Health transitions
- Communication between parents and CAHMS
- The provision of courses for parents of children with ASD

CYPS Update – John Shaw

JS updated the forum on the situation with Beryl Perrin (Commissioning Officer for Aiming High for Disabled Children), who he reported is still unwell but hopes to be back at work in about two weeks. Jeanette asked that 'best wishes' be sent to her from the forum.

John has now been appointed as the Strategic Lead and coordinates all action and delivery plans. He no longer operationally manages any of the services.

Carers Breaks

The Department for Children Schools and Families (DCSF) is currently grading each local authority to see whether they are ready to receive extra monies for Fair Access to Carers Breaks (FACB). Currently Devon has been assessed as almost meeting the full criteria. Most of the revenue, if granted, will be going into the provision of short breaks, implemented with the full cooperation of service providers.

JS proceeded to report that a SEN strategy group had been assembled four months ago, with members including Anne Porter and Ernie Lloyd. CYPS are currently spending £66.6 million on the provision of services for children with additional needs, the SEN framework scrutinises how that money is spent, by whom and on what.

Integrated Early Years Services for CSN: Inclusion

'Stepping Stones Continuum: Devon Integrated Provision Strategy for Children with Additional Needs 0-19' handouts were distributed. The intention is to provide an equitable service for all children within Devon.

The issues under examination are to include (i) the lack of provision in some areas (ii) ad hoc specialist provision across the county (iii) the inefficient deployment of resources and (iv) the historical inequality of funding. The strategy will be scrutinising in particular the level of provision in mainstream educational bodies for SEN individuals.

The desired outcomes of the Stepping Stones model would be:

- A positive education experience for all
- Partnership between schools, the LA and the PCT
- Equality of access and opportunity
- Increased achievement through personalised programmes
- Fewer disruptions for children and improved life chances
- Provision close to home
- Increased support for mainstream staff
- Access to multi-agency support across provisions –AXS
- Improved attendance
- Continued reduction in exclusions
- Reduction of NEETS (individuals Not in Education, Employment or Training)

There will be a strategic movement towards a single point of referral, which will integrate the assessments carried out within health and social care and that compiled within the statementing process.

The handout contained several diagrams/provision maps, on which JS invited feedback from the forum attendees.

The idea of Partnership Alternative Curriculum Centres (PACCs) was introduced, which will provide alternative personalised packages for children and young people. These centres will offer places to children (yr 9/10/11) who have been permanently excluded from other schools.

There has been some good feedback on the Stepping Stones model from the schools and governors of North Devon so far. JS would like to encourage the distribution of the handout at locality meetings, as this is currently only a proposal, and so would welcome any feedback and comments from parents.

CAMHS Update – Steve West

Steve reported that the Choice and Partnership Approach (CAPA) is working well across Devon.

SW would like to see whether it would be possible for a PCV training event or conference to be organised with a CAMHS theme, maybe in spring 2009. SW would like to see parents be able to choose workshops which are relevant to their issues and experiences etc. It was proposed that a few County members should meet up with Lyn Davis to arrange date and discuss in more detail.

Children’s Trust Update – Jeanette Kemlo

A development meeting has been scheduled for 2009 and the Trust is getting ready to produce the next annual report. Meetings will now run from 10.00-12.00, every other month in Exeter. It is planned that all future meetings will be screened live online, and made available for all parent carers and professionals who would like to watch.

ACTION: When this is all up and running, JK will let County know how to access the online feed.

Forthcoming elections of Chair, Vice Chair and Children’s Trust Representative

JK has recently attended a meeting with Julia Lock and Pam Hogan, which discussed the forthcoming elections. If anyone would like to nominate or self-nominate, please apply in writing to Julia Lock at 14 Bridgeland Street, Bideford, EX39 2QE; ready for the appointment of chairs and representatives next year.

Roles and Responsibilities

JK has recently been in discussion with Matthew Byrne –looking at the work of chairpersons.

ACTION: Development workers to survey what parent carers think the roles and responsibilities of a locality and county chair are and please forward to JK.

PCV Contract

The current contract with TTVS winds up in October 2009, and PCV are looking to be facilitated again by TTVS.

Parent Participation Bid

PCV can apply for £3500 as part of the parent-led Parent Participation bid from the Aiming High for Disabled Children monies (£3million). Devon is an accepted model of good parent participation, there are county-wide support initiatives and the region is esteemed as an emblem of good practice, whilst other authorities are way behind in their engagement of parents.

ACTION: If anyone has any ideas for what the money could be spent on then please contact JK and put those thoughts forward.

Parent Partnership Service Update –Sue Brealey

Staff Changes

Debbie Wheeler was appointed as a Parent Partnership Officer in October; she is covering East and Mid Devon and part of Exeter.

PP are currently looking to recruit in North Devon and are looking to appoint new staff in December 2008, SB is pleased that PCV are actively involved in this process.

Training

PP would like to meet the need for training that is often identified at PCV county and locality forums. Since the last county meeting, training has been delivered to SENCOs and school governors. It was discovered that some governors had no understanding of funding streams, SEN frameworks etc in some of the schools that PP visited. JS and SB discussed the best course of action for the utilisation of Parent Partnership Officers in the education of governors regarding the provision of services for SEN children. SB hopes to be able to provide day long training, not just the two hour session that is currently available.

There then followed a detailed discussion concerning school governors. NR expressed her concerns that it is often difficult for parent carers to find out who their SEN Governor is and how to contact them. ML related that she only met her own child's SEN Governor at their exclusion meeting.

It was agreed that all governors and staff members need to be educated about SEN inclusion and that input from PCV would be helpful in any initiative put forward.

JS and NR discussed the fact that school governors rarely challenge their Headteacher on issues such as SEN funding. JS related the case where a Headteacher had spent monies which had been specifically allocated to the provision of materials, equipment etc for SEN children, within other budget headings that the funding was not intended for. SB felt that governors need to be empowered to be able to challenge headteachers and she hopes that the training will help to instil this.

IPS Information Days

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. There have been over 50 responses so far from interested volunteers. 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.

ACTION: Parent Partnership Officers to attend a future County meeting in order to discuss possible criteria in the vetting of volunteers for training and the best way to deliver the training.

SB is ideally looking to appoint a trained parental supporter at each school throughout Devon, specifically trained to support their needs. However, PP will remain realistic about how long this will take to put in place.

JK felt it would be quite useful if PP could attend a future County meeting after the IPS Information Days have taken place, and give some general feedback on the number of parents and carers raising issues about issues

such as transport, statementing etc. So PCV can best evaluate what are the concerns of parents across different regions.

SB offered to compile a database with the information highlighted above.

ACTION: Chairs and development workers to email JK with ideas for what information might be useful for evaluation purposes.

AOB

'Improving behaviour and attendance: guidance on exclusion from schools and Pupil Referral Units' booklets produced by the Department for Children, Schools and Families and 2009 Primary and Inclusion catalogues were made available to County attendees.

'2008 SEN –A Guide for Parents and Carers', which provides readers with information all the way up to transition services, is available on the DISCplus and DCFS websites.

JK and HP, amongst others, expressed their concern that interviews had taken place to appoint a Parent Participation worker on November 3rd, with no parent present during the interview process. It was highlighted that there is also growing confusion over the presence of so similarly named carers groups, parent groups, carers link groups, generic carers' county meetings and the roles and responsibilities of different but similarly named workers –parent strategy workers, parent participation workers etc.

A reminder that £2000 that has been designated for each locality for training and other purposes, JK would like to invite the composition of proposals on how the money should be spent.

It is likely that this will be DP's last County Forum for a few months, as he has a lot of development work to concentrate on. However, he hopes that a DISCplus representative will continue to attend.

On PS's request that PCV be represented at the forthcoming JAT management committee meeting, which will be shaping future funding strategy in Exeter. ML and IS volunteered and arrangements were made.

***The next meeting will be Wednesday 14th January 2009 10:00 am
at the Fisherman's Cot, Bickleigh***