

**MINUTES of COUNTY FORUM of PARENT CARERS' VOICE**  
***for Families of Children with Special Needs***  
**held on 12<sup>th</sup> September 2007 at St George's Hall, Tiverton**

**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
Ann Deadman	Parent (PCV Transition representative for North Devon)
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
Liz Carroll	CYPS Early Years & Childcare Service
Margaret Ladbury	Locality Chairperson - Exeter
Cathie Wreford-Holden	Acting Locality Chairperson - Teignbridge
Heather Fuidge	Parent/carer - Mid Devon
Bronwyn Nott	Locality Chairperson – Mid Devon
Nichola Winstanley	Locality Chairperson – South Hams & West Devon Chairperson

**Apologies:**

Dennis Platt	DISCplus Co-ordinator
Liz Batchelor	Parent Partnership
Peter Holman	Parent Partnership
Maddalena Cawse	Parent Partnership
Cath Butland	Parent Partnership
Chris Aston	Devon County Council

**Minutes of previous meeting of 04.07.07 were agreed.**

**Matters Arising**

**Children Services Devon PCT:** There will be a meeting on the 25th September between parents and CAMHS representatives to cover issues raised about the services from the localities. Miles Hapgood has been informed and should attend the meeting.

**Transition Programme:** Parents/Carers were meant to provide Case Studies around "Too late" contact with adult services to Kate Sandel but none have been received. This should be followed up on in the localities.

**Devon Equipment:** The planned meeting was held and attended by Jeanette Kemlo with the view to find out how to apply for these funds however there was no time to raise this issue. Jeanette will do this at next weeks meeting.

**JAR report – John Shaw**

Agreed joint commissioning programme for children with special needs has been produced pre-draft – PCT commissioners as well as local authority commissioners have been involved.

**ACTION: Pre draft joint commissioning plans to be shared prior to next meeting**

Devon is seen as a leading beacon for the rest of the counties. The Local authority has signed up to 'Every Disabled Child Matters' charter which received much publicity. They are in contact with 3000 parents and yet have a very low percentage of formal complaints, so all indications are good, although some things will still take time. Jeanette Kemlo raised the point that this is because parents are more willing to deal with things on a local basis.

There will be a formal Joint Agency team by November. Local CAMHS, local JAT and therapy bodies all involved.

John Shaw then ran through the main JAR areas providing an update, some of the points highlighted included:-

- Occupational Therapist assessments in Mid East Devon rapid improvement plan is in place and working. There is a maximum of a three months waiting list.
- Health and education are working together to resolve issues regarding access times to learning disabilities nursing. Miles Hapgood is hopeful that there will be more learning disability services in Devon.
- Transition Development Programme Protocol is being revised and is a very big piece of work that Kate Sandel is working on along with Adult Services. The final report is not out yet.
- Devon Primary Care Trust commissioning objectives for the Joint Agency Services in the South West have just been achieved.
- Common agreed Keyworker training programme is now up and running with JAT providing training to parent keyworkers of children with special needs.
- 4,600 children between 0 – 18 years of age have been identified as part of a mapping exercise carried out for 'Fair Access to Carers Breaks Services' (FACBS). This is a fantastic tool not just for FACBS but also for all children services allowing appropriate planning based on true numbers. It was discussed that this now needs to be kept current, i.e. dynamic data and not just a snap shot in time.
- This means all children between 16 and 18 are identified on the Transitions list. As part of the transition plan they are looking to include all children from 14 upwards on this list in future.
- All financial and demand capacity exercises have highlighted that there is a 41 million collective budget for children with special needs in Devon, with 9 – 10 million being spent on children receiving services out of county.
- The special Schools Commissioning Group is looking at a joint bid/investment providing a core offer of health and social care that will look to reduce the dependency on out of county placements by 80%. Jeanette Kemlo raised the point that it is often the residential requirements i.e. social & health, and not the schooling requirements that drives the out of county placements.
- CAMHS points...
  - Need more focus on foster support workers for CAMHS
  - A single referral assessment and service delivery framework is in place. Just two years ago there was a two year waiting list now the 'Choice and Partnership Approach' (CAPA) has reduced this wait. The national target is 26 weeks for assessment. As a result of integrated working this has been reduced to 4 weeks in most areas in the South West with the rest to be brought into line before January.
  - CAMHS have been transferred across all of Devon except Plymouth
  - There is agreement with Adult Services to provide out of hours cover for the whole of Devon.

**ACTION: John Shaw to provide contact details for CAPA**

## **Locality Reports**

### **Exeter**

The last meeting was held on 11<sup>th</sup> July at The Imperial in Exeter. It was a fairly informal meeting that included coffee and lunch. A wide range of issues were discussed including school issues, respite and plans for the summer. There was also some discussion about the format of future meetings and what topics parents/carers would like covered.

At the beginning of September some Exeter parents attended the 'Breaking the Barrier' event at Bigbury on Sea. This was a surfing event organised by Lifeworks for children with an ASD. It appeared to be a huge success with instructors from both this country and the USA taking part.

Several Exeter parents will be attending the transition day in Tiverton on 26<sup>th</sup> September.

Nicky has emailed Frank O'Friel to arrange a meeting to discuss what is happening in Exeter and to discuss the possibility of arranging a workshop day in Exeter.

### **East Devon**

No meetings since last forum

### **Mid Devon**

No meeting report as they have not met however would like to inform the county forum that there will be a Transitions event on 26<sup>th</sup> September, 9.30 – 2pm at the Tiverton Hotel. This is being hosted by the Mid Devon Joint Agency Team for Children with Special Needs in partnership with the Adult Services and Parent Carers Voice and should be seen as an information sharing event. This event is specifically aimed at parents/carers and young people and hope that as many people as possible will take advantage of this opportunity to learn more about the transitions process for young people with special needs.

Adult Services invited to the event include: Adult & Community Services; Adult Learning Disabilities Team; Community Mental Health Team; Connexions; Benefits & Pensions; FE and Specialist Colleges; Legal Advisor; Fulfilling Lives and many more. There will workshops and feedback sessions to look at how services could be develop and improve. A finger buffet lunch will be provided and Parent Carers Voice will be able to reimburse travel costs for parents/carers and will look to fund child care costs. Please contact your key worker or the Joint Agency Team for further details.

### **Teignbridge**

The meeting was held on Thursday 6<sup>th</sup> September.

Ernie Lloyd from DCC Exclusions delivered a very informative and passionate speech on exclusion, covering many areas, detailed information can be found on [www.teachernet.gov.uk/wholeschool/behaviour](http://www.teachernet.gov.uk/wholeschool/behaviour) or [www.devon.gov.uk/schools/exclusion](http://www.devon.gov.uk/schools/exclusion)

Joan Mead officially stood down as chair and asked for nominations to take over the post; two people came forward and were seconded. These were Vicky Skinner and Cathie Wreford-Holden. The new chair is to be elected at next meeting.

**The locality and the County Forum would like to thank Joan Mead for all her hard work.**

Helen Philips shared information in a number of areas.

The 'Every Disabled Child Matters' event for Parents is on the 11<sup>th</sup> October in Exeter information and booking forms are available from Helen.

Accessible Play – Debbie Marshall Project Officer for Play Areas -Teignbridge Council – will be coming to the next meeting in Nov.

In Victoria Park on Mondays after school during term time Tepee play can be found. This is probably the most accessible scheme as they tailor the activities to the children's needs and things are very child led. All activities are free of charge; parent and carers must accompany children. Please let Robin Brown, (Tepee play ranger) know if there are any families near Buckfastleigh who would be interested in getting involved with the project. Further details can be found at [www.tepee.org.uk](http://www.tepee.org.uk)

### **North Devon**

A meeting of the of Northern Devon Parent Carers' Voice was held on Tuesday 10<sup>th</sup> July 2007 at Barnstaple. 11 parent/carers attended, with 3 apologies.

Theresa Hemmens talked to the meeting about Face2Face, a support group for parents of children with disabilities run by parents of children with disabilities. Two parents who are training to become befrienders shared their experiences. They found the training more thorough than anticipated, stimulating them to both look at their own experiences and emotions and explore how to offer support in a non-judgemental way.

Sandra Cottrell and Heather Thompson then gave a talk on Carewatch - an independent provider of domiciliary care across the UK. They hold the Bideford franchise and are looking to extend the service they offer to younger people with physical disabilities, complex physical needs, additional mobility or sensory needs or a learning disability.

Before making any plans they wanted to consult with parents on what would kind of a service is required. The group highlighted the need for:

- child friendly settings where there is a lot of adult interaction.
- support for children over 12.
- care over weekends, evenings and school holidays
- activity based care; for example, bowling, swimming, out for a snack.
- male carers for teenage boys
- care over blocks of time
- care provided simultaneously enabling group activities for the children

Jeannette requested comments for the Special Educational Needs Task Group, a County wide group due to report in September. The lack of appropriate training for SENCOs, Heads and teachers was raised in an extended discussion on the difficulties caused by the inability of teachers to be flexible or to treat children as individuals and a challenge, not a burden.

The importance of going to tribunal to challenge a statement where necessary was discussed, along with concerns about how to choose the right school when advice seemed to vary between professionals.

A parent reported that the recent 'Coping with Challenging Behaviour' event was very successful and professional. She was particularly pleased to see a lot of new faces there. Evaluation results indicated parents would like more on the topic of behaviour.

The group heard that the Cathedral Celebration was excellent and the children from Pathfield, Ellen Tinkham and Oaklands were the stars of the show.

Regarding other groups, parents are to be invited to a meeting with professionals regarding CAHMS; the Patient and Public Involvement forum has been very busy looking at children and young people's services; a new chair, Mary Nesbitt, has been appointed to the Children's Trust Board and the Patient Carer Information Group are looking for ideas on how to improve the new Patient Information Centre at the hospital.

Jeanette Kemlo would like it noted that the support our JAT manager provides the PCV in North Devon is phenomenal and should be held up as an example for the other localities

## **South Hams and West Devon**

Monday 16<sup>th</sup> July 2007 was the first meeting of Parent Carers Voice in South Hams, facilitated by Helen Phillips (New Development Worker for Teignbridge, South Hams and West Devon)

Nichola Winstanley agreed to stand as chair for the South Hams & West Devon area.

After a welcome and introductions from Nichola there were a number of discussions. Two areas in particular were; early age intervention, the lack of pre-school special educational needs provision and issues of transport and the virtual PCV chat room / forum. It was asked if the latter could be linked to the website development.

Rachel Gaywood HCPT -The Pilgrims Trust – Torbay Group 179, gave a lively and enthusiastic talk on The Pilgrims Trust and that they are looking for children with special needs between 7 – 16 years to take next year. The pilgrimage is a holiday with a spiritual side to it. They all enjoy a great time and share an unforgettable experience. This is a holiday which is stimulating, fun and spiritual. They leave on Easter Sunday and return the following Sunday. They are looking for nominations from children with special needs who will be between 7 – 16 years next year. The children may belong to any religious background or none at all. Children should be able to join in and benefit from the Pilgrimage activities in some way (respite care is not provided). Funds will be available to sponsor children, through donations, fundraising events and awards made by other agencies. If you would like more details please contact Rachel Gaywood, 7 Carlton Mews, Carlton Road, Torquay TQ1 1NG. Phone: 01803 215775 or 07967 881478 Email: [hcpt179@hotmail.com](mailto:hcpt179@hotmail.com)

After the talk a few news items were publicised. Firstly in spring there will be two workshops for parents looking at the Every Disabled Child Matters campaign and how parents could get involved locally. As a result of really positive feedback a further 10 regional events for parents around the country are planned for the autumn. A workshop will be held in Exeter on 11<sup>th</sup> October 10.30 – 3pm. For further information phone Liz Ranger, Parent Participation Manager 0207 608 8784 or email [liz.ranger@catamily.org.uk](mailto:liz.ranger@catamily.org.uk)

If anyone attended the Carer's Service in Exeter Cathedral they would have been aware of the fantastic work that Wren Music does with special needs children. Wren Music is a Devon-based folk and community arts development charity and has been short listed for the National Lottery Awards 2007 for its Nice Warm Socks project, and now needs votes from the public to stand a chance of winning the £200 first prize, which will go towards further work in arts education. The Nice Warm Socks project uses folk songs to develop the basic communication skills of children with severe learning difficulties and physical impairments. For further information or to place your vote by phone 0845 386 8062 (calls charged at BT local rate mobile cost will vary) Email: [www.nicewarmsocks.org.uk](http://www.nicewarmsocks.org.uk)

Autism Awareness – Tavistock Tyres v The Union Inn, 'The Son-Rise Cup' Sunday 19<sup>th</sup> August. Band starts@ 2.30pm – 3pm Kick Off at TAVISTOCK AFC Ground after match presentations, party, refreshments, bar and Bouncy – Auction & Raffle.

At the county forum a general discussion around the work Helen is doing to raise PCV's profile transpired after the locality report and a request was made to ensure that Cathy Hill from DISCplus who supports South Hams and West Devon was thanked. Her expertise and follow up is felt to be invaluable and she has tried to help raise the profile of PCV in every way possible

### **Beryl Perrin Carers Development Worker – Fair Access to Carers Breaks Services (FACBS)**

As an aside Beryl is looking to promote a new service, 'Over the Wall Club'. This organisation is primarily set up for children with complex medical conditions. This runs in Poole. They will also look at children in between treatments for leukaemia and cancer. This is 8 – 16 year olds; it is mainly for main stream children. For further details look them up on the website.

Regarding Beryl's County role she has been asked to look at the links between carers across Devon including young Carers. The funding and activities have been mainly around the information collating exercise conducted for Fair Access to Carers Breaks.

Her second focus has been to look at the Fair Access to Carers Break Process. There is now a guide for parents explaining what it means for parents. Since 1st September the new points system was fully launched. In the early days from July to September there were some teething problems, now 70 moderations have been implemented and the process seems more equitable. There are still ambiguous areas requiring management discretion but this will always be the case.

Jeanette Kemlo raised the issue that no Parent Carers have been involved in producing this point system. Beryl formally apologised as she believed the PCV forum had been involved.

**ACTION: Nicky Ruane to be included back in the process e.g. included on mailing lists etc.**

Beryl feels from her experience that a Carers Assessment has always been tied up with funding but should also include progression plans for Carers and look to identify changes in the Care Package that could socially benefit the Carer. Thus the Fair Access to Carers Breaks does call out and ask the Carers if they would like a separate formal Carers Assessment not tied to funds.

There were discussions as to the financial capacity of the Fair Access to Carers Breaks scheme, i.e. concerns that there are not enough funds to meet parent's needs. Beryl feels it is a case of appropriate allocation and that there is a transition fund to cover any short falls as they move from the old to the new system. Jeanette Kemlo suggested by talking and liaising closely with parents they could actually save themselves money.

An example of the points system providing a taster of the descriptors for the child was discussed with the County Forum and explained. Concern was raised as not all areas were covered; Beryl explained this was just a subset of the full point system that could be found in the guide. As much feedback as possible was requested by Beryl who can be contacted on [beryl.perrin@devon.gov.uk](mailto:beryl.perrin@devon.gov.uk)

**ACTION: Beryl to e-mail the full parents guide explaining the points categories and scoring process.**

The Chair raised the issue that is parents only have children with special needs then they may not be able to grade their child appropriately. It was suggested that a guide to normal child development would be useful to the practitioners. Beryl stated there is not a child development programme along side the points system however normal childhood behaviour is implicit throughout the FACBS process and guidance is provided by the key worker. The forum was still concerned that there would be variations dependent on the key workers guidance but also concerned that defining 'normal' behaviour has its own issues in as much as levels of expectation for 'normal' behaviour is very subjective.

An example of the Carer's Points Assessment was also briefly explained and feedback from the forum requested.

**ACTION: Jeanette Kemlo to circulate all information and invite Beryl back to receive feedback and comments at the next meeting.**

### **Feedback from Children's Trust**

Unfortunately as the meeting ran over Nichola Winstanley had to leave prior to providing an update.

### **Date for diary 25<sup>th</sup> September CAMHS update**

This is to be held at Tiverton Hotel possibly a 10 am start. Full details will be available shortly. Please e-mail Jeanette for further details and also to let Jeanette know who is coming and their full details.

### **Any Other Business**

**Invitation** – Parent Partnership Coordinator is to be interviewed on the 1<sup>st</sup> October. They have requested a PCV representative

**ACTION – Margaret to attend**

**Transition Team** – Bronwyn Nott is officially on the TIG and Jeanette Kemlo is on the SPIG.

**ACTION – Ask Kate Sandel to update the forum**

**Pro-forma Letters for parent lobbying** – Jeanette has provided these as requested in previous meetings. She has asked the forum to review and feedback

**ACTION – Everyone to feedback via e-mail**

**11<sup>th</sup> October “Every Disabled Child Matters” meeting** - Is being organised by ‘Contact Family’ at the X centre in Exeter – Contact Liz Ranger from contact family E-mail:

<mailto:info@cafamily.org.uk> or visit <http://www.cafamily.org.uk/> for further information

**OCP** – Information of a study of Osteopathy for Children with Cerebral Palsy was distributed to the forum to be publicised in the localities.

**County Forum Meeting Location** – After the meeting in November the venue for the county forum will be changing to the Fisherman's Cott Public House in Bickleigh

**The next meeting will be 7<sup>th</sup> November 10:00am  
at the St George's Extension, Tiverton**