



## Minutes of County Forum of Parent Carers' Voice For Families of Children with Special Needs

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8 July 2009 at Fisherman's Cot, Bickleigh

### Present:

Jeanette Kemlo	County Chair/Locality Chairperson for North Devon
Lois Markworth	Locality co Chairperson for East Devon
Ian Simmins	Locality co Chairperson for East Devon
Julie Wilson	Locality Chairperson for Mid Devon
Jo Woodcock	Locality Chairperson for South Hams
Lyn Wolstencroft	Acting Vice-Chair Teignbridge Locality
Charles Maxwell	Parent Teignbridge Locality
Emma Baldwin	Project Development Manager, TTVS
Cathy Hill	DISCplus team leader
Sue Brealey	Parent Partnership Liaison Officer
Beryl Perrin	Commissioning Officer for Aiming High for Disabled Children
Abby Buckley	Inclusion Officer
Claire Lloyd	Associate Research Fellow in Child Health, Cerebra Research Unit
Donna Langmead	North Devon Locality
Nicky Ruane	PCV Development Worker for Exeter and East Devon
Pam Hogan	PCV Development Worker for Mid and North Devon
Helen Phillips	PCV Development Worker for Teignbridge, South Hams and West Devon.

### Apologies:

Margaret Ladbury, Liz Carroll, Julia Lock, Lyn Davies, Gillian Kurdziel, Cathy Sharp, John Shaw, Gwen Pearson

### Welcome and Introductions

JK welcomed everyone to county meetings: particularly those who were attending for the first time.

### Minutes of previous meeting and matters arising

#### Correction

In the Parent Partnership report point 7 should read 'advisors' not 'officers'.

#### Libraries

Hazel skinner from Libraries will be attending later in the morning

#### Annual Report Picture Competition

Jeanette will be presenting the prizes to the winners of the competition later this week

#### Playground funding bids

The bids for money to improve play areas are currently ongoing. Parents from North Devon have been involved in the submission for a bid.

### Other Matters

Attendance at County Forum

Jeanette queried which of the locality Managers should have attended this County Forum as none were present.

**Action:** JK to speak with Miles to ensure attendance by one Locality Manager at each County Forum

## **Locality Meetings**

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

#### South Hams

Issues from the meeting held in Kingsbridge on 26th June 2009

#### Concerns about Individual Educational Plans

- Issue with IEPs being written just below 'Statement' levels, use of Common Assessment Framework (CAF) not been introduced.

#### Concerns about CAMHS Service

- Issues with CAMHS – appointments made then cancelled and re-arranged only to be cancelled again. Is Plymouth or Devon responsible for the CAMHS service in Kingsbridge?

Parents have suggested that some assertiveness training might be useful.

#### West Devon

Two new Co-Chairs, Gillian Kurdziel and Cathy Sharp have been elected.

Issues arising from the West Devon meeting held in Tavistock on 4<sup>th</sup> June 2009

#### Concerns about Tavistock College

- There isn't a program of life skills for SN children at the college.
- Alternative courses and provision for non-academic students is very weak.
- A lot of other schools have constructive alternatives.
- Communication between school and parents is difficult.

#### Concerns about Speech Therapy provision

- Speech therapy services are patchy, difficult to access and inconsistent.
- At Secondary level there doesn't seem to be any provision. It seems as though it is assumed that any input will have been completed at primary level.
- Children in mainstream don't have the same Speech therapy provision as those in special schools.
- It is demoralising for parents to keep having to fight for Speech therapy.

#### Concerns about lack of professionalism from service providers

- Parents have experienced a lack of professionalism from service providers including a lack of timely response, reports on children often being wrong, e.g. wrong dates of birth, wrong historical timings. Parents lose confidence when they receive information about their children which is wrong.

### **Teignbridge**

Issues arising from the Teignbridge Meeting held 16<sup>th</sup> June 2009

#### Dyrons Holiday Club

Parents are still very unhappy about the extra charge now being made for the holiday club. There was a discussion about whether it was discrimination for SN children not to have the same financial access as able bodied children As direct payments are currently frozen, monies cannot be recovered that was. The DLA is spent many times over already.

Parents will contact the Disability Rights Council about this matter

It was requested that Sarah Mumford, Martin Spragg and Sue Bolt be invited to the next locality meeting to try and resolve this issue.

#### Wheelchair Access in Secondary Schools and school transport

- Currently only one local secondary school, Teign School, has sufficient wheelchair access to allow a wheelchair bound child to attend. This limits children and parents choices. Although parents

recognise that schools have to have an accessibility plan, these are often insufficient. Local parents would like the county Chairs to pursue this agenda at county level.

- Children in wheelchairs are unable to travel with their classmates to and from school and on school trips because of a complete lack of buses/coaches with wheelchair facilities.

The discussion then moved on to the wider issue that if there were a difficulty for children to access the school then it would also preclude staff with mobility/wheelchair needs from working at the school.

Abby offered to make further enquiries as she felt that where necessary adaptations should be made.

It was agreed that this issue needs to be discussed further at a future meeting. The issue of transport will be dealt with in September.

This led on to further discussions about the exclusion of children from school trips for a variety of reasons. Children with disabilities in mainstream schools must be fully included and the school must provide transport for trips. Parents should not be obliged to transport their child on such trips.

It was agreed that the aspiration is to have full inclusion in mainstream schools alongside their peers, but this can sometimes be difficult. From a DDA point of view a school must make 'reasonable adjustments' to meet the needs of the young person. There followed a discussion of what was 'reasonable'.

Parents who feel their child may have been discriminated against can contact the Equality and Human Rights Commission on 0845 604 6610 or see their website <http://www.equalityhumanrights.com/>

If parents feel their child is being excluded illegally they can contact the Exclusion and Reintegration Team

David Archer - North and Mid Devon  
01272 388559

Sue Meacham – Exeter and East Devon  
01392 383944

Marc Kastner – South and West Devon  
01392 383940

## **East Devon**

Parents attended an information day at the beginning of June in Honiton that covered a wide range of topics. One of these that had raised issues was the East Devon Activity Scheme and the increase in the cost of it. Some families are now finding it difficult to afford the same number of days as in previous holidays.

There followed a discussion about the need of the service to be self-funding and how the increase in the cost was a true reflection of what it costs to run.

Beryl said that parents need to ensure that the care plan states the number of sessions that are required. Care plans generally say that the carer needs regular breaks and that the child needs social inclusion activities. If the care plan states that a certain number of sessions are needed and this is cut then this is not meeting the needs identified in the care plan. However, Devon currently offers more in terms of respite than other Local Authorities and we need to look wider and more creatively in order to keep up with these demands. Beryl suggested that a further discussion around the Islington judgement might be beneficial at another time.

There followed on further discussion about costs, childcare, working families' tax credits etc.

## **Exeter**

The meeting held last week was well attended. The morning session was spent looking at sensory integration with Chris West presenting an extremely interesting talk to parents and providing loads of practical tips on how to help children with sensory problems.

Following on from lunch Tina Norman gave some practical advice on how to deal with stress, and talked parents through exercises to help them relax and to breathe deeply. She also stressed the importance of having realistic expectations and of not trying to be superman or woman in what we are trying to achieve each day.

Steve West introduced himself as the new Further Response Manager for Exeter from September. He explained about the new structure in the Joint Agency Service and then answered questions from parents.

Louise Edmonds from the East Devon Activity Scheme and Trish Oliver from Ceda explained what their respective holiday schemes could offer children and young people in the area and how they could access them.

## **North Devon**

2 meetings have been held since the last County forum:

Forum – May 19<sup>th</sup> - on the theme of respite and direct payments. Total of 36 parents and professionals attended.

**David Johnson**, the direct payments/FACB coordinator summarised the present situation

- new guidance would be available very soon
- assessments caught in a backlog during the financial freeze should now be looked at.

However, this information hasn't yet filtered through to the Joint Agency Service in North Devon so it may take a while for key workers to get up to speed.

**Issues** arising included:

- in making changes to avoid inappropriate spending, parents are losing the element of choice that direct payments were set up for in the first place
- Cost of respite is a major concern.

**Welland House Update** – May Andrews, Manager, gave an update of the changes being made at Welland

- moving towards giving respite to children with total care/complex needs, a focused resource, not the babysitting service that it may have been perceived as in the past
- changes may take 2-3years but the overall concept is of developing children .

**Issue** – what provision is there for children who would previously have been catered for at Welland?  
Suggestion - PCV could conduct an audit of unmet need

**Play Builder application** has been submitted for inclusive equipment in Victoria Park in Bideford.

**Makaton course** will be running at Pathfield.

Health and Well-Being day – a joint event on June 8<sup>th</sup> with Carers Link and the Adult Learning Disability Carers forum as part of Carers Week.

Around 120 carers and professionals were present, considering the caring role through discussion and some forum theatre and joining sessions on:

- The practical side of caring
- Taking care of the carer
- Individual physical and financial health checks
- And fun dance fitness – ballroom style!

Next meeting: July 21<sup>st</sup> – discussion on what needs to be included in the next PCV contract

## **Mid Devon**

Since the last county forum there have been 2 meetings in Mid Devon

### Forum - July 8<sup>th</sup> 2009

Julie welcomed 15 parents and professionals to her first meeting as Chair of Mid Devon Parent Carers' Voice.

**David Johnson**, direct payments/FACB coordinator summarised his task of reviewing Fair Access to Carers Breaks (FACB) and direct payments and how the process works.

**Louise Rains** summarised her involvement working on the new guidance for direct payments, trying to give parents a clear picture of what's available, and ensuring that it's being applied consistently across Devon.

There was an emphasis on ensuring that services are available. More providers = better choice.

The group highlighted the following issues:

- Confusion or a lack of consistent information amongst workers
- Need for re-training of all workers
- Concerns that eligibility may change – even though the child's needs haven't
- Concern over the requirement to pay back any money held over e.g. to cover emergencies
- Concern that the importance of the tracker forms was not stressed enough

### Coffee morning at Okehampton

7 parents enjoyed an informal get together, sharing experiences and concerns. Direct payments was by far the most significant topic.

Next Meeting: July 15<sup>th</sup> – 10.30am-12.30pm at the Fisherman's Cot, Bickleigh, near Tiverton. The topic was to have been '[Boobs and Black Tights - understanding your teenager](#)', given by Miriam Guard, parent and autism trainer but this has been postponed due to personal health reasons.

## **Parent Partnership Service Update - Sue Brealey**

### Website

The Parent Partnership Service is currently reviewing and revamping their website and would like parents to look at it and give their feedback on how easy it is to use, what information was useful and what else they might like to see.

### Monitoring and Evaluation

They are going to take feedback termly from parents using a questionnaire either by telephone or by letter.

### Policy Development

Policies are currently being written. The draft will be completed by the middle of August and they would like to bring it to the forums for scrutiny in September.

### Steering Groups

This is to be developed with Choice Advisors. There will be a meeting in November and they would like parent reps to attend that meeting

### CSET

Sue has fed back comments and concerns from parents on how some staff deal with parents and she understands that CSET staff will be receiving training.

### Independent Parental Supporters (IPS)

Interviews are currently taking place and it is anticipated they will start in September.

### Holiday cover

There will be cover over the summer holidays although the hours some workers are available will be reduced.

### Staff

Cath Butland is now working in the West Devon and Mid Devon areas

### Training

It was wondered whether some parents may find it useful to have some training in how to feed back their concerns to Ofsted now the inspection format has changed and inspections take place at short notice. It is known that some parents are concerned that comments they make through the questionnaire and sent back into school can be seen by the school and they feel that if they make negative comments about the school this may be reflected in the future support their child receives in school. It was felt that parents need to be made aware of the fact that they can contact Ofsted at any time, not just when the school is being inspected.

### **Claire Lloyd – Cerebra Research Unit**

Claire explained that the unit is based at the Peninsula Medical School and that their aim is to look at interventions and treatments for children with special needs, she would like input from parents as to what they should be looking at.

Recently they have held two launch events – one in Exeter and one in Plymouth – and both were well attended.

There followed a lively discussion about some of the areas that have been suggested for research:-

Nappy services were one area of interest.

Recently in Devon this service has changed but these changes have meant that parents are suddenly receiving deliveries of many boxes of pads which is causing storage issues. The change of type of pad used is also causing problems, especially as there was no notice of the change or consultation with families.

Sensory integration is another area that has been suggested for further research.

Another topic suggested was the evidence of effectiveness of 6 hours of stretching for children with cerebral palsy.

All ideas suggested will be posted on their website - <http://www.pcmd.ac.uk/cerebra/> - and Claire would like as many parents as possible to join in the discussions in their forum to decide what should be researched.

One of the junior doctors at the RD&E has noticed that the needs of children with disabilities are not always being met so they are asking about that on the forum. This may become a piece of research at some point.

Claire was keen to know if there is anything that parents think is important. She suggested that anyone interested look at the website to see what has been done already and then let her know if they have any ideas.

### **Palliative Care Strategy**

This is currently out for consultation. All comments should be made by the end of the month.

Robert Chugg and Beryl recently took this strategy to the hospices where it was well received.

The Palliative Care Strategy is about Quality of Life and Life Chances and Life Opportunities. Advances in recent years means that young people with life limiting conditions are often living longer and this is all about that quality of life.

It is hoped to do the Life Limiting/Life Threatening Strategy soon.

### **CYPS Update**

Ofsted are currently undertaking their inspection.

Jeanette has highlighted to the Ofsted Inspector some of the different areas that parents are involved in within CYPS.

The organisation of CYPS is progressing with the appointments being made of the First Response and Further Response Manager posts across the county.

They are about to pull together Fair Access to Carers' Breaks 2 and which will focus on those children with ASD and EBD. Beryl asked for parental involvement and it was agreed that Donna, Lois, Jo and Julie should attend.

The meetings dates are:

8 September	10 – 1
23 September	1 – 3
14 October	10 - 12

Devon has been nominated as Aiming High Champions and have been invited to London on 29 July. Beryl would like to hold events in Devon as training for other Authorities and this may involve parents.

### **PCV Tender**

They have done lots of work on what could or could not be included in the contract, it will be similar to current contract, They have agreed to do a review of what support parents want and what money is available.

They will be including the parent conference in the contract

They would like to tie it up with monitoring with Joint agency staff so everyone knows what is expected of them. Also there is the need to be clear about what the parent forum will deliver.

Jeanette was clear that it needs to remain parent led – by parents for parents. This asked the question of 'what is the expectation of parents?'

**ACTION:** Jeanette to arrange a Chairs meeting for September to discuss

### **PCV Budget**

Emma handed out details of the current budget and explained the current position. Of the £20k for Locality initiatives only Teignbridge and South Hams and West Devon have any monies remaining.

### **Children's Trust Meeting Feedback**

The last meeting of the Children's Trust was cut short due to the letter about the Ofsted inspection arriving.

Changes are being made to the parking arrangements at County Hall for visitors. Blue badge parking should still be free if you press the button on the barrier and ask to be let in.

### **Libraries**

Hazel Skinner was to have attended the meeting but did not show.

Jeanette asked that if anyone knew of any good books that would be of benefit to children with additional need could people let her know and she would feed the information back.

Some books suggested included:

- Comic style books
- Henrietta's Dream
- The Magic of Thinking Big

It was discussed whether libraries should have a separate section for carers, but it was felt this may be unworkable as the range of topics would be so wide.

It was also queried whether there are books that use widget symbols.

Nicky raised the point that currently it appears impossible to access a list of books that are available in large print for children that have visual impairments and that families would find such a list useful.

It was also discussed that during the holidays many libraries run a range of events and schemes, and that if families ring the library in advance the scheme may be able to be adapted to meet an individual child's needs.

### **Any Other Business**

Ian Simmons was unanimously elected as Vice Chair.

Jeanette wanted it noted that the last issue of the DISCPlus newsletter was excellent and thanked Cathy and her team.

Pam advised everyone that the next Mid Devon locality meeting was to have had Miriam Guard speaking but this has had to be postponed to a later meeting.

### **Close**

The next meeting will be on Wednesday 9<sup>th</sup> September at the Fisherman's Cot, Bickleigh