

**PARENT CARERS PLANNING GROUP**

**Notes of meeting held on Wednesday 18<sup>th</sup> January 2006 at  
10.30 a.m. at Pulborough Village Hall**

**Present:**

Sue Aldred	Manager, Camelia Botnar
Debbie Buckwell	Service Manager, Child Disability
Cathy Caine	Asst Group Manager, Child Disability, S&CS
Kelly Colbourne	Parent, Parents Action for Respite Care
Ruth Cottington	Adur, Arun & Worthing Primary Care Trust
Anna Cowie	Parent, Parents Action for Respite Care
Bernadette Daly	MENCAP/Family Placement Team, S&CS
Barbara Dolan	Parent, Parents Action for Respite Care
Annabel Forbes	Community Fieldworker, SCOPE
Caroline Gibbins	Sure Start, Early Years & Child Care Development
Jenni Herrett	Kangaroos
Peter Moor	County Councillor
John Parsons	Service Development Manager, WSx PCT
Kim Paul	Parent
Nigel Scott-Dickeson	Springboard Project
Geoff State	VSLDO
Jo Tyler	Parent Partnership Officer, Education

**Attending:**

Gillian Hillier	Case Worker, Horsham CAB
Tracey Boxall	Note Taker

**Apologies:**

Robert Dunn (Chair)	Deputy Cabinet Member, Children's Services
Joan Martin	Parent
Jon Philpot	Group Manager, Specialist Services, S&CS
Pippa Taylor	Parent, Parents Action for Respite Care

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**1. Welcome and Introductions**

As Robert Dunn had had to give his apologies for this meeting, Cathy Caine, Asst Group Manager, took the Chair. Cathy welcomed members and in particular Barbara Dolan who had been unable to attend a previous meeting due to illness.

## **2. Minutes and Matters Arising from the meeting held on 19.10.05**

Kelly Colbourne said that on page 4, 3<sup>rd</sup> paragraph the wording should read "One parent had been informed by the Worthing area that her daughter would not be seen until she reached the age of nine."

With this correction the minutes were accepted as an accurate record of the meeting.

### ICount cards

Nigel Scott-Dickeson asked if there had been any progress with the scheme. Cathy Caine responded that she did not have any details and suggested that this item be placed on the agenda for the next meeting.

### Accessible Housing

Cathy Caine reported that she had spoken with the Occupational Therapy Team who had advised that the District Councils have a lead on the provision of housing, affordable and accessible, through local Housing Associations. The Housing Associations in turn work in partnership with OT to provide suitable housing for wheelchair users and others with specific needs. Nigel Scot-Dickeson commented that the Local Area Agreement would make provision for accessible housing.

Cathy Caine agreed to refer this item back to Jon Philpot for further input. Ruth Cottington advised that Ruth Sweeney from the OT team had been working very closely with the coastal District Councils and may be a further contact for this group on this subject.

### Continence

Anna Cowie advised the meeting that she had written to parents and head teachers inviting them to a meeting with the press on 19<sup>th</sup> January to express their concerns.

Cathy Caine confirmed that Jon Philpot had written to all the lead managers in the Health Care Trust to try and set up a meeting to address the concerns raised.

### Direct Payments

Debbie Buckwell advised the meeting about Direct Payments and the processes involved. She reported that staff were now working their way through the waiting list. In response to a question from Nigel Scot-Dickeson, Debbie said that more advisors were now being recruited to deal with demand.

### 3. **Topic for Discussion - Joint Area Review**

The meeting had before them an extract of the Joint Area Review Action Plan which Cathy Caine went through in detail. The Members' Short Breaks Task Force is looking at a number of areas where improvements could be made for children and young people with learning difficulties and disabilities including the development of play schemes.

Debbie Buckwell reported that a mapping exercise had been undertaken to identify gaps in services, across the county, for children with ASD. These would be highlighted in an action plan later this year.

The Group were also advised that Transition Protocol had been signed up to by all the key organisations and agencies across the county. This would enable the issues regarding young people in transition to be addressed locally. Ruth Cottington advised that a transition meeting was due to take place on 7<sup>th</sup> February.

Kim Paul commented that she felt that nothing was really happening as far as transition was concerned, that there was a lack of information and that parents were generally unsupported in the process. Nigel Scott-Dickeson Annabel Forbes on the group working on producing a guide; however it was going to cost £10,000 to get guide published and distributed.

Cathy Caine asked the group if they felt there was a role for a Connexions representative on PCPG. The group generally felt there would be an advantage to having someone from Connexions being invited to a future meeting to clarify their role and possibly considering joining the group.

**Cathy Caine to invite a representative from Connexions to attend a future meeting.**

### 4. **Topic for Discussion – Benefits**

A representative from Horsham CAB had been invited to attend the meeting: Gillian Hillier, Benefits Case Worker.

Gillian Hillier began the session by outlining the different types of benefits that were available making specific reference to the Disability Living Allowance.

Gillian acknowledged that the process for identifying care for children is more complicated than for babies who have total care needs. Parents have to provide details and evidence of all the different levels of care they are providing for older children so as to be able to get a particular level of the benefit allowance. Gillian suggested keeping a diary of all needs, getting supporting letters from GPs and School; showing development skills, education and social skills. Gillian advised that if a parent/carer was not successful in their claim they had the right of appeal and also suggested going to the DSS offices in person. Other benefits were also

available to parent/carers depending upon the level of care they were giving e.g. Child Tax Credit with a Child Disability premium attached.

When a young person reaches 16 years of age, Gillian advised that there were different options available. Gillian advised that there were different options available dependent upon needs.

Finally, Gillian advised that a number of relevant leaflets are available from any of the Citizens Advice Bureaux across the county.

### **Questions and comments then followed from the Group**

- Anna Cowie commented that she knew of someone who had Disability Living Allowance having been granted "for life" as opposed to her experience of having to reapply every four years.

Anna outlined the general concern that the forms are far too long and complicated for many parent/carers and asked for a complete list of everything the child in question could not do. Parents found having to list all their child's weaknesses very depressing and overly intrusive. Parents of a child with disabilities preferred to concentrate on the positives, what their child could achieve however big or small.

- Sue Aldred commented that first time applicants needed help to complete the form as they had nothing else to go by. There was a concern that they were not being consistent with the details they were needed to supply.
- Anna Cowie made reference to the Community Care Grant. To meet the criteria, the application had to be either for:
  - A young person out of residential care coming back into the community and needing to be re-housed
  - A family under extreme pressure
  - Looking after a child or young person and preventing the need for them to go into care
- John Parsons commented that there were too many forms. He referred to a scheme that was being piloted with adults in that they had control of individual budgets and thought it might be possible to try this scheme with children

Cathy Caine responded that the pilot was working with adults at present, and that staff were currently monitoring the process to see what could be learnt from this new system. There are different funding schemes for children and adults and it was necessary to establish whether this new scheme would work for children.

- Nigel Scot-Dickeson commented that it was important that lead professionals were identified to advise on what range of support there was available for parents with regard to the administration of

the scheme. Ruth Cottington suggested that there might be a role for the Children Centres, also that the Department for Work and Pensions (DWP) needed to be one of the agencies involved.

**It was agreed that addresses for the CABs would be obtained and included in the minutes. (Appendix A)**

#### **5. Young Person/Parents' Voice Project**

Jo Tyler presented two papers to the group and advised them that she had produced a questionnaire which she was hoping to distribute to the various interest groups, on the Web and through the Parent Partnership Service. Parent carers attending the meeting were invited to join Jo over lunch to consider the Project questionnaire.

Jo informed the group that they had received 35 responses from parents wanting to join the new multi agency group, mostly from people along the south coast. Unfortunately, there had not been a very high attendance at the day-time meetings.

John Parsons asked if there was any parent representation on the Children's Trust. There followed a discussion on this point and the group felt that it was very important that parents had a voice on this important group. Cathy Caine advised that at present there was not any such representation but that it would be considered in the near future. Nigel Scot-Dickeson cited the example of Sutton Children's Trust where the parent representative played a role in the strategic partnership alongside professionals and voluntary organisations.

#### **6. Any Other Business**

John Parsons asked the group if they would wish to be part of the consultation process with regard to the NHS reorganisation. The focus would be on the provision of NHS services to young people.

At present there are five PCTs which will be amalgamated into one for the whole of West Sussex. GPs will have more a role in and make decisions about local services

Nigel Scott Dickeson asked if the extended schools programme could be included in the agenda for a future meeting/.

#### **7. Discussion Topics for Next Meeting – dependent upon speakers**

- Connexions
- Extended Schools
- Work & Pensions Department

8. **Date of Next Meeting**

Wednesday 19<sup>th</sup> April 2006  
10.30 – 12.30 followed by lunch  
Pulborough Village Hall

## Appendix A

### Citizen Advice Bureaux in West Sussex

Bognor CAB  
Town Hall  
Clarence Road  
Bognor Regis  
PO21 1LD  
(01243 820667)

Burgess Hill CAB  
Delmon House  
38 Church Road  
Burgess Hill  
RH15 9AF  
(01444 241252)

Chichester and District CAB  
Bell House  
6 Theatre Lane  
Chichester  
PO19 1SR  
(01243 784231)

Crawley CAB  
The Tree  
103 High Street  
Crawley  
RH10 1DD  
(0870 126 4087)

East Grinstead CAB  
Cantelope House  
Cantelope Road  
East Grinstead  
RH19 3BZ  
(01342 321638)

Haywards Heath CAB  
Oaklands  
Paddockhall Road  
Haywards Heath  
RH16 1HQ  
(0870 126 4054)

Horsham CAB  
Lower Tanbridge Way  
Horsham  
RH12 1PJ  
(0870 126 4080)

Lancing & Sompting CAB  
Parish Hall  
South Street  
Lancing  
BN15 8AJ  
(01903 755585)

Littlehampton & District CAB  
14-16 Anchor Springs  
Littlehampton  
BN17 6BP  
(01903 724010)

Midhurst CAB  
c/o Resource Centre  
North Street  
Midhurst  
GU29 0LT

Rustington CAB  
c/o The Woodlands Centre  
34 Woodlands Avenue  
Rustington

Selsey CAB  
The Parish Hall  
High Street  
Selsey  
PO20 5BA

Shoreham & Southwick CAB  
Pond Road  
Shoreham  
BN43 5WU  
(01273 453756)

Worthing CAB  
11 North Street  
Worthing  
BN11 1DU  
(01903 232116)