

<b>SOCIAL &amp; CARING SERVICES, EDUCATION &amp; THE ARTS AND THE NATIONAL HEALTH SERVICE</b>
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**PARENT CARERS PLANNING GROUP**

**Notes of meeting held on Wednesday 26 January 2005, 10.30am  
at Pulborough Village Hall**

**Present:**

Sue Aldred	The Camelia Botnar Children's Centre
Cathy Caine (chair/part)	Service Manager, Child Disability, S&CS
Anna Cowie	Parent, Parents Action for Respite Care
Bernadette Daly	Family Placement Team, S&CS
Barbara Dolan	Parent, Parents Action for Respite Care
Robert Dunn (chair/part)	County Councillor
Jenni Herrett	Kangaroos
Peter Moor	County Councillor
Jon Philpot (chair/part)	Group Manager, Specialist Services, S&CS
Nigel Scott-Dickeson	Springboard Project
Jo Tyler	Parent Partnership Officer, Education
Sandy Palmer	Minute Taker
Di Kelly	Inclusive Leisure Opportunities Research
Emma Maynard	Project Officer, Young Carers, S&CS

**Apologies:**

Pat Arculus	County Councillor
Liz Catchpole	Horsham PCT
Caroline Gibbins	Early Years & Child Care Development
Wendy Jones	Assistant Education Officer
Joan Martin	
John Parsons	Western Sussex PCT
Dot Rae	Autism & Asperger Action Group
Louise Williamson	VSLDO, S & CS, Horsham

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**1. Welcome and Introductions**

Jon Philpot outlined the background to the group and introduced Robert Dunn, who will be taking the chair at future meetings. Existing and new members were welcomed and introductions made. As Jon Philpot and Robert Dunn would be attending part of the meeting, they would in turn chair the first two sections of the meeting. Cathy Caine would take over the chair for the final section.

**2. Minutes and Matters Arising from the meeting held on 13.10.04**

***Page 2, item 3. Respite Care***

Jon Philpot informed the group that a task force is being established to look at the issue of short term respite care. The aims of the task force were presented to the group. The task force would involve representatives from other agencies: Education, Health and the voluntary sector. Evidence is being gathered for presentation to the Select Committee in July.

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Sue Aldred said that the reference to the Camelia Botnar Children's Centre was incorrect, as the Centre does not use volunteers. (To be deleted from the minutes.)

Matters arising from the previous minutes would be discussed during the course of the meeting.

**3. Research on Inclusive Leisure Opportunities for children with disabilities – Di Kelly**

Di Kelly began her presentation by extending thanks to Jon Philpot and Nigel Scott-Dickeson for the advice and support she had received. The research is sponsored by the Sure Start Unit and represents one of three pieces of national research which have been commissioned. The remit is to look at opportunities for children with special needs and disabilities in sport, physical activities and play across six local authorities in the South East.

The work commenced end November 2004 and is to be finalised by end March 2005. Data from existing research and surveys will be incorporated e.g. the National Parent Partnership Network.

The survey focuses on after school activities, holiday playschemes and leisure centres and is seeking views from parents and children from 8 to 16 years, activities providers and strategic planners. Parents' views will be gathered by personal interview or over the telephone. Voluntary organisations will also be visited and arrangements have been made for Di Kelly to visit the Springboard Project.

Di Kelly distributed copies of Research Questionnaire 1 (Providers) and the accompanying letter of explanation. Research Questionnaire 2 is for completion by facilitators.

The aims of the research are:

- (1) To put forward recommendations for good practice.
- (2) To identify the barriers to good practice and ways of overcoming them.
- (3) Information on training opportunities available for providers.

The following issues were raised for discussion:

Range of providers: The range includes private providers although most are registered charities. Some providers focus mainly on physical access and often leisure centres hire out facilities to organisations but do not make their own provision.

Views of parents: The researchers will be asking parents what is available and whether there is a choice of provision. Also whether leisure opportunities were inclusive.

Funding: Emma Maynard of Young Carers informed the group that there is funding available in the Young Carers' budget, which could be made available where there is a need for a support worker. Emma Maynard to contact Di Kelly with information.

Availability of facilities: Robert Dunn raised the issue of colleges (e.g. Lancing College) which will set aside sessions for children with special needs and disabilities. Di Kelly responded that such facilities are often not marketed well and difficulties are experienced in making parents aware of the provision available.

Transport: Parents were concerned about the difficulties of accessing some schemes which are some distance away and where transport is not available. Di Kelly said that this was one of the barriers which would be highlighted by the research.

Publication of research: Barbara Dolan asked how the research findings would be made available. Di Kelly replied that Sure Start would include the material on its website at the end of the Summer Term. When finalised, the research findings would also be accessible from the Parent Partnership Network. Jon Philpot suggested that the website link could be posted on the Wellspring Newsletter website.

Barriers to provision: Parents outlined some of the barriers they had encountered. Children are often not able to use facilities because provision is not sufficient to cover a wide range of disabilities. Providers tend to focus on physical rather than sensory needs. Parents also lack confidence to approach providers. Di Kelly gave the example of a leisure centre in Guildford where staff received a high level of training. This gave parents confidence in the level of support and the facilities provided.

Robert Dunn thanked Di Kelly for an interesting presentation.

#### **4. West Sussex Children's Trust group on children with special needs and disabilities – to consider parent carer representation.**

Jon Philpot presented the draft terms of reference for this new workstream group.

At the first meeting in December it was agreed that the group should be approached to ask how parent members would like their views to be represented, either by means of parent representation at meetings or regular reporting. Jon Philpot said that efforts were also being made to seek the views of young people with special needs and disabilities.

Anna Cowie and Barbara Dolan expressed interest in participating in the workstream group as representatives of the Parent Carers Planning Group. Jon Philpot to take this forward at the next meeting on 15 March.

Barbara Dolan asked if there would be a role for IMPACT in accessing the views of young people. Jon Philpot responded that at present he was pursuing this through the PAR organisation and also through the Youth Cabinet.

Nigel Scott-Dickeson requested information on the role of the Children's Trust. Jon Philpot explained the structure, headed by the Management Board, through the Children and Families Strategic Development Group, leading to a number of workstream groups operating in particular areas. In reply to a question concerning representation of the younger age group, Jon Philpot said that the Early Years and Child Care Partnership represents this group.

*Robert Dunn introduced Emma Maynard to the group and Cathy Caine took over the chair.*

## **5. Children with Caring Responsibilities – Emma Maynard.**

Emma Maynard outlined the work of the CCR team. The three full time posts are funded by the Children's Fund, Connexions and the Carers Grant. Major changes in the team are planned for the future and they are looking at how other agencies work with young carers. The framework is a set of postcards which help young people identify how they need support. The team is also working on a range of resources for professionals such as leaflets, posters and other resources linked to the family and group work.

Education are interested in producing a team training resource to deliver to all schools countywide. This would simulate a day in the life of a young carer.

The support group which has been set up in Mid Sussex will soon be passed to the Youth Service, with sessions increasing from monthly to fortnightly. It is hoped that a similar group will be established at Shoreham.

The item was offered for discussion and the following issues were raised:

Age group: Emma explained that the team supports young carers from the age of 10, although referrals are received for younger children.

Value of service: Parents expressed appreciation of the service. The focus is often on the disabled child and siblings often feel left out. There was an example of the Young Carers team going into the school of the young carer to work with the peer group. Emma Maynard expressed concern that there may not be sufficient short-term work in schools and that information needs to be available to all teaching staff.

The team does not have sufficient resources at present to work with special schools. It is hoped that more training will make this possible in the future.

Growing need: Emma Maynard informed the group that numbers of young carers have increased from 51,000 to 175,000 nationally.

Definition: The definition of the term “caring” in Children with Caring Responsibilities is any child who experiences an emotional or physical impact.

Relationships within the home are often positive – problems are apt to arise outside the home environment, associated with the reactions of others.

Meeting Young Carers: Peter Moor said that County Councillors were to meet with a group of young carers. Dates to be confirmed to Emma Maynard.

Counselling: Cathy Caine read an email which had been received from a parent regarding the need for specialised counselling for siblings. The group was informed about a counselling coordinator who is hoping to extend to include young carers from April using counsellors interested in specialising in this area. The value of family based activities was acknowledged, where young carers and parents can share experiences in a comfortable environment.

Cathy Caine thanked Emma Maynard for bringing this topic to the group for discussion.

Contact details for the Young Carers Team are as follows:

Emma Maynard, Project Manager, Young Carers	01243 852786
Jenni Link, Support & Development Worker	01243 852761
Angela Woodcock, Support & Development Worker	01243 852761

## **6. Any Other Business**

- Mapping Exercise: Nigel Scott-Dickeson said that a web page with respite information has now been included on the NHS website: [www.westernsussexhealth.com/respite.htm](http://www.westernsussexhealth.com/respite.htm)
- The mapping exercise conducted by the Children’s Fund in the 5 – 13 age group may be found on the ICIS website. Parents expressed opinion that the ICIS website was not user friendly but that telephone contact was of a high quality.
- Updated information on government legislation can be found on: [www.childpolicy.org.uk/enghome/index.cfm](http://www.childpolicy.org.uk/enghome/index.cfm)
- The report on disabled people by the Prime Minister’s Strategy Unit can be found on: [www.strategy.gov.uk](http://www.strategy.gov.uk) (Tel: 0207 2761881)

## **7. Discussion topic for next meeting – 20 April 2005**

It was agreed that the topic for discussion at the next meeting would be **Transport**. Cathy Caine agreed to invite appropriate speaker/s to address the group and respond to issues raised. Nigel Scott-Dickeson informed the group that the School Transport Bill includes children with special needs and is due to receive Royal Assent before end March 2005. It was agreed that a précis of the school transport policy would be helpful for the April meeting.

Parents felt it would be beneficial to invite a representative from the Incontinence Service and it was agreed that this issue could be the topic for a future meeting.

There was general discussion concerning difficulties experienced with assessment by the DLA and the whole issue of claiming benefits. It was agreed that this topic would be researched for the meeting in July.

### **Dates of meetings in 2005**

The following dates were agreed:

20 April 2005  
20 July 2005  
19 October 2005

Time: 10.30 – 12.30 followed by a buffet lunch

Venue: Arun Hall, Pulborough Village Hall.