

SOCIAL & CARING SERVICES, EDUCATION & THE ARTS AND THE NATIONAL HEALTH SERVICE

PARENT CARERS PLANNING GROUP

**Notes of meeting held on Wednesday 13 October 2004, 10.30am
at Pulborough Village Hall**

Present:

Sue Aldred	The Camelia Botnar Children's Centre
Pat Arculus (part)	County Councillor
Cathy Caine	Service Manager, Child Disability, S & CS
Debbie Carr	Parent
Katherine Cook	Parent, Parents Action for Respite Care
Anna Cowie	Parent, Parents Action for Respite Care
Barbara Dolan	Parent, Parents Action for Respite Care
Anna Geall	Crawley & Mid Sussex Carers Liaison
Caroline Gibbins	Early Years & Child Care Development
Lindsay Haines (Chair)	Parent Partnership Officer, Education
Julie Langton-Smith	PPI Forum, Horsham & Chanctonbury
Peter Moor (part)	County Councillor
Kate Mulligan	Parent
Richard North	Carers Liaison Project
Madaleine Owens	Service Manager, S & CS, Arun Locality
Sandy Palmer	Minute Taker
John Parsons	Western Sussex PCT
Jon Philpot	Assistant Group Manager, Child Disability, S & CS
Janet Reeves	Parent, Parents Action for Respite Care
Nigel Scott-Dickeson	Springboard Project
Pippa Taylor	Parent, Parents Action for Respite Care
Ellen Tomlinson	Parent & G.P
Sandy Verrall	Parent, Parents Action for Respite Care
Tracy Whittle	Forum Development Worker-PPI Forum, Horsh & Ch
Louise Williamson	VSLDO, S & CS, Horsham
Shelley Woodage	Parent

Apologies:

Liz Catchpole	Horsham PCT
Robert Dunn	County Councillor
Jenni Herrett	Kangaroos
Wendy Jones	Assistant Education Officer

1. Welcome and Introductions

Jon Philpot explained that, as Pat Arculus, County Councillor, had become West Sussex County Council Cabinet Member for Education and the Arts, Lindsay Haines had agreed to chair the meeting. A welcome was extended to existing and new members and introductions made.

2. Minutes and Matters Arising from the meeting held on 14.07.04

John Parsons wished it to be recorded that he had forwarded apologies for the July meeting.

Page 4, para 3

The first sentence was corrected to read: "Disabled Facilities Grants".

Learning & Skills Council & Transition

page 2, para 2

The next parent carer information day was to be held in late April 2005 with transition as the theme. Parents were welcome to join the planning group or to receive notes of meetings. Interested parents were asked to inform LH.

A.O.B

SEN transport: LH advised the group that the DfES good practice guidance on SEN transport would be published in November.

3. Respite Care

Jon Philpot gave an overview of the topics covered in the discussion paper on respite care and the revised Child Disability Strategy, which had been circulated to the group.

Parents expressed their appreciation of the quality of respite care currently provided. However, there was great concern over the lack of adequate respite care to enable families to stay together. Increased services and more immediate help were required in order to meet the needs of growing numbers of children, with greater support required by older children.

The following specific areas of concern were raised by parents during the meeting: overall lack of support and services; services required for moderate as well as severely disabled children; difficulty in accessing existing services; budget shortfall means cuts in services; more full-time support required immediately; failure of SCS to deal with long-term outcome of disability; reliance of many organisations on donations and voluntary help; proportion of budget allocated to assessment v. services; eligibility criteria for assessment means cases of family breakdown have priority; holiday activities at Orchard House turned down through lack of funding; the need to raise awareness and issue of funding.

Sleep deprivation is a common problem for parent carers and can often lead to depression for parents who find it difficult to cope without adequate support and respite care.

The impression was that the budget shortfall could result in cuts in provision of services, which were currently inadequate. Placements in residential units with trained staff were being reduced and playschemes and many other facilities relied on financial donations and volunteer help.

Pat Arculus responded that lack of adequate funding was a national problem. Financial resources were not available to provide adequate services. It was confirmed that, of a total budget of circa. £700 million, 20% was allocated to Social & Caring Services.

It was suggested that the LEA needed to explore the use of the education budget for children with disabilities and that there needed to be greater flexibility within budget allocation. Peter Moore informed the group that a joint collaboration was being organised between Education and Social & Caring Services working together to examine the problems of families with disabled children.

Concern was expressed about the desirability of relying on the willingness of volunteers. MO responded that efforts were made to involve people with special qualities and that volunteers were greatly valued by voluntary schemes.

The importance of voluntary organisations was recognised. NS-D outlined the problems of funding within the Springboard Project and the need to apply for the Carer's Grant on a yearly basis. Funding needs to be sustainable.

The view was expressed that the need for greater provision of resources was being responded to. There was continuing collaboration with other agencies and the sitting service was now supporting 70 families. Community engagement was a positive route to change and agencies needed to work together.

Parents were asked about the value of including young carers in the Strategy document and the issue of siblings needing respite. LH suggested that this could be a topic for discussion at a future meeting.

The question was raised as to how parents could exert more pressure on Government. It was explained that the PCT PPI Forum has a direct link to central Government and would take up the issue at a national level.

The support of the group was offered to the Parents Action for Respite Care. The aim of the group was to raise awareness of the need for adequate respite care. A questionnaire had been circulated to obtain information about provision of services.

The group agreed that a mapping exercise should be carried out to consolidate resources countywide. NS-D agreed to take on responsibility for this task. John Parsons agreed to assist.

4. Daring Dozen

It was agreed to defer discussion on the 'Daring Dozen' to a future meeting due to lack of time.

5. Any Other Business

No points were raised.

6. Discussion topic and date of next meeting

It was agreed that the topic for discussion at the next meeting would be **Young Carers**. Emma Maynard, Project Officer Young Carers, would be invited to address the group.

Date of next meeting: 26 January 2005
10.30 – 12.30 a.m.
Pulborough Village Hall