

**Children and Young People's Services and the National Health
Service**

PARENT CARERS PLANNING GROUP

**Notes of a meeting held on Wednesday 18th October 2006
at 10.30 am - at Pulborough Village Hall**

Present:

Cathy Caine	Asst Group Manager, Child Disability
Debbie Buckwell	Service Manager, Child Disability
Sue Aldred	Manager, Camelia Botnar
John Parsons	Service Development Manager – Western Sussex Primary Care Trust
Kelly Colbourne	Parent
Kim Paul	Parent
Jon Philpot	Group Manager, Specialist Services (Chair)
Joan Martin	Parent
Barbara Dolan	Parent, Parents Action for Respite Care
Jenni Herrett	Kangaroos
Nigel Scott-Dickeson	Springboard Project
Anna Cowie	Parent, Parents Action for Respite Care
Ann Boss	Carers Support Service, North and Mid-Sussex
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Hilary Woolgar	Adult Services
Ranti Fallowfield	Parent
Jean Voicey	Parent
Sue Berry	Connexions
Ruth Cottington	Community Partnership Manager, Western Sussex Primary Care Trust
Jane Lewison-White	Panel Administrator

Attending:

Janet Horsburgh	Extended Schools Consultant
Sir Colin Wilsdon	Member for Hassocks and Victoria

Apologies:

Robert Dunn (Chair)	Deputy Cabinet Member, Children & Young People's Services
Jo Tyler	Parent Partnership Officer, Education
Wendy Jones	Assistant Education Officer (SEN)
Peter Moore	County Councillor for WSCC
Pippa Taylor	Parent, PARC
Bernadette Daly	Family Placement and MENCAP

1. Welcome and Apologies

Jon Philpot extended a welcome to the group and explained that he would chair today in the absence of Robert Dunn and read out the apologies.

2. Minutes and matters arising from meeting held on 19th July 2006

Transition

Jon Philpot commented that transition had previously been put forward as a topic for this October meeting as there was a general need for focus on this item. Cathy Caine explained that a Joint Task Force for members has been set up to see how transition can be improved. The Joint Task Force are looking at children services and adult services and are working hard to gain a better knowledge of education and health.

Cathy Caine explained that there are three forums and parents with children between the ages of thirteen and sixteen, interested in transition are selected for invitation via a questionnaire/survey. They would very much like a parent present here today to join the Joint Task Force as a volunteer. Kim Paul volunteered and the group agreed she was the right choice.

Connexions

On page 4 Kim Paul requested that "...stated that until a couple of months ago she had not even heard of Connexions..." be omitted from the notes and the rest of the paragraph modified to include "...and my son had been interviewed without my knowledge...".

Update on Continence Issues

Anna Cowie reported to the group that she had recently attended a Continence Work Shop coordinated by Sue Giddings set up to explore issues, in preparation for the tender process next year. Anna felt that although the workshop was useful from a parent's point of view in terms of sharing and putting forward parents views, no solutions were found.

Debbie Buckwell agreed that issues were revisited at the workshop. However, it did highlight that younger children could be dealt with but older children with ongoing continence issues need addressing – two separate issues.

Sue Aldred commented that at the moment no free nappies are offered to those with children over five, but felt that we should be looking at the size of the child not the age as children develop at different rates.

With the contract for the present supplier of products up for renewal next September the need for a new supplier was great. Anna Cowie also felt

that pull up pants were definitely the way forward, particularly with older children and wondered if we should be approaching someone like Huggies who may be interested in supplying a specialist market.

Barbara Dolan commented that nothing is happening where it counts. There are health issues not being met and that a better service is required.

John Parsons understood the frustration surrounding continence issues and agreed something should be done to improve matters. He stated that regular assessments with an NHS specialist are vital to plan and design an individual health plan to ultimately provide commitments. He went on to state that he would contact his local colleague to ensure this need was being met.

Jon Philpot advised the group that a project looking at products for continence was being supported at the highest level - Robert Back. Jon went on to state that we will continue to pursue this issue as best we can.

Terms of Reference

This would be presented on the next agenda.

3. Short Breaks Task Force

Cathy Caine referred the group to the Short Breaks Task Force (SBTF) "Holiday Playschemes" leaflet.

Cathy commented that PARC had produced an "unmet needs" paper which the SBTF found very helpful.

The SBTF which formed in 2005, runs in three phases:

1. First phase – play schemes.
2. Second phase – members are putting together their recommendations for over nights. They will be discussed at a future meeting.
3. Final phase – after school services. Janet Horsburgh will be the link with Extended Schools.

Cathy went on to explain that this had been a long complicated piece of work, but hoped the leaflet summarised the work they did.

The SBTF had started with six members in May last year when they firstly looked at playschemes. They looked at staffing and considered whether parents were looking for a break themselves or a break for their children. Issues were investigated such as the impact on siblings, transport etc. It was recommended (in summary below) that:

- funding for respite care should be maintained or increased.
- Advice should be more accessible.

- Streamline funding and provide security for long term funding.
- Children with special needs should have their needs met under the umbrella of Extended Schools.

The SBTF presented these recommendations to the Select Committee who then made a recommendation to the Cabinet Member who is currently considering the report in detail.

Cathy presented Sir Colin Wilsdon who was here to represent the SBTF. Colin explained that Margaret Collins was the chairman of the Task Force with four other people with no former experience of children with disability. He went on to explain that Barbara Dolan had attended a SBTF meeting where it was agreed that funding should be increased and at the very least maintained.

He was conscious of problems in not having a big enough staffing establishment at Orchard House for example. Out of County placement has been looked into but cost is high. He stressed a genuine need for better specialist provision and improvement in resources. Colin also stated that issues had had a huge impact on him and emphasised the need for investment.

Colin also commented that he is in support of the need to invite parents to attend the Disabled Children's Placement Panel (DCPP) to have the opportunity to present their child's case.

Questions and comments then followed from the group:

- Barbara Dolan told the group she felt very passionately about this issue both for herself and others. She had had no idea how under resourced this area is and shocked this service is managed on a crises level basis.

Barbara fears that however good/well meaning these recommendations are, without adequate funds nothing will improve. "Our Partnership Our Plan" cannot be achieved without more money.

- Sue Aldred is in disagreement with running schools on an academic year.

Barbara Dolan answered that it was not feasible to have different holidays in a family environment, even though it might be better for children with disabilities.

- Anna Cowie was concerned that the recommendations may not be accepted by the Cabinet Member. She appreciated that there is a lot of work being done and there are financial issues, but that it was necessary for parents to get a break.
- Anna Cowie wondered what happens to excess monies beyond committed expenditure.

Jon Philpot said that it was probably swallowed up as there may be over expenditure in other areas perhaps.

- Jon Philpot suggested we await the outcome of the second phase and report back.

4. Extended Schools

Cathy Caine introduced Janet Horsburgh an Extended Schools consultant to the group.

Janet Horsburgh handed the group some literature about Extended Schools and explained that by 2010 all schools are expected to provide access to the following services for school age children and their families:

- A varied menu of out of school hours activities all year round
- Childcare to be available for working parents before and after school and in the holidays (8-6)
- Family and parenting support to include access to information and opportunities for family learning
- Swift and easy referral to a wide range of specialist support services
- Community access to ICT, Sports and Arts facilities and to opportunities for Adult and Vocational Learning.

The District Council are putting together the inclusive play strategy using allocated lottery funds. However, there are 94 pages of guidance to negotiate.

Currently the county is split into twenty four localities and there are eight consultants identifying what is already available and identify the gaps.

Partnerships are very important and some already developing are CYPS and voluntary organisations. West Sussex role in this is to make sure play issues are met. There is a gap that needs addressing for 13-16 year olds.

Janet summarised her role as “tying things together” and emphasised that access and working together is the key.

Questions and comments then followed from the group:

- Sue Berry from Connexions asked if there were any schools actually delivering extended schools at the moment.

Janet Horsburgh reported that there is one school looking at an information pack listing what is available during half term. Heronsdale have some fantastic facilities and are keen to work with some other schools.

- Ruth Cottington commented there was a need for parents to become more involved with their local schools.

Janet commented that a leaflet was available to parents full of material.

- Janet thought Transport would be a big issue that needs addressing in terms of accessibility and suggested it could be included as an agenda item for a PCPG meeting.

Jon Philpot commented that it is a very ambitious agenda and looked forward to hearing an up date at a future meeting.

5. Items Suggested for Next Agenda

- Transition
- Transport

6. Any Other Business

Joan Martin informed the group that there was an informative documentary on BBC2 at 9.00pm entitled "My Heart belongs to Dad". Joan thought it might give a good sight into dealing with disability for those who don't work in this area.

John Parsons informed the group that there is an electronic bulletin available to all which contains twenty to thirty interesting points regarding children and young people with disabilities.

The website is as follows:

www.icwhatsnew.com

Nigel Scott-Dickeson shared with the group that he has just taken up a position representing the voluntary sector on behalf of Horsham District and Children's Services with the West Sussex Public Service Board (PSB) which oversees performance on the county's Local Area Agreement. He is also soon to take up the position as voluntary sector nominee on the National Children's Bureau national executive, subject to approval at their AGM on 23rd November 2006. The group wishes Nigel well.

Nigel also advised for information purposes, that the website for "Every Disabled Child Matters" which is being operated through the National Children's Bureau's Council for Disabled Children is:

www.edcm.org.uk

7. Dates for next year

24.01.07

25.04.07

18.07.07

17.10.07

**10.30 – 12.30 followed by lunch
Pulborough Village Hall**