

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

Parent Carers Planning Group

**Notes of a meeting held on Wednesday, 17th October 2007
at 10.30am – at Pulborough Village Hall**

Present:

Debbie Buckwell	Service Manager, Child Disability Teams
Sue Aldred	Manager, Camelia Botnar
Jon Philpot	Principal Manager, Child Disability and Special Needs (SEN)
Peter Moor (Chair)	Vice Chairman of the County Council
Ranti Fallowfield	Parent
Jean Voisey	Parent
Kim Paul	Parent, Parent Carers Forum
Kelly Colbourne	Parent, Parent Carers Forum
Nigel Scott-Dickeson	Springboard Project
Bernadette Daly	Family Placement Team
Joan Martin	Parent
Hilary Woolgar	Adults' Services
Catherine Bigg	Head of Inclusion Support, Children and Young People's Service
Grannie Saunders	Parent
Caroline Williams	Sussex ADHD Group
Anna Geall	Crawley and Mid-Sussex Carers Liaison Service
Katie Hallums	Springboard, Activities Manager
Elizabeth Squire	Parent

Attending:

Jane Lewison-White	Notetaker
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Apologies:

Robert Dunn	Deputy Cabinet Member, Children and Young People's Service
Sue Berry	Connexions
Anna Cowie	Parent, Parents Action for Respite
Barbara Dolan	Parent, Parents Action for Respite Care
Caroline Gibbins	Inclusion Officer, Children and Young People's Services
Annabel Forbes	Community Development Officer for Sussex & Surrey, MENCAP

Michelle Burdis	Parent, Sussex ADHD Support Group
Hilary Vaughan	Educational Inclusion Manager, Children and Young People's Service
Debbie Newson	Wellsprings Newsletter
Judy Clark	Connexions
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Ruth Cottingham	Community Partnership Manager
Jacque Bickers	Carers Strategy Speaker

1. Welcome and Apologies

Peter Moor extended a welcome to the group and explained that he would chair today in the absence of Robert Dunn. The group then introduced themselves to each other.

2. Minutes and matters arising from the Parent Carers Planning Group held on 18th July 2007

Short Breaks Task Force Phase 3

Jon Philpot said that the budget paper was still under consideration but noted that a significant additional sum had been put into the provision of direct payments in this financial year, despite the significant projected overspend for Children's Services as a whole. However it was the intention to apply to be a pathfinder for the "Aiming High for Disabled Children" short breaks finance in 2008/9 and if successful, this would release funds for the provision of additional short breaks".

3. Carers Strategy – Jacque Bickers

Unfortunately, Jacque Bickers' car broke down and she was unable to attend the meeting. Debbie Buckwell explained that emergency respite care monies have been introduced to the children's budget this month. Anna Geall stated that the strategy is also about commissioning these services to 2009. Grants are to go to the voluntary sector, joint financing sitting service.

Kim Paul explained that at a recent conference she was alarmed to discover that many parents don't regard themselves as "carers" and there is a need to highlight them and let them know what is available. Anna Geall commented that Parent Carer Leads need to be appointed and Kim agreed that there was a definite need for clearer communication.

Anna Geall felt that what is missing is funding for Parent Carers. A specialist Parent Carers Support Worker is needed. We have a lead but not a specialist and this is a gap. Anna felt an action plan was needed.

Debbie Buckwell informed the group that in terms of emergency respite, £25 million is available to Local Authorities in England this year in addition to Carers Grants – it is expected that 20% will be used to support Parent Carers.

The policy is to provide home based cover for a 48 hour period with some flexibility for families with disabled children who may need more support. This covers family emergencies to include a family funeral or a real risk to carers employment etc.

Of the overall £300,000, £62,000 is awarded to children. Whilst this is a positive step, this is not a huge sum and there is still uncertainty surrounding future of all the Carers Grant monies.

Kim Paul remembered that when her husband had suffered a heart attack they had had respite care for longer than 48 hours which had been very useful.

Anna Geall asked if financial expenses would be paid to parents and Debbie Buckwell explained that in a lot of cases, in an emergency, families often use friends or family members to aid them, who never claim, but could be reimbursed under the remit of this policy.

Sue Aldred asked if there were a lot of carers available to assist in an emergency and Bernie Daly explained that there are in fact limited carers and it is necessary to draw from existing provision. Bernie explained that there has been three emergencies so far this year and family placement had managed to cover them all.

Jean Voisey commented that she herself had been unable to drive for six weeks having had an operation on her leg and had been lucky enough to find someone else to help her out.

Jean Martin wondered if there was any virtual value to recruit drivers to cover emergencies and Bernie explained that recruitment is an issue

Jean Martin wanted to know if the group thought it might be necessary to go back to National Government to increase on the £62,000. Anna Geall responded that nothing came out in the

budget except they agree to increase it, but the details are not clear. Peter Moor assured the group that this situation is being closely monitored.

Anna Geall also explained that there are other areas that can be looked at to increase on the £62,000 such as the Princess Royal Trust. Anna has the national breakdown of how the monies were distributed which she will email to Debbie Buckwell for distribution to the group.

Peter Moor commented that West Sussex overall budget was the lowest out of the 150 Local Authorities.

Debbie Buckwell explained that in terms of the use of this money, West Sussex are testing out where the need is. Jean Martin commented that flexibility is the key with spending aimed at services rather than people.

Sue Aldred stated that parents require an instant response and they keep children all day at nursery for parents with problems.

Katie Hallums was concerned that disabled children have not always received the respite they've needed, so if this is not in place to begin with an emergency could prove difficult. She also asked if there was a directory of emergency numbers and respite providers for everyone to access. Anna Geall responded that this would prove difficult to provide as needs were specialist and not generic.

Hilary Woolgar agreed that flexibility is good and went on to state that practitioners as well as parents need to know what is available and cascade this information down.

Elizabeth Squire commented that at this stage she felt it is more important for social workers to know what is available as in a crises this is often the first place parents turn for help.

4. Aiming High – (Debbie Buckwell)

Debbie Buckwell explained that the aim is that all children have the opportunity for the best start in life to fulfill their potential. It is based on the five outcomes – in the Every Child Matters agenda.

A figure of £340 million to be released over a three year period is for the improvement of three priority areas: -

- Access and Improvement - Core offer of minimum standards on information, transparency, participation assessment and feedback.
- Responsive Services and Timely Support - Disabled children are given priority. The Government are developing a performance indicator to see quality and quantity are measured.
- Improving Quality and Capacity - £280 million is for Short Breaks, £19 million is for Transition, £35 million is for childcare accessibility project and £5 million is for parent carer forums.

Debbie explained that West Sussex County Council had registered to become a pathfinder for Short Breaks and Jon Philpot explained that there would be a formal process to follow if we are accepted.

Debbie went on to explain that pilot sites are tested and bulk of the monies go out in the third year for short breaks.

Nigel Scott-Dickeson commented that there is a differentiation between the amount needed and received. This money is to grow provision and he is worried about the future of carer grant monies. He is also worried about other significant areas like training and how to pay for it.

Jon Philpot answered that it is going to be difficult but we need to make a good effort to become a pathfinder. Nigel stated that it is important for parents to have a massive input.

Peter Moor commented that we are the eleventh largest authority but much of the monies which we should be getting is going north as we are considered a wealthy area.

In terms of becoming a pathfinder, Jon Philpot stated that parents wishing to be involved needed to contact Kelly Colbourne as soon as possible.

5. Any other business

Nigel Scott-Dickeson informed the group that ECDM has launched a Parent Carers Trust Charter (paper attached) with some really good items listed to sign up to, including:

- Knowledge about children

- How we identify needs
- Input into young peoples plans
- Staff with disabilities and training
- Information and advice available to parents
- Monitory services for wheelchair users

The focus is about training things up better.

Nigel also advised the group that a new piece of guidance was launched in March, Every Parent Matters, and then tracking back, "Parent Support" to develop the strategy – interesting. It talked about £7.5 million to put strategy in place by 2008 (a few copies of this document will be available at the meeting).

It was agreed that enquiries should be made about the use of the £7.5 million and parent carer strategies should be in place.

The future of Carers Grants was a concern raised as continuity of funding is very important. Jon Philpot said that he had read the "Comprehensive Spending Review" on the web which looks like it could include monies for carers - but nothing is certain.

Peter Moor stated that he would telephone John Dixon for clarity on the situation. **Action PM.**

7. Discussion Topics for Next Meeting

- a. Continence – update
- b. Short Breaks – update
- c. Transport - revisit
- d. Carers Strategy (Jacquie Bickers is unavailable for Jan meeting but will be attending the April meeting).

8. Dates for Next Year:

30/01/08 23/04/08 16/07/08 15/10/08

10.30am – 12.30pm followed by lunch.

Please note that the venue for next year has changed and all meetings will be held at [Ashington Community Centre, Foster Lane, Ashington, West Sussex, RH20 3PG](#) (location map enclosed).