

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

**PARENT CARERS PLANNING GROUP**

**Notes of a meeting held on Wednesday 9<sup>th</sup> May 2007  
at 10.30 am - at Pulborough Village Hall**

**Present:**

Debbie Buckwell	Service Manager, Child Disability
Sue Aldred	Manager, Camelia Botnar
Jon Philpot	Principal Manager, Child Disability and Special Education Needs (SEN)
Elizabeth Squire	Parent
Jenni Herrett	Kangaroos
Nigel Scott-Dickeson	Springboard Project
Anna Geall	Carers Support Service, Crawley and Mid-Sussex
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Robert Dunn (Chair)	Deputy Cabinet Member, Children and Young People's Services
Sue Berry	Connexions
Jo Tyler	Parent Partnership Officer, Children and Young People's Service
Ruth Stewart	PACSO
Ruth Cottington	Adur, Arun and Worthing Primary Care Trust
Anna Cowie	Parent, Parents Action for Respite
Bernadette Daly	Family Placement Team
Jean Boisy	Parent
Ranti Fallowfield	Parent
Kim Paul	Parent
Kelly Colbourne	Parent

**Attending:**

Mike Smith	Transition Project Manager
Stuart Fairweather	Strategic Manager, Children's Centres
Jane Lewison-White	Notetaker

**Apologies:**

Lesley Strong	Children's Head, SE Area Director for West Sussex PCT
Barbara Dolan	Parent, Parents Action for Respite Care
Pippa Taylor	Parent

## **1. Welcome and Apologies**

Robert Dunn extended a welcome to the group and the apologies were noted.

## **2. Minutes and matters arising from meeting held on 24<sup>th</sup> January 2007**

Kim Paul referred to the Terms of Reference (TOR) and asked what SPACE stood for. Jo Tyler agreed to find out and report back (please see attached information for SPACE)

Kelly Colbourne asked what VSLDO stood for and Debbie Buckwell explained it is an acronym for Voluntary Sector Liaison Development Officer and commented that there would continue to be a link within Children and Young People's Services (CYPS) in the future.

It was agreed that all acronyms would in the first instance be noted in full for ease of understanding and thereafter abbreviated.

### Continence Issues

Jon Philpot reported back from the recent Children's Trust meeting that Lesley Strong is the new Children's Head for Primary Care Trust (PCT) as well as one of the Directors. PCT will address the problem and look into two specific areas:

- Quality of product
- Access to specialist advice

Lesley Strong will then report back to the next meeting.

There is a need to get a grip of the issues and Lesley Strong is looking into one contract for the whole county.

Anna Cowie was disappointed that Lesley Strong was not present at the meeting to speak to parents. Anna had a report from the Commission and highlighted the fact that there was reference to a lack of national guidelines for the quantity of pads for individuals. Ruth Cottington expressed Lesley Strong's sincere apologies for not attending today, but unfortunately an urgent work matter had prevented her from attending.

Robert Dunn asked Anna to send a copy of the report to Jane Lewison-White to pass onto Lesley Strong.

Anna was keen to see changes on ground level now and had thought we needed to look at two separate issues – one for adults and one for children. Jon Philpot responded that Lesley had not made a commitment on that. Ruth Cottington advised that specialist advice would work across both adults and children.

### New Structure for Child Disability Team (CDT) and Special Educational Needs (SEN)

Jon Philpot stated that the new structure is a new service within Children and Young People's Services (CYPS). He explained that he is the new Principal Manager. The Child Disability Service has joined with the SEN, Parent Partnership and Sensory Support Team to form the Special Needs and Disability Service. It is planned that we will work in a more integrated way.

It was agreed that it might be helpful if a structure of "who is who" and "what they do" and how this relates to the whole infrastructure, could be presented to the next meeting.

### Short Breaks Task Force 2<sup>nd</sup> Phase

Debbie Buckwell reported that work was in progress. Currently, monitoring for the 1<sup>st</sup> and 2<sup>nd</sup> phase is almost complete and will be placed before the Select Committee on 6<sup>th</sup> June. The 3<sup>rd</sup> phase is still ongoing.

Anna Cowie stated that she and other parents, if they wish to join her, will attend the Select Committee accompanied by their children who could then comment to the Members directly letting them know what they want.

Nigel Scott-Dickeson commented that the I Count Scheme which runs in Sutton enables young people to access activities/amenities without having to plead their case all the time.

Robert Dunn commented that we need to look at problems faced and find the answer.

Anna Geall told the group that the Carers Strategy has gone through the Select Committee and maybe we should bring it back to this meeting to see how our children fit in.

### **3. Transition**

Mike Smith, Transition Project Manager, had been invited to attend the meeting to provide an update on work undertaken on Transition.

Transition is the process children with special education needs go through moving from Child to Adult services from the age of 14 – 18 or in some cases 25. Mike passed the group a Recommendations sheet. The Joint Select Committee recommended to the Joint Task Force on transition, that West Sussex Protocol is put into practice by all professionals working with children, and proper training is implemented to achieve this and provide a seamless approach to transition for young people. These recommendations could be achieved by sharing information between organisations/services with a jointly funded (by Children's and Adult's Services) appointment to manage and keep under review the transition strategy and ways of measuring performance. The recommendations will be reviewed in six months.

Mike provided a useful link for the transition task force report on transition: [www.westsussex.gov.uk/CS/committee/chserv/chserv250407ji2.pdf](http://www.westsussex.gov.uk/CS/committee/chserv/chserv250407ji2.pdf)

A "Transition Model" is being worked on, so all year 9 pupil's are identified and the organisations working with each child. Then each child will have their own Lead Professional acting as single point of contact for them and their family, alleviating overlapping and gaps.

Mike went on to inform the group there is now an updated Transition Protocol in place based on professional input. The Protocol went to the Chief Officer for sign up in April. All the services are signing up to it with some very good work from Health. Training of staff is implemented and teams are working together more effectively.

Mike is attending a Parent Forum in June where he will be talking about "Transition the Guide". After receiving feedback from Manor Green School year 11 pupil's as well as having discussions with Northbrook students, the guide will be produced. This guide will be presented in one format and organisations will be asked to provide a translation.

Parents agreed that a hand book on transition would be very useful. Nigel Scott-Dickeson informed the group that there is a "Quick Guide" framework currently going out to schools which consists of a flow chart showing the overall picture so parents know what to expect when their child reaches year 9.

#### **Questions and comments from the group:**

- Kim Paul informed the group that she had been involved in the training professionals and feels that from a Social Services point of view, more input is needed for Adult Services – Children Services is working well.

Mike went on to explain to the group that all professionals who sign up must agree to undertake the training.

- Elizabeth Squire asked who would have the Lead Professional Role.

Mike explained that Teachers, Social Workers or any professionals involved could be the Lead professional. It would usually be the person who has the most involvement with the family and could be handed to another professional if necessary.

- Elizabeth Squire stated that not all parents want this sort of relationship.

Mike explained that parents are written to advising them who their Lead Professional is and can then access them as and when they want to.

The model was provided in the Western area and 49 Lead Professionals were allocated back in November. Next year it will be county wide so all year 10 pupil's will go through this process. Each year they will check back with Lead Professionals picking up feedback and sorting out any issues early.

- Ruth Stewart was concerned that respite carers have to “retrain” once a child reaches 18 despite the fact their level of care will continue to be the same. Individual’s needs should be addressed.

Mike stated the legal situation changes over night of 18 and recognises it needs to be softened.

Robert Dunn commented that parents don’t see the difference in a child’s age when it comes to caring. The system dictates a child carer and then an adult carer – needs to be customer driven instead of organisation driven.

- There was concern that young people were being placed in organisations for work experience based on the infrastructure in place rather than that young person’s career desires.

Parents felt there were currently very few choices for young people and emphasised how important it was for people to encourage and support them with work experience so that other organisations will follow and offer work experience.

- Kim Paul who explained her child was part of “In Control” felt the process had not been explained very well to her. Kim had previously contacted the Carers Liaison in Worthing and initially they couldn’t find anyone to help her. It took four to five months before a person had been pinpointed.

Anna Geall responded that the Carers Support Service had recruited 3 more workers and part of their role will be providing information to parents. They need to be trained around this and will be in post in June. Anna also said that she would be happy for Kim to talk to her if she needed to.

#### **4. Children’s Centres**

Stuart Fairweather, Strategic Manager had been invited to attend the meeting. Stuart explained that in 1997 the Government undertook a major review on children services. A clear view came about:

- Need for much earlier intervention (under 5s)
- Best delivered by joined up co-related services

Between 1997 and 2002 another review of children services came up with “Every Child Matters”. The focus is on the child, but we also needed to concentrate on parent/carers – guidance now includes “Parents Matter”.

Currently, there are six children’s centres in West Sussex, facilitated by West Sussex County Council, based in the most disadvantaged areas. The Office of National Statistics produced three levels of council wards. The strategic team were asked to look at low levels. By going to the super output areas, it was possible to pinpoint them and a centre was established in these areas.

The Children Centres deliver easily accessible services for families with young children forty-eight weeks of the year. They aim to provide:

- Early education integrated with childcare
- Family support and outreach to parents
- Child and family health services
- Training, support, and information

This lifts people out of poverty and gives them informed choices for their future. It is believed that 42,000 children under five (according to 2005 census figure) will have access to a centre in West Sussex.

All Children's Centres will have internet cafes as research suggests that 40% of contact between parents and professionals take place at internet cafes. At Littlehampton Children's Centre there is a timetable of when certain professionals will be "dropping in" for informal chats which is proving very useful.

Thirty more centres are planned in order to provide a centre in every community. It is envisaged that by late summer, funding will be provided to produce twenty-five more centres. By 2012 the centres should all be up and running in West Sussex. 2020 is a realistic time scale for the whole integrated service.

#### **Questions and comments from the group:**

- Jon Philpot asked specifically how the centres will deal with special educational needs?

Stuart Fairweather explained there will be sign posts and direction to the appropriate service required, providing a good point of access.

- Anna Cowie wondered if the centres were able to deal with disabled children, who may throw things and shout etc.

Elizabeth Squire commented that the Littlehampton Children's Centre was very welcoming of disabled children.

Stuart Fairweather went on to explain that the Family Centres are critical in their work with families. The intention is to combine Children's Centres with Family Centres forming "West Sussex Children and Family Centres" within, in some cases, twelve months.

- Nigel Scott-Dickeson was keen to learn where the proposed new Children's Centres were proposed to be built (please see attached information for these details)

#### **5. Special Educational Needs (SEN) Forum and Parent Carers Planning Group (PCPG)**

Jo Tyler informed the group that the next meeting on 18<sup>th</sup> July would mark the relaunch which is predicted to include a lot of new people. It will now be necessary to confirm attendance for all future meetings.

**6. Any other business:**

Ruth Cottington will confirm with Lesley Strong to attend the next meeting.

Anna Cowie informed the group that the Department of Health are undertaking research and came to a recent Parent Carers Support Group to talk to parents.

With regard to school transport taxi services, Kim Paul informed the group that after seven years of continuous service, her child's would change. Despite the transport service assuring Kim they would keep her informed, she has heard nothing from them since January. Children with difficulties find uninformed change very hard to cope with and this might present a big problem for parents. Jon Philpot said he would investigate this matter.

**7. Discussion Topics for Next Meeting**

- Transport – speaker needed
- Lesley Strong to speak
- Phase 3 of the Task Force – invite Janet Horsburgh to speak

**8. Date of Next Meeting:**

18<sup>th</sup> July 2007  
10.30 – 12.30 followed by lunch  
Pulborough Village Hall