

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

PARENT CARERS PLANNING GROUP

**Notes of a meeting held on Wednesday 19th July 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
Lynette Humphrey	Parent
Jo Tyler	Parent Partnership Officer, Education
Bernadette Daly	Family Placement and MENCAP
Ruth Nathan	Service Manager, County Services for Adults with Learning Difficulties
Kelly Colbourne	Parent
Kim Paul	Parent
Wendy Jones	Assistant Education Officer (SEN)
Jon Philpot	Group Manager, Specialist Services
Peter Moore	County Councillor for WSCC
Jenni Herrett	Kangaroos
Nigel Scott-Dickeson	Springboard Project
Robert Dunn (Chair)	Deputy Cabinet Member, Children & Young People's Services
Anna Cowie	Parent, Parents Action for Respite Care
Ann Boss	Carers Support Service, North and Mid-Sussex
Jane Lewison-White	Notetaker

Attending:

Phil Thomas	Team Leader for Connexions
Marion Moffatt	Scheme Coordinator for Face to Face
Gill Young	Special Needs Officer, Education
Geoff State	Crawley VSLDO

Apologies:

John Parsons	Service Development Manager – Western Sussex Primary Care Trust
Anna Geall	Carers Support Manager – Crawley and Mid- Sussex Carers Liaison Service
Ruth Foster	PACSO Facilitator for Chichester
Joan Martin	Parent
Barbara Dolan	Parent, Parents Action for Respite Care
Pippa Taylor	Parent, PARC

1. Welcome and Apologies

Robert Dunn extended a welcome to everyone present and read out the apologies.

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

Transition

Kim Paul had comments and concerns regarding transition and Robert Dunn agreed it should be put forward as a topic for discussion at the next meeting in October.

3. Connexions

Phil Thomas, Team Leader for Connexions in Sussex had been invited to speak at the meeting:

Phil Thomas explained that Connexions for Brighton and Hove, East Sussex and West Sussex had been set up in September 2002. It's aim is to offer guidance and support to all young people aged between 13 and 19 to prepare them for adult life. Connexions is governed by the Code of Practice and comes under the Learning and Skills Council.

Personal Advisors known as PA's are trained to give careers advice and information. Phil is a PA with a specialism with special educational needs but there are other PAs with specialist skills available for dealing with other areas: youth offenders and teenage pregnancy for example. These PAs are there to make the transition from School to College as seamless as possible. In cases where needs can't be met in County, Phil also has responsibility for out of county college places.

Information is collected and monitored for all thirteen year olds in year 9. By the time young people are 16 a comprehensive database of information will be in place enabling PAs to work closely with young people, parents and schools to meet needs required for the future. Additional support that a young person needs is described in a section 140 report for the college called a "moving on plan"

Young people statemented in mainstream schools as well as students in special schools are entitled to information and guidance.

Mainstream maintained schools in West Sussex will have a dedicated careers advisor and if a Section 140 is required PAs will help and assist with transition planning.

Questions and comments then followed from the group:

- Anna Cowie asked what happens if there is no moving on plan in place.

Phil Thomas explained that Connexions are in place to advise and assist where ever possible but could not enforce a moving on plan. A list of year 9's is sent to her and she then writes to anyone who has not approached her offering them the service.

Phil later explained that after meeting a young person, a careers summary is typed up and sent to parents for their child.

- Kelly Colbourne was concerned that some young people might be too disabled to decide on a plan and would therefore slip through the net.

Phil explained that Connexions PAs would work directly with the parents of those young people to consider options to best suit their needs. She went on to explain that parents are always consulted even where more able young people can decide for themselves what provisions are needed. Annual reviews are a way for PAs to meet parents and they are written to if they do not attend as Connexions is keen to keep communication flowing.

- Anna Cowie, who explained that her son has downs, autism and has no speech, wondered where some of these young people will be moving on to.

Phil thought that day provision in a specialist college for 2 – 3 years could be an option with a recommendation for funding to the Learning and Skills Council. In May/June Colleges assess what extra funding is required for September for any particular student. The Learning and Skills Council endeavours to meet these needs. Out of County is expensive but may be necessary if a high level of assistance is a requisite.

- Lynette Humphrey was anxious as to how parents could obtain much needed advice on education from Connexions.

Phil explained that leaflets and information were freely available in school and Schools always invite Connexions to Annual reviews for year 9 and 11s. She did appreciate that Out of County and Independent schools did not always remember to invite them.

Phil went on to explain that lists are updated in year 10 and 11 so we can check and pick up any young people missed. Therefore, no one slips through the net.

- Kim Paul whose son is going to a Specialist College in September, stated that until a couple of months ago she had not even heard of Connexions and felt that even if information is available in school, they are not doing enough to pass it on to the parents. With this in mind she wondered if information could be presented to parents at Annual Reviews.
- Nigel Scott-Dickeson told the group of two young persons (autistic) leaving a mainstream school having been accepted at a sixth form college in Horsham who were ultimately rejected as the college were not aware of the level of support available regarding disability issues. He felt there was not enough expertise to assist in mainstream schools.

Phil Thomas' advice was that they should have gone straight to the Connexions Centre for help. She added that both herself and mainstream advisors would have invited parents to ask any questions by the end of year 11. If young people leave school without seeking any advice, it is assumed their plans are satisfactory.

- Robert Dunn stated that although the system is in place for the customer, it is difficult to negotiate, particularly when coping with disabilities.

Phil Thomas felt every effort was being made by Connexions to help with moving on but if there were any complaints they should be addressed to the Chief Executive of Connexions in the first instance. Phil would be more than happy to address queries personally.

- Cathy Caine asked Phil Thomas if she had seen an increase in the ability to meet disability needs in colleges.

Phil Thomas felt that at the moment demands are not going to be met in college, but did feel optimistic for the future and stressed that things were constantly improving.

- Generally, although there were some issues and concerns surrounding Connexions the general consensus was that Phil Thomas and the team were making headway.

4. Update on Continence Issues

Cathy Caine stated that following the last PCPG meeting Sue Giddings from Horsham and Chanctonbury PCT had chaired a meeting she and others had attended. The meeting discussed a position statement from the Continence Advisers and material researched by Anna Cowie.

A workshop is planned to record and explore issues, in preparation for the tender process for the contract which is coming up in 2007. They will also explore how immediate needs can be addressed.

Cathy Caine also informed the group that the Policy and Development Group had discussed this issue and Sue Berelowitz Head of Partnerships agreed to see what we can negotiate with Health to alleviate the immediate needs.

Questions and comments then followed from the group:

- Anna Cowie commented that she had seen the Position Document but needed to see something more concrete. She said she was more than happy to put her thoughts and comments forward but felt that at this stage action was needed.
- Robert Dunn expressed that the Policy and Development Group was 100% in agreement that the customer was not being considered and that things really did need to change. He stressed that he would pursue this issue through the Policy and Development Group. He also stated that he would speak to Sue Berelowitz.
- Sue Aldred commented that larger nappies were required as there is no provision for larger children in the market place.
- Anna Cowie stated that children were only 8% of the customers of the continence service. Some of these children would never be toilet trained and could not reasonably be expected to wear these inferior products indefinitely.
- Nigel Scott-Dickeson thought that there was always a battle with the budgets. He wondered why direct payments for children couldn't be made, giving the parents the budget and control to buy products for the year.

Robert Dunn asked where Nigel thought the money should come from.

- Jon Philpot injected that continence was defined as a health responsibility.
- Kelly Colbourne stated that the nappies are so uncomfortable that her daughter refuses to wear them and so argues that she is not even receiving a service.
- Robert Dunn said he would pursue the question of budget along with the Policy and Development Group.

5. Role of Parent Carer Planning Group – Terms of Reference

Jon Philpot explained to the group that the Terms of Reference are out of date and requires re-writing. However, this would not be immediate if more change was expected. Robert Dunn stated that the PCPG need to get more information and move forward. He also thought the process was slow and may not change many decisions.

It was felt that more parents need to come to the PCPG meetings to voice their opinions and Peter Moore stated that he wanted very much to see more parents attend. Their input would be most valuable in amending the TOR. These meetings inform the Policy and Development Group for carers.

It was hoped that parent carers would access the information for PCPG on the website www.westsussex.gov.uk and access the information available in schools. Ann Boss thought a letter to parents with the dates for the year might be a positive approach.

- Kelly Colbourne referred to 2.(f) of the Terms of Reference and asked when any annual conference for parent carers was likely to occur.

Jon Philpot thought that such a conference might be a bit optimistic at the moment.

- Peter Moore advised that he raises issues from PCPG with Robert Back.

Cathy Caine told the group that the alterations for the Term of Reference would be prepared for the January PCPG meeting.

6. Items Suggested for Next/Future Agendas

- Transition
- Extended Schools and Children Centres
- Short Breaks Task Force
- Education Transport Arrangements

The mention of Transport sparked a great deal of interest. Wendy Jones commented that it was a national issue. Arrangements are made in the summer holidays for arrangements once it is known what schools the children are going to attend.

The general consensus from the parents was that this was too late and decisions should be made sooner. Kim Paul's son missed the first two weeks of the September term as transport arrangements were not in place.

Geoff State commented on the Social Car Scheme in Crawley.

7. Any Other Business

Marion Moffatt introduced herself as a new coordinator for Face to Face.

Marion explained this is a befriending service for parents of disabled children who may feel isolated, frightened or angry upon learning of their child's disability. The service is made up of parent volunteers who themselves have disabled children and have had to face similar problems. They are trained to listen and chat offering much needed support at very difficult times.

Marion is keen to recruit parents in West Sussex to provide this kind of service and left a hand out sheet for parents to read.

Anyone wishing to contact Marion can phone her on:

**01342 832123 or email her on:
marion@facetofacesurreysussex.org.uk.**

Parents can also visit the Face to Face web site:

www.facetofacesurreysussex.org.uk

8. Date of Next Meeting

18th October 2006
10.30 – 12.30 followed by lunch
Pulborough Village Hall