

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

Parent Carers Planning Group

**Notes of the meeting held on Wednesday 30th January 2008
at 10.30am at Ashington Community Centre**

Present:

Ruth Stewart	PACSO
Nigel Scott-Dickeson	Springboard Project
Katie Hallums	Springboard Project
Fiona Mackison	West Sussex PCT
Bernadette Daly	Mencap & Wellspring
Jon Philpot	Principal Manager, Special Needs & Disability
Sue Aldred	Manager, Camelia Botnor
Anna Cowie	Parent; Parents Action for Respite Care
Ranti Fallowfield	Parent; West Sussex Parents Forum
Lindsey Butterfield	Parent; West Sussex Parents Forum
Joan Martin	Parent
Kim Paul	Parent; Vice Chairperson, West Sussex Parents Forum
Sarah Ffloulkes-Roberts	Dame Vera Lynn School for Parents
Jenni Herrett	Kangaroos
Lesley Strong	West Sussex PCT
Margaret Unwin	Parent Partnership Officer, Parent Partnership Service
Tina Nichols	Connexions, Horsham
Caroline Williams	Sussex ADHD Support Group

Attending:

Bill Leath	Principal Team Leader, Transport Co-ordination
Suzanne Fuller	Notetaker

Apologies:

Councillor Peter Moor	Vice Chairman of the County Council
Debbie Buckwell	Service Manager, Child Disability Teams
Hari Chhokar	Carers Liaison Service
Kelly Willard	Parent; Chairperson, West Sussex Parents Forum
Barbara Dolan	Parent; Parents Action for Respite Care
Liz Hall	ICIS
Jean Voisey	Parent
Hilary Woolgar	VSLDO, Littlehampton
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Hilary Vaughan	Educational Inclusion Manager, Children & Young People's Service
Sue Berry	Connexions
Jane Tickner	
Sue Palmer	Integrated Services Delivery Manager, Worthing ISDA

1. Welcome, Introductions and Apologies

Jon Philpot extended a welcome to the group and explained that he would chair the meeting in the absence of Peter Moor and Robert Dunn. Jon welcomed Margaret Unwin, new Parent Partnership Officer and Bill Leath, Principal Team Leader, Transport Co-ordination to the meeting. The group then introduced themselves to each other.

2. Minutes and matters arising from the Parent Carers Planning Group held on 17th October 2007

Aiming High for Disabled Children

Jon informed the group that West Sussex was not successful in its bid to become a Pathfinder Authority for the short breaks funding. Over 100 Local Authorities applied. Brighton & Hove and Kent were among those successful.

West Sussex will not get the funding in the first year, but the following amounts had been agreed for future years:

Year 1 - £60,000 for 08/09 (These are the correct dates)

Year 2 - £747,000 for 09/10, with £360,000 capital

Year 3 - £2,400,000 for 10/11, with £840,000 capital

Jon said that it was agreed at a recent Children's Trust meeting that a project group will be set up to include all relevant people, including voluntary organisations. Proposals for ways of using the funding will be considered by this group. The message from the department was that the money should be used to find more flexible services. The next Children's Trust meeting is in March and Jon will report back at the next PCPG meeting in April.

Action: JP

Primary Care Trust Charter

An amendment was made under point 5 of previous minutes; it should read Primary Care Trust Charter.

Jon informed the group that the Local Authority Charter is being re-launched, with a more flexible timescale on it. A meeting is to be arranged to discuss how West Sussex could sign up to the Charter* on the basis of a joint action plan. (*a copy of the Local Authority Charter is attached).

Carers Grant

Jon informed the group that the Carers Grant is being continued for another 3 years. West Sussex as a whole will receive the following funds:

Year 1 – £2,800,000 for 08/09

Year 2 – £3,100,000 for 09/10

Year 3 – £3,300,000 for 10/11

This will be split 20%/80% for Children's and Adult's Services. This is an increase in line with inflation.

Debbie Buckwell will be convening a panel to consider short breaks grants for voluntary organisations.

3. Continence Update (Lesley Strong and Fiona Mackison)

Lesley Strong updated the group with regards to the tendering process for continence products. There was a slight delay on this as there used to be separate contracts across West Sussex, but there will now be only one. They were hoping to split the contracts between adults and children, but this has not been possible as the children's contract is too small to be viable on its own. At present Lesley was not able to say where the contract had been awarded. If there is to be a change of provider there will be a whole change management process behind it.

Lesley said that there is also going to be a review of the policy on the provision of products and they are looking at having one policy across the County. Anna Cowie asked if this covered how many pads people were entitled to and Lesley confirmed this.

Lesley agreed that there was not the provision for teenagers and the action was to keep lobbying companies to get products available.

Anna said she had a number of concerns. There seemed to be a lot of action but she isn't seeing any changes. Anna went to look at the products available from companies, but was disappointed that she was unable to meet the suppliers so she could discuss her concerns directly with them.

Anna asked why there were plans to set up a contract with a company that cannot supply the need. Lesley said that it has not been possible to find a company to supply products for young people. She was hopeful that once the contract was awarded it might be possible to work with the company to get them to develop the products.

Anna felt that this aspect should have been part of the tendering process but Lesley said it would have caused too much of a delay.

Anna said that there were a lot of issues with regards to products young adults. She could not see how Every Disabled Child Matters objectives could be realized if West Sussex was not able to meet their basic human needs.

Nigel Scott-Dickeson queried whether we had looked overseas for products and Lesley said the tender was put out worldwide. The current supplier is from Holland.

Lesley confirmed that it would still be possible to get supplies from NHS Logistics outside of the contract, but the issue is that they do not offer home delivery.

Fiona Mackison updated the group with regards to service developments. They have employed two new Paediatric Continence Nurse Specialists Nina Bunce and Tina Fellen who are now in post and are looking at a range of needs.

They are also going to appoint a nursery nurse to work with parents to do more assessments.

It was confirmed that there is now a single point of contact based in Worthing, so parents hopefully know where they need to go for information.

Tina and Nina are working closely with school nurses and it is thought that special school nurses need to be specialists. They are currently looking at a pilot using schools nurses to be launched in April.

They are also looking at standardising paperwork so it is clearer and easier to read.

Anna carried out a survey in 2005 involving parents whose children use continence pads, and she feels it would be beneficial to identify those children who have multi-complex needs, and in particular where children have no language, as it was difficult to toilet train these children.

Anna expressed that 5 pads was insufficient for a 24hr period. Ruth Stewart agreed with this, and queried why it should be the same amount for each child. Lesley informed the group that this was being looked into as part of the review of the policy. She would like to come back to parents to discuss this once the policy was being formulated.

It was agreed the key thing was an individual assessment of the child's need.

Nigel asked whether Lesley or Fiona were in contact with a Disabilities Nurse called Becky Gold Jones. He thought that she was employed by the West Sussex PCT. Nigel to pass on details so Fiona can contact her.

ACTION: N S-D

Jon commented that he thought matters were improving, but he could sympathise with Anna and other families who are still experiencing difficulties.

It was agreed that Tina or Nina, one of the specialist nurses, would be invited to the meeting in July.

ACTION: LS

4. Transport (Bill Leath)

Bill confirmed to the group that he understands that things have been difficult for parents during the restructuring, and commented that it has also been difficult for staff.

Bill also highlighted that the budget noted in the minutes from the meeting on 18th July 2007 was incorrect. The actual budget is £13 million for home to school transport. He informed us that at least half of this was spent on special needs and £5,500 was spent on taxis.

There has been a restructure within the service, to make the team more accessible for those children with special educational needs and adults.

Bill informed the group that Heather McIntosh is now the Team Leader of the Accessible Transport Team. Within her team there are three Transport Planners, who deal with school transport; Ani Beams covers the coastal area, Nick Thomas covers the Western area and Jackie Bowles covers the North and Mid Sussex area

There used to be 250 providers, but the transport department carried out a thorough health and safety evaluation and they now have 90 approved providers across the County.

To ensure that standards are being met, there is a Compliance Officer we will go around the County.

There is also a review of the escorts currently being undertaken, and they have been working with St Anthony's and Fordwater Schools as well as with Hampshire County Council, which has a good escort system. Training for escorts is being provided.

They are re-procuring taxis. Those that did not opt into the service will be given the opportunity to come back on board this year.

Highways and Transport are no longer using e-auctions, as although substantial savings were made, these were insufficient. They are now going back to e-mail bids, which is a slower process.

There will also be a review in the future of passenger and community transport and Bill's colleagues will be working with the PCT regarding hospital transport.

Bill explained that all disabled children will have transport care plans. Questionnaires are sent to parents to help complete these. All taxis and buses should have a copy of each child's care plan. Anna asked whether the drivers regularly refresh their memories as to what the care plans contained, as they could have a number of different children a day with different needs and also children's needs change. Bill advised that the Escort Co-ordinator will be keeping an eye on this.

Jenni Herrett asked what would happen if a child's escort is off sick. Bill explained that this was a very difficult situation and they are looking at ways of coping with this.

Kim Paul queried whether it was possible for training to be made compulsory to escorts that are not employed by WSCC. Bill advised that training courses were being run throughout the County.

Kim said it was frustrating that information about taxis always comes very late, ie at the start of a new school year, when it is too late to query anything. Bill agreed to look into this.

ACTION: BL

Ranti said she had not been aware her son had a Transport Care Plan. She queried how often the Transport Care Plans should be updated. Bill agreed that this should be done following every annual review.

There is a question about savings made as a result of the restructuring and Bill confirmed it was £100,000 out of a budget of £5,500,000. He said there was an issue about whether the savings were sustainable.

Bill confirmed that the main contact for any issues regarding transport is Heather McIntosh.

Jon thanked Bill for attending the meeting.

5. Parenting Strategy

Unfortunately Sue Palmer was unable to attend the meeting, so Jon circulated a briefing note from the last Children's Trust meeting in November, which he talked through (a copy of which is attached).

There is a stakeholders meeting on Friday at the North Eastern Area Professional Centre, to discuss the framework, which Nigel will be attending.

Jon asked for feedback about how people wanted to take part and contribute to the strategy.

Nigel expressed his disappointment that there has been no involvement of parents and there is now very little time to take part. He felt other Authorities were further ahead and had produced a good strategy, for example Brighton and Hove.

Margaret Unwin suggested it might be possible for Parent Partnership to facilitate a mechanism to consult with parents and it was agreed the Parent Partnership Service would put together a contact list so that we can send any information like this on to to enable consultation with parents who are interested.

ACTION: MU/SF

Bernadette Daly advised that she had worked on a Parenting Working Group several years ago, which had looked in to mapping etc, so there should be a framework already set up. It was agreed it might be useful to revisit this. Nigel also had information about work in other authorities.

Jon will feedback to Sue Palmer and Claire Potter the concerns about the lateness of the strategy and the lack of parental involvement.

Nigel felt the Parenting Strategy should be generic and not made the responsibility of someone in one of the ISDAs.

Nigel will update the meeting next time about the stakeholders day.

ACTION: N S-D

6. Any other business

None.

7. Discussion topic and dates for next meeting

Parenting Strategy (Sue Palmer to be invited)

Carers Strategy/Young Carers

Extended Schools

Update on Countywide Play Strategy and Specialist Nurses

The next meeting to be held on Wednesday 23rd April 2008 from 10.30am at Ashington Community Centre.