

<b>Children and Young People's Services and the National Health Service</b>
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**Parent Carers Planning Group**

**Notes of a meeting held on Wednesday, 18<sup>th</sup> July 2007  
at 10.30am – at Pulborough Village Hall**

**Present:**

Debbie Buckwell	Service Manager, Child Disability
Sue Aldred	Manager, Camelia Botnar
Jon Philpot	Principal Manager, Child Disability and Special Needs (SEN)
Jo Tyler	Parent Partnership Officer, Children and Young People's Service
Peter Moor (Chair)	Vice Chairman of the County Council
Lesley Strong	Children's Head, SE Area Director for West Sussex PCT
Ranti Fallowfield	Parent
Jean Voisey	Parent
Kim Paul	Parent
Kelly Colbourne	Parent
Sue Berry	Connexions
Ruth Cottington	Adur, Arun and Worthing Primary Care Trust
Anna Cowie	Parent, Parents Action for Respite
Barbara Dolan	Parent, Parents Action for Respite Care
Annabel Forbes	Community Development Officer for Sussex & Surrey, MENCAP
Nigel Scott-Dickeson	Springboard Project
Michelle Burdis	Parent, Sussex ADHD Support Group
Ann Boss	Carers Support
Bernadette Daly	Family Placement Team

**Attending:**

Ian Gwenlan	Principal School Transport Officer (Client), Children and Young People's Services
Jane Mules	Head of Worthing Locality for West Sussex PCT
Suzanne Fuller	Notetaker

**Apologies:**

Robert Dunn	Deputy Cabinet Member, Children and Young People's Service
Hari Chhokar	Carers Liaison Service

Caroline Gibbins	Inclusion Officer, Children and Young People's Services
Joan Martin	Parent
Geoff State	VSLDO, Adult Services
Hilary Woolgar	Adult Services
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Mike Branson	SCOPE (Chair)
Hilary Vaughan	Educational Inclusion Manager, Children and Young People's Service
Catherine Bigg	Head of Inclusion Support, Children and Young People's Service
Grannie Saunders	Parent

## **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. He also explained that this was the first joined up meeting of the Parent Carers Planning Group and SEN Forum.

## **2. Minutes and matters arising from the Parent Carers Planning Group held on 9<sup>th</sup> May 2007 and from the SEN Forum held on 21<sup>st</sup> February 2007**

In regards to the Parent Carer Planning Group minutes, Jon Philpot referred to the new structure for Special Needs and Disability Service, previously circulated. Jon has also put together information on the Aims and Objectives for Special Needs and Disability Service (a copy of which is attached), which includes information about the roles of individual parts of the service. Jon explained that this was a draft and has been sent to staff for comments and it will be discussed at the next Parents Make Yourselves Heard Forum. He invited members to comment as well.

Nigel Scott-Dickeson asked if the Carers Strategy could be bought up at a future meeting – this was agreed.

### SEN Forum letter from Mark Dunn

Jo Tyler explained a parent at the SEN Forum had raised the issue of the difficulties she had had trying to access her son's file at his school, other forum members had had similar difficulties. For this reason a letter was drafted by the forum chair and sent

to Mark Dunn . Mark's response was available at the meeting It was suggested that this situation should be monitored and reviewed through future meetings. Kelly Colbourne and Kim Paul explained they hadn't had a chance to read this response and it was agreed that they would contact Jo if they had any queries.

### SEN & Disability Team Structure

Jon Philpot had already covered this topic under matters arising.

### Short Breaks Task Force Phase 3

Debbie Buckwell informed the meeting that the budget briefing was discussed at the Select Committee on 7<sup>th</sup> July and confirmed that this is the 3<sup>rd</sup> and final phase.

Nigel Scott-Dickeson commented that there seems to be a lot of frustration with regards to getting information and being told that it is always down to budget problems. He also feels there is a lot of bureaucracy which effects accessing buildings for disabled children including school building, this is especially difficulty during school holidays. Nigel felt that there needed to be some incentive to encourage schools to offer their premises and equipment.

Nigel has experienced difficulty with one school since Christmas, and has lost 3/4 activities because of this. On the other hand one school was extremely helpful and proactive but this was then halted by paperwork and 'processes'. Nigel expressed his concern that it is every child that matters, not policies and procedures.

Peter Moor said that he had asked for comments from the Task Force, but as yet has not received any. Peter also commented that the running of the school is down to Governors and Head teacher.

Barbara Dolan commented that she has been involved in the Task Force and has a lot of faith in the fact that the Councillors where trying to do the right thing, but she has a nagging fear that nothing will change, as it hasn't in the last 2-4 years.

Jon Philpot hoped that the situation will change in a year, but explained that a lot of the issues were longer term. He confirmed that they are trying to work with schools and is hopeful things will change.

Jon said that the budget paper has been produced to clarify how much extra respite can be provided if resources were available. Peter confirmed that he would speak to Robert Dunn, to see what can be done.

### **3. Continence**

Lesley Strong, Children's Lead and SE Area Director for West Sussex PCT, had been invited to attend the meeting to provide an update on the continence issues.

Lesley explained that there had been a lot of changes within the Primary Care Trust (PCT) as 5 PCT's have merged into 1. Lesley's Area Director role has responsibility for Worthing and Adur.

Lesley introduced Jane Mules to the group and explained her role as Head of Worthing Locality for West Sussex PCT and informed the group that she used to be a Continence Nurse. Jane reported that at a recent workshop for parents and carers, there were two main issues:

1. Separate contracts for children & adults.
2. Provision of products.

There has been money set aside for a Childrens Continence Nurse Specialist and they are hoping that they should have someone in place by Christmas. This person's main priorities will be to get children who can be toilet trained, toilet trained and to work with schools and other agencies, offering training, support, advice etc.

Anna Cowie asked if they would be working with parents, Jane agreed that they would be and Lesley said that this is a key issue. Lesley also commented that she would like to invite parents to sit on the Interview Panel for the new post – Anna has said she would like to be involved.

The tendering process was discussed and it was explained that some of the difficulties were due to two contracts running and both need to come to an end to allow them to tender for one contract. It was confirmed that they would be looking at joining up with other counties for the new contract and there maybe the possibility splitting adults and children. Parents input would be welcome in the tendering process. If the contract cannot be split, it has been suggested that NHS Logistics could be used for

children as they have a small range of continence products, but they currently do not have driver available in South East area, so parents would have to collect from nearest Health Centres. Many of the parents present felt they would collect products if they were better/more appropriate for their child.

Anne Boss queried whether Huggies and Pampers were big enough for young people with continence issues. Jane agreed that there was gap in the market for suitable products for young people. They would specify in the tendering process that this age range needed to be catered for.

Anna commented that there is a need for strong campaigning about this topic Lesley commented that there would not be a 'quick fix' to the problem as there simply aren't the products.

Anna raised her worries about the difficulties for young girls who are also having periods and for boys for whom the products do not offer adequate absorbency. Jane agreed and said that she would inform Anna of places to contact and Anna can then write to them to inform them of these important issues.

Anne asked if pull-ups are offered. Jane responded to say that this needed to be looked into as they are more expensive and every child is different.

The group thanked both Anna and Barbara Dolan for all their help and information provided to the meeting.

Jon Philpot thanked both Lesley and Jane for this update and asked whether these types of difficulties are just in West Sussex or are other authorities experiencing them too? Jane thought some of the actions being taken to resolve these issues may be the first of their kind.

The progress that had now been made in this issue was welcomed and Peter Moor asked for this to be added to a future meeting for further progress.

#### **4. School Transport**

Ian Gwenlan attended the meeting and explained his role and the service.

Ian informed the group that School Transport is now under the Transport Co-ordination Group and is split in to two parts:

1. Operations – Planning, taxis etc

## 2. Policy – Policy development, budget etc

Ian confirmed that transport is provided to 11,000 children in West Sussex, 1,650 have special needs. They have a budget of £30 million and approximately half of this is spent on SEN transport.

Ranti Fallowfield asked about the new bids for September.

Ian responded to say that as a result of the Fundamental Service Review and needing to save money on procurement an auction style bid has been set up and companies have been asked to bid for particular routes since April. Ian commented that parents have been informed about this change.

Barbara Dolan said that the letter scared them and also commented that she had received 2 separate letters (regarding different children) one saying that they will definitely be changing driver and the other one saying that it was changing but they would not know until September. Barbara was concerned at the impact this could have on the children and that the standard of the transport may not be maintained if the new company is cheaper. She also raised concerns about the rumours that surround transport and the general stress and strain this 'not knowing' puts on parents. Barbara has written to the transport department, but has not had a response.

Michelle Burdis raised the issue of her son's school transport, she has experienced a lot of issues for example different drivers, arriving late or early or not at all, and the escort was also not suitable. She had to e-mail Transport for 3 weeks to be able to get the service changed to another provider. She noted the new driver and escort were now excellent but the stress and strain of getting to this point was very difficult.

Kim Paul commented that in the letter that they received in January said that they would be kept informed of what is happening, but this has not happened. She also mentioned that the company had changed in May, but she is not sure if it would be changing again in September.

Ian responded to say that the people involved were trying to deal with the situation as best they can and as quickly as possible. As soon as any details are known parents will be informed.

Jean Voisey queried how they could tell what children will be able to cope with what transport.

Ian responded to say that information was sent to schools for checking and parents talk to the transport department as well.

Barbara asked who decided for consultancy bid, as this must have cost money.

Jon Philpot responded to say that West Sussex County Council made the decision to invite a consultancy firm in to help and advise them in the best ways to make the savings the county as a whole needed to make. A company called KPMG have come to do this through the Fundamental Service Review process. KPMG have offered a range of strategies to ensure the County Council is working effectively efficiently, the developments with school transport are just one part of this.

Sue Aldred queried who checked drivers and escort?

Ian responded to say that all drivers go through an enhanced test to get license through District Council and all drivers and escorts have a CRB check through West Sussex County Council.

Sue queried whether they get trained and expressed her concern over children's safety in the car and asked whether harnesses are provided?

Ian responded to say that their own escorts go through training and as part of the contract this training is offered to staff employed by the other firms, but there has been a disappointing take up from drivers and escorts. Ian also hoped that the training will improve and hoped that all drivers would attend aswell. Ian said that the drivers have a duty to ensure the child is safe in the car and confirmed that they do provide harnesses etc.

Anna said that her son has an Individual Transport Care Plan (ITCP) and on it it says that he has challenging behaviour, does the escort have training? And also commented that training should be taken before the job given.

Ian responded to say that it was difficult to get all the information on children before they start school. Ian also said that parents need to check and sign the ITCP and make any changes they feel are necessary.

Ranti and Jean commented that they had never seen an ITCP. Anna confirmed that her son's ITCP was looked at during his Annual Review.

Kim Paul queried why it is left to the summer holidays to sort out transport, wouldn't it be better to do it in March?

Ian responded to say that it is carried out at this time as they not always aware of what transport will be needed and circumstances may change. They often do not know which children are going to which schools until very late in the school term.

Barbara Dolan queried whether the auction process would be carried out yearly.

Ian responded to say that he didn't think they would be in the same place again. Ian also agreed to report back with all comments received from parents.

Debbie Buckwell queried whether there had been a process put in place for taxis, if there are problems in September. Ian agreed that parents should contact their usual transport representative.

Michelle raised a query with regards to 4 personal cases she is aware of and queried who makes decisions with regards to transport.

Ian responded to say that the decision is made through panel and Jon confirmed that Patricia Morton, Service Manager (Special Educational Needs – Multi Agency) and himself chair these panel meetings.

Nigel asked Ian for an update with regards to Out of School hours as he is struggling to get transport for children in wheelchairs to get to activities, as they don't have mini bus with wheelchair ramp.

Ian responded to say that transport department try to be as flexible as possible, but can't always make provision due to budgetary issues. He also confirmed that his colleagues would do their best to meet needs and adjustments.

Nigel commented that QEII school have a fleet of buses, but due to a clause within their insurance they are unable to use them.

Ian was surprised as he thought it would be easier during the summer.

Nigel asked for a list of school who have extended licenses – Ian to provide.

Peter Moor thanked Ian for attending.

## **5. Any other business**

The Wellspring Resources booklet is now available – if you would like a copy please contact Wellspring direct by sending 2 second class large letter stamps to:  
26 Goldsmith Road, Worthing, West Sussex, BN14 8ER or  
by e-mail [info@wellspringwestsussex.org.uk](mailto:info@wellspringwestsussex.org.uk).

## **6. Discussion Topics for Next Meeting**

Suggested topics were

- Carers Strategy
- Review on 'Aiming High'

## **7. Date of next meeting**

Wednesday 17<sup>th</sup> October  
10.30 – 12.30 followed by lunch  
Pulborough Village Hall