

**Adults and Childrens Services and the National  
Health Service**

**Parent Carers Planning Group**

**Notes of the meeting held on Wednesday 16<sup>th</sup> July 2008  
at 10.30am at Ashington Community Centre**

**Present:**

Tracey Light	VSLDO, Worthing
Sue Aldred	Manager, Camelia Botnor Children's Centre
Tina Nichols	Connexions
Steve Large	Carers Support North & Mid Sussex
Nigel Scott-Dickison	Springboard Project
Ruth Stewart	PACSO
Caroline Williams	Sussex ADHD Support Group
Debbie Buckwell	Service Manager, Child Disability Teams
Jon Philpot (Chair)	Principal Manager, Special Needs & Child Disability
Kelly Willard	Chair, West Sussex Parents Forum
Kim Paul	Vice Chair, West Sussex Parents Forum
Carys Wreyford	West Sussex Early Childhood Service
Ranti Fallowfield	Parent/West Sussex Parents Forum
Lindsey Butterfield	Parent/West Sussex Parents Forum
Margaret Unwin	Parent Partnership Officer, Parent Partnership Service
Suzanne Fuller (minutes)	Administrative Assistant, Parent Partnership Service
Bernadette Daly	MENCAP and Wellspring
Michelle Burdis	Parent/Mid Sussex Family Support Group

**Attending:**

Tina Fenner	Children's Continence Nurse Specialist, West Sussex PCT
Nina Bunce	Children's Continence Nurse Specialist, West Sussex PCT

**Apologies:**

Councillor Robert Dunn	Deputy Cabinet Member
Jenni Herrett	Kangaroos
Joan Martin	Parent/West Sussex Parents Forum
Councillor Peter Moor	Vice Chairman of the County Council
Jean Voisey	Parent
Grainne Saunders	Parent
Julie Birch	Parent
Caroline Johnston	You Can Do It

**1. Welcome, Introductions and Apologies**

Jon Philpot extended a welcome to those present. Jon informed the group that Peter Moor had been ill. All present sent their best wishes to Peter. There was a round of introductions.

## 2. Minutes and Matters Arising from the Parent Carers Planning Group held on 23<sup>rd</sup> April 2008

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Jon Philpot distributed the updated Implementation Plan for the Every Disabled Child Matters (EDCM) Local Authority/PCT Charters and apologised for not distributing this earlier.

Jon explained that EDCM is a national consortium of disability organisations aiming to raise the profile of disabled children. The consortium has produced two charters: one for Local Authorities and one for Primary Care Trusts (PCTs). WSCC and the PCT have decided to sign up to them jointly. An action plan has been drawn up and this has been discussed and agreed at the Children's Trust. Jon explained there would be a meeting next week to look at the plan and actions and set timescales.

### School Escorts

Jon had been in touch with Dave Nelson, Team Leader Finance and Contracts in Transport Coordination who confirmed that the Council reserves the right to require all escorts involved in the transport of passengers with special needs to undertake training arranged by the Council's Authorising or Instructing Officer.

Kim Paul felt that training was not being enforced on the taxi companies. Jon said that the ability to enforce was there and advised parents to go back to the transport department if they had concerns.

Debbie and Jon were planning to meet with Integrated Service Delivery Managers (ISDMs) next week and agreed to raise this issue.

**ACTION: JP/DB**

Nigel Scott Dickison suggested having an ISDM on the Parent Carers Planning Group. It was agreed to follow this up.

**ACTION: JP/DB**

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Kim Paul raised the issue of having a policy lead for Children's Services. Jon said he has overall responsibility for policy on children's services. It was discussed though that other services have a policy lead who has no operational responsibility. Jon advised parents to write to Cabinet if they wished to have this matter considered.

### Aiming High

Jon gave an update on the Aiming High for Disabled Children work. The Project Group has now been set up and there have been two meetings. The group is currently beginning the process for how to develop a plan for the work and is discussing staffing for the project. There is likely to be a Project Manager as well as a Professional Lead. They are looking to advertise this position in September and may bring in a consultant in the meantime to get work underway.

Jon explained that 'Together for Disabled Children' had been set up nationally to assist Local Authorities to develop plans under Aiming High. West Sussex was visited recently and was self-assessed as making reasonable progress in most areas.

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Kim Paul and Kelly Willard reported that they had attended MENCAP's 'In Control' conference, which they had found interesting. They felt there was still a lack of understanding about the issue.

### **3. Specialist Nurses**

Nina Bunce and Tina Fenner introduced themselves to the group and explained their roles as Senior Children's Continence Nurse Specialist and Children's Continence Nurse Specialist respectively.

Both have previously worked for other agencies and recognised the need for improvements in continence services. They have been in post since November/December.

Nina talked through a Powerpoint presentation (attached).

Nina explained that children can be assessed for products from four years onwards. There was some discussion about this and some parents present remembered the age limit being three years old. However it was felt that in the past there had been some variation in practice across the County. Nina explained she and Tina hold clinics that are for all children, but they are seeing an increase in children with more complex needs attending. Current referral rates are 150 per year. Nina and Tina offer treatment and behavioural management interventions. There is a vacant post in the North of the County and they are currently covering this area too.

They plan to train more health visitors and school nurses and are working on practice guidelines. There is a clear link between Autism and continence problems.

Children using special needs transport often have a very long day and this can cause continence difficulties. Tina and Nina are having a meeting with West Sussex County Council's Health and Safety team to discuss the policy around these issues.

Nina stressed that they do not administer the product service, but they are aware of the recent change of supplier and that it is a challenging time at present for parents.

There followed a discussion about some of the issues and difficulties parents faced.

Ranti Fallowfield explained that she is unable to find a product that is the right size for her son. She had this problem before and it has not improved since the new supplier came in.

Caroline Williams asked how children get referred. Nina said referrals can be made through the paediatrician, school nurse or by parents themselves

Jon asked about priorities for the service. Nina confirmed the main priority is clinic work including addressing complex needs and also working with special schools.

Lindsey Butterfield commented that she had been in contact with Tina for the last 2 years and feels it is a valuable service.

Debbie Buckwell said it was a pity if the new contract had not resulted in improvements. It was suggested that parents should put any concerns or complaints in writing.

Nina said she believed PALS (the Patient Advice and Liaison Service) have received a number of complaints.

Jon raised the issue regarding the lack of products for adolescents. Tina confirmed that this is a problem nationwide. Nina advised that there is a company that will make washable products, although the PCT would not currently fund these products.

Margaret Unwin asked about work being done with schools. Nina advised that there is currently a review of school nurses underway and she is hopeful they can develop their work in line with the new role for school nurses, but this is yet to be worked out.

Ranti Fallowfield said she was still waiting to see the continence nurse, and had been told that her son will not be seen until next year. Nina was surprised at this and said appointments were available in the clinics.

Michelle Burdis was also having difficulty accessing help and Nina offered to discuss issues with Michelle and with other parents present after the meeting.

Kelly Willard expressed concern that the PCT would not fund washable nappies. Nina advised that this was because it has not been decided whether it is suitable for adults to use washable nappies.

Kim Paul expressed concern that parents have to pay for products. Jon asked how the service was being publicised and suggested Nina and Tina may wish to put an article in Wellspring. Nina said they were making publicity a priority in the coming months.

Nigel Scott-Dickson suggested the continence service should be included as part of the new commissioning strategy. He was concerned parents were being encouraged to complain as he felt issues should be sorted out before they became complaints.

Debbie Buckwell suggested it would be useful to have more detail about the continence product contract.

Lindsey Butterfield wondered whether the specialist nurses would be helping children in mainstream schools as she feels there is a big void there and a lot of issues that school nurses are unable to deal with. Nina agreed that they would be looking at this once they had worked out a plan for the special schools.

It was suggested the service should register with ICIS. Other possible sources of publicity were the Sussex Autistic Society newsletter and the Parent Partnership Newsletter.

**ACTION: LB/MU**

Margaret Unwin asked whether the priority was face-to-face work as there was clearly a lot of development work that might be done but only limited resources. Nina agreed that their main priority was to work with individuals.

If parents would like to speak to either Nina or Tina, they can be contacted as follows:

Nina Bunce  
Tel: 01243 833858  
E-mail: [nina.bunce@wsx-pct.nhs.uk](mailto:nina.bunce@wsx-pct.nhs.uk)

Tina Fenner  
Tel: 01903 846523  
E-mail: [tina.fenner@aaw.nhs.uk](mailto:tina.fenner@aaw.nhs.uk)

Jon Philpot thanked Nina and Tina for their very helpful and informative presentation.

#### **4. Carers and Stress**

Michelle Burdiss had asked for this item to be included. There was a discussions about the difficulty parents can experience trying to access help.

Steve Large advised that carer' organizations like his own can help parent/carers access support, including practical support.

Ruth Stewart mentioned the sitting service and Margaret Unwin mentioned Parent Partnership, which offers parents support with SEN issues.

There was a discussion about Carers Assessments and under what circumstances carers were able to request one.

The issue of reduced timestables in schools was raised. Michelle felt this can work for some children in come circumstances. However, reduced timetables should not be in place long term without plans for a return to a full time timetable. Jon Philpot agreed to check the policy on reduced timetables and feed back at the next meeting.

**ACTION: JP**

There was a discussion about Direct Payments. Debbie explained that a child is not able to access Direct Payments until they are 16/17, but

parent/carers can access Direct Payments, if they are assessed as being entitled to receive services.

Nigel Scott-Dickison mentioned Springboard's Buddies Scheme, which provides short breaks for parents whose children are aged 11-13.

Jon thanked Michelle for putting this item on the agenda.

## **5. Feedback from West Sussex Parent's Forum**

Kelly Willard reported that the Forum has now received the funding from West Sussex County Council and was awaiting funding from the PCT. This funding would enable them to purchase equipment needed to set up the Forum independently.

The Forum is planning a large meeting on 9<sup>th</sup> October to discuss Transport issues. There will be a report produced from the meeting to be launched in April 2009.

## **6. Any other business**

Kim Paul explained that she is trying to get special splints for her son's feet to help him walk, but has been told that the PCT won't fund them as it has not been proved that they work. The physiotherapist at her son's school recommended the splints and it is frustrating that they are not being provided. Kim's family is going to fund the splints themselves as her son needs them. Kim feels they are in the same situation as with the continence issues, i.e. parents know what is needed but are unable to access it. Debbie Buckwell agreed to discuss this issue with Kim further.

**ACTION: DB**

Ranti Fallowfield suggested inviting someone from the SEN team to future meetings, perhaps an Assistant Education Officer. Jon confirmed that he is the representative for SEN. However he agreed to discuss this further with the SEN team to decide whether someone else should also attend.

**ACTION: JP**

Lindsey Fallowfield informed the group that Sussex Autistic Society had held a 'Question Time Panel' at the Parent Support Group meeting on 15<sup>th</sup> July, which was attended by a range of professionals. The meeting had been a great success. It was a good opportunity for parents to meet professionals face to face. Lindsey said Margaret Unwin would be attending the September meeting to talk about the Parent Partnership Service.

Bernie Daly mentioned 'Celebrate! West Sussex' which is a cultural day including disabled children.

Steve Large informed the group that thanks to money from the short breaks fund the group You Can Do It are hiring Knowles Tooth for a weekend to give carers a break.

Nigel Scott-Dickison commented that he was disappointed that no-one was able to attend to discuss the Parenting Strategy again. It was agreed to invite Sue Palmer to the January 2009 meeting.

**ACTION: SF**

## **7. Discussion topic and dates for next meeting**

The next meeting to be held on Wednesday 15<sup>th</sup> October 2008 from 10.30am at Ashington Community Centre.

Items for Wednesday 15<sup>th</sup> October:

Play Strategy – Marilyn Barton (confirmed)

Extended Schools – Janet Horsburgh and Anne Parkinson (confirmed)

It was agreed that alternative venues would be looked at for the 2009 meetings. Suggested venues:

- Billingshurst Village Hall
- Sallington Village Hall
- Pulborough Village Hall
- Children and Family Centres

Suzanne to research venues and discuss at the next meeting.

**ACTION: SF**

Suggested topics for the January meeting were:

- Young Carers
- Parenting Strategy
- SEN/Statementing