

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

Parent Carers Planning Group

**Notes of the meeting held on 23rd April 2008
at 10.30am Ashington Community Centre**

Present:

Jon Philpot	Principal Manager, Special Needs & Child Disability, West Sussex County Council
Peter Moor (Chair)	Vice Chairman of the County Council
Caroline Williams	Sussex ADHD Support Group
Ruth Stewart	PACSO
Lesley Strong	West Sussex Primary Care Trust
Bernadette Daly	Mencap & Wellspring
Sue Aldred	Manager, Camelia Botnor Centre
Sue Berry	Connexions
Michelle Burdis	Parent/Mid Sussex Family Support Group
Steve Large	Carers Support North & Mid Sussex
Ann Boss	Carers Support North & Mid Sussex
Katie Hallums	Springboard Project
Nigel Scott-Dickeson	Manager, Springboard Project
Debbie Buckwell	Service Manager, Child Disability Teams
Lesley Worrell	Inclusion Co-ordinator, Early Childhood Services
Lindsey Butterfield	Parent/West Sussex Parents Forum
Ranti Fallowfield	Parent/West Sussex Parents Forum
Jean Voisey	Parent/West Sussex Parents Forum
Sarah Ffloukkes-Roberts	Dame Vera Lynn School for Parents
Gráinne Saunders	Parent
Kim Paul	Vice Chairperson, West Sussex Parents Forum
Kelly Willard	Chairperson, West Sussex Parents Forum
Joan Martin	Parent, West Sussex Parents Forum
Jenni Herrett	Kangaroos
Natalie Biegstraaten	Parent/You Can Do It
Margaret Unwin	Parent Partnership Officer, Parent Partnership Service
Suzanne Fuller (minutes)	Administrative Assistant, Parent Partnership Service

Attending:

Jacque Bickers Carers Strategy

Apologies :

Robert Dunn	Deputy Cabinet Member
Myrna Eccles	Parent
Elizabeth Squire	Parent
Hilary Vaughan	Educational Inclusion Manager, Adults and Children
Catherine Bigg	Head of Inclusion Support, Adults and Children
Beky Golds-Jones	Complex Needs Nurse Specialist, West Sussex PCT
Julie Birch	Parent
Barbara Dolan	Parent
Hari Chhokar	Carers Liaison Service

1. Welcome and Introductions

Peter Moor extended a welcome to the group. All present introduced themselves.

2. Minutes and matters arising from the Parent Carers Planning Group held on 30th January 2008

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Under part 2 of the minutes it should read 'Every Disabled Child Matters Charter', not 'Primary Care Trust Charter'. Minutes to be corrected.

Action: SF

Jon Philpot informed the group that there are two charters. He has since had a discussion with Lesley, Debbie and Geoff (PCT) about signing up to these. This will be an agenda item at the Children's Commissioning Forum. Partners will hopefully sign up. Jon will bring the Joint Action Plan back to the PCPG meeting.

Action: JP

Continence

Lesley Strong updated the group to say that the contract is now in place. There are some new products. Some parents are happy, some not. Complaints are being dealt with as they come up.

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Kim Paul highlighted that she felt she still did not have a clear response with regards to compulsory training for escorts. Jon Philpot agreed to discuss this with Bill Leath.

Action: JP

3. Carers Strategy (Jacquie Bickers)

Jacquie Bickers introduced herself to the group and explained her role as Commissioning Policy Manager for Adult Carers. Her reason for attending the meeting today was to discuss the Carers Commissioning Strategy, which was produced last year. The Strategy sets out the work that West Sussex County Council will be developing and delivering to carers. This Strategy runs from 2006-2009. There have been two previous strategies.

Jacquie explained some of the carers' policy context. The White Paper: Our Health, Our Care, Our Say, contains key policy about carers, including the New Deal, which makes provision for emergency respite for carers. All Local Authorities have to develop plans to address this. The Government is funding a new National Carers Information Helpline, to be launched shortly. This will be a 24-hour helpline for all carers. The new National Carers Strategy is due out in summer 2008.

Jacquie talked about the self-directed support agenda. West Sussex was one of 13 individual pilot sites, piloting Individual

Budgets, which is a way of ensuring customers have greater flexibility and choice of their support. Self directed support which is the term used now the Individual Budgets pilot has ended is being rolled out across various groups, including, people with learning difficulties, and mental health problems.

Jacque explained that a separate strategy for young carers has been written and Mark Frankland is the lead for young carers.

The Adult Carers Strategy builds on the previous two strategies and has been developed in partnership with the 3 carers' organisations. Jacque intends to have a cohesive partnership approach.

Jacque talked about national statistics on number of carers. 73,800 carers were identified in West Sussex from the 2001 census. 12,390 (55%) were of working age and providing unpaid care. 44% of carers provide 30 or more hours of unpaid care. The next census is due in 2011.

There was an event last year with the University of Leeds, who have undertaken an extensive piece of work around carers and employment, which produced an interesting document about the realities of working carers in West Sussex.

The Carers Grant continues until 2011, which is good news.

A key service development is the Carers Emergency Respite Service. WSCC has been given £312,000 (20% of this is for parent/carers) and it has been decided that Crossroads will deliver the service to carers of adults.

The Carers and Disabled Children Act 2000 gives Local Authorities power to give one off payments to carers, especially carers where the disabled person is refusing support from services.

Cash payments can be used for anything apart from to pay for respite for the person they care for, as long as needs are identified through an assessment, including driving lessons, white goods and visits to relatives.

Parents present asked for clarification about how parents/carers request a cash payment. Jacque confirmed that one-off payments had been established as a pilot. Debbie Buckwell explained that the area of Carers' Assessments was being looked at. Debbie said that the parent/carer needs to be providing 'regular and substantial care' to get the one-off payment.

Nigel Scott-Dickeson felt that parents were not aware of one-off payments.

There was a discussion about the new Integrated Service Delivery Areas (ISDAs). There was a need to educate staff in the ISDAs and ensure connections between ISDAs and the Child Disability Teams.

There is a some underspend in this year's Carers Grant that will be used to further develop the use of one off payments to carers and direct services for carers. West Sussex was fully committed on its Carers Grant spend last year.

Lindsay Butterfield felt that communication with parents could be improved. Jon Philpot said he was now meeting regularly with Nicki Gibbons, who is the overall manager for the ISDAs and he is hopeful this will aid communication.

Jacque Bickers said funding had been identified for three Carers Support Workers (Learning Disabilities), who will be attached to the three carers' organisations. They should work closely with the three information workers, a key part of whose role is to identify hidden carers.

Natalie Biegstraaten felt it was not just hidden carers that were having difficulties. Many carers can be asking for help for a long time and do not get it.

Joan Martin felt that what people need is action and a response to their particular problem. If ISDA managers were completely up to speed, they may be able to help. She also felt that there was a lot of talking about systems and money, but less about what is available for people? Carers frequently reached 'screaming pitch' because they were being given incomplete information or no answer at all to a very real problem they faced.

Jacque Bickers agreed there was an issue about information. Information is available through a number of avenues including the voluntary sector and via the website. The problem does not appear to be a shortage of information but that carers do not seem to be given the correct information or the information they need at that point in time.

Jacque said that all local carers' organisations produce handbooks, which contain all the basic information carers might need.

Debbie Buckwell suggested that when the National Carers' Helpline was launched there would be publicity associated with this. It was hoped this would help parents to identify themselves as carers, which they did not always do.

Kelly Willard informed the group that the West Sussex Parent's Forum had hoped to put together a booklet of information for parents like the one produced by Amaze in Brighton. However this project had to be put on hold, due to lack of funding.

Jon Philpot informed the group that there is a 'Where do I go from here?' booklet, which is in the process of being updated. There will be a small working group doing this work. The current version of the booklet is available at:

http://www.westsussex.gov.uk/yourcouncil/ppri/sci/PDF_files/Where_do_%20I_%20go_%20from_%20here.pdf

Bernie Daly mentioned that the Wellspring Resources booklet could be found online at www.wellspringwestsussex.org.uk

Michelle Burdis said she has been told that funds were not available to provide support. Her son only goes to school for 2 hours a day.

Kim Paul asked who the Policy Lead was for Children's Services. Jon Philpot and Debbie Buckwell confirmed that they were the contacts.

Nigel Scott-Dickeson felt that young carers' issues needed a higher profile and there should be better recognition of young carers.

4. Update on Aiming High for Disabled Children

Jon gave an update on the Aiming High for Disabled Children work.

There were three issues:

- short breaks
- transition to adulthood
- Parent's Forums.

Jon discussed the draft core offer for parents, which was distributed around the group (attached). Jon explained that this is a national statement describing what parent-carers are entitled to. New indicators are being issued to Local Authorities to cover the core offer.

Joan Martin said she felt if the core offer 'does what it says on the tin' it will go a long way to providing what parent/carers want.

Jon Philpot also discussed the new legislation about short breaks (paper attached) that had been tabled by Lord Adonis and Lord Rix.

Jon circulated a proposal to develop a project group and informed the group that the Government wants Local Authorities to look much more creatively at short breaks provision. Jon talked through the objectives. He said that West Sussex has few independent providers.

Jon discussed the Full Service Offer and confirmed that West Sussex would be expected to meet this. There needs to be a plan in place by March 2009 to get Government Funding. £800,000 is available for 09/10 and £2.4m 10/11 for West Sussex.

Kelly Willard said that a parent at the last Parents' Forum meeting felt a lot of work had been done already in West Sussex through the short breaks taskforce. Will this work be re-used? Jon confirmed that any and all previous work would be incorporated.

Debbie Buckwell said that funding for short breaks was being allocated on the basis that Local Authorities could achieve a step change in service provision. She said it was the end of 'respite care' and the start of 'flexible short breaks'.

Debbie felt that a lot will be learned from pathfinder authorities and West Sussex would be able to pick up on the messages coming through.

Sue Berry queried why parents could not get residential overnight breaks if their children were under 12. Jon Philpot confirmed this was no longer a rule. Sue said she still had a lot of parents saying that they could not get a service. Jon commented that for very young children a family environment was usually felt to be best.

Ruth Stewart raised her concerns about parents on Direct Payments. Debbie Buckwell explained there is legislation around Direct Payments. Parents are strongly advised to take CRB checks and have to give written explanation if they decide not to do this.

Sue Aldred talked about her organisation. For 25 years the Camelia Botnar Centre has been taking care of children under five. She felt that parents using the service had frequently not been able to access any other service. A year ago the Centre announced that their funding had been reduced significantly, no statutory agency stepped in to help, so as a result they had to stop providing transport and parents had to pick this up. Parents ask if children with complex needs can attend the centre but she cannot help. 150 children attend the centre per week. Sue felt she had heard all these discussions before and feels that the voluntary sector do the majority of caring. The centre costs £1m per year to run. This year the organisation has received £350,000 from the Charitable Trust. She wondered how many parents whose children have severe autism are happy for them to go into mainstream nursery?

Jon Philpot said he recognised the value of the voluntary sector. Debbie Buckwell felt that there was a clear message about working closely with voluntary organisations. Debbie was looking at using existing partnerships and asking organisations to provide different things. She felt that the profile of disabled children had never been higher and Aiming High for Disabled Children was a positive step.

Sue Aldred said she was still worried there was a lack of strategic vision in West Sussex.

Nigel Scott-Dickeson was concerned about the message being given about 'doing something differently'. He felt he had run out of ways to do things differently and felt there needed to be some continuity. He hoped the PCT would provide more financial support for the voluntary sector.

Nigel informed the group that he was working on projects in Brighton & Hove. He was being invited to sit down and discuss priorities for disabled children. He hoped this could be replicated in West Sussex too. He was concerned about providing something new for parents and then taking it away.

Nigel asked for clarification about use of the Children's Fund money in West Sussex. Jon said he was not aware of the full picture. He commented that this group was focussed on giving parents a voice and was keen to hear their views about their priorities.

Sarah Ffoulkes-Roberts informed the group that School for Parents at Ingfield Manor provides support for a large number of parents each week.

5. Feedback from the West Sussex Parents Forum

Kelly Willard updated the group about the Parents Forums recent activities. The previous meeting had been held on 3rd April in Horsham and was quite well attended.

Questionnaires were sent out across the county and 79 were returned, which was pleasing. Kelly is currently collating the information from the forms.

At the last Forum meeting transport was the main topic of conversation. The Forum intends to consult with parents about the issue of transport and produce a report. The Forum was seeking funding for this piece of work.

Kelly said that the Forum was pleased to receive a certificate from the Arun Voluntary Service in recognition of the contribution of volunteers.

The Forum now has its own mobile number and e-mail address, which are as follows:

Mobile: 07528 418149

E-mail: parents@westsussexparentsforum.co.uk

There is a joint commitment from West Sussex County Council and PCT to fund some start-up costs.

6. Any other business

The Sussex ADHD Support Group has a new leaflet and these were distributed to those present.

MENCAP would be holding a conference on Saturday 24th May called 'In Control' at Pulborough Village Hall from 10am until 1pm. This event is free for people with learning difficulties and carers.

Wellspring's latest newsletter had gone out. Bernie Daly told the meeting about the Caudwell Trust Fund, which provided funding for treatments including physiotherapy, conductive education, ABA therapy, speech and language therapy etc.

Jacquie Bickers informed the group that the Care Services Improvement Partnership were organising a learning event aimed at service users and carers who have been through self-directed support.

Michelle Burdis raised her concern about the amount of stress associated with asking for help and being turned down. How do people cope? What can be done about trying to prevent parent-carers becoming desperate? The issue of carer stress will be an agenda item for the next meeting.

ACTION: MU/SF

Steve Large informed the group that the Carers Support Service were supporting a newly established parent-carers group covering Billingshurst and surrounding areas. An Information Officer from the Parent Partnership Service would be attending the meeting next Wednesday (30th April).

Nigel Scott-Dickeson said he was concerned about the Parenting Strategy. It was confirmed Claire Potter would be attending the next meeting. (Update: Nigel and Margaret Unwin will be meeting with Claire Potter on 11th June).

Lesley Worrell asked for Carys Wreyford to be added to the group, who is the new Lead Early Years Advisory Teacher (Inclusion), and would be attending future meetings.

ACTION: SF

Sarah Ffoulkes-Roberts informed the group that there was a professional information day being held at Ingfield Manor on 1st July.

Kim Paul raised a concern regarding transition. She was aware that it had been discussed on a number of occasions, and that there was work ongoing but she felt matters needed to be resolved. It was suggested Mike Smith be invited to the meeting as parents still wanted more information.

ACTION: MU/SF

Joan Martin raised a concern about the West Sussex Wheelchair Service not funding wheelchairs that were needed. Lesley Strong advised that she was aware of problems and the PCT would be reviewing this service.

Jenni Herrett said that there was a 'Fun Day' being held at Horsham Rotary Club for special needs children. Tickets were available through Kangaroos.

Suzanne Fuller informed the group that the Parent Partnership Service were organising an Information Day to be held on 10th June at the Ardington Hotel, Worthing. A copy of the poster is attached for further information.

Peter Moor confirmed he chairs the Policy and Development Group for Carers, and has done since 1998. John Dixon, Executive Director of Adults and Children, is also a member of this group and Peter said he would ensure he discussed the issues raised from this meeting with John.

Peter explained to the group that West Sussex County Council were undergoing major restructuring and there were now only 4 executive directors running West Sussex County Council. These are:

- John Dixon – Executive Director, Adults & Children
- Lesley Ottery – Executive Director, Business Services
- Keiran Stigant – Executive Director, Customers & Communities
- Bryan Robinson – County Treasurer

7. Discussion topics and date of next meetings

The next meeting is set for:

Wednesday 16th July from 10.30am at Ashington Community Centre:

Parenting Strategy (Claire Potter – confirmed)
Specialist Nurses (To be confirmed)

The following meeting is set for:

Wednesday, 15th October from 10.30am at Ashington Community Centre:

Play Strategy (Marilyn Barton – confirmed)
Extended Schools (Janet Horsburgh – to be confirmed)