

## West Sussex County Council and Partner Organisations

### Parent Carers Planning Group

#### Notes of the meeting held on 22<sup>nd</sup> July 2009 At 10.30am at Brinsbury College

##### Present:

Jon Philpot	Principal Manager Special Needs & Disability (Chair)
Margaret Unwin	Parent Partnership Officer (Notes)
Linda Bell	Acting Service Manager, Child Disability Teams & Sitting Service
Heather Mackintosh	Team Leader, Transport Co-ordination Group
Ian Gwenlan	Principal School Transport Officer
Jenni Herrett	Kangaroos
Steve Large	Senior Carers Support Worker,
Michelle Burdiss	Parent/Mid Sussex Autistic Support Group
Annabel Forbes	Community Development Manager, MENCAP
Nigel Scott-Dickerson	Manager, Springboard
Fiona Mackison	Head of Specialist Children's Services, West Sussex PCT
Caroline Gibbins	Inclusion Officer, Early Childhood Service
Caroline Williams	Parent/Sussex ADHD Support Group
Sue Aldred, Manager	Camelia Botnar Children's Centre
Ranti Fallowfield	Parent/West Sussex Parents Forum
Liz Robbins	Commissioning, Policy & Development Manager, Adult Services, WSCC
Lindsey Butterfield	Parent/West Sussex Parents Forum
Kelly Willard	Parent/West Sussex Parents Forum
Cheryl Francis	ICIS: information for life
Lynda Jones	Consultant, Outcomes UK (from 11.25am)

##### Apologies:

Kim Paul	Parent/West Sussex Parents Forum
Debbie Buckwell	Lead, Aiming High for Disabled Children
Bill Leath	Group Manager (Transport Co-ordination)
Councillor Robert Dunn	Deputy Cabinet Member
Sue Berry	Connexions, Crawley & Mid Sussex
Gemma Orpwood	ICIS: information for Life
Janice Ellis	West Sussex Dyslexia Support Group
Debbie Buckwell	Aiming High for Disabled Children lead
Bernadette Daly	MENCAP and Wellspring
Tracey Light	Voluntary Sector Liaison & Development Officer
Carys Wreyford	Lead Early Years Advisory Teacher
Jane Barker	Parent
Catherine Bigg	Head of Inclusion Support, Adults and Children

## **1. Welcome, Introductions and Apologies**

Jon Philpot explained he would be chairing the meeting in place of Cllr Robert Dunn, who had a prior engagement. Those present introduced themselves.

## **2. Minutes of 22<sup>nd</sup> April 2009 and Matters Arising**

### Aiming High for Disabled Children

Steve Large asked about progress on the appointment of a parent carers worker. Jon Philpot explained this was a 'parent participation worker'. He asked Kelly Willard for clarification and she said the panel had interviewed three people last week and were due to interview one more on 30<sup>th</sup> July.

Jon reported that the Fun Days had been very successful and parents had asked for more days like these. The purpose of the days had been two-fold: they were both consultation events and Fun Days. Jon said one of the centres had put forward an expression of interest to run future days. It was hoped to hold two more in different parts of the county.

Jon reported that grants had been given to 12 organisations to run additional activities this summer. These events were being commissioned outside the normal commissioning process.

The AHDC Commissioning Group was due to meet after the PCPG today. Jon said there had been a number of expressions of interest from different organisations and the group was now deciding whether to have a system of open tenders and/or selective tenders. He hoped there would be a significant number of applications. Decisions about funding would be made in September.

Jon told the group that 'mystery shoppers' were being utilised. These were parents interested in evaluating services and checking quality. Lindsey Butterfield said mystery shopper training was being run on 29<sup>th</sup> July.

Jon Philpot said young people would also be involved in assessing provision, including disabled young people.

Caroline Gibbens asked whether information about AHDC was on the WSCC website. Kelly Willard said some information had been included in the Parents Forum newsletter. Kelly asked about the workshops for young people in September and how WSCC was planning to identify young people for these workshops. Jon Philpot suggested contacting Judy Crocombe, Project Manager for AHDC for

more information about AHDC generally, including the young people's workshops and the website.

Nigel Scott-Dickerson asked for an update about the I-count card. Jon Philpot explained that this card was run by one of the PCTs in London and enabled families with disabled children to access activities. It also enabled the County Council to gather useful data from families who signed up to the card, meaning there was a more comprehensive picture of families' needs. West Sussex had previously held a register of disabled children but this was no longer current and would need to be updated. The I-count card was expensive and Jon said he envisaged it being funded jointly by WSCC and the PCT. Debbie Buckwell was finalising a draft of a report about the I-count card, which would probably need to be agreed by the Cabinet member.

#### ADHD NICE Guidelines

Caroline Williams asked for an update about the ADHD work being planned. Fiona Mackison confirmed the work would start in the Autumn. However she was changing her role and the work would be on the 'to do' list for her successor. Caroline felt the work was urgent as West Sussex was currently not meeting the NICE Guidelines.

Caroline Williams and Michelle Burdiss both expressed an interest in being on the ADHD working group. It was agreed this would come back through the PCPG for a decision about representation on the working group at a later stage.

**Action: PCPG**

#### Knowles Tooth

Steve Large reported that the weekends for carers at Knowles Tooth had been successful. Depending on availability of Carers Grant he expected that these weekends would be repeated.

#### Continence

Fiona Mackison reported that she was looking to run pilots using personalised budgets for continence products. There was discussion about the difficulties parents faced accessing products, as there were a limited number of collection sites for continence products in the county. Some families were reportedly travelling from Chichester to Worthing to collect products. Fiona confirmed that this arose where families were not 'on contract'. If people were 'on contract' then product delivery was part of their package. She said the PCT was looking at having two more delivery points, probably in Chichester and Crawley.

### Where do I go from here?

Margaret Unwin had the first proof of the booklet with her at the meeting. Changes were being made to this and the second proof was expected shortly.

### **3. Feedback from Parents Forum**

Kelly Willard said the Forum had been very busy. The group was still working on transport. However she had been ill and out of action since June. The Forum had held a couple of roadshows in June, as part of Carers Week, in Worthing and Burgess Hill. A further roadshow in Shoreham was planned.

Lindsey Butterfield said some of the parents she had met at the roadshows had told harrowing stories. One parent who had had a heart attack was being looked after by her severely autistic daughter. Many parents still said they were getting no information about services or support.

Kelly Willard had met with PACSO and was hoping to have Forum meetings at other parents' groups. The Forum had decided it made sense to go out to existing parents groups, rather than try to get parents to come to Forum meetings. Jenni Herrett asked whether the Forum would be able to attend Kangaroos' AGM, planned for 14<sup>th</sup> September.

#### **Action: Parents Forum**

Kelly said the Forum's AGM would be held on 16<sup>th</sup> September.

There was a discussion about information and about how parents find out information. Jon Philpot said information was part of the AHDC offer. Michelle Burdiss felt that GPs and schools are often not able to help parents when parents need it.

There was a discussion about children and family centres and their provision for disabled children. It was agreed there was some good work going on in some children and family centres (Billingshurst and Horsham included) and Caroline Gibbens felt it might be helpful to invite an Area Manager for a group of children and family centres to a future meeting.

#### **Action: Margaret Unwin/Gemma North**

Kelly Willard finished off her slot about the Parents Forum. She said the Forum was meeting with Worthing Carers Support, which had recently employed a Parent Carers Support Worker. The Forum was

hoping to utilise some young people as volunteers over the summer.

Cheryl Francis reminded the group of ICIS' role in disseminating information and signposting people to helpful services.

Kelly asked if those present knew of sign language training as she had received a query from a parent about this. Fiona Mackison suggested the parent should be in touch with the sensory support team and in particular Liz Beatty, who was based at Rydon Community College.

It was noted that the child involved in the example was attending a nursery in Portsmouth and a discussion followed about availability of local provision. Caroline Gibbens said that many early years staff were now trained in sign language to enable them to support children with hearing impairments in their nursery. Sue Aldred reported that Camelia Botnar have staff trained in sign language, who are also able to teach it to parents. Steve Large suggested that parents seeking funding for sign language training and other training may be able to access funding from the Short Breaks Fund through their local carer support organisation.

#### **4. Transport**

Ian Gwenlan said he was very grateful to the Parents Forum for their transport report and charter. He said the transport service had embraced the vision of having a charter and he proposed establishing a working group to work-up the charter, using the Parents Forum model as the basis. Ian said he envisaged the working group would meet during the Autumn term and report back by the end of the year.

Ian had drafted some terms of reference for the working group and these were circulated at the meeting (attached).

Kelly Willard agreed that having a working group was a good idea. It was felt it might be helpful for the Forum to have a pre-meeting with the transport team to explore some of the issues.

The PCPG meeting considered the draft terms of reference Ian had circulated. Jon Philpot asked for clarification about point 3, which stated that 'The County Council's policy and its legal obligations are outside the scope of this project.'

Ian explained there were things the County Council could not promise and/or could not be changed, for example it was not

possible to say that every child in the county could have free transport.

Nigel Scott-Dickerson asked whether issues around extended schools, in relation to transport, were being picked up as part of the work? Jon Philpot pointed out that this point was included in the Parents Forum's charter, and therefore it was expected it would be covered by the working group.

There was a discussion about membership of the working group. Kelly Willard requested more parent representation on the group. Jon Philpot suggested it would be necessary to go through Heads Executive to identify a special school head (and possibly a mainstream head).

The group agreed the work on the charter as proposed was a positive step forward. Jon Philpot asked those present to forward any further comments they may have direct to Ian Gwenlan.

**Action: All**

Nigel Scott-Dickerson raised the issue of the cost of minibuses. Ian suggested this would be looked at separately by Bill Leath.

**Action: Bill Leath**

Jon Philpot thanked Ian Gwenlan and Heather Mackintosh for coming to the meeting.

Lynda Jones arrived at 11.25am.

## **5. Parenting Strategy**

Lynda Jones explained that she was working for Outcomes UK as a consultant and had the task of pulling together a parenting strategy for the county. She said she was very pleased to be invited to the PCPG to talk to parents about the strategy.

Linda explained that the parenting strategy was being located within the Children & Young People's plan. She was looking at county and district priorities and was locating evidence based programmes. She also has links with the national academy for parents.

Linda said she had been asked to put together a job description and person specification for a Parenting Commissioner and this person had now been appointed: Dr Juliet Starbuck. Linda would be working in tandem with Dr Starbuck over the next two months, at which stage Linda's work would come to an end.

Linda explained the Council was taking a 'Think Family' approach and was proposing a 'team around the family'.

Linda was taking a 'bottom-up' approach and was asking people 'what works well in West Sussex?'. Also: 'where are the gaps?'. She said it was intended this last question referred to gaps in geographical provision as well as missing services. She was putting together an outline strategy to take out for consultation in the Autumn. Linda said she was looking at identifying maybe four key priorities and she intended to write these priorities in outcome terms.

Nigel Scott-Dickerson commented on the 'windscreen' diagram that Linda had circulated. He felt it was an example of 'top-downism'. He said that many things work well in the county but there was a lack of joining up. He felt the voluntary sector operated often in tier 0.5 (where Lynda's model included tiers one to four). He said there should be more focus on prevention and on the voluntary sector's role in providing information and activities and services that people enjoy going to. Nigel felt that there should be more of a focus in the parenting strategy on hard to reach groups.

Lynda suggested that getting information to hard to reach groups could be one of the underpinning principles of the strategy.

Lynda said she was organising workshops for parents in September and October. Kelly Willard offered to publicise these workshops through the Parents Forum newsletter.

**Action: Parents Forum**

There was a discussion about terms. Steve Large asked if reference could be made to 'carers' as well as parents. Lynda Jones agreed it might be useful to define what was meant by 'the family'.

Liz Robbins said the parenting strategy should dovetail well with the planned new local carers strategy (see AOB).

It was felt important to have good quality data underpinning the strategy as well as to engage with the Local Strategic Partnerships. The group discussed the value of having a 'one stop shop' or one portal for parents to access information and services.

Michelle Burdiss felt parents needed an allocated person to help them to navigate systems. She said the 'one stop shop' was a dream and in reality parents were pushed on to a lot of other agencies. Lyndsey Butterfield said she had found a family link

worker useful. Jon Philpott said the role Michelle was describing was most like that of the lead professional.

Nigel Scott-Dickerson said that many parents preferred to access voluntary sector services because they were suspicious of statutory services. Caroline Williams felt the voluntary sector had a key role to play in supporting parents and parenting.

Lynda asked about the PCPG's priorities for work around parenting. It was noted it would be useful for her to make contact with health colleagues, Aaron Gain and Linda McEntaggart.

**Action: Lynda Jones**

Jon Philpot explained he would be conducting a review of disability services. Referring to Lynda's 'windscreen' diagram he said he felt tier 4 was probably quite well covered but there were some problems with tiers 3 and 4.

Michelle Burdiss felt some parents did not contact social services because they thought they would not reach the thresholds for services.

Caroline Williams said that when a child was diagnosed with ADHD it might be apparent that the parent has ADHD too. Caroline said under the NICE guidelines services should be doing more for adults.

Kelly Willard asked Lynda what had happened to work done earlier in the year. Kelly said she had attended a meeting on the parenting strategy and had said she wanted to be involved in the work but had heard nothing further.

Lynda Jones confirmed she was 'not reinventing the wheel' and had access to all material that had previously been generated. She was now looking at the 'building blocks' of the strategy, for example top quality information to parents, and at what was needed to ensure West Sussex could get there.

Nigel Scott-Dickerson referred Lynda to the Crawley Parenting Forum, which he said was the only one still meeting. He felt there were a large number of themes and a variety of tricky scenarios facing parents and it would be difficult to distil out just a few objectives.

Lynda thanked the group for their comments and said she would be happy to receive further ideas, comments etc from individuals. Please email her: [lyndajones1220@aol.com](mailto:lyndajones1220@aol.com)

Jon Philpot thanked Lynda for her input and said he knew the PCPG would be watching with interest how the work developed.

## **6. Any Other Business**

Margaret Unwin explained she would be leaving the Parent Partnership Service on 21<sup>st</sup> August for a post in London working with GPs. Jon Philpot thanked Margaret for her work for the PCPG.

Liz Robbins said she was developing the new West Sussex carers' strategy, in line with the new national ten year carers' plan. There had been a county carers conference in May, at which 60% of attendees were carers. The conference had asked carers how they wanted their voice heard and carers had proposed a variety of means. Liz said 12 or 14 carers had put their names down to be consulted during the development of the West Sussex strategy and she was keen to have more parent-carers involved. She was planning to consult with carers through Carer Support Services, the Primary Care Trust, the County Council and hopefully the Parents Forum. Members have said they want to look at the strategy. Liz is hoping to produce a draft strategy by September, for consultation during October, to be ready to go in early December.

Kelly Willard asked for the information on the carers strategy consultation to be sent to her.

**Action: Liz Robbins**

Nigel Scott-Dickerson asked about young carers and Liz Robbins said young carers were involved.

Kelly Willard thanked Margaret Unwin for her work for parents and wished her well.

Jon Philpot said he had been asked to lead a disability review across children and adults services. Coincidentally health was also doing a review of child disability services and it made sense to link the two reviews. Jon said he would be setting up a project team to enable him to steer the review. In light of this Jon's SEN responsibilities would pass to a new post that was being put in place: Principal Adviser, SEN. Jon said interviews had taken place for the new post and retired head, Rick Turney, had been appointed, who would take up post in January 2010.

## **7. Date and Time of Next Meeting**

The next meeting will be:

Wednesday 21<sup>st</sup> October

In the Conservatory Room, Brinsbury College

From 10.30am to 1.00pm (Lunch from 12.30pm)

Margaret to circulate a list of provisional dates for 2010.

**Action: Margaret Unwin/Gemma North**

#### **8. Items for Next Meeting**

- Update on Transport
- Update on Parenting Strategy
- Carers Strategy (substantive item)
- CAMHS
- PCT update – Aaron Gain

The meeting closed at 12.30pm.