

West Sussex County Council and Partner Organisations

Parent Carers Planning Group

Notes of the meeting held on 22nd April 2009
At 10.30am at Brinsbury College

Present:

Sue Aldred	-	Manager, Camelia Botnar Childrens Centre
Jenni Herrett	-	Kangaroos
Bernadette Daly	-	MENCAP and Wellspring
Jon Philpot	-	Principal Manager, Special Needs and Disability
Lindsey Butterfield	-	Parent/West Sussex Parents Forum
Debbie Buckwell	-	Service Manager, Child Disability Teams
Sue Berry	-	Connexions
Steve Large	-	Senior Carers Support Worker
Michelle Burdis	-	Mid Sussex Family Support Group
Nigel Scott-Dickeson	-	Springboard Project
Fiona Mackison	-	West Sussex Primary Care Trust
Margaret Unwin	-	Parent Partnership Officer, Parent Partnership Service

Attending:

Jane Lewison-White	-	Note taker
Judy Crocombe	-	Aiming High Development Officer
Lynda Bell	-	Manager, Child Disability Team South West

Apologies:

Ruth Stewart	-	PACSO
Kelly Willard	-	Chair, West Sussex Parents Forum
Kim Paul	-	Vice Chair, West Sussex Parents Forum
Valerie Evans	-	Office Manager for PACSO
Councillor Robert Dunn (Chair)	-	Deputy Cabinet Member
Carole Aspden	-	Principal Youth Officer
Ranti Fallowfield		
Ruth Stewart		
Colin McCabe		
Elizabeth Squire		
Mike Branson		
Catherine Biggs		
Julie Birch		
Jan & Craig		
Jane Barker		
Valerie Evans		

1. Welcome, Introductions and Apologies

Jon Philpot explained that he would be chairing the meeting in place of Robert Dunn and welcomed everyone present. The group then introduced themselves.

2. Minutes of 28th January 2009 and Matters arising from the Minutes

Aiming High for Disabled Children – Update from Debbie Buckwell and Judy Crocombe

The recent Aiming High Stakeholder Event had been a success with an attendance of 72. Judith Cousin our consultant took everyone through the first steps of the commissioning process.

Judy Crocombe is new to post as the Aiming High Development Officer and the Assistant Aiming High Development Officer has been recruited to begin soon.

There are two Fun Days planned for 10th May 2009 at Arun Leisure Centre and 14th June 2009 at Broadbridge Heath Leisure Centre. There are 75 places available for 10th May and so far only 15 have been booked.

Action: – Gemma North will circulate flyer to help promote the day.

Clare Brittain has been in touch with some groups and will revisit. The Workforce development is an ongoing huge piece of work and there is a need to recruit a person to assist. An Aiming High Information Sub-Group is in the process of being set up.

Families in receipt of middle and high rate DVLA, which is 3,700 children fit the criteria for Aiming High monies.

Ann Bowman has agreed to come and do a presentation regarding the Icount Card – date to be confirmed.

Parent Partnership Information Day, The Hawth, Crawley

Margaret Unwin reported that there has been a good uptake for the day, which was about ASC.

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Action: - Jon Philpot will speak with Michelle Burdis direct regarding out of school learning.

3. Feedback from Parents Forum on Transport Meeting – Lindsey Butterfield

Lindsey Butterfield explained that she was unable to provide any results from the day as reports need to be considered, but did feel the day was positive. This will be discussed at the next Childrens Trust Meeting.

Lindsey read out the main recommendations from the Transport Report that the Parents' Forum produced, which include:

1. Special Education Needs transport charter to be set up.
2. Communication with parents – to include parents.
3. Escort communications – escorts to provide mobile number.
4. Compulsory training – required.
5. Provide flexibility around transport.
6. Taxi passports – to be used.
7. Hand control of school transport to Schools.
8. Better communications between parents and representatives.

The group then discussed the issues around transport and Jon Philpot stated that the Education & Schools Cabinet member had said he wanted a taskforce to examine this issue.

Lindsey Butterfield was pleased to announce that the West Sussex Parents Forum now has its own website:

<http://www.westsussexparentsforum.co.uk/>

Lindsey went on to explain that they distributed a mailshot of 3,000 letters and have had a fantastic response with a lot of parents wishing to get involved. The news letter can be found on the website.

4. ADHD National Institute for Clinical Excellence (NICE) Guidelines – Fiona Mackison

Across West Sussex children who are believed to have ADHD are referred to CAMHS or Child Development Centres – we need to look at this. Advice to families is inconsistent and management of the disorder can take on a variety of forms, e.g. medication, behaviour management programmes, advice to schools and preschool settings. The West Sussex County Council behaviour support team can provide support and advice to schools at their request.

Currently, PCTs and CYPs do not meet all priorities from the NICE guidelines at present. Organisations are aware of this and need to form a working group to address implications from this guidance.

A meeting is planned to include paediatricians across the county to discuss the issues around ADHD, which we are nowhere near getting right and need to liaise with CAMHS.

Lindsey Butterfield explained that her son has ADHD and there are issues around never seeing the same CAMHS consultant twice, which means having to constantly repeat information.

Fiona Mackison explained the key priorities are being looked at and that there should be specialist ADHD teams – a lot of work to be done around this. At the moment Health Visitors are in contact with mental health people – but there is no training programme in place. Teachers need training around ADHD too.

The group discussed issues around ADHD and agreed that the approach needs to be holistic.

Bernie Daly stated that Sally Bundy has undertaken National work around working with hyperactivity.

Lindsey Butterfield stated that The Eagle Clinic have a Doctor who specialises in ADHD who doesn't use medication.

5. Play Strategy (Carole Aspden)

Carole Aspden sent her apologies and Margaret Unwin tabled an update report for the group to peruse.

There will be 22 play spaces available over the next two years. Grants will be allocated to organisations who can identify the need. All schemes must be fully accessible to all, inclusive of young children and young people with special needs, but also in relation to differing cultures and known social barriers.

It was recognised that this is only open to new schemes and not existing ones and that funding is only released at the end and with a cost of around £50,000 per scheme, this could be difficult for voluntary organisations to fund.

22nd May is the closing date for submitting applications for anyone wishing to apply.

Nigel Scott-Dickeson stated there is a need to check recognition for disabled children is included and also range and types.

Action: - Margaret Unwin to liaise with Carl Burton to ask how it was envisaged disabled children's needs would be considered as part of the Play Strategy (see attached update).

6. Any other business

Booklets

Bernie Daly shared that a Resource Booklet is currently in the process of being compiled to cover a whole range of activities and organisations. This will be posted on ICIS website with a link from Well Spring, plus hard copies available once the final draft is completed.

Bernie also stated that last year work had started on a Transition Booklet which is planned to go on a data set.

Debbie Buckwell commented that Mike S Smith is working with Kelly Willard and Lindsey Butterfield from the West Sussex Parents Forum looking at information around transition.

Bernie concluded that there are plans for a Health Booklet and she has asked Helen Neve for information and plans to discuss this with Fiona Mackison.

Margaret Unwin stated that the Where do I Go From Here? booklet has been updated and will go to publication after a final consultation with the Parents Forum.

Action: Sign up from Parents Forum - Lindsey Butterfield

Continence

Debbie Buckwell stated that work is moving ahead with an event at the Hawth shortly. Kim Paul and Kelly Willard have not yet heard from Sara Weech regarding pilots she was keen for them to be involved in.

Action: - Fiona Mackison under took to follow this up

Early Years Path Finder Event

Nigel Scott-Dickeson commented that the above event is on Monday and he will feed back to next PCPG.

Action: - Nigel Scott-Dickenson

Knowles Tooth Children Centre

Steve Large has hired the Knowles Tooth Children Centre in May and July. Already over subscribed, so looking for cancellations, but may look to the Carets Grant for more funding.

Steve commented that in partnership with Billingshurst Family Centre, there is a Friday afternoon drop in for parent carers and children to access activities. Will hopefully develop these sessions further if successful.

Transport for College

Sue Berry expressed how worried parents are regarding transport issues for young people who have made applications to college. Lynda Bell commented that parents had been contacting the child disability team as they are concerned as their children may not be able to access public transport.

Parents Support Group Meeting

Lindsey Butterfield stated that the next Sussex Autistic Society Parents Support Group Meeting will take place next Tuesday 28th April and the topic for discussion is "After Education". Special Needs advisor from Connexion will attend with David Cane from an Employment Agency who assist people with special needs. For the following meeting a representative from CAMHS plans to talk about medication.

Lindsey was pleased to announce that 90 parents are now on the mailing list for the group.

7. Date and Time of next Meeting:

Suggested Items

- Parent Support and Parenting Strategy – Lynda Jones from Outcomes UK

Work is starting on the co-ordination and development of a West Sussex wide approach to parenting and family support. There are 5 objectives:

1. Review of existing provision of parenting support across the Childrens Trust Partnerships.
 2. Review of existing draft strategy and develop a revised strategy for agreement by the Childrens Trust Partners.
 3. Ensure West Sussex is prepared and ready to take up the NAPP training places from September 2009.
 4. Develop and implement an engagement plan for parents to inform the Childrens and Young Peoples Plan 2010 – 2015.
 5. Make recommendations as to the requirements for a permanent Parenting Commissioner.
- CAMHS – Brian Baskerville
 - Play Strategy?
 - Transport update

**Wednesday 22nd July 2009
10.30 – 12.30 (followed by lunch)
The Conservatory, Brinsbury College**

**Then:
Wednesday 21st October 2009
10.30 – 12.30 (followed by lunch)
The Conservatory, Brinsbury College**

The meeting closed at 12 noon.