

**SOCIAL & CARING SERVICES, EDUCATION & THE ARTS AND THE  
NATIONAL HEALTH SERVICE**

**PARENT CARERS' PLANNING GROUP**

**Notes of Meeting held on Wednesday 28<sup>th</sup> April 2004, 10.30am at Pulborough Village  
Hall**

**Present:**

Margo McIntosh	Group Manager, Specialist Services (Children), S & CS
Jon Philpot	Assistant Group Manager, Child Disability, S & CS
Pat Arculus (Chair)	County Councillor and Policy Adviser for S&CS and Children's Trust
Cathy Caine	Service Manager Child Disability- Social & Caring Services
Annabel Forbes	Community Fieldworker – Scope (Sussex)
Lindsay Haines	Parent Partnership Officer – West Sussex County Council
Jill Lovejoy	Strategic Partnership Manager for Children, S & CS
June Martin	Parent
Debbie Newson	Wellspring - West Sussex
Claire Prince	Early Years Inclusion Projects Officer
Nigel Scott-Dickeson	Springboard – Project Manager
Shelley Woodage	Strides
Louise Williamson	Horsham & Chanctonbury PCT
Angela Hole	Management Support Social and Caring Services – Notetaker

**Apologies:** Bernadette Daly (Committee Member, Mencap); Madaleine Owens (Service Manager, Arun, S & CS); Liz Catchpole (Acting Director for Public Health); Wendy Jones (Assistant Education Officer, WSCC); Caroline Gibbins (Early Years & Child Care Development); Julie Holt (Parent); Kim Paul (Parent)

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**1. Minutes and Matters Arising from last meeting held on 21.01.04**

**Learning & Skills Council & Transition**

It was clarified that the Learning & Skills Council operates across all children 16 – 19; no distinction for any particular group. It is the funding mechanism for most further education. However if a statement of special educational needs is maintained and the young person remains in a special school right through until 19, funding comes from LEA.

Post 16 planning begins for children with statements at the Year 9 annual review.

When a young person leaves an LEA maintained school post 16 the statement lapses or will cease to be maintained.

A statement is not required for Further Education College provision and all post 16 funding is via the Learning and Skills council.

A young person with special needs going to college will have a separate assessment by the Further Education College and provision is arranged according to need. Up to £19,000 is available per young person from the Learning and Skills Council to support their needs.

An individual claim has to be made for young people over the age of 19.

If the young person remains in a special school post 16 then the statement will be maintained.

The Connexions Service is involved from year 9 Annual Review and is available to assist parents and young people prepare for the move from school.

Learning Skills Council covers all of Sussex and is working with Pupil Services and Inclusion and Learning Support to try and identify whether young people with particular needs are able to access college placements locally & to identify better services - work in hand to identify gaps. A number of students in residential provision at very high cost. LSC wants to bring provision back to the local community where possible.

Parents felt that it was difficult to get support & information. It was noted that Springboard has a PA assigned to the Centre to help parents. There may be difficulties when a child is placed in a school not within county – an issue which Connexions Services goes to the annual review. If a child is coming back to West Sussex to live Connexions would have to work locally.

JP would welcome another representative from PCPG to join the Transitions Planning Group – names to be forwarded to JP. A lot of work to be done; also a need to consider what information parents and young people require. NSD noted that Springboard is to run a parents' focus group about a Parents' Information Pack.

### **SEN Forum**

The West Sussex Special Educational Needs Forum is facilitated by the Parent Partnership Service. It was confirmed that membership of the Forum is open to representatives of parent support networks in West Sussex. The representatives may be parents or paid employees.

It had previously been agreed that the Forum and the Parent Carer group would continue to function separately as timing and frequency of meetings as well as agenda and focus differ.

P.A indicated that she hoped to attend a future meeting of the SEN Forum.

The minutes of both meetings are now shared to increase understanding and opportunities for collaboration would be sought.

Any parent wishing to have opinion represented or questions raised at the SEN Forum would be welcome to contact the Parent Partnership Service.

### **2. 'DARING DOZEN' (Paper prepared by NSD and sent out to parents).**

This had followed a discussion at SEN Forum re. Speech and Language Therapy. Concern that despite a lot of work to identify problems little change has actually been achieved. JP said that a response has been drafted within SACS/Education. Some progress is better than others and it was felt that some national issues i.e. Tribunals would be difficult to change. Was this response sufficient or was there more we could do to take things forward?

MM advised that West Sussex has set up a pilot Children's Trust in an attempt to be more responsive and improve inter-agency working – currently a focus on prevention. Introduced Jillian Lovejoy - the new Strategic Partnership Manager – working to the commissioning manager within SACS, but a joint agency post. Jill will be working to the Children's Trust.

JL said a lot is already happening within West Sussex. The agencies are working together, but a need to consider how we can do more.

In response to a question on how the need for a statement would be minimised, LH said that meeting the needs of children was paramount. The aim is to support schools in building up their knowledge and the ability to meet the wider range of needs so that financial support and provision could be directed to the child rather than resources being tied up in a costly and time consuming paperwork exercise. The current method of needing to obtain a statement to provide additional resources is taking responsibility away from the school.

MM explained that the process to obtain a statement was very costly and that the money could be better used to provide resources and support for a child. There would still be a few children who would need to have a statutory assessment in order to fully determine the child's needs and make adequate provision.

The LEA has appointed an Education Inclusion Manager to work with the LEA and schools to promote access to inclusive schooling.

L.H. explained that only children with severe or complex special educational needs are eligible for a statement. Children who do not fit this criteria are supported through the resources available to schools for children with special educational needs.

There are times when parents, the LEA and schools do not agree, and then a parent may have the right of appeal to the SEN Tribunal or can access mediation, both of which services are independent of the LEA. This is usually around a decision relating to a statutory assessment or statement. As yet parents in West Sussex and other LEA's are more likely to pursue the Tribunal route rather than try mediation. A few parents are exercising the right to do both. Parents' right to access mediation is well-publicised at the key points requires within the SEN Code of Practice.

It was suggested that some of the reasons mediation was not being used could be because:

- ❖ Parents may feel nothing to be gained by speaking to the local authority.
- ❖ Mediation is not binding – a need to build up trust.
- ❖ The tribunal may be seen as giving parents power.
- ❖ Some hesitancy as Mediation still relatively new within SEN

However it was noted that mediation was much quicker than an appeal and that taking part in mediation in no way effected a parent's right of appeal.

It was felt that early opportunities to promote mediation should be encouraged.

### **3. EARLY YEARS**

*Presentation by Claire Prince, Projects Officer for Sure Start.*

A pre-school visiting educational service for children with additional support needs; comes under the umbrella of FIRST. Promotes inclusion and support within pre-school and childcare settings. Facilitates Inclusion through Reflection, Support and Training. Encourages practitioners to be reflective, to access training, to try strategies and ideas and to develop their practice.

- 1) **FIRST training sessions.** Held weekly at venues around the county, e.g libraries. Community based support. Training programme sent out to all registered pre-school providers and updated each term. The sessions are very popular and cover a wide range of topics; will hopefully be increased to meet the demand. A multi-agency input; a wide range of professionals giving ongoing professional support and advice (e.g. Educational Psychologists promoting positive behaviour; Speech and language therapists), sharing ideas and best practice sharing, to develop practice within settings. Also looking at traveller lifestyle; disability discrimination act. A workshop looking at transition for children transferring into school; brain gym; an 8 week quality play course which is very popular. A play plan written for a particular child in their setting. 187 practitioners throughout the county have attended the FIRST sessions each term so a lot of demand. The programme is now in its fourth year, and trying to develop the training programme

- 2) **FIRST Visiting team** – setting-based support. 4 area based teams. An inclusion advisor of qualified teacher status specialises in early years and advises the setting based SENCOs. Practitioners are encouraged to attend training sessions first to access support and advise - then talk with parents and share information and strategies tried. The parents' permission is required to go and visit in a setting. A referral form is completed over the telephone, to refer to the visiting team and then e-mailed to the advisor. A red folder contains the parents' permission slip. FIRST visiting team then visit – usually the Inclusion Advisor - sometimes already know the parents. Observing what is happening as a whole rather than the child in isolation. Follow up visits are also made, and all ideas are recorded. A Next Step form in 2 parts, giving a summary of what is working well and the next steps to try. This is agreed with the parents, and they are given a copy. Emphasis on supporting the child within the setting; looking at changes that the setting can make in practice. Sometimes the other children could benefit from the changes i.e. challenging behaviour – not necessarily just one child finding something hard. FIRST is looking at a social model - not a remit to assess or diagnose children or see them as a problem in isolation, but looking at the setting as a whole, and offers ideas of working within social model of inclusion so that all the children can be included.

Some examples of how it has made a difference:

- a) A day nursery; a 6 months old child; significant support needs; attended portage quality play course. A range of multi-sensory activities. Other babies also valued the experience. Weaning and feeding etc. They received some funding from FIRST for a hoist. Practitioners have adopted a positive approach. The child has benefited from the other children within the setting.
- b) A pre-school. Requested support from the team to write their education advice for a 3 year old's statementing process. Inclusion advisor met with the parents at the setting and wrote education advice for the statutory assessment. Pre-school were praised for the quality of the report etc. Helped to raise the status of the Centre and increase their confidence.
- c) Pre-school wanted a child to have red folder to access initial support for transition into school. Discussed some of the changes made for other children. Felt the strategies would work well. Felt previous visits had given them confidence to change their practice to include other children e.g to change their snack time; develop the use of outdoor area; produce a visual time table. Good early years practice is inclusive and will benefit a number of other children too. Staff all shared a very positive approach and wanted to include all children; willing to change and try different ideas.

Trying to develop FIRST and the programme. Commencing autumn term, an extension to the existing training programme, to explore some of the issues in depth; also to see if FIRST sessions can be accredited, working with ACR. Hoping to develop links with other agencies e.g Health, and involving the Joint Access team. How to extend from 0-3s in terms of training and support from the visiting team e.g. nurseries and children cared for by child minders. Also to develop FIRST for out of school clubs. Some support from the Behaviour support team, and some training sessions will be offered, working alongside Educational psychologists. They will be made aware of any child who has received support from the FIRST Visiting team (subject to the parents permission) so that transition into school can be smooth and work better for children and their families. Also need permission from the Learning Support team, who have regular meetings with the schools.

In discussion the following points emerged:-

- The Visiting Team can meet the current need - sometimes need to wait a couple of weeks but can generally respond fairly quickly.

- Pre-school settings receive termly updates. Several access the training sessions. Quality mentors visit settings each term, and they can access support from the FIRST Visiting team.
- An arrangement with other local authorities for children living on the border or parents working in a different county but living in West Sussex and attend pre-school out of county. If a child is funded within West Sussex, the Inclusion Advisor would support in the setting. If not receiving funding, they are supported from the area SENCO of their local authority. Regional meetings are held with the other Inclusion advisors to make sure that the links are going well.
- At present 2 children's centres (Crawley and Littlehampton) built around existing Sure Start programmes. A One-stop shop for parents; also multi-agency input from a range of professionals linked to the Children's centres. A quality advisor for each of the Children's Centres. A Children's Centre Strategy Manager recently appointed to oversee the work and ensure that Nursery provision and other agencies have support and run parents groups (health visitors; paediatricians; speech and language therapists) - all under the one umbrella, but very early stages of being launched.
- Staff cannot visit without the parents' permission. Sessions are about working with parents and developing good relationships with them. Build up relationships to work with the setting and ease some of the difficulties. Inclusion advisors cannot visit a setting for a FIRST visiting team visit without the parents' permission. Work within the setting to develop their practice but not just for a particular child without the parents' permission. A lot of work on developing relationships with parents. Also trying to encourage settings to be proactive in establishing a good relationship with the parent.
- Some funding difficulties at Crawley Opportunity Playgroup and at Horsham. Some specialist playgroups require more staff than the regularly funded, and rely on fund-raising and charity status. They can apply for Inclusion funding to help with increasing their daily rota, and access funding through the FIRST visiting team if they make a referral for children. Otherwise they are run in the same way as other voluntary playgroups. Crawley and Littlehampton are supported through their identified wards.
- Some duplication when Homestart, Surestart and independent and voluntary groups were set up. Also duplication with some of the government schemes. Funding requests are not small. It is difficult to decide which to fund, and better to invest in one service across the county. A financial envelope for funding organisations, and a need over the next year for some integration to ensure no duplication; also to look at areas of deprivation in terms of funding. If more money put into some wards than others it can be difficult and divisive, so a need to be clear about what services we are putting in, and to develop services that parents actually want, rather than something that people don't access.
- Early Years team and transition to school – a Pre-school Panel for children with special needs; overlaps requirements for the health service; a process for children coming through from Health with a problem if a parent does not give permission. Unless the threshold for child protection has been crossed you cannot operate without the parent's consent to a referral being made.
- A complex situation re. a young person attending Chailey Nursery and problems with transport i.e. who should pay for it. Involvement from 3 different agencies and parents stuck in the middle. Also happens with transition i.e. when a parent wants to get a child transferred from an early year setting into the first year of school and there are educational needs, special needs, disability etc., so a need for a clear transition pattern. Acknowledged that the responsibility for transport is a big issue across the whole range, including for adults. Each case needs to be looked at individually, depending on the circumstances of the particular child. A need for joint commissioning budgets (SACS, Health and Education) then look at the needs and provide the service. The Children's Children's Multi-agency Support Panel meets monthly to consider applications for joint funding that need to be resolved between the 3 agencies.
- LEA Support Team looking at how transition from primary into secondary can be facilitated. A need for different protocols for different age ranges as there are educational issues from primary into secondary. Noted that generally the main transitions issues for the younger age groups are with Education. Proposed that

Education should look at this issue and liaise with the other agencies. SACS to take the lead on transitions to adulthood and Education to take the lead on the other transitions.

#### **4. ANY OTHER BUSINESS**

A. Joan Martin spoke on behalf of Kim Paul as unable to attend.

- 1) **Schools accessibility.** 2 disabled children, both included in mainstream education. Had chosen a particular school due to certain criteria she wanted for her child; permission refused due to son being in a wheelchair.
- 2) **Education transport.** Difficult for many parents. Children having to spend a long time on the school bus, particularly autistic children.
- 3) **Direct Payment Scheme:** has taken part in the pilot scheme; found it a very positive move for SACS to have implemented; would like them to consider expanding the scheme in due course when they feel able to do so; would be beneficial for a lot of parents.
- 4) **Carers Liaison Project:** Noted that no representation on PCPG from CLP. Invited to attend as a visitor; could be beneficial for representation from one group to disseminate information down to the others. Noted that PCPG feeds back to the Carers Planning Group and they receive a copy of the minutes. **Agreed:** JP to take forward.
- 5) **Wheelchair service:** Started process of applying for Disabled Facilities Grant 2 years ago. Issues about **access and equipment**; whether it would be a useful topic for the group to discuss; a senior OT; wheelchair service.

**Agreed:** **Access & equipment** topic for next meeting. Invite Hilary Vaughan from LEA re access. **Community Equipment Service** - Senior OT or Team Leader to be invited. **Transport** – invited Bill Leath from Transport Section + feedback from Springboard.

B. **Chailey Heritage** – a Yahoo group to exchange ideas on the internet. Some quotes from other people were brought to the meeting's attention

C. Information from Louise Williamson, Horsham & Chanctonbury PCT: A Fun Day during **Carers Week on 16<sup>th</sup> June 10-7pm (venue Holbrook Club)** to promote Healthy Living and looking after yourself for Carers. Being arranged by the Carers Association, PCT, Horsham District Council and SACS. Various leisure activities including archery, curling, tennis, yoga, head massage, stress management. Also some advice sessions. Please contact Louise for further information. Some fliers made available. Also some leaflets re. starting a pre-school for children with additional needs for parents and carers.

**Date of Next Meeting date: 14<sup>th</sup> July 2004, 10.30 a.m. Pulborough Village Hall**