

Minutes of PaCC Meeting  
Held On  
Wednesday, 28 September, 2011

At  
Conference Room, Community Base, Queens Road

Present: Sam, Nicola, Sharon, Martin, Gillian, Doreen, Sarah, Juliette, Emma, Jill, Debbie,  
Apologies: Amanda, Ruby, Gilli

1. Welcome and Apologies

With the gap left by Chrysi leaving the group we welcomed Emma Parker. Emma has a child with Downs Syndrome and helps to represent the younger age group of children. Sadly, we had to say goodbye to Gillian, Debbie thanked Gillian for her hard work, right from the start of PaCC, and her contribution over the years.

2. Accuracy of Minutes and Matters Arising from the last meeting

Amanda set up the **Calendar Sub Group**. (Details to follow later)

We still have 13k allocated to spend. Neither Rachel nor Debbie had received any ideas as to how to spend the money. Rachel would welcome emails re the Budget. Martin mentioned if we had no ideas what would happen to the money. Debbie said that Amaze will use the money.

**Training:** Carrie had led two days of training for parent reps last year which some of the group had attended. It was agreed that many from the steering group would benefit from doing the training again along with others who had not been trained. Training was welcomed by everyone. We also need to include parents who may be reps in the future.

**Action: Debbie to ask Carrie for a repeat of the training she carried out two years ago.**

**Therapies:** More therapies. Debbie filled in about how the therapies are proceeding. Gillian pointed out that the therapy review needs to be revisited. Debbie said that therapies will be focused on in the health project next year.

**Bulletin:** Not had chance to get the E-Bulletin done over the summer. Debbie is meeting Amanda today after the meeting to start the E-Bulletin to wider members.

**Next project - Health.** Debbie will bring us up to speed later in the meeting.

**Partnership Charter** will be launched in November. An email version of the Partnership Charter is available on the Amaze website. Parent ambassadors have assessed Extra Time, Drove Road, OT Service as part of the pilot. 5 more services are to be assessed - Link Plus, Tudor House, Social Work, Physiotherapy and SALT. 4 more parent assessors will be trained up so there will be 10 in all. It had been two years in coming to fruition and put into action. Juliette asked if parents were matched with settings. Debbie said no it was not appropriate to send parents who actively used the service. Parents who had not used the service would be sent to assess the service. Martin explained further. Managers and Parents work together in partnership to help change the service.

After assessment each service gets a score and given a certificate. 3 stars indicates they are doing well. 1 Star indicates they are not engaging with parents. This would be for all to see on the Amaze website. James Doogan (Strategic lead for Children and Families) has been presented with the charter and is keen for it to be rolled out to all Children & Families Services. Eventually mainstream and disability schools will hopefully be included, but not at this stage. James Doogan has a 'Task Force' working on this.

**Action: Debbie will send revised score sheet to the steering group.**

Marian: **Extra Time** need more parents as trustees. No parents are coming forward. The newsletter is being used to reach parents to ask others about becoming a trustee. Point was made that if the service is running well parents tend not to get involved.

**Academies:** Not on the agenda. Varndean is not an Academy. Sarah informed us of the Anti Academy Group.

Rachel has access to the Wave login via a password. Rachel can forward the Wave or School Bulletin on to the group. Anyone can come into the Amaze office to log on with Rachel. Concerns have been raised 'Why is it so difficult?' and 'Where's the transparency?'. Gillian said we need to find out why we cannot access this anymore as there is a lot of information for parents on the bulletin.

**Action: Martin to ask Governing Board at Blatchington Mill. Debbie will ask Jo Lyons why there is no access to the Wave/School Bulletin and feedback at next meeting.**

**Support for Parent Forums** has been allocated by Department of Education to Contact a Family who have been given the responsibility of administering the £10K. This is good news for forums as they want to engage with us and support us in the work we do.

Debbie said that Rita Wiseman is carrying out a phone questionnaire by 4.15pm today.

**Action:-Leave message with any questions.**

3. **Calendar Group:** Sharon, Amanda, Susmitha, Nicky agreed subject of families – to include extended family, carers, grand parents thus thinking about the wider concept of family.

It was decided to include new families who have not been in before.

**Action:-Sam and Marian to photograph their sons.**

Debbie said quotes to match the pictures would be undertaken by Amanda who would interview the parent for a quote. The back page will depict services used by our families. ?PaCC photo on the back.

**Action: Photos to be emailed asap to Amanda and must be in High Resolution by 12 October celebrating diversity with families.**

4. **Information Fair 10 November, 2011, Hove Town Hall.** Copies were available of letters that were sent out to key people. Amaze AGM will launch the PaCC Event. 40 Stall holders have been invited. Juliette asked about info for stalls. E-mail Ros at Amaze for list of attendees.

The topic is Health and Wellbeing. Parents are invited from 9.30am.

There will be 3 workshops for parents to attend:-

10:00am-12:00pm The SALT service will be running a workshop on Communication & Visual Strategies. The OT's (not confirmed) will be running a workshop on developing co-ordination.

12:00pm-2:00pm LINKS, Claire Stevens, will be running 'Getting the most out of appointments with your GP.'

Amaze AGM 1.45-2pm.

12.15 - 1.15pm Parent Focus Group on communication. Parents have been invited to come along – some of whom are steering group members to talk about their experiences of communication with health care professionals.

Dr. Nalletamby and Dr. Tim Ojo from Sussex Partnership Trust have been invited to listen to parents. This will inform the PaCC event on 08 February at Brighthelm Centre.

**5. Reps Items: Therapy Quality and Standards - Ruby.** She needs to know what kind of training parents want to receive from the therapists. There is still concern that we do not have enough information. Is there a way of monitoring advice given by therapists to all families so that treatment programmes can be carried on at home.

Time is scarce for therapists so could parents follow T.A's training programmes. (Brighton & Hove Training, Makaton Training, Core Skills Training.)

**Action:-Debbie to look into Core Skills Training for Parents.**

It was pointed out that professionals are wary of training alongside parents. However, there is a lot of training to dip into, for instance, training with your child's TA. This may be good for some parents, but not for others. Training needs to be child focused and specific to the child's needs.

Action: **Debbie to feedback to Ruby.**

Training on inset days or twilight hours would not suit parents. The information on the Wave was useful. Sarah has been to Teacher Training. Agreed that there needs to be consistency in the same school.

**Communication and Consultation Meeting – Gillian.** Group is chaired by Miranda Wareham, with a membership of 10 each time. They want to hear feedback from parents re meaningful communication and consultation regarding all aspects of communication. We will use the e- Bulletin to access parent's experiences of this. The membership of the group does not have mainstream representation and is therefore not fed back to mainstream schools. PaCC member to take over from Gillian needs to be a mainstream parent. Emma offered to replace Gillian and upon a vote this was agreed.

My Hospital Passport. Copies were circulated to the group. The plan is to roll this out to Young People going to hospital. Louise Loadsmann is the nurse to contact if you want one. The passport is being used by adults in hospital. Parents were not consulted regarding the format. Martin recognised Passport. It would be useful to look at standardising across other agencies i.e Police? Discussion about who the passport should go to. PaCC cannot influence changes. Gillian to take back to Community Group all our ideas discussed recognising that children are vulnerable.

Debbie is supposed to be informed about places available for training, if places available. Debbie has never been informed yet.

**CAMHS - Doreen and Gillian.** Sam Beal feedback on bullying. Years 7-11 fill in a Health and Well being survey. We questioned the accuracy of the results. Bullying motivated specifically by special

needs is not included in survey and so Gillian asked for it to be included in the future. There was concern over the increase in the numbers and severity of young people who are self harming particularly at primary school age.

Autistic Spectrum Tier 2 and 3. There have been problems with CAMHS across the board. CYPOSC have asked to take forward an independent review by services users. Debbie, Ros, Rachel have a meeting with CYPOSC next week to discuss this. Alison Nuttal must report back to CYPOSC once the review has taken place. The PaCC event in February will be looking at CAMHS as a whole not just from an Autistic Spectrum perspective. Doreen gave out the leaflet What Can I Do for young people.

**LDPB – Juliette.** Housing 3yr plan on accommodation aims to address gaps in the service. There is not enough of the right information re housing getting to parents.

Big health check survey was carried out. There were concerns over the new Mental Capacity Act and what happens after 16+. We identified a training need for Amaze.

Funding - Amaze had 2 bids successful from the LDDF. They will be training up new volunteers to support parents of young people at the Cedar Centre and Down's Park who do not receive any transition help from Connexions.

**Education Update:** 1 year on the PaCC education report has been presented at CYOSPC. Brighton & Hove is part of the successful SE7 bid for pathfinder status to pilot the changes suggested in the SEN Green Paper. The Local Authorities need to meet to discuss issues. Rachel and Debbie have concerns because the bid was led by East Sussex who are very bad at involving parents. The Pathfinders- have to involve parents and have to implement various parts of the green paper. The SEN change board set out in the Green paper stipulates that 2 parents have to be part of the group – volunteers are Nicola, Martin and Sam.

**Health PaCC Event February:** Topics agreed so far are CAMHS and Therapies (re-visit, changes and cuts)

**Action: email Debbie with anymore topics.** Meeting in November will concentrate on Health Event.

**AOB: Communication with the wider membership.** Debbie failed to send out communications as she was so busy.

**Action: Debbie to ask Amanda if she can be responsible for the e-bulletin**

There needs to be a system for including all points raised at boards on the publications so that the wider membership can be kept up to date with everything that is discussed.

**Action: Feedback forms to be included on the internet with the minutes. Clear links to this to be included in the bulletin.**

Think about a new chair as Amanda will be leaving in April. The post is paid for 3hours per week, term time.

**Action: any parent interested in becoming the next chair to contact Debbie for a chat.**

Martin raised the point that we need to be mindful as seeing to be in agreement when invited to meetings. The word 'consulted' can be used in lots of different ways, and as a group we need to be

aware. Carrie's training to include how the group can deal with the use of 'consulted' at meetings. There is a PaCC Behaviour Agreement within meetings.

**Nominations needed for Awards** this can be anyone in Health, Education, Social Care or Voluntary Sector.

Replacement for Gilliam at CAMHS, Jill put forward, and this was agreed. Debbie thanked Gillian once again.

Due to a fire alarm the meeting ended at 12.50 in the garden grounds.

**NEXT MEETING IS ON THE 29<sup>TH</sup> NOVEMBER AT 10:00AM TILL 12:30PM IN THE COMMUNITY BASE BASEMENT ROOM NEXT TO THE CAROUSEL OFFICE**