

**AHDC Parent Reference Group
Old Treasury Building
12pm- 2pm**

Present: CM, EB, JD, HL, TB-L, VH, TW, AP, KM, CP, TY, JT, SL, AM, SB, GO, IB, HB, AP.

Apologies: PB, GA, EG, SC, JC, LJ, JM-C.

1. Welcomes and introductions

2. Notes from last meeting

- PSAs taking over Key Worker role in Single Point of Contact. This is still in discussion. Need to differentiate between the Lead Professional Role and the Key Worker role.
- Eligibility criteria for Short Breaks. JG-S will keep the group informed. The Draft Regulations for Short Breaks are on the PPP website.
- Please check the PPP website for updates and news- www.parentref.org.uk
- There is no news on the Early Years Childcare Grant.
- The Phase 3 AHDC form needs to be submitted by Friday, parents and professionals are needed to sign up to it. Needs to be proven that it is multi agency.
- ASD conference- TBL has spoken to CL, the next meeting is the 7th May, TBL will discuss it then.

3. Tracey Yarde- Contenance Service views

- TY is writing a report for HM on the Contenance Service. The report needs to be done by the 25th May; TY does not know if it will be published, or when.
- The Pathway procedure was explained to the group.
- If you need a bed alarm then you have to be referred back to a GP, this is an issue.
- Supplies from the Contenance clinic are fragmented. The supplies come through the Primary Care Trust but the Contenance Service sits within the Plymouth Hospitals Trust. It is a very complicated process, and is very difficult for parents using the service.
- **Supply-** contracts change too often, and no information is disseminated about when it is changing.
- The change over to Tena was a 'messy' process. Consistency is needed for families.
- When new nappies are needed at the end of the month parents have to remember to phone and request the new supply. This should not be the parent's responsibility. Also when ringing there is always a queue.
- **Sizing-** If you are delivered the wrong size, the delivery person cannot take it back with them, they can only deliver.
- Changing a child's nappy size is a long process. Also parents have been delivered nappies which say that they are the same size but fit differently on the child.

- The daily limit for a child's nappies is four. Some children require more than four a day, this should be needs based. There is also no third party supply, so if Tena do not meet the need then families have to pay for their own.
- The nappies are also causing rashes for some children and are not absorbent enough.
- The previous contract with Huggies was more successful.
- There is no evaluation process. Parents have never been asked their opinion.
- Clarification is needed around the role of the school nurse and nappies. Are they allowed to measure children for nappies?
- A diagram of the referral process is needed.
- **Action:** TY to arrange a meeting for parents re the Continence Service.
- **Action:** CM and JD will ask their groups to put forward any issues.
- TY is unsure whether the report will be published but it will be put on to the PPP website if it is.
- **Action:** TY will put all of the issues raised together and email them to PPP. PPP will then email these to the PRG. It will also go on the website.
- An evaluation/feedback group needs to continue beyond the report.
- Children know that the nappies are not fit for purpose, they can feel stressed and it affects their self esteem.
- **Action:** TY will speak to HM about the report coming back to the group.
- 'Fledglings' provide swim pants for older children. **Action:** Fledglings to be added to the PPP website.

4. Phase Three Grant Application

- Sustainability for the things that this grant have achieved is very important. PPP would eventually like Health and the LA to provide money for parent participation also.
- The Parent and Family Forum is for all parents including parents of children with SEN and disabilities. Another Parent and Family Forum will be held in November 2010 around Aiming High.
- Parent Participation training is continuing at Courtlands School on the 18th May. It is a two day course and can take up to 15 parents. This information has been given to all Special School PSAs.
- JC and EG will look into PPP delivering their own parent participation training for parents, it will focus on Plymouth. This will also enable the training to run frequently. The grant covers travel costs.
- Parents will be paid £7 an hour to attend three or more meetings.
- A text service is now up and running, if you would like to be reminded about meetings please give PPP your mobile phone number.
- Teleconferencing is up and running, SG trialled this at the last meeting. GA and EB have also trialled it. Teleconferencing also gives parents the chance to attend meetings anonymously. PPP have purchased web cams for parents to borrow.
- JT passed around the Phase Three Parent Participation Aiming High Grant Application for parents to sign.

5. Parent Representatives

- There has been a request for parents of children with ASD to sit on an evaluation group. The group will be looking at bids for summer holiday play schemes and whether they are appropriate for children with ASD.
- The group will be meeting on 7th May 9.30am- 12.00pm at Douglass House.
- Where is the money coming from?
- It would be helpful if information for children's schemes and events went out early before the holidays.

6. Wheelchair Users Group

- GA raised the issue that the Wheelchair Users group were not consulted properly on eligibility criteria.
- The group is held at 9.30am at Mount Gould Hospital.
- There is currently a two year waiting list for wheelchairs.
- **Action:** JT will write to HM on the PRG's behalf.
- **Action:** JD to speak to her parent groups and gain any feedback on Wheelchair service.

7. AOB

- Information about the Carers Forum has been sent out. It is being run by the PCC and Zebra collective. The forum is to replace the previous Carers Forum which dissolved.
- The current Carers Strategy was developed adult strategies. A Young Carers strategy is currently being developed. This will be for all young carers.
- Lamb Enquiry- Improving Parental Confidence in SEN System (Implementation Plan). This document lays out what the DCSF have done so far and what will be done in the future. It is on the PPP website.

8. Date of next meeting

- Wednesday 26th May