

## **Parent Reference Group Meeting**

**Wednesday 30<sup>th</sup> September**

**6:00pm- 7:30pm**

**Parent Partnership Offices  
The Old Treasury, Catherine Street**

**1. Present:** GA, BB, SB, IB, PB, MB, TBL, JC, WD, JGS, ML, HL, SL, JT.  
**Apologies:** CM, AF, LM, ED

### **2. Welcome and Introductions**

- New members were welcomed to the group. Everyone introduced themselves.

### **3. Short Breaks- JGS.**

- JGS introduced her role to the group, in place of HM, to talk about the results of an Occupational Therapy questionnaire that was sent out to 149 families. The criteria for choosing the families are not known.
- The results were not very user friendly so JGS explained the layout of the results to the group.
- Comments from parents were read, general view that parents need more information about what is available in Plymouth for their children.
- The group felt that the questionnaire was aimed at older children, hardly any children aged 0-5 were represented.
- JGS said that the Break into Autumn newsletter is due out Friday 2<sup>nd</sup> October. If a child uses any of the related services then they will be sent a link via email for the website. They cannot send out hard copies because it is over 30 pages long.
- JGS explained parent's comments website about what parents would like in terms of information. Childcare is a big issue, parents become employers which can be difficult. JGS is looking into how to improve this and make it easier for parents.
- JGS has begun work with the Youth Service on a project for 12-16 year olds at the Woodview campus, pan-disability (open to all disabilities.) The children will attend with one to one youth workers, who will either be paid by PICSS or direct payments.
- The group expressed concerns that parents may have to pay for the one to one workers out of their direct payments. Some parents don't actually have direct payments or know anything about them.
- The project cannot be advertised across the whole board because there are only 15 spaces at the moment. Once a group is established then it can be proved to the Youth Service that it is necessary. That would be when it can be rolled out across the city. They do not want to advertise widely because they do not want to raise expectations that cannot be filled.

- Question: If people have the money to pay for a one to one worker will they be prioritised?
- Answer: Definitely not. It is not being money or transport led.
- PICSS will be training the youth workers on working with disabilities.
- Only two other Local Authorities in the region are doing anything with their Youth Services.
- Four people are working on the project; JGS and three youth workers.

### 3. i.

#### • **Update on Small Grants.**

- The criteria for Small Grants were to increase the number of places/ services available in the long term for disabled children.
- Aiming High has to be used for services that parents do not have to be present for.
- A previous application which the group awarded £2,000 to has been given the extra money they asked for through funding from Health. JGS is monitoring it.
- Parents Again made an application for £500 for a coach for a day trip, the group approved it but the Short Breaks board decided to award them £295 because they had found a cheaper quote for a coach.
- Jump were so impressed with their session for disabled children that they have reduced the cost further and are looking at doing a day every holiday only for children with disabilities.
- There is a opportunity for parental involvement. Beckly currently supply a weekend and holiday support service which is under tender until the beginning of December. There is a evaluation and parent group for the tender application, made up of parents whose children will use the service. JGS will do a formal request to the parent reference group for five to six parents to get involved. Children are also being asked for their opinion.
  - Question: How do parents find out about all of the Small Grants that have been agreed?
  - Answer: They are all in the newsletter. The newsletters will also be sent to all PSAs. PPP can provide hard copies.

### 3.ii. Applications

#### • **Downham Parents.**

- The parents want to organise training to use Mackaton, a form of non verbal communication for children with disabilities.
- Question: Have the parents shopped around for a price?
- Answer: Need people who have actually been trained by Mackaton. The differences between other training and that done by Mackaton are shocking.
- Downham are committed to Mackaton, Sign Along is also used in Plymouth. Consistent and coherent signing is needed. One is a language, one is more of a communication system.
- Initially the training will only be for Downham parents. They hope to be able to include more parents eventually.
- With Mackaton once you have done the initial course you can then train other people.
- When the school use it they get positive results but then when the children go home their parents cannot communicate with them. It is a basic human right to be able to communicate with your child.
- Question: Would parents need further training after first course?

- Answer: No, but can go further if they want to. Rarely do parents need further training. The length of the course is suited to parents needs.
- Plymouth University do Mackaton training, two parents from the group attended and were very impressed.
- The group agreed that it would be scary to think what it would be like if Mackaton was taken away.
- There was concern that only twenty people may benefit, there should be statutory money for it. The issue should be taken forward to put pressure on the relevant organisations to make it statutory.
- **Down Syndrome Conference**
- A group for parents of children with Down's Syndrome want to hold a major conference for parents and professionals looking at the effects on families and children.
- People would be asked for a contribution- £50 for professionals and £20 for parents. It needs to be booked soon as they want to hold it in September 2010. They want a national speaker on education and how it affects the young person.
- The group had concerns around charging parents to attend a conference. 'Huge objection to charging parents'.
- JGS will send to JT. There is another meeting on the 21<sup>st</sup> of October so the group will look at a hard copy of the application then.
- JGS commented that it would be 'really worthwhile'.

#### 4. Information distribution

- JT handed out information re the Friends and Family Coffee morning which will be focussing on Direct Payments.
- There has been a request for parents to sit on the Woodview Executive Board. The facility is moving from 14 beds down to 6. Parents will not lose their night allocations, but it will be reorganised. The LA has been to the parents and asked for their concerns, one being that no parent was asked to be on the planning board. They need a parent who ideally would use the facility.
- This invitation should go out to all parents.
- **ACTION:** JT will send this invitation to all parents who access Woodview and ask if they would like to attend the Parent Reference Group.

#### 5. AHDC Parent Participation Grant & Web page

- JC handed out a round up of what the grant money is to be spent on.
- The Parent Participation training is booked and everyone is welcome to attend, it is free. Contact JC at Parent Partnership if interested in attending- 01752 258933. The training enables parents to have a voice and be able to use government regulations and policies when speaking to the Local Authority. Enables parents to communicate with services at every level and gives them confidence.
- Will childcare be provided? Parents can arrange childcare and then they will be reimbursed. The training is also during school hours to reduce problems.
- An Oasis group may be set up in Green Ark Children's Centre. PB will let the group know when she knows.
- BB- video conferencing. TU from the LA is instigating a trial which at first will be done internally. BB needs to put a business case forward and then it will go from there. BB will find out who cannot attend the next meeting and then will arrange to use it then.

- JC- parents professional fees/vouchers. JC has done lots of research, many organisations nationally are using different schemes but none of them guarantee that benefits will not be lost or that self assessment tax forms will not have to be done.
- If a parent is paid then it is their responsibility to tell the benefits office and to fill out self assessment tax form.
- It was decided to go ahead with payment. There was discussion around the rate of pay per hour for parents. Agreed on £7 an hour initially. Parents will have to attend two or more events before they will be paid. They will be paid from the time they leave home to the time they return. If PPP needs feedback etc then parents would also be paid. Parents can also be paid for reading time. Payment will be backdated until May 2009.
- It is uncertain whether the grant will be given again next year, the group needs to give feedback so that it can be proved that parent participation has increased.
- BB- Website. BB showed the group the new website. Navigated through to show the group how it will appear when it goes live. The group approved of the website. It will have a hit counter and will be advertised through JGS's newsletters etc.

**Next meeting:** Wednesday 21<sup>st</sup> October 10:00am- 12:00pm, Old Treasury Building, Catherine Street.