

**Parent Reference Group**  
**Wednesday 25<sup>th</sup> November 2009**  
**Old Treasury, Catherine Street**  
**6:00pm- 8:00pm**

**Present:** JC, SB, TBL, BB, JT, SL, GO, KM, EB (attended via video conferencing) SC

**Apologies:** CM, PB, HL, ML, CP

**1. Welcome and introductions**

- Everyone introduced themselves to the group. BB stated that we will be testing video conferencing in this meeting. The notes of this meeting will also go on the new Parent Reference Group website (anonymised) so that people can access the notes if they could not attend.

**2. Feedback from previous meeting/actions arising**

- No Limits- JT explained No Limits to the group. There have been issues around transport to and from this group. JT has spoken to the Youth Worker and fed back parent's comments. The flyer was also not very clear. JGS has said that no transport can be provided.
- Small Grants- JT explained Short Breaks grants to the group. TBL explained that she accessed the funding for a course at her school for parents of children with Autism and it was very successful.
- JT explained the application process. The applications come to the Parent Reference Group so that parents can have input and voice their opinions.
- Question: Do PSAs know? Yes. They have the application forms, which are very easy to fill in.
- You can apply for up to £5000.
- TBL has heard of a course for parents of mainstream children to spot signs of whether their child may be Autistic. Discussion followed over this.
- KM- it can be very difficult for parents whose children do not have visible disabilities or SEN. SC and KM both have ID cards which explain their children's behaviour.
- SB is thinking of asking parents at Downham if they would like one made for them.
- Special Needs Handbook- contains useful tips for parents of children with SEN. They are asking for parent's tried and tested tips to include.
- Request for parent to sit on Woodland's Executive board- a parent is now actively taking part in these meetings, along with KO.
- There has been a request for parents to join the Plymouth Disablement Services group. The next meeting is in January 10am-12pm. They need around 8-10 parents and young people to make the balance equal. It is a multi- disciplinary strategic meeting consisting of staff from PCT. HM chairs the group and it is for parents of children with wheelchairs or other forms of disabulatory aids.

### 3. Parent and Family Forum Update

- There was a very good turnout at the forum, which was focussed around SEN and disabilities. [www.parentref.org.uk](http://www.parentref.org.uk) was also launched at the forum and is now up and running.
- TBL felt it was more interesting than other forums she had been to.
- The display boards were very good.
- SC felt that if everything the services promised to do happen, then it will be brilliant, but she has low expectations.
- JT- feedback has been collated from the post its. There were none for parent participation and childcare.
- SC- it was good being able to confront professionals.
- JT- JS and HM can come to meetings on parents requests. Questions can be put to them. The purpose of the Reference group is to flag up issues, however not necessarily for individuals.
- The Incontinence Service- this service is not working at the moment. HM is looking into how to make the service better. The PSA at Mill Ford has collected feedback from parents re this service.
- The group discussed their frustration at how expensive nappies are and that you cannot get the sizes that you need.
- Why do children have to pay when the elderly get them free?
- SB will collate info from the whole of Downham.
- The answers from the post its will get fed back to the next forum and put on the website.
- JT read post-its that were gathered from the forum.
- KM noted that the forum ran very smoothly and was very well organised. Some of the professionals seemed uncomfortable; more questions were needed for them.
- Single Point of Contact- the Children's Integrated Disability Service have pooled money from all different services so that parents/carers do not have to contact so many different people, with the hope that there will eventually be a 'Single Point of Contact'. They are looking that this person being the Lead Professional from the CAF process.
- There are so many pathways into the system you cannot guarantee how a parent will get information about the services.
- There are some assumptions that parents know who to contact in the first place.
- SC- felt that a lot of parents at her children's schools are unaware of Plymouth Parent Partnership. She also felt that some parents are scared of PSAs because they think that information will be passed on to the school. Special School parents rely more on PSAs.
- KM- PSAs are doing a fantastic job; they are worth a lot more hours than they actually do.
- There is supposed to be a 'team around the child approach'. SC key worker at the moment is the school. This does not work.
- SB has trained 140 people around 'team around the child' and promotes the scheme..

- Single Point of Contact- a parent would be ideal for this role, with the relevant training. They have empathy and know how difficult it can be for parents. **ACTION:** JT will put forward this idea.
- An after hours service is needed for parent's peace of mind. Once you are in the system, the professionals should be chasing you, not the other way round.
- KM discussed his personal experience of statementing and changing his son's school.
- SC explained her experience of the statementing process and the fact that she got all of her information from other parents.
- KM- you need someone who is ahead or behind you. Parents swapping information is very powerful.
- The Disability Service is looking at communication, meetings are being held re this issue.
- Question: How do people find out about the P and FF? All PSAs are required to attend as part of their role. It is in their contracts. They must promote this to the parents in their school.
- Some parents do not come into school. The same parents seem to attend all of the meetings.
- Question: Is anyone in the city aware of the exact number of disabled children in Plymouth? No. There is the SPIN database but it is optional for parents to sign up to it. Social Care by law has to hold a database of children with disabilities. Three hundred people have signed up to it so far.
- The term disabled sits in the Disability Act. Arguments take place over this still. They are currently arguing in courts over what affects day to day life and so can be specified as a disability.
- The group felt that something is needed for all parents to sign on to. Some parents get overwhelmed by information; they need someone to say 'this is available'. It comes down to funding.
- Disability questionnaire- very long and complicated. Parents did actually make the questionnaire.
- Question: What does DAMP mean? Deficits in Attention, Motor control and Perception.
- There are issues around parents not being able to access information on the internet for example as they are not computer literate or do not own one. Parents want information from all different sources and get varying amounts. It is hard to please everyone.

#### **4. Parent participation conference**

- JC and GO attended the conference in Taunton and said it was really good.
- It was interesting to see how PPP matched or exceeded other services for parent participation.
- Cornwall Parent Partnership have set up payments to parents and the pilot is currently up and running. They use a points system where a certain amount of points are equal to gift vouchers. There are 35 active parents and £425 has been claimed so far, a high number of parents chose not to claim.

- It was suggested that a coffee morning for all Special Schools should be held on a quarterly basis. It would be a chance to meet new people and network. PSAs could ask their parents if they are interested. Parents do not like titles, has to remain laid back and parent led.
- There could be a capacity issue. However you do not need a lot of staff and the parents can run it themselves. Children can also bring their children along. GO will ask the PSAs to set up an invitation at their next Practice Development Session. It could be held at Courtlands.
- Coffee mornings are ideal because they are drop ins; you do not need an appointment, and they are a good way to meet people, it can be very isolating staying at home.
- KM mentioned a 'Carers Club' which is run by the Zone. They have a junior and senior group and it is free to attend. They run all sorts of fun and interesting activities. They also provide transport for the children. However there is currently a 5 month waiting list.
- Discussion over Break into Summer. There seems to be many provisions for over 5's, what about the younger age group? What about siblings?
- Hard copies of Break into... are not readily available as SF has no funding for printing. JT has raised this at the ??? meeting. JS and MG ensured that hard copies would be available. **ACTION:** JT to follow this up. PPP have printed them out before, but cannot afford to keep doing so.
- There was a suggestion that if parents are not computer literate they could speak to the Plymouth Adult and Community Learning Service (PACLS). However childcare needs to be provided and time is an issue.
- SC went to a coffee morning at a mainstream school and it was not well attended.
- Social Services have just started a 'Mobile Phone Buddies' scheme. JC has just been to a conference in Cardiff around Social Services peer mentoring by telephone. It starts in January for two days on a rotational basis.
- There is an issue around locations of conferences for parents. People want parents to attend, but locations such as London are unrealistic.
- On the 10<sup>th</sup> December Scott Hospital are holding a carol service 6-8pm. All are welcome.

## 5. Opportunities for parent participation

- Committee of services for Integrated Disability Services would like parents to be involved in a policy and performance meeting on the 14<sup>th</sup> December. It is from 9.30am- 11am. They would like 10-15 parents to overwhelm the professionals. Contracts are going out to tender and people are not necessarily choosing the right contracts.
- Training is currently ongoing for parent participation, which helps parents to make sure that their views are heard.
- There is a guestbook on the Parent Reference Group website. If a parent cannot access it then PSAs can do it for them.

- PPP are currently developing a message board for the Parent Reference Group website.
- The Parents on the Plaza questionnaire results are being finalised, they should be printed in January.

**6. Date of Next Meeting:** 16<sup>th</sup> December 2009.