

**Parent Reference Group
Wednesday 21st October 2009**

**Old Treasury, Catherine Street
10:00am- 12:00pm**

1. Welcome and Introductions

Present: EB, SB, JC, SL, ML, JT

Apologies: GA, TBL, SB, MB, PB, ED, WD, DF, FJ, HL, JS

2. Notes from Previous Meeting

i. 'No Limits'

- **ACTION:** JT will send out a leaflet for 'No Limits', the youth group for disabled children. It is run on a Wednesday evening which provides problems such as childcare and travel.
- ML is looking to take her son to the scheme, she has been told to speak to Social Services to access the Disability Team. Accessing 'No Limits' will be a problem for ML because of travel and care for her other child.
- Direct Payments are changing, now when you apply, someone from the Disability Team and a Social Worker sit down with the family and assess their needs.
- You cannot use Direct Payments for education purposes.
- JT will feedback the comments about 'No Limits'.

ii. Small Grants application

- Concerns were raised that at the previous meeting members of the group did not have the chance to discuss the Downham's parents Small Grant application openly. Some parents had other questions that they wanted to ask but felt uncomfortable doing so.
- JT explained the process of discussing Small Grants. Any questions are put to JGS after the meeting that cannot be resolved within the meeting.
- The application has gone to the Short Breaks Project Board now. We do not yet know the result.
- The parents were asked to stay and explain their application but were then told they could stay throughout the comments. SB said that the parents were confused over when they would receive a decision from the group.
- Question: Do parents who put an application in to the Small Grants fund get a briefing of what happens in a Parent Reference Group meeting?
- Answer: No. Not all applications come through the group, and it is rare that the applicants attend the Parent Reference Group meetings.

- Another issue was that when an application was made previously by the Parents Again support group and went on to the Short Breaks Project Board they were given less money because JGS found a cheaper quote for coach hire. Why was this process not followed regarding the Downham parents application?
- There seems to be a lack of consistency with Small Grants in regards to shopping around etc.
- In regards to Mackaton there are cheaper versions which vary. More research needed to be done.
- Applications need to come to the Parent Reference Group in good time so that comments can be taken to the Short Breaks Project Board, who make the final decision.

ii. Woodview

- There is a meeting on Friday 23rd October. JT has sent out reminders that the Executive Board needs a parent to sit on the group and has had one positive response.
- The Head of Care has also sent out invitations.
- The parent who sits on the board needs to be outspoken and strong.
- Woodview belongs to the campus which is run by JB, who does not have a background in disabilities.
- Downham is the only other overnight residential provision in the city.
- What can parents do for overnight respite? It needs to be advertised more. The group felt that it is not advertised because then more people would know about it and subsequently more money would have to be spent.
- **ACTION:** JT will send the invitation to the Parent Reference Group again.
- There are two other parents in mind so may need to ask the board if they will accept more than one parent.

3. Small Grants Application

i. Down's Syndrome conference.

- There are big concerns over parents having to pay to attend. Adults have to pay £20 each. Ideally they should charge professionals and parents could go free.
- It amounts to a lot of money when considering conference fee alongside travel costs and possible childcare for two days.
- It would be interesting to see the cohort of young people with Down's Syndrome, it is low incidence in Plymouth.
- Both ML and JC have received the NI54 questionnaires. ML will give JC her spare copy for the group to have a look at.
- ML has two children so had to fill in two separately. It will be interesting to see the difference in satisfaction between the age groups.
- The difference between what is available now for the younger children and what was available for older children is immense.

- If a school does not have any children who attend with Down's Syndrome then they most likely will not attend.
- Is the conference aimed at school age children?
- SB said that feedback from her parents included concerns around how the organisers can know how many people will attend. Also how much experience do the organisers have of organising large events? How much research have they undertaken to ensure people will attend? How will it be evaluated?

4. Representatives for tendering process

- At the previous meeting JGS said that the tendering for Beckly's Holiday Play Scheme is up for renewal in December 2009. A panel is being made up to look at the tender and they would like parents of children with ASD to sit on the panel.
- ML, CP and JC volunteered to be on the panel.
- **ACTION:** JT will put an email out to all members of the Parent Reference Group.

5. Parent and Family Forum 24th November.

i.

- The group discussed Parents on the Plaza. It was an extremely successful day with lots of positive feedback.
- The Parent and Family Forum on the 24th November is centred around SEN and disabilities.
- Question: Is the forum going to replace the Parent Reference Group meeting in November?
- The Guildhall is booked and invitations have been made. They will go out to all parents of children with additional needs.
- JS will be speaking and possible MG.
- Display stands were discussed. A list of relevant services was put together to invite to the forum.
- The group felt that someone from the Woodlands Executive Board should be there. Hopefully JB.
- SB noted that she has many parents coming to her with issues around nappies. HM has called for a major review of the Incontinence Service. Tenor currently have the contract for providing nappies in Plymouth. Large nappies are completely out of stock. PPP shall invite the Incontinence Service to the forum.
- **ACTION:** SL to look at the services that were invited to Parents on the Plaza and see if any are relevant.
- The special school Practice Development Session for PSAs is scheduled for November 19th.
- JT will discuss everything with BB who facilitates the forum along with EB.

ii.

- SB asked if there is a city wide policy for use of mobile phones in schools.
- Answer: the LA has issued guidance on this. Most early years settings have banned them completely. It currently depends on each school.

6. Parent Reference Group web page

i.

- The web page was shown at the last Parent Reference Group meeting. Everyone approved. JT gave the feedback to the AH team.
- JT has received an email from a trainee Health manager who has been helping with Short Breaks and has previously met with JT to discuss the Parent Reference Group.
- He has been asked to design an outline for the ChIDS section of the Plymouth City Council website. Why are they doing this? Who commissioned it? PPP have built their own page as the facilitators of the group.
- The group felt that another page is unnecessary and a link just needs to be put on the PCC website directing people to the PPP Parent Reference Group page.
- JT- this just highlights the fact that PCC are duplicating PPP's work. Many things are not run by the Parent Reference Group, e.g. the situation at Woodlands was not run by the group, the group found about the Short Breaks DVD by accident.
- It was agreed that instead of having a parent on the Short Breaks Project Board that everything would be run by the Parent Reference Group. It was supposed to make things more transparent and link it to parent participation.
- The group felt that sometimes they are just 'ticking a box' for the Aiming High strategy and the Project board pick and choose what they run by the group. They are listening but not hearing. The group feel that they are bypassed because they are too outspoken. It was also felt that in other groups parents feel intimidated and unable to speak their mind.
- Short Breaks rely on parent participation to create new services that parents want through small grant applications. All other activity that is to do with Short Breaks goes to the board.
- The Parent Reference Group have previously put together a flow chart by which the process of approval and discussion for applications happens.
- JGS is on the Aiming High board and the Small Grants board.
- JT has also received information about a 'Special Needs Handbook' which will contain useful tips. The organisers of the book would like to hear from parents if they have any tips not included. **ACTION:** JC will investigate.
- The group felt it could be a useful resource. Once compiled will it be sold?
- JT will wait until JC has gathered more information and then it will be sent out and made available at the forum.

- **ACTION:** JT will check with JS or AG what is happening with the PCC ChIDS website and see if they can work together with PPP.

7. Aiming High update

- The parent participation training is filling up. JC has still not been able to contact SD.
- EB phoned Scope and SD has now left. JA is now the Face 2 Face co ordinator.
- BB and AS are looking at the trial of a webcam. What is available at the moment is unsuitable, so they will keep looking.
- The flyer for parent participation training will be brought to the forum. The training is on the 26th November and the 3rd December.
- The statutory services were disappointing for Parents on the Plaza- not enough of them came.

8. Next Meeting: