

Children's Integrated Disability Service Reference Group

Wednesday 28th January 2009.

Present: JT, EB, TB-L, AF, SR.

Apologies: CM

- From now on meetings will be formalised with a register and minute taking.
- AF is not officially associated with NAS.
- Meetings at Longcause first Tuesday of every month have been changed to last Thursday of every month at Greenark.
- Plymstock SENCO has not been appointed yet.
- Parents feel that CHIDS reference group is not a snapshot of views anymore, need more members so to collect a larger cross section of parents of children with disabilities.
- CHIDS is about keeping parents informed about decisions being made and feedback about decisions.
- Beckly have asked their parents if any of them belong to this reference group.
- Campaign has been launched by EDCM called 'Going Places' which is looking into what the government should be doing to make sure disabled children have places to go and enjoy themselves. They are essentially making sure that play and youth strategies in the city are delivering.
- Contact a Family bullying leaflet- PPP have purchased 50 of the books. How should they be distributed?
- JT and L have looked at a document sharing protocol for the group. When drafts come through the group then feedback on them. Should develop a clear process on how to deal with paperwork.
- Previously parents have felt that paperwork has had hidden agendas, JT said that the intention was not to burden parents with too much paperwork, it should be clear and transparent.
- Do parents want to be involved in Short Break applications? A couple of parents could meet with HM on behalf of the group.

- The group needs more parents to share their views. Would moving the time or day help this problem? Aiming High parents were invited but none have shown an interest so far.
- JT- CHIDS have distributed a leaflet about Lay People, and how they can be paid for voluntary work. Would this be an incentive for more parents to come?
- AF pointed out that parents would be coming for the wrong reasons. You shouldn't have to pay parents for them to care about making a difference.
- SR also pointed out that because her son does not need the same level of care as others there is a danger that he will get lost in the system.
- There is a general feeling that nothing is ever achieved from meetings, no results are ever seen. The incentive to come to meetings should be that you can see that things are changing for the better. Was noted that a meeting with GS was full one week, but because nothing that was discussed was actually put into motion the next meeting was much quieter.
- EB- some changes are beginning in April- a 'single point of contact' is being developed.
- SR now needs plenty of warning for meetings during the day as she has just started a new job.
- **Short breaks application:** The application is much improved this time. There is a criteria for application, explanation and a section for parents comments. Applicants will know if it has been granted by the middle of February.
- An Issue was raised that a lot of parents do not want home based respite. It appears to be what the government would prefer. Most parents would like their children to go to clubs and activities outside of the home environment so that they can relax and have time to themselves in their own home.
- Parents want their children to be able to do activities that every other child can do
- DF- have to prove that they are using their grant properly- there is a widespread local provision around childcare.
- Would it be feasible to set up a new focus group with parents?

- JT stated that a questionnaire does not give the same quality of feedback that a meeting achieves.
- Parents feel that the communication between people in power and the parents is very poor. 'United you stand divided you fall'.
- Meeting to discuss Short break application will be held on Monday 2nd February at 6pm, Martins Gate.
- Any parents who have applied for Short Break cannot be present for the discussion.
- VC has suggested trying to pull a focus group together to get views on childcare. Friends and families could be invited and it could be held at Catherines St.
- **Aiming High:** Grant has been offered through IDS of £3,200. This has to be spent by the end of March on the condition that training should be found for parents. EB and BB are going to Truro and PB is going to Saltash to see if the Contact a Family training is worth paying for or whether they should develop their own. The course will ensure that parents have transferrable skills and will be affective in encouraging change.
- The parents are entitled to £10 per hour to go on course, but this may affect a lot of parent's benefits entitlements and so a point system will be introduced. Points will earn parents vouchers for high street stores. Anne pointed out that this is a good idea as it could help with things such as weekly shop without affecting their income. These vouchers have to be called gifts. The parents will only know about vouchers after they have signed up for the course to avoid it being seen as an incentive.
- The course is suitable for 15 people at a time. BB is doing the application forms.
- JT raised concerns about being able to spend all of the money.
- EB will book the training before March for later in the year to ensure the money is spent before the deadline. As long as the course and dates are earmarked then details can come later.
- They are hoping to be granted the 2nd stage which is worth around £10,000. This will be managed through PPP because parents would feel it too much responsibility.
- The course will be publicised through PSAs, Friends and Family Forum etc.

- JT will contact V ASAP and will email KO about focus group.