

# Children's Integrated Disability Service Parent Reference Group

Wednesday 25/03/09

## 1. Welcome and Introductions

- JT welcomed everyone to the group.
- Everybody introduced themselves and how they are connected to ChIDS.

## 2. Present and Apologies

- **Present:** GA, IB, EB, PB, BB, SD, AF, HL, ML, SL, LM, CM, AN, J S, JT, SL
- **Apologies:** JF

## 3. Jo Siney, Integrated Disability Services Manager

- JS explained Aiming High for Disabled Children and gave background on the project; respite care, Short Breaks, encouraging LA's to give a greater range and quality of services, accessible childcare.
- Transition to Adulthood project. Not a great deal of funding. Focused on 13-19 year olds.
- Explained Short Breaks grants, £229,000 this year and over £400,000 next year. Explained what the money is to be spent on.
- The money is for services over and above what the LA is already committed to providing.
- JT asked how much money is available for other grants. Transition is £10,000.
- Plymouth Short Breaks is taking on board messages from parents who have been feeding back for last few years.
- JS explained the guidelines for the readiness criteria.
- Planning through priority group- understanding population- who are and are not able to access provision at the moment.
- Developing Short Break provision for overnight care.
- Developing the enabling role. Aiming to increase staff within a setting.
- Qu. Were there any parents on the tendering panel? Why did it not come to ChIDS?
- Qu. Who received the grant?
- Action for Children and FCA were offered the tender under a framework contract.
- JS agreed to email all information to attendees.
- Discussion around how parents can find out about grants etc. Agreed that communication needs to be improved greatly.
- Most people find out about Short Breaks and suchlike through word of mouth.

- The PSA role is very important to getting the word out to parents.
- Parents agreed that professionals from the medical field and education field do not share information. Parents get mixed messages and are having to inform one what the other is doing.
- SD- parents in Cornwall are on a register and the parents on the list receive a newsletter which is very helpful.
- There is a register in Plymouth called Spin but none of the parents from the group who have signed up to it have received any information. There is also a register in Devon called Disk.
- A lot of parents do not want to sign registers because their child is not technically disabled.
- There is not a complete figure for how many disabled children there actually are in Plymouth.
- There is no motivation to sign a register because no information is received from it.
- The Cornwall register had a big launch. SD will take the registration form to all parents that she visits in Plymouth.
- Agreed that Spin registration forms should be in all schools in Plymouth, PSAs could hold these.
- EB discussed the criteria for Short Breaks. Suggested that the eligibility criteria is taken out of context by officials.
- To access the activities you shouldn't have to go through Social Services to assess eligibility. Wastes Social Workers and parents time.
- JS noted that they are beginning to develop work around localities.
- Trying to open up so that the organisations that run the activities have their own eligibility criteria.
- Qu. Who decides how much money Plymouth receives?
- Ans. DCSF decides based on knowledge of the local area. JS's team provided huge amounts of data to the government.
- PICSS; their funding is limited but have a huge success rate in letting children access mainstream provision.
- Devon- Fair Access for Carers Breaks. This is a way of assessing which parents/carers receive what. They do it on a score basis. EB helped a parent do this and said her opinion was that it made the parent feel like they had to appear desperate in order to get anywhere.
- JS will bring this to the group.
- Bournemouth, Poole and Dorset run the Social Model of Disability which is based around the parent indicating what their child needs e.g. a calm environment to assess what help they should receive. Group very positive about this suggestion.
- JS will ask Dorset for more information about this.
- Qu. Is the money sustainable? What happens when the grant runs out?
- Ans. JS is taking that question to a conference on Aiming High.
- JT Aiming High is not going away.
- Qu. What grants are actually available for Plymouth?
  - Carers grant
  - Two overnight residential provisions (Downham and Woodlands)
  - Some families use foster carers
  - Beckly Centre

- Replace behaviour support service
  - Enabling service through the sanctuary.
- ML pointed out that the majority of parents do not know about these grants, it seems that the only parents who do are working with Social Services. Again are being forced to use a Social Worker when not really needed.
  - There are five Social Workers for SEN and disabled children.
  - Discussion around Occupational Therapists and how many are available in Plymouth. At the moment some are being covered by temporary staff.
  - Individual budgets are being introduced. Direct payments. Allocation of money is made and then the money is used for other services that meet the need. Gloucester are the path finders for this.
  - Flexibility of budgets. Person centred planning from transition to year 9.
  - Jo Siney will come to next meeting and discuss Devon taking this on.
  - JS- Where are the gaps? Need new creative ways of filling the gaps. Small grant funding- helping small local voluntary groups set up clubs/groups etc.
  - CM explained about the Plymouth MSI group. £5,000 was granted and so they were able to buy equipment which could be shared between all of the families that attend. Meet frequently to give each other mutual support. They meet at Woodlands school, but would like more input from an OT. Caters for a specific niche, with a specific need.
  - Spin was supposed to be used for planning ahead.
  - JT provided handouts of the timetable for achieving the second phase of the Short Breaks fund. It was made to accommodate for CHIDS meetings.
  - Group feedback on timetable.
  - JS informed of a Joint Equipment Store which would involve a short loans scheme for equipment. This will be organised from May/June 09 onwards.
  - Needs to be established as an actual equipment service.
  - EB suggested asking schools and families to donate equipment they do not use anymore.
  - Database and bar coding will be organised so that the equipment is tracked at all times.
  - This can all be announced at the next P&F Forum. JS will attend next forum and will talk about individual budgets and person centred planning.
  - JS- key point to take away is communication.
  - JT pointed out that PPP has a statutory commitment to provide SEN parents with information. However other services neglect to share with PPP.
  - A page is being built on the PPP website for the ChIDS reference group.
  - GA- A website is needed for grants etc that is regularly updated.

#### **4. Phase One of Aiming High Grant**

- The money was spent on Dixerit website software, Parent Participation training bought in from Contact a Family which was done in Plymouth. (Feedback very positive)
- BB writing a report on how the money was spent, due in 6<sup>th</sup> April 2009.

## **5. Phase Two of Aiming High Grant**

- Bid must be submitted by 15<sup>th</sup> May 2009.
- CHIDS focus group for making decision of how the money should be spent.
- Must have a meeting to discuss how the £10,000 will be spent.
- This money must be spent on building on what was spent in phase one.
- Possible training for professionals and how they work with parents?
- Possibility of role play videos which could be sent out to professionals as examples of how to work with parents of disabled children.
- SD- Face 2 Face run a two hour training course which is run over three workshops focusing on emotions, PC language and role play reversal. It is delivered by parents to professionals. Several children's centres in Plymouth have already expressed interest in buying the training in. Initially will bring in parents from Cornwall to be examples of how to run the training and then Plymouth parents can run it themselves. The training uses real life experiences. Targeting SENCOs next. Funded by Aiming High Accessible Childcare money. Costs £350 for up to twenty participants. IB is starting training soon.
- Vouchers- parents who attend meetings given vouchers to spend on shopping etc. Issues with parents just coming for the money, or not wanting to be paid.
- Point system for feedback and contribution.
- Parents conference, invite everyone from the Spin database.
- Use the money for various ways of communicating and making people aware.
- JT- must not duplicate LA policies.
- It was noted that £10,000 will not go very far if paying parents or running a conference.
- Parent Participation course- £1,000. Max 15 people.
- PB explained the course to the group. It shows the extra requirements and skills that parents of disabled children have, builds the confidence of parents. Learn how to use Every Child Matters so that you can approach professionals and ask for what you want. Teaches how to change a personal issue into a group issue. More parents are needed to train so that they can spread ideas and make a difference.
- Professionals need to be trained more than parents.
- This reference group was set up to prevent individual parents having to represent everybody.
- CHIDS supposed to be official consultation group but they were not told about the tender which went out.
- A decision needs to be made by the end of Easter at the latest so BB can organise everything.

- There will be a meeting to decide what the £10,000 should be spent on, on Tuesday 31<sup>st</sup> March 9.30am- 12.00pm. BB will email everyone about the venue.