pinpoint
for parents by parents

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Cambridgeshire Partners in Commissioning Group (SEND)

10 am-12 noon, 16 July 2013, Bridge Street, St Ives

Present:
Sue Platt, pinpoint/parent of children with additional needs
Caroline Goodall pinpoint/parent (NAS Cambridge)
Richard Holland, Head of Disability (Social Care)
Eva Alexandratou, Joint Commissioner for County Council and NHS Services
Mary Whitehand, Family Information Service (Cambridgeshire Children and Young People's Services)
Adrian Loades, Executive Director, Children, Families and Adult Services
Bob Wilson, Parent Partnership Service
Elizabeth Locke, Healthwatch
Eve Redgrave, parent (St Ives Parent Support Group)
Liz O'Donnell, GP, Cambridge City
Bianca Cotterill, parent (children with complex needs)
Christine Stocker-Gibson, pinpoint management team and carer
Lorraine Williamson, parent (Transitions)
Jane Ryder-Richardson, Head of Access

Apologies
Caroline Lea-Cox, Jane Tuck, Lenja Bell, Joan Adamson, Annmarie Superville, Judith Davies, Fay Haffenden

1. Welcome and Introductions

Sue welcomed everyone to the meeting and everyone introduced themselves. Parents also gave the disability of their child/ren.

2. Notes from last meeting and matters arising

The minutes of the meeting of 16 April 2013 were agreed. All action points discharged except **Action Point 3** (updating the terms of reference) which Lenja will do if necessary after this meeting.

With regard to **Action Point 4**, Eve attended 4 of the Area SENCo meetings with Lenja. **Action Point 5** prompted positive feedback from parents and

Action Point 1 from Nov 2012 resulted in Faye Haffenden from Cambridge Dyslexia Association being invited.

3. Sponsorship of Group

Adrian is happy to support the group to help get messages across and to help remove barriers. Adrian recognized the importance of the group as it provides balance between parents views and services provided by CCC.

Sue hopes that Adrian will raise the profile of the group, so that parents know that messages from them are being heard. Also, if something is not being acted on. Adrian has offered to help support if there are issues that are not being progressed.

Eve felt that Adrian's presence at the group may focus other services, encouraging them to send people to the meetings.

Richard talked about childcare brokerage and sufficiency of childcare for children with SEND. Current policy is that payment is made to settings but it is acknowledged that there are no settings for older children. Is this because of funding levels from CCC?

Sue said that it is important for parents to understand the challenges facing CCC, such as legislation and budget issues that stop parents receiving what they ask for. In this way, parents expectations can be managed.

Adrian said that challenge from pinpoint is important. Sometimes it's good to have someone ask why something is done a particular way. Also, CCC can't afford duplication or services that don't work.

Sue pointed out that although there is a lot of information on the CCC website, parents are not always aware of it and we need to improve awareness of the FIS website

There was some discussion around the fact that not everyone has a diagnosis, and sometimes those without a diagnosis get forgotten as services tend to be diagnosis based. Everyone agreed that services should be needs based, not diagnosis or label based. Liz asked for examples to take back to clinicians.

Jane explained that the Local Offer should make things more explicit for those with a diagnosis, while detailing what support is available for those without one.

It was also agreed that young people are successful if they judge themselves successful and that there is a balance between being happy with their lot and perhaps challenging themselves a little.

Richard suggested a workstream on childcare sufficiency for children with SEND; this is being followed up with a meeting between Sue and Graham Arnold later this week. Adrian agreed to be involved with this, if needed.

4. Discussion topics

Recruitment of pinpoint Executive Officer:

Christine reported that the job description has been revised and now reflects the more strategic role that the EO will be doing. Ten applications have been received, with interviews to be held on 23 July. Christine thanked the pinpoint staff for keeping things going and also Juliet Snell, for her invaluable work on the Management Group.
Sue mentioned that there would be no parent panel this time, as it is the last day of term for many, or their children are already on holiday. Richard pointed out that pinpoint needs to make sure it doesn't lose parents when they become staff. Sue and Caroline are both parents of additional needs children and it is still important for them to have a voice as a parent.

June 2013 SEND meetings key messages

Sue went through the key messages of the June meetings.
Messages that prompted further discussion were:

- Cross border issues with keyworkers, want to keep keyworkers

Richard advised that children from other county councils already access CCC services such as short breaks, and the other county councils pay for them. This is a reciprocal arrangement with neighboring counties.
Eva reported that parents accessing services across borders happens a lot in health, and that it works better for the under 5's than for the over 5's.
Jane reported that protocols are in place for education near borders, which covers educational psychologists, speech and language, etc. There are also cross border protocols for looked after children.
Action Point 1: Sue to follow up with parents who live near borders, especially in the Fenland area.

- Parents need support to complain / challenge

Parents don't know what happens in school. Bob reassured the group that the Parent Partnership Service (PPS) will support any parent in their dealings with school.
Jane said that monitoring of schools will be more rigid under the Single Plan.
Eva pointed out that we need to stop relying on one channel of communication, i.e. school. If a child is seen in school by a health provider, information should be given to home as well as school.

Richard noted that outcomes are good for parents who know about PPS, although it is recognized that Parents with children on School Action or School Action Plus may not be told about PPS.

Mary said that the FIS are distributing their information postcard to as many parents as possible.
Action Point 2: pinpoint to ensure it is signposting to FIS and CCC SEND websites. Sue to speak with Vanessa (pinpoint technical support) about this.

Sue reported that pinpoint had received calls from SENCos following the recent Area SENCo meetings.
Lorraine asked what good practice for communication with parents by schools looked like, and Mary advised that we set out what parents can expect schools to do, and then put this on the FIS website with access for all, including parents. This should be distributed widely, and GP surgeries should be part of the dissemination.
Christine suggested we flag this up on the pinpoint home page.

- Educational Psychologist sooner and more often; want EP involved again regularly, things change

This comment generated a discussion about reviews and assessments in general. The group recognized that it is not good to have reviews more often than necessary, but that children change over time. Parents need to be able to request a review if they feel one is needed.
Jane asked who are the key people involved in reviews/assessments, and who supports the outcomes? CCC needs to be clear with parents about who the key professionals are who are working with a child. She also noted that there is a balance between being part of the review process and doing direct work with a child or young person.

ASC Pathway Workshops

Jane reported on this multi-agency group that is developing a pathway for autistic children and young people from pre diagnosis through assessment, diagnosis and service delivery. The workshops were well attended by a range of parents resulting in lots of parental contributions. A wider consultation is needed on how the information is given out. The feedback from parents was good although they felt the early help section needed to be clearer. Jane reported how valuable it was to have personal experiences.

Talk about Transitions 6

Lorraine reported that the event was a success, with 32 parent carers and 45 service providers attending. The stands and workshops were well attended, and parents found the day useful and enjoyable.

Emotional support for parents

Eve has been to the Area SENCo meetings, getting the parents' view across. Many of the SENCos were enthusiastic. Eve talked through the recommendations made, highlighting the following:

- Schools don't realise that they need to provide emotional support
- Teachers need to not take comments and questions personally, and to remember that the parents are dealing with other issues, and are tired!
- Support needs to be offered at all times and in different ways

Eva commented that parents need professionals to give information as and when parents are ready, not necessarily all at once, which can be an overload. Parents also need peer support.
Christine pointed out that when parents meet with other parents, they get answers to questions they do not know they have.
Bianca noted that parents need somewhere to go in the holidays where children can play and parents can talk, e.g. school play areas. Some schools already do this.
Liz said that GP's recognize that a parent with a disabled child needs more emotional or psychological support than other parents.
Bob noted that Children's Centre Hubs will also be useful for SEND groups.

In-Control

Richard talked about this national organization, set up in 2001 around self directed support and personal budgets. In-Control use a tool called POET – Personal Budgets Outcomes and Evaluation Tool, and CCC is piloting this for children. The system is more complicated for children as adults are predominantly accessing social care, but children's services encompass education and health as well.

Richard showed the group a questionnaire designed to highlight parents' priorities, CCC is aware that more information from parents and respect for parents early on generates better outcomes.
Action point 3: pinpoint to circulate questionnaire to parents (Sue)
Parents views will then inform the initial draft of the children's POET, with a group of parents to evaluate. Richard acknowledged that Social Care should be person centred, and that it is important to get the technical aspect and spirit of personal budgets right.
Richard is also liaising with the Papworth Trust to get more young people involved.
There is a Conference taking place in Birmingham on 12 September, and Social Care can cover travel expenses of any parents who wish to go.
Action point 4: Sue to follow this up with Richard.
Jane reported that In-Control are also coming to the SEND project board (which delivers the Special Needs and Disability Action Plan). It is not yet known which bits of the personal budget could extend into the Single Plan.
Action point 5: pinpoint and Richard to liaise on getting parents in to meet with In-Control in September. Parents need to see the questionnaire soon for this to happen.

DofE Grant
Sue reported that pinpoint had submitted the declaration for last year's funding, and also the application for this year's funding. She asked members of the group to sign to support the application. Main areas of funding for pinpoint will be the conference, facilitation training, website development, a parent carer admin worker, publicity and childcare costs and travel expenses for parents.

5. Feedback from participants

Mary – There is the opportunity to use a children and young people's version of Ask Sara (an online resource around equipment, already in use in Cambs for adults), and to add in local information to it. Would like to get parent reviews of this.
The Childcare Information Service telephone service is working well.
Adrian - It is important to follow up on recommendations around emotional support.
Eva - Early Support principles have worked well with early years, so extending this into Single Plan. Also working on workforce development with regard to communication to parents.
HomeStart and pinpoint are developing peer support process with Early Year professional groups.

Jane – The way that children are assessed for statements is moving forward, and needs fine tuning. This will be done with Lenja and Richard.

Date of next meeting
Set for 10 am – 12 noon, 5 November 2013, first floor, 11 Bridge Street, St Ives.

AOB
Richard expressed his thanks to Jane Crittenden for her help with the Innovation Fund panel.
Jane reported that CCC is now the eastern training hub for Autism training. This means free training will be offered to all staff in all schools. Spring Common school is delivering training to staff who lead on provision for children with autism such as SENCos and special school staff.
Lorraine would like to see safeguarding training for all.