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Parental involvement network for parents of disabled children

Notes from the East Cambs network meeting

Date: 18 October 2013 **Time:** 10am – 2pm

Venue: Cathedral Centre, Ely

Number of parents and carers: 7

Professionals joining at 11am: 8

Facilitator: Liz Dunn, pinpoint

This was the 15th parental involvement network meeting for East Cambs.

Workshop ground rules

The workshop ground rules were put up as a reminder for participants at the beginning of the meeting.

- Everyone is valued, we respect the views of others
- Everyone will have the chance to speak, be heard and to hear the person speaking
 - No side conversations
 - No talking over others
- There are not wrong answers or silly questions
- No jargon please
- We respect confidentiality
- Anything else?
- Mobile phone on 'silent' please

Updates

Pinpoint gave updates from previous network meetings. These are outlined in the document: *Parental involvement network for parents of disabled*

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children: feedback for October 2013 network meetings. Additional updates were:

- pinpoint asked parents to feedback on continence services so more information can be provided for parents on the pinpoint website. pinpoint will like to hear top tips from parents and what questions they would like answered.
- pinpoint is running three Talk about Transitions events in early November. The focus is 'independent living'.
- pinpoint is running an Empowering Parents course with Home-Start for parent of children with additional needs 5 years or younger. A course is currently running in March and the next one will be in Cambridge in November. More will be scheduled in the new year.
- The parent well-being and support group that runs in Cambridge once per month on a Monday morning has had its funding extended and will now run through March 2014. Each session has a well-being topic and speaker.

Hot topic: changing schools (transitions)

Parents only session

Cambridgeshire County Council is reviewing its services around school transitions, from early years to adult services. A Transitions Development Manager Anne Richardson is leading the process and is keen to capture parents' views regarding their experiences and what type of support they would like. Parents were asked to look at different stages of transitions:

Early years to primary

Primary to secondary

Other – mainstream to special school, special school to mainstream school, from out of area, from home-schooling, etc.

For each of the areas, parents were asked to feedback on the following questions:

What worked well?

What didn't work?

What was missing?

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What would you like?

Parents answered the questions individually and put their answers up on the sticky wall. We then discussed the answers as a group and added more comments. Parents' comments are listed below. Comments in italics were made by service providers and commissioners during the second part of the meeting when we discussed parents' comments with them. A Burning Issues area was also created to capture more general concerns.

Early Years to Primary

What worked well?

- Primary SENCo and Head recognised issues immediately
- Full support during statement process
- Once awarded a school place, great transition by school to settle him in
- Been provided a statement from nursery and early support teacher, felt supported
- Dependent on good early year support and school
- Occupational therapist identifying what needed to be in place
- Family support worker
- Family meeting with specialist and nursery staff for suggestion to school
- Recognising individual needs
- Statement ready nice and early (in pre-school)

What didn't work?

- SENCo attitude / ability
- START Team seemed understaffed and slow to respond, long timescales
- Process to apply to special school was too slow
- Not enough guidance and preparation early enough re: choice between special and mainstream
- Forms for statemented childrens' school application too early for guidance available (before started pre-school)

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- Professional involved with child unwilling to comment / advise on choice between mainstream and special
- 1 space for Rainbow Unit for every kid in Cambs.

What was missing?

- More training at pre-school level
- Experiences vary between settings, no consistency
- IEP's not given in EY setting
- Case workers not covering each other works – START
- More Jane Tuck's!

What would you like?

- More guidance for parents of 2-3 year olds to prepare early
- Consideration of sensory needs by school
- Trained SENCo
- TA's to receive specialist training
- SENCo with time and passion and empathy
- Early statementing
- A framework to help parents consider and decide between mainstream and special, time correctly
- Need someone to guide through SA process
- Cover for STAR Team holidays
- Guidance – special vs. mainstream

Primary to secondary

What worked well?

- Second Step Youth Project – through school holidays, got to know school
- Extra school visits

What didn't work?

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- SENCo attitude / ability
- STAR Team do not ring back
- Revised statements taking too long

What was missing?

- Only 2 specialist ASD units in mainstream schools
- 23 secondary places in mainstream cabins
- Parent support with transition
- Criteria for entry to cabins

What would you like?

- Info re: how secondary schools deal with SEN pupils
- Advice and guidance on school place choice, affects transport
- More support and advice from both sides
- Better communication from school
- SEN achievement information – stats and data
- Sensory needs consideration to meet needs
- Pastoral care within school, for parent and child
- TA's to receive specialist training
- Statistical data to show how SEN pupils are progressing
- Consistency from all schools
- Help finding school

Highlights

- Parents should be listened to
- Who should SEN parents ask? PPS
- FAQ's for school moves

Burning Issues

- An Early Years Centre being awarded 'SEN Hub' status when there have SEN complaints and SENCo isn't doing job properly

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- Being told no transport
- School doesn't tell parents about PPS (Soham VC)

Feeding back to service providers and commissioners

Commissioners and service providers joined the meeting at 11am. After introductions, going over the ground rules, and a short introduction from Anne Richardson, we discussed parents' feedback from the earlier session. Responses and comments from professionals are written in italics in the above section.

The overarching themes from the discussion were:

- The need for the transition process to start early
- The value of good communication between settings
- The need for staff to be trained to meet the needs of pupils coming into the setting
- The need for support for parents in the transition process as well as the pupil
- Help for parents in identifying the right school for their child
- The need for good quality communication between school and parents – open, honest and timely.
- The importance of consideration of the social as well as academic needs of the child.
- The difficulties of the statementing process including knowledge of key milestones.
- The need to give support for children not in school and their parents.
- Working in partnership with parents important.
- The ability for parents to visit schools including special schools
- Lack of specialist placements in the area
- The good practice of having a holiday club in the school during the summer which allowed familiarisation

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Group work

Anne then asked the parents to work in groups with service providers to review two items:

- An A3 page outlining the transitions process from early years to primary school with specific points of information on childcare / early learning, health care, starting school and co-ordinated support for you and your family.
- A draft website page with information about starting school.

Anne wanted to find out if the information is useful to parents and if the layout is clear. Scribes in each group noted parent feedback which Anne collected and will use to develop the work further.

The group work ran over lunch, parents and service providers continued to talk and work together over sandwiches.

Evaluation

We asked parents and service providers to feedback on the meetings by answering a few questions on a flip chart. This was voluntary so unfortunately feedback was not always gathered. Comments from professionals are in italics. See feedback below:

Liked this

Format

Refreshments

Presentation

Everything!

All relevant professionals attended

Didn't like this

No comments made

More of this

No comments made

Anything else?

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No comments made

Next meeting

The next meeting will be held on 14th March 2013 from 10am – 2pm at the Cathedral Centre, Ely.

pinpoint actions

In response to issues raised at this meeting, we will:

1. Summarise and report findings to the Disabled Children's Action Group and SEND Project Board, and other groups that pinpoint is represented on.
2. Add the network meeting notes and summary report to the pinpoint website. Share the link in our weekly update.
3. Discuss key issues arising from the district network meetings at the county Partners in Commissioning (SEND) Group meeting in November 2013.