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Parental involvement network for parents of disabled children

Notes from the Cambridge City network meeting

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

Venue: Masonic Hall, Cambridge

Number of parents and carers: 11

Professionals joining at 11am: 8

Facilitator: Lenja Bell, pinpoint

This was the 15th parental involvement network meeting for Cambridge.

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?

- Infant school worked well to provide junior school with information and special timetables. However junior school wanted to see for themselves – so it took longer for routine to be established.
- TA in early years went to primary to visit with child.
- Early years setting and primary meeting with family together – good idea
- Get statement in place/under way before starting primary.
- Wonderful SENCO at Homerton getting statement sorted in pre-school so not facing that challenge at same time as starting primary.
- Head teacher/SENCO very well informed and welcoming. Pre-school advisor helpful, but needed to find own school. (Hertfordshire)
- A very good SENCO who spotted problem early. Local community center support – child out of school for six months.
- Member of council who looks after cluster of schools – primary/secondary. Of course personal touch so if leaves one will feel knowledge lost.
- A very good SENCO who was her teacher and spotted the problem very fast (2 days).

What didn't work?

- More notice about fact that primary school application has an early deadline for statemented kids. (31 Oct rather than January, 2 weeks' notice to decide on school).

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- Catchment schools not helpful, did not want to help (Hertfordshire)
- Also in Cambs (see above) – not welcoming especially if no statement.
- My son was on the cusp of going to a special needs school, but is in mainstream. We were actively discouraged from taking our son to see how he felt about going to one.
- Early years attached to school helped with planning less so with private nursery.
- Treated insensitively
- How I was told about my child
- Lack of information
- Lacking in support for parents.
- Work 'with' you and not 'for' you.
- New school waited until they had seen specialists for themselves before daughter's special needs were fully understood.
- It feels that SENCO does not have full support from rest of staff. Initial attitude was that staff knew best not parents.
- I felt we were on a conveyor belt – whilst we were extremely lucky that our son's difficulties were spotted early at nursery and he was given support, the transition process felt as though we were being pushed in a different direction that suited the support services.

What was missing?

- Information from schools and how they support children with additional needs.
- Unbiased view e.g. not just brochures
- Child out of school waiting for school place
- Teachers and TA need training re: communication skills and special needs
- Professional not trained or aware of autism and needs.

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- Awareness that female aspergers is different.

What would you like?

- Would like to know how to recognize a suitable school for children with additional needs – what to look out for, who to speak to (not just SENCO/Head), useful questions to ask.
- *Parent Partnership Service – parent school preference advisor.*
- *Council for Disabled Children has shorter version of Code of Practice, local offer from LA and each school.*
- Ofsted and league tables not always what you need.
- Need disability information - number of TA's, SENCO
- List of questions for school visits.
- Would like to know what to expect from transition – will they visit/observe child in pre-school, how they will plan for him starting.
- A better communication between school and medical professionals would have helped.
- Relationships depend on personality
- Communication very important.
- *Childrens Centres run groups to support transitions from early years to primary.*

Primary to secondary

What worked well?

- Parent Partnership Service– transition session info/dates/processes. Needs to be advertised for year 5 (not just year 6)
- Early transition support from year 5. Good SENCO in primary and secondary – extra sessions and meetings

What didn't work?

- Available information about which schools are better at dealing with challenge to do with disabilities e.g. Comberton/Witchford/Cottenham. Viewed as parents preference instead of child centered view where the will thrive.

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- Early year/secondary school: more information, such as school choices/resources. Where to get information, who to contact. Give parent more time to think and evaluate.
- What school is appropriate, no direction to where we should be looking (what is our catchment area secondary special school?)
- Review meetings not long enough, and in wrong setting (i.e. classroom).
- Access to transport.
- Inappropriate meetings regarding child (IEP/formal meetings, etc.) with child concerned present. No after school care offered. What happens if you don't work part time or if you cannot attend these meetings, what do schools offer? Video conferencing? Where could one do these? Could LA have a place for these or even pinpoint?

What was missing?

- Trade fair for schools, parents to visit.
- Suggested schools? Need to do leg work
- Objective info about schools
- Need to talk to someone personally – school and LA
- Looking ahead... I've heard rumors of bullying – that a child now schools in Hastings because my child's feeder school didn't address issues. I've been recommended to start looking at secondary schools 2 years before my son is due to leave primary school, suggesting there isn't a supported system in place.
- Access to other parents' views.
- Parent feedback re: schools on pinpoint website
- More trial or settling in days.
- Parent groups for clusters of schools.

What would you like?

- Assurance they will meet her needs: disability and intellectual.
- Ask for inclusion and bullying policies.

Other

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- LA and education do not work during school holiday periods but life still goes on and transitions still need to be planned (frustrating)
- Y11 to 6th form – finding right school is still difficult, parent has to do leg work.
- *Additional needs personal advisor*
- Administration process is right and works well within the legal framework that LA are requested to adhere to. Moves have been early years to primary and primary to primary. However, feed of information and transfer of records from primary to primary was almost nonexistent.

Burning Issues

- Changing years within same school is hard for a child on the autistic spectrum but with a new SENCO and teacher basic info about her care had not been passed on.
- Within primary moving from year to year is variable at best and viewed as inclusive by treating SEN children same as peers.
- Lack of accountability for SENCO's
- Special schools – area catchment?

General

- University schools feedback site
- SEN parents at open evenings?

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

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- 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 – information in addition to Ofsted reports
- 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.
- Transport - crucial for transition to be smooth.

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:

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Liked this

The board; the ground rules.

This was done in a very positive way. I thought before coming that it may be a moan session which it wasn't.

Didn't like this

No comments made

More of this

No comments made

Anything else?

No comments made

Next meeting

The next meeting will be held on 6th March 2013 from 10am – 2pm, venue to be confirmed.

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.