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Parental involvement network for parents of disabled children

Notes from the Cambridge network meeting

Date: 20 June 2013 **Time:** 10am – 2pm

Venue: Cambs FA HQ, Impington

Number of parents and carers: 12

Professionals joining at 11am: 11

Facilitator: Lenja Bell, pinpoint

This was the 14th 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
- There are no wrong answers or silly questions
- Everyone will have the chance to hear and be heard – mobile phones on silent
- We respect each other's opinions
- We respect confidentiality
- We respect each other's values and cultures
- Every will be able to understand what people are saying – avoid jargon
- The whole is bigger than the sum of the parts.

Updates

Pinpoint gave updates from previous network meetings. These are outlined in the document: *Parental involvement network for parents of disabled children: feedback for June 2013 network meetings*. Additional updates were:

- pinpoint was successful in its bid for the parent participation contract with Cambridgeshire County Council. Pinpoint will therefore be working with parents for at least another two years.
- pinpoint is actively recruiting more parent volunteers and is holding a volunteer morning on 12th September. For more information see: <http://pinpoint-cambs.org.uk/events/pinpoint-welcome-and-update-volunteers-and-parent-reps> .
- The *People to Talk to* leaflet has been updated and reprinted. Hard copies are available from pinpoint or view an on-line version: <http://pinpoint-cambs.org.uk/support/support-groups-linked-to-the-pinpoint-network> .
- pinpoint is working with Home-Start to deliver *Empowering Families* training to parents of children under five with a disability or additional need. A four week course is running at March Children's Centre from 19th September, and more courses will be scheduled in other areas. See <http://pinpoint-cambs.org.uk/events/empowering-families-course> for more information about the March course and contact details for information about future courses.

Hot topic: Update on the Cambridgeshire County Council SEND Strategy and the Single Plan

Background

At the June 2012 network meetings parents were asked to identify the actions they wanted to see around 14 identified priorities in the new SEND strategy. The outcomes of these meetings can be seen on the pinpoint website: <http://pinpoint-cambs.org.uk/pinpoint-reports> and were presented to the SEND Project Board in February 2013.

Parents identified six top priorities in June 2012. At these June 2013 network meetings, pinpoint shared a hand out with the six priorities which showed the actions that parents had requested.

Pinpoint also shared a Parent Partnership Newsletter (Special Edition) which outlined how each of the 14 priorities was being addressed. See: <http://www.cambridgeshire.gov.uk/childrenandfamilies/specialneedsdisabilities/supportforparents/parentpartnership/parentpartnershipnewslettertrainingevents.htm> for a copy of the newsletter title Parent Partnership Service update on SEND strategy 2013.

Parent feedback on actions for the six priorities

pinpoint put up each of the six priorities on the blue sticky wall and underneath each priority, the actions that were highlighted in the Parent Partnership (PPS) newsletter. Pinpoint then asked parents what they thought of the actions. In all of the meetings, there wasn't enough time to gather feedback on all six priorities so we worked through as many as possible, sometimes prioritising ones that parents felt were most important.

Parents' comments are listed below in bullet points under each of the priorities and under the specific actions for those priorities. Comments from professionals (from when parents' comments were fed back to them later in the meeting) are written in italics. Priorities and actions that were not discussed or commented on in the meeting are not listed.

Priority Information on SEND to be easily accessible and available

General:

- Rely on pinpoint newsletters, format easy to read, good that it is weekly
- Website (SEND) is very good but need to be notified

Action Consultation with parents in February 2013 on 'Local Offer': 3 events; on-line questionnaire

- Parents need to give email to lots of different organisations
- SCIP useful for activities and referrals
- SCIP – not sure what it gives parents
- Emphasis on parents being pro-actively notified
- Heard via pinpoint, no emails from PPS
- Parents need to know when things changes

Action SEND website: information by age range or topic, type of SEND to be added; link box for feedback

- SEND website very good
- Note everyone understands the term SEND
- Search for website – additional needs, special needs?
- *Let us know what words would help*

Action Easier to understand reports – Community Educational Psychologist (EP) Service has reviewed and improved how they communicate in writing to parents.

- No change in statements notices
- Send by email (electronic) please

Action Continue to seek feedback on: development of local offer and SEND website; ways to receive information other than internet; evaluation of SEND services and communication

- Alerts for when content changes
- Key new things on a weekly basis
- Template approach – opportunity to look at
- Online public forum
- FAQs
- *Improve information from schools*

Priority Continuing professional development for those who work or support children and young people with SEND

- Include social care and health professionals

Action Training provided this year: recognised qualifications for all new SENCOs; qualifications for dyslexia; autism (Early Bird Plus); speech and language (Elklan); effective use of TAs; managing positive behaviour (Team Teach); restorative approach – promoting behaviour that builds and maintains relationships

- Depends on good head teachers
- Any good head should be doing this
- Parents need to ask for it – funding issue?
- Had most of above and very good
- Inconsistent approach – training from parent or medical professional. Need process e.g. catheters / epi-pens
- Staffing issues stop TAs attending courses
- More use of technology (assistive)
- Flat in Grantchester – open to parents?
- Parents need to know what training is available
- Support parents to ask this re: training
- *Termly training brochure and flyers*
- *pinpoint website – add assistive technology*
- *Education ICT service exists*

Priority Parents value SEND support networks and forums

Action PPS provided 23 sessions for parents to consult and discuss including: behaviour and attention difficulties; helping your child to read; advice on who can help with further education and employment

- Always in day – need evening session (*July 2014 will have an evening session*)
- Make it online and video
- Is there a crèche?
- Improve email from PPS
- Sometimes fully booked and then poorly attended
- Book by phone or email
- More alerts and reminders
- Want info about private services
- *Have no control over services and keeping a directory up-to-date can be difficult*

Priority Services should work together

Action Working to extend 'key working' approach to coordinate services, and provide emotional and practical support

- Parents support of this concept
- More use of email
- Loved 1 person to coordinate and liaise
- People move on – gap in service (nothing for 2-6 months)
- Older children needing more support (10 – 13)
- Children not able to access services without a social worker

Action Developing a multi-agency Autism Pathway

- What about physical disability pathway?

Priority Parents want to be treated as equal partners

- Statement review process too lengthy
- Panel too secretive, need transparency
- Information should be shared with parents re: who is on a panel?
- Panel terms of reference on website
- Parents not getting paperwork in advance of meetings

- *Looking at opportunity for parents to be involved*
- *Factual information on panels is on website*

Feeding back to commissioners and service providers

Commissioners and service providers joined the meeting at 11am. After introductions and going over the ground rules, parents fed back on the priorities and actions from the morning. Comments from professionals are written in italics in the above section.

Update from commissioners:

Jane Ryder-Richardson, Head of Access for Enhanced Services, gave an update on the reforms to SEND at a national level with key highlights from the Children and Families Bill. See **Appendix 1**.

Jane also gave a talk on the Single Education, Health and Care (EHC) Plan, also known as the Single Plan. See **Appendix 2**. Jane asked parents to work in groups with service providers to answer questions on what would a good single assessment look like, what do you value about the current assessment process and system, and what would you like to change? Jane collected parents' responses which she will summarise and use for the development of the single plan.

Michelle Docking, Manager for the STAR Team, told parents that the statutory assessment process is being reduced from 26 to 20 weeks and shared a table which outlines the steps in the old and new processes. See **Appendix 3**. The new process will be practiced on statements from September 2013. Michelle asked parents to feedback on how they would like to be involved in drafting statements in the new process. Parents fed back as follows:

- Template (process) good, email feedback on it
- Personal budgets will be good, meeting to discuss best approach
- Panel members to see more of the process / be involved? Understand background
- Like parents being involved but advocacy / mentoring may be needed
- Who can advocate for non-education issues?
- Include special schools in pilot
- FSP approach is good, continue
- How does single plan fit / integrate with PIP (16+ years) and other plans?

Evaluation

We asked parents and professionals 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

- Great session, thanks
- Enjoyed it
- Very informative
- Meeting other parents and service providers

Didn't like this

No comments made

More of this

No comments made

Anything else?

No comments made

Feedback received via email after the meeting:

I was thinking it might be an idea after the initial parent feedback gathering and discussion to go straight into the service provider section, that would naturally bring the feedback out and would allow more time for the SPs to present and for those who have to leave early to have heard from the SPs. We know you have captured and will represent our views from the first section anyway so once you have them you have them, we don't necessarily need to go through them again with the SPs . Does that make sense?

Next meeting

The next meeting will be held on 10th October 2013 from 10am – 2pm, venue t.b.c.

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, presentations 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 July 2013.

Appendix 1

Update on the Reforms to Special Educational Needs and Disability (SEND)

The National Context: SEND Green Paper and proposals for new Children and Families Bill 2013

- ◆ The vision
 - Early recognition and support
 - Staff knowledge, understanding and skills
 - Parents knowing what they can expect from services
 - An integrated assessment and single plan 0-25 years for children and young people with complex needs.
 - Greater control for parents
- ◆ The commitments
 - single assessment process
 - Education, Health and Social Care Plan
 - offer of personal budget
 - a 'Local Offer'
- ◆ Draft Legislation and indicative SEND Code of Practice

Children and Families Bill - Key Highlights

- ◆ Involvement of children, young people and parents at the heart of legislation, including assessments and local offers.
- ◆ More streamlined assessment process, which integrates education, health and care services, and involves CYP and their parents.
- ◆ New 0-25 Education, Health and Care Plan, replacing Statements and Learning Difficulty Assessments, which reflects the child or young person's aspirations for the future, as well as current needs.
- ◆ New requirement for LA, health and care services to commission services jointly to meet the needs of CYP with SEND.
- ◆ LAs to publish a clear, transparent 'local offer' of services for all CYP with SEND, so parents can understand what is available.
- ◆ New statutory protections for young people aged 16-25 in FE, and a stronger focus on preparing for adulthood.

Timetable for the new Code of Practice

- **Stakeholder engagement** - September 2012-January 2013
- **Initial Drafting** - New Year 2013
- **Publish indicative draft of Code to support Parliamentary progress of the Children and Families Bill** - Committee Stage, Spring 2013
- **Public consultation on draft Code** - Autumn 2013
- **Code of Practice laid before Parliament** - Spring 2014
- **Final Code of Practice published** - Spring 2014

This means that there will be opportunities throughout the process to be involved in commenting on the new Code.

Appendix 2

Single Education, Health and Care (EHC) Plan

EHC Plan

- ◆ 0 – 25 years
- ◆ A streamlined assessment process, which integrates education, health and care services
- ◆ Children, young people and families are central throughout the process
- ◆ Replaces statements and learning difficulty assessments, and Individual Healthcare Plans (IHP)

EHC Plan

- ◆ Threshold for an EHC plan is the same as for a statement of SEN
- ◆ EHC plans extend statutory rights and rights to appeal to the Tribunal into further education.

We'd like to hear your views...

- ◆ What would a good single assessment look like?
- ◆ What do you value about the current assessment process and system?
- ◆ What would you like to change?

Appendix 3

STATUTORY ASSESSMENT PROCESS

	Request received	Parental Agreement	LA Decision	Statutory Assessment	Drafting	Final and Resources
<p>Current process</p> <p>26 week process</p> <p>Final outcome is a Note in Lieu or Statement of SEN</p>	<p>Request received from school, parent, setting or other professional</p> <p>Day 1 of week 1</p>	<p>LA secures parental permission to consider the request</p> <p>To be received within 29 days</p>	<p>LA decides whether the evidence indicates that it is necessary to undertake a statutory assessment</p> <p>Within 6 weeks a decision must have been made</p>	<p>If agreed LA contacts parents and professionals requesting up to date advice (reports). LA monitors receipt of the advice and gathers the reports submitted</p> <p>Must be received within 16 weeks on the start date</p>	<p>The LA considers the advice submitted. If the advice received supports the drafting of a Statement the LA will agree to issue a draft/proposed Statement If not agreed a Note in Lieu (NiL) will be issued</p> <p>LA issues a draft/proposed or NiL by week 18</p>	<p>Parent/carer has 15 days to respond to the draft statement. At this stage parent/carer can ask for a meeting or just confirm their agreement to the draft Statement. The parent will also indicate their preferred school. LA agrees (through a panel process) the level of resources required to meet the needs detailed</p> <p>Process must be completed within 26 weeks</p>
<p>Proposed Process from September 2014 (TBC)</p> <p>20 week process</p> <p>Education, Health and Care Plans (EHCP)</p>	<p>Request received from parent, young person (or person acting on their behalf) school or other professionals such as Health, Youth Offending Team</p>	<p>?</p>	<p>LA decides whether the evidence indicates it is necessary to undertake a statutory EHC assessment</p> <p>Within 6 weeks a decision must have been made</p>	<p>If agreed LA contacts parents and professionals to gather the evidence required for a statutory EHC assessment. LA monitors receipt of the advice/reports and gathers the reports submitted</p> <p>Must be received within 12 weeks of the start date</p>	<p>The LA considers the advice submitted. If the advice received supports the drafting of an ECHP the LA will agree to issue a ECHP.</p> <p style="text-align: center;">Drafting Process</p>	<p>Parent/carer has 15 days to respond to the draft EHCP, At this stage parent/carer can ask for a meeting or just confirm their agreement to the draft plan. The parent will also indicate their preferred school. LA agrees (through a panel process) the level of resources required to meet the needs detailed. The ECHP will name a setting, school or college.</p> <p>Must be completed within 20 weeks</p>