

Pinpoint Cambridgeshire is a Registered Charity, No: 1156920

Parent Network Meeting – Community Health Services

South Cambs, 13 June 2016 (daytime)

Papworth Trust, Papworth Everard

Attendees

Parents: 8

Service Providers: Jo Sollars, Siobhan MacBean (From 12pm), Janine Newby-Robson, Diane Gypps, Jackie Taylor, Stevie Parker, Amanda Mckenzie, Liz Morris, Marie Tamou, Laura Potter.

Pinpoint: Eve Redgrave, Kari Payne

Overview

The topic for these network meetings was improving community health services. Professionals from Cambridgeshire community services (CCS) presented on the new service model 'The Flower' and answered questions on their services and how to access them. Parents worked in groups with providers from services including local authority representatives from E and P (Enhanced and Preventative services) social care, core assets and healthwatch as well as CCS to discuss the new model for services and information on Global Development Delay and development milestones. After the group work, each provider fed back the key points which had been captured on flip chart paper and are recorded below. There was then a mini training session around Incontinence run by Dr Jackie Taylor a paediatrician that included information about the service and treatments as well as a Q and A session. The parents had a chance to talk individually with each other and service providers over lunch.

Feedback from group work

The Flower

Multi-disciplinary teams:

- Need an explanation of who attends

Access to Services:

- Signposting is needed regarding the opening of CAF and a route back into the service.

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Quality:

- Managing expectations for service users – a visual guideline to who does what in areas such as social care, Health and Education etc.

Development skills leaflet

- Not too easy read – parents want a leaflet that treats them as intelligent individuals
- RNIB guidance could be included.
- Nutrition information needs to be included.
- Expand sensory and cognitive developmental aspects.
- An online option for the red books?
- Expand the social community aspects.
- Universal colour coding would make navigation of services easier.
- While an average age for milestones would be beneficial the order is more important. In addition, an explanation of why each stage is important.
- Signposting – for example; ‘if you are unsure about this you should contact Health visitor’
- Would be beneficial to have the leaflet in advance rather than parents doing on the spot reviewing. Would assist parent contribution.

Next Steps

The feedback from the group work will be collected and analysed across the five network meetings and shared with Cambridgeshire Community Services, Social care and Education services, including the Health Joint Commissioning Board. Our new ‘Are You Listening to Parents’ feedback form will be used to highlight the issues around Post 16 healthcare and lack of transition planning. Pinpoint will update parents on how this work is taken forward.

Incontinence/Contenance Training Notes

Timescales

Typically developing children become “toilet aware” between 3-4 years old. For children with delayed development, that milestone will be later. Only a small group of children will never become continent – usually those with gastro problems, spina bifida and learning disabilities or cognitive issues who have a development age of less than two.

Urinary continence

Night-time wetting is usually due to children sleeping very deeply and not connecting the need to wee and waking-up. There are aids available to tackle this, such as alarms.

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Dr Taylor said a lot of children start school still in nappies – perhaps because of today's busy lifestyle and because disposable nappies are so good and so convenient. "We've seen a real slip back. Nearly every school we questioned had children starting in nappies."

Bowel continence

Constipation: it's not how often you go to the loo, it's how difficult it is to go. Constipation can start early, when babies move from breast-feeding to formula or when starting to wean. Dr Taylor advised parents to "nip the problem in the bud because if it is not tackled early, it can go on for years and years and cause long term effects. Some 5% of five year olds have constipation but it is very easy to treat. Very few children have a physical problem that causes constipation.

TOP TIP: After a big meal, your bowel will contract, so sit the children on the loo 10 minutes after eating. Make this a regular part of the daily timetable.

Good to try first:

- More fruit
- More water

Who to talk to if you are concerned

If your child is pre-school age see a health visitor.
For school age children, see your school nurse or GP.

Online information

ERIC is a children's continence charity that is recommended by the NHS. [Visit the website](#)

Autism and continence leaflet: [download](#) via the Cambridgeshire Community Health website

Runny bowel movements

If your child has regular runny bowel movements, try dropping fibre from their diet.