

Pinpoint Cambridgeshire is a Registered Charity, No: 1156920

Parent Network Meeting – Community Health Services

Ely, 24 June 2016 (daytime)

Ely Library, Ely

Attendees

Parents:

Service Providers: Janine Newby-Robson, Sharif Al-Rousi, Josh Hang Gong, Nicola Foreman, Caroline Noble, Diane Gypps, Susanne Jessop, Sylvia Nicklin, Sam Marshall, Tessa Shaw, Chloe Darlow, Judy Hunter, Helen Goddard, Mandy Mayes, Donna Sparrow

Pinpoint: Eve Redgrave, Carole Darlow

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, development milestones and the current sleep service, including individual sleep issues. 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 selective eating run by Sam Marshall, Dietician that included information about the service and tips 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

- Early support is vital but needs to continue
 - Should include support for the whole family
 - Support with parents' relationships
- Technology
 - A digital passport could include all information in one place.

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- Would stop the need to have to start from scratch when moving to a new area
- Not just health, needs integration between health, education and social care
- Due to staff turnover a lead clinician may not be the most appropriate mean of co-ordination – perhaps family led support?
- Offer alternatives to face-to-face meetings such as teleconferences or Skype appointments.
- Information and signposting – ‘one stop shop’ for information
- Include crosslinks between websites which are kept up-to-date.
- Transition to adult services
 - Who helps to co-ordinate this?
 - Clarity on the role of a parent in managing a young person who is legally seen as an adult but not necessarily able to describe their needs and problems
 - There is a need for a 0-25 service to fill the gap left by different transition ages for different services
 - Parental input post-18 is not valued by professionals
 - Working within the Mental Capacity Act 2005
- No access to services where there is no diagnosis

Development Skills Leaflet

- Who is the leaflet aimed at?
- Could suggest that it is only for those with a diagnosis of Global Development Delay, would ‘Does your child have Global Development Delay?’ be more appropriate?
- Where would the leaflet be available? Children’s centres, School receptions, pre-schools, health visitors?
- Should include environmental aspects and expectations of the adults
- Could it be offered online/interactive? Click the stage your child is at and it could signpost what could be expected next.
- Issues relating to clarity such as unclear information and lack of emphasis on stages
- How often would the leaflet be updated? Should include date produced and proposed review date in order to keep information relevant
- School training
 - Recognising SEND
 - Turn-over of staff would require a rolling programme and a succession plan
 - Only one member of staff with training is not enough
- Early intervention is the key
- Signposting of someone to talk to would give a personal approach
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Sleep

Concerns raised:

- Strategies are not working
- Early waking and once awake refuses to go back to bed
- Concerns over keeping the child safe (tired parents are not always aware when a child has woken up)
- Parents feel that there is often a lack of knowledge from professionals.
- Is there specialist support, such as help and advice as an alternative to medication?
- Parents feel they need more support in management of waking periods and parental tiredness
- It is felt that there are too few professionals with training relating to sleep issues and knowledge regarding the relevant medication
- There is no continuity or 'joined up' support
- It was felt there were not enough visits for children who had complex needs
- come from peers and via social media such as youtube.
- Where some support is available such as through the GP not all families are able to access the help and support
- Some families felt that they were not always able to access their GP and were instead left being judged by a GP's receptionist.
- Information and knowledge as to why the issue with sleep was arising.

Moving forward:

- More information relating to diet (including timing of meals), environment and routines
 - Advice should be appropriate to age and capability of the child
- Additional peer support such as parent groups.
- There are limited visual aid resources and simply worded leaflets
- Some parents found that so far the most valuable support had come through social media such as youtube and it was felt that this resource could continue to be useful. For example, a real time support network via skype or a dedicated app.
- It was felt that more vulnerable families may have issues accessing the help and support, such as those with learning difficulties.
- Creating regular reviews with a dedicated individual
- All support should focus on the needs of the child/family rather than being budget led.

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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.

Selective Eating Mini Training Notes

Most people have a food preference, humans are visual, we know what is safe to eat through our senses. What we learn as children follows us through to adulthood. We are all naturally programmed to love sweet and fatty foods and we have to work hard to like tastes of foods that are better for you. The more you try the more you get used to it. When a baby is 6-12 months old they need to try as many new foods as possible, by the time a child is 1-2 years old they develop a fear of the new so will try less. This dies down between the ages of 5-7 years. At this point you should calmly try new foods again and don't give up. Everyone is on a sliding scale of sensory hypersensitivity, some feel difficulty eating and this causes stress. Exposure to new foods will help this, do not try to hide foods in others as a child will find these and clam up even more. Put a separate plate for new foods so it doesn't touch their 'safe' food. Relax! If they don't eat they will still be fine. Meals should last no longer than 30 mins, if they haven't eaten, let it go for that meal. Check the child's weight and growth but as long as there is a balance of foods throughout the **day** not necessarily each meal all will be fine. Multi vitamins will help. Doing messy play and cooking with new food first can help them wish to try it. Use motivation charts, get the child to rate the food from 1-10. They can get points for 'yummy' food. If a family eats well it is likely a child will too, role models are very important. Talk through what is expected at dinner time, plan times and how long they will be at the table for. This can be a slow journey, be prepared. Red flags to watch out for are losing weight and more restrictive diet occurring. For stomach/bowel issues keeping a food diary can help. There are actually no true tests for intolerances, you just have to note what foods seem to cause problems. It is trial and error. For those children who emotionally eat, try to work out the trigger situation, find other things that keep them happy and distract them from the food. Give them a drink first to dull the hunger.



0318 - Food Refusal Toddlers.pdf



0329 - Food Refusal 4 - 11 years.pdf