

Pinpoint Cambridgeshire is a Registered Charity, No: 1156920

Parent Network Meeting – Community Health Services

Huntingdon, 14 June 2016 (daytime)

The Medway Centre, Huntingdon

Attendees

Parents: 15

Service Providers: Jo Sollars, Janine Newby-Robson, Diane Gypps, Stevie Parker, Sandra Okpeoha, Jo Laur, Alison Hanson, Hollie Willett, Jane Crittenden, Jade Hellett, Heather Davies, Diane Jackson

Pinpoint: Eve Redgrave, Carole Darlow, Jackie King

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 Hypermobility run by Stevie Parker Physiotherapist 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

- Parents need more information about all the different services and how they benefit/impact children.
- It was felt that there is a lot of targeted support for individuals with autism and families of children with other difficulties felt over looked at times.
- Would be advantageous to have the referral criteria for paediatricians, CAMHS and other services to avoid repetition.

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- Would be helpful to have a 'job description' for each department in relation to what each individual does would be advantageous, for example what is the difference and overlap between and the Occupational Therapy and Physio teams.
- It is important that parents know who the lead professional is.

Development skills leaflet

Required additional information:

- Signposting
- How to contact services
- When checks should be made and health service contacts
- Awareness of mimicking and masking over of symptoms

Health visitors

- Importance of think family
- Identifying concerns

Educational psychologists

- Link for cognitive and social emotional sections

'Jargon'

- As many professionals will only use 'jargon' it is considered helpful that parents have encountered this language previously (along with explanation)

When should the leaflet be available? Suggestions

- In maternity services pack
- Electronically in local offer
- In poster form in paediatric waiting areas
- It was felt that a hard copy was the preferred option

Additional leaflets

- Advice on sensory needs, for example socially acceptable strategies such as fidget boxes in class
- 'Easy read' leaflets

Colour co-ordination throughout, for example pre-rolling

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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.

Hypermobility Training Notes

What is Hypermobility?

Joint hypermobility is when some or all of the joints have more flexibility than average. Some people refer to it as being "double jointed" or "loose jointed". It can affect different joints such as the elbow, wrist, fingers and thumbs that bend backwards, legs and feet. And can range in severity. Hypermobility is more common in children where one or both of their parents were also hypermobile (inherited). Hypermobility can resolve itself on its own. Children with hypermobility need to develop good muscle strength, control and stamina to help control the extra movement of the joints. When a child has low muscle tone, their joints can become hypermobile due to reduced muscle control.

There are two types of hypermobility

- Benign – bendy with no symptoms
- Symptomatic – bendy with pain

What difficulties does it cause?

In most people, hypermobile joints don't cause any problems. It is important to remember that in conjunction with strong muscles, hypermobile joints can be of great benefit e.g. the ability to stretch fingers widely when playing the piano. Some of the best sports people, gymnasts, dancers and musicians-have-hypermobile-joints. However in some children, it can lead to painful joints and stiff muscles. The pain is related to strength and endurance, not the hypermobility itself, and this can affect co-ordination.

Children's bones and joints need some degree of "bend" to because they fall over so much.

Some are truly hypermobile, some are just normal but with some variations.

Core strength can affect hypermobile hands. A strong core is vital and helps bodies work at their best.

Top Tips

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- If they are listening or watching TV, think about getting them to try sitting in a better position for their body.
- If a child is concentrating on trying to sit still and straight, try not to ask them to do much else. If they need to concentrate to do this, let them sit in a position that's most comfortable for them.

Ideas to improve co-ordination and strength

- Balance bikes. These bikes have no pedals, gears, or a chain. Your children push themselves along with their feet, learning balance
- Regular exercise such as swimming, which supports the weight of your body
- Targeted exercises. Read and download some example sheets from the [Cambridgeshire Community Services website](#)