pinpoint
for parents by parents

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Parental involvement network for parents of disabled children

Notes from the Huntingdon network meeting

Date: 5 March 2013 **Time:** 10am – 2pm

Venue: Medway Centre, Huntingdon

Number of parents and carers: 13

Service providers joining at 11:00am: 18

Facilitator: Lenja Bell, pinpoint

This was the 13th parental involvement network meeting for Huntingdon.

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 each other's views
- There are no wrong answers or silly questions
- Everyone will have the chance to hear and be heard
- We respect confidentiality
- Everyone will be able to understand what people are saying – avoid jargon
- We do not judge others

Hot topic: Emotional and well-being support for parents

Background

For a long time parents have been emphasising the importance of emotional support. This type of support is a cornerstone to enable parents to look after their children and themselves. After the March 2012 network meetings which focused on health services, commissioners (those who purchase services) started to listen and build this type of support into service specifications. Specifically:

- Home and Community Support – service provided to families with children under 5 now includes peer support for families of disabled children
- CAMH LD Service – emotional support for parents built into service provision
- Midwifery/Health Visitors – support at time of diagnosis
- Early Support - development of key workers
- Parent Support Strategy – to pick up need for wider support for children over 5 and their families
- Additional Needs Family Worker – one–to–one and group support
- Transitions – one-to-one support, peer support and advocacy
- Adult Services – support groups for parent/carers

The provision of emotional support has not been completely specified yet and this is an opportunity for parents to say what kind of support they need: when, where, how (from whom), etc.

Group Work

Parents worked in groups to answer the following questions:

- What is good emotional support?
    - **When** do you or did you most need emotional support? At what points? e.g. at diagnosis, after diagnosis, during assessment, during transitions, etc.
    - **How** would you like to receive emotional support? **From whom**? **Where**? e.g. paediatrician, school (from whom?), parents, etc.
- What emotional support has worked well for you? What made you feel better? e.g. parent groups, friends, a service provider, etc.
- What emotional support is missing? When do you feel most vulnerable? What makes you feel vulnerable?
- Anything else?

Some earlier quotes from parents around emotional support needs were read out before the group work started:

- Help me help my child.
- Support needs to be proactively given – including when no diagnosis – when and where needed
- Listening ear
- On-going, continues as child gets older
- From other parents and one-to-one support
- Family therapy
- Support for siblings

Discussion with service providers

Service providers joined the meeting at 11am. pinpoint reviewed the ground rules and updated everyone on what parents had been working on in groups. Parents then fed back their responses to the questions from their groups and individually. Parents and service providers discussed the responses together. Comments from service providers are in italics.

What is good emotional support?

When do you or did you most need emotional support? At what points? e.g. at diagnosis, after diagnosis, during assessment, during transitions, etc.

- Transition to secondary school
- Dealing with school
- At ADHD diagnosis
- Dealing with other parents at school
- After starting school
- After diagnosis, and the following months
- Secondary school
- When problems begin in school
- During assessments, prior to diagnosis
- During assessment process and no diagnosis (from 1½ to 4 years old)

How would you like to receive emotional support? From whom? Where? e.g. paediatrician, school (from whom?), parents, etc.

- From whom?
  - pinpoint
  - Paediatrician at diagnosis
  - Peer support
  - Positive views from other parents
  - Parent with a child with similar diagnosis
  - Parent to parent – introduction
  - Keyworker
- Where?
  - From school to parents (website, leaflets)
  - Parent working with school
  - Entering school

What emotional support has worked well for you? What made you feel better? e.g. parent groups, friends, a service provider, etc.

- Homestart up to 5
- Camsight group
- Parent support group
- Other parents of disabled children
- Butterfly team – autism nurse
- Health visitor visits
- Mental health nurse for ADHD for parents and young people

What emotional support is missing? When do you feel most vulnerable? What makes you feel vulnerable?

- On-going mentor from start of journey, peaks and troughs
- Nothing when letter comes through post (x 2)
- Stressful just trying to get support
- Reading a statement – person to support with it
- Support after 5
- Need service provider to attend meetings with you
- Ask me if I'm alright
- No evening and weekend (out of hours) support
- Portsmouth keyworker – 999 response
- Misinformation around family workers, social workers, etc. – what do they do?
- Support for parent older teens and young people
- *Communication needed*

Anything else?

- Cross-boundary support, school/home
- Knowledge base – lost when people change jobs
- Schools and school websites
- Reports in easy language
- Social workers not for me
- Parents need to be listened to
- Lack of awareness of services and organisations

- Didn't know about CAF (Common Assessment Framework)
- Statement and CAF?
- LSA's and teachers need training
- Raise pinpoint profile
- Parents want to help
- Family worker drop-in – tell parents
- CAF for family worker
- How can we get service providers to come to annual reviews?
- How do we get info to parents?
- Scared of service providers – interference?
- Parents being told 'over-reactive' mum – no support

<u>Emotional Support for Parent Table</u>

Eva Alexandratou, Joint Commissioner for County Council and NHS Services, passed out a sample of a table which she is developing around emotional support for parents. She asked for feedback from parents and service providers. Comments were:

- Age group it applies to
- On internet
- Come from paediatrician, default with brown envelope
- From SENCo's
- Come up in a search on the internet
- Paper copy from service provider
- How do we know if we need help?
- Add transition element (to adult services)

<u>Evaluation</u>

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. See feedback below:

Liked this

Parents:
- Lots of providers
- Very interesting

- Listening to other parents and providers
- Someone with an ear ☺

Didn't like this

No feedback given

More of this

No feedback given

Anything else?

No feedback given

Next meeting

The next meeting will be held on 18 June 2013 from 10am – 2.00pm at the The Medway Centre, Huntingdon.

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 other groups that pinpoint is represented on.

2. Add the network meeting notes and summary report to the pinpoint website. Send the link to all those attending the meeting, and include in our weekly update.

3. Discuss key issues arising from the district network meetings at the county Partners in Commissioning Group meeting.