
Parental involvement network for parents of disabled children

Notes from the East Cambs network meeting

Date: 15 March 2013 **Time:** 10am – 2pm

Venue: Ely Cathedral Centre, Ely

Number of parents and carers: 13

Service providers joining at 11:00am: 14

Facilitator: Lenja Bell, pinpoint

This was the 13th parental involvement network meeting for East Cambs.

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.

- While coming to terms with diagnosis, grief, etc.
- When there is no diagnosis
- Always – need never goes away
- Value what I say
- Before reaching crisis
- At delivery of diagnosis and prognosis
- At the beginning, pre-diagnosis
- Not just when things go wrong
- Pre-birth, after birth, school, leaving school, changing school

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

- From whom?
 - Someone with life experience
 - One point of contact, any time
 - NAS helplines
 - Family workers
 - Key worker – continuity of care
 - Other parents generally and with same diagnosis
- Where?
 - 24 hour helpline
 - By phone, timing!

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

- Tea and cake
- Community nurse

- Doing something different for self
- Parent Partnership Service
- Parents and parent groups
- The Croft – family counselling
- Good GP
- Social services
- Highfields Parent Support Group
- pinpoint meetings
- Continuity of keyworker – in Leicestershire for ASD
- SIBS – sibling group, also supported parent
- Papworth Trust
- Talking to others in/not in same situation

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

- Service providers need to listen and believe parents = good emotional support
- Support for all parents not just those that are assertive
- Lack of Aspergers support
- Offer of support for parents
- Parents given worst case scenario without counseling and support
- Support not timely
- Mental health support for dad
- Needs are often urgent – mental health too slow to respond or give appointments
- Difficult to get services and support without diagnosis
- Continuous support – statement or not, diagnosis or not

Anything else?

- Education finding right support – difficulties with SEN
- Family support very variable – need to inform extended family
- Finding support for rare disorder and diagnosis
- Direct parents to CAF
- Unclear how 'system' works, nothing offered – parent has to search or ask

- Something to look forward to
- Delivery of diagnosis need to be more sensitive and supportive
- Parents have to push and fight for services
- Need to know you are not on your own fighting the system
- Some services more/less supportive – sight services good
- Information needs to be in a place parents can access e.g. disability benefits (Papworth)
- Services not focused on prevention of crisis
- Let down by health and education
- Parents not able to ask for help, too emotionally exhausted
- Parents need to be ready to accept help and support
- Parents blamed for problems
- Support in school very variable
- Services need to improve communication with and informing parents
- If we are not well we cannot look after the kids
- Service providers need to be well-informed and able to sign post
- Parents reluctant to show they are struggling emotionally – fear of repercussions
- I'm not only a 'parent of a disabled child'
- Service providers to listen and hear message – parent is expert

Emotional Support for Parent Table

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:

- Improve information from schools. Make it more available – every child goes to school.
- Make sure no one gets in the way of sharing information, specifically schools.

Evaluation

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

No feedback given

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 28 June 2013 from 10am – 2pm at Ely Cathedral Centre, Ely.

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.