
Parental involvement network for parents of disabled children

Notes from the Fenland network meeting

Date: 13 March 2013 **Time:** 10am – 2pm

Venue: Oasis Community Centre, Wisbech

Number of parents and carers: 12

Service providers joining at 11:00am: 12

Facilitator: Lenja Bell, pinpoint

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

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.

- During hospital admissions – parent cannot leave the child
- Before a crisis, not in a crisis
- After diagnosis when parent has had time to think about questions
- Diagnosis, pre-diagnosis – during assessment
- When you know your child is different
- Going into school at foundation
- Never stops, any time
- At different stages of development – transitions, etc.
- At delivery of diagnosis – blunt delivery

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

- From whom?
 - How the news is delivered is very important
 - By phone
 - Other parents – parent to parent support
 - Parent support groups
 - Family worker signposted by school
 - Service providers now giving more consideration to parent well-being
 - Someone calling you – pro-active
- Where?
 - Schools need to be communicating to families about family workers
 - When there is no diagnosis where do you get help?
 - Map would be helpful

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

- Children's Centres
- Educational Ombudsman
- Family Service Coordinator (now gone) for any child with additional needs
- Parent support workers
- Parent support groups
- Emergency carers response
- Health visitor
- Befriending service – Scope parent to parent, no age limit (Peterborough)
- Paediatrician

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

- Parent battling and feeling unsupported
- During statement process – parent not supported
- Service providers/other parent helping and supporting at meetings
- Pamper days
- Homestart service for over 5's
- Services need to be more focused on the child
- Sibling support groups

Anything else?

- Open and transparent dialogue with parents from all involved
- Having to battle creates emotional needs and problems for parents
- Parents are the experts – need to be believed, not exaggerating issues/ characteristics
- Child presents differently in different places e.g. school/home; holistic view
- Clear explanation from service providers
- Preparing parents for road ahead – fighting for your child
- Schools are gate-keeping information
- Why would a parent lie about their child's behaviour?
- Consistency in practice e.g. paediatrician – not dependent on individuals
- Parents drained by fighting the system
- Parent giving up work due to lack of support

- Child's emotional well-being not considered during statutory assessment – need more holistic view
- Special needs associated with poor parenting
- Different routes to get services – too many links in the chain
- Family outings need extra adult support – sibling support
- Outings – coach trips with family workers
- Cross border county/LA issues
- Entry threshold to CAMH is high – long waiting times
- Services haven't changed or improved in 20 years
- Service depends on individuals going extra mile
- Outcomes/needs centered planning

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:

- Get information from paediatrician at diagnosis
- Get information from parent support groups
- Combine pinpoint 'People to Talk to' leaflet
- Website with flow chart – age, problem, social need, to who to contact
- Include sibling support
- Challenge to keep up-to-date
- Include autism specific information

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

Parents:

- To hear different views on what people have experienced with their child/young person

Service providers:

- Chance to really hear the parent/carer perspective

Didn't like this

No feedback given

More of this

Service providers:

- Parents being able to be part of the solutions!

Anything else?

Parents:

- Workshops/talks for autism
- Benefits

Next meeting

The next meeting will be held on 28 June 2013 from 10am – 2pm at the Oasis Community Centre, Wisbech.

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.