pinpoint
for parents by parents

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Parental involvement network for parents of disabled children

Notes from the Cambridge City network meeting

Date: 7 March 2013 **Time:** 10am – 2pm

Venue: Orchard Community Centre, Cambridge

Number of parents and carers: 12

Service providers joining at 11:00am: 17

Facilitator: Lenja Bell, pinpoint

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

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.

- Diagnosis of 2nd child – support needed
- School exclusions and part-time attendance
- Life long support
- At diagnosis
- At diagnosis, ante-natal if possible
- Someone to talk to when first recognised delay
- Pro-active peer support, in hospital, at home (1st year important)
- Before, during and after
- Ante-natal support
- 1-to-1 support from service provider/parent, etc.
- More focus on parent well-being, not just child
- Different life stages and transitions
- Sibling dynamic changes
- Entering secondary school

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

- From whom?
    - LEA obligation and home tutoring
    - Downs Syndrome group
    - Carers support group, pinpoint
    - Other parents but with support and right reason
    - School nurse
    - Meeting others parents who listen and understand
    - Specialists and other families and parents
    - Family support practitioners at Addenbrooke's

- Where?
    - Luck of the draw, support depends on health visitors, school nurse

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

- Pre-birth support and information (not UK)
- Counsellor pre-birth and first 12 weeks
- Specialist advice pre-birth and post-birth
- Home Start, but stopped at 5
- Portage worker – good service provider relationship
- Family support workers from Disability Team (gone now)
- Children's Centres

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

- Needs a place to let our negative feelings and quilt, safe environment
- Therapeutic support group and good judgement
- Counselling for parents
- Honest, open communication with parents
- Dealing with shame, isolation
- No emotional support offered during early months
- Parents need to be listened to
- Someone to come to meetings with you
- *Increase in stressed parents contacting pinpoint*

Anything else?

- In-built fear with parents trigger a negative effect, OK to ask for help
- Some parents worried about Social Services intervention (fear)
- Balance of reassurance and follow up of parent concerns
- Information about benefits
- Support for siblings and whole family
- Training of service providers re: special needs and disability
- Issues around sleep deprivation – impact on health and well-being
- For fathers and wider family
- Value as a carer (higher allowance)

- Respite and short breaks
- Gap between parents and service providers – awareness training
- GP's – waiting room, recognition of carer (How are you?), receptionist
- Services can be "luck of the draw"
- Can you trust the service provider – what's their agenda?
- Matching parents can be difficult
- Relationship with siblings – looking a family unit
- Parents feel ashamed – don't want to go out

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:

- Need both – paper and electronic copy
- Need help explaining it
- For Parent Partnership Service, include information other than education
- More specific information on each organization
- Add age group
- Parenting programmes –specific on disability
- Search facility – age, condition filter
- National links e.g. Carers UK
- Facebook/Twitter
- Out of hours support line
- 'Child not born with additional needs' – take about 'born'
- Add newly diagnosed, entering school
- Bereavement – continuous struggle e.g. loss of child, loss of your own life
- Chronic – too medical, say long-term diagnosis. Are they health problems, how is this defined?
- Need to include acquired disabilities specific needs
- (Support) given at point of contact – when needed is identified e.g Welcome Pack

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:

- Opportunities to meet other parents and share experiences
- Feel our comments and experiences may be of use to shape polich and documents (feel values)

Service providers:

- Hearing directly from parents – useful to know what works and what doesn't, & I will more easily remember and act on their views
- Hearing it straight. Knowing what isn't helpful or hurts.

Didn't like this

Parents:

- Needed to shape parents views/experiences into more coherent whole
- The way feedback happened was too unstructured and too much time spent on one area (for example)
- Quite a lot of time on 'housekeeping' – would have liked to have had more time to make contributions

Service providers:

- The frustration of not having answers yet
- Similar heard for many years, not much better
- Wasn't sure what to expect when I came
- The table discussion was a little bit too long

More of this

Parents:

- Needed a break after parent feedback for Service providers to digest and then for them to feedback to us.

Service providers:

- More time to explore issue of sleep deprivation
- More work for parents to express their needs/strategies

Anything else?

Parents:

- Don't use surnames on badges or share personal information with parents
- Keep them coming!!
- Great opportunity to feel useful and valued

Service providers:

- Emotional wellbeing of siblings without disability

Next meeting

The next meeting will be held on 20 June 2013 from 10am – 2pm at the Cambridgeshire FA Conference Rooms, Impington.

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.