Disabled Children's Action Group
13 May 2013

Hot Topic: Emotional support for parents

Feedback from the pinpoint parent carer participation network meetings
March 2013

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Parent carer participation network

- **Local networks**: around 1200 participants, including 900+ who get our e-mailings; 500+ who are parent carers; 45 who are facilitating a parent support group; plus service providers and commissioners
- **5 district networks**: around 160 participants, including 80 parent carers
- One **county-wide network:** ‘Partners in Commissioning SEND’

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Parent carer participation network

- **Network meetings**: five termly meetings with a ‘hot topic’ focus, 60 - 80 parents attend
- **Action groups**: time-limited, e.g. Addenbrooke’s Action Group – which led to the introduction of a hospital passport; Continence Action Group
- **Agenda events**: one-off topic-focused events e.g. workshops, wheelchair workshop

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Parent carer participation network meetings

The network meetings are an opportunity for partnership working:

- openness and transparency
- different balance of power
- shared ground rules
- self-confidence
- independent facilitation
- support

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Parent carer participation network – March 2013 ‘hot topic’

Emotional support for parents

- What is good emotional support?
- What works well?
- What is missing?

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Emotional support for parents: What is good emotional support?

Parents (59 across the county) worked in groups to answer questions

- **When** do you or did you most need emotional support?
- **How** would you like to receive emotional support? **From whom**? **Where**?
- What emotional support has **worked well** for you? What made you feel better?
- What emotional support is **missing**?
- Anything else? What emotions are you struggling with – depression, grief, exhaustion?

Feedback was shared and discussed with service providers

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When do you or did you most need emotional support? (1 of 3)

- In hospital ante-natal, at birth, early months
    - Pro-active support
- At identification of need / assessment
    - “When you know your child is different”
    - During assessment
- At diagnosis
    - Sensitive and supportive delivery
    - “Nothing when letter comes through post”

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When do you or did you most need emotional support? (2 of 3)

- No diagnosis – "difficult to get services or support when there is no diagnosis"
- At school – "support after 5"
    - Starting school and transition to secondary school
    - Dealing with school and parents at school
    - Support in school is variable
    - Support is term time only
    - "Negative feedback from school affects parent well-being"

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When do you or did you most need emotional support? (3 of 3)

- Continuous
  - “Always – need never goes away”
  - “Before a crisis, not in a crisis”
  - “On-going mentor from start of journey, peaks and troughs”
- Other
  - No evening and weekend (out of hours) support
  - Out of school – child can be difficult
  - “More focus on parent well-being, not just child”
  - Support not timely – waiting lists
  - “Value what I say”

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How would you like to receive emotional support? From whom?

- Other parents
    - Parent support groups
    - Parent to parent support
- Service providers
    - Key workers, family workers, portage
    - Health visitors, midwives, nurses, paediatrians
    - School - respect for parent expertise
- Other comments
    - Reading a statement – person to support with it
    - Someone to come to meetings with you
    - Someone calling you, pro-active

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How would you like to receive emotional support? Where?

- School
    - “At school (can be a big source of negative)”
    - From school to parents (website, leaflets)
    - Parent working with school
- Telephone
    - 24 hour helpline
    - “Phoning during the day (weekday) can be very difficult for many reasons”
- At home, in person, email

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What emotional support works well?

- Parent support
    - Parent groups
    - Other parents of disabled children
- Under 5 support
    - Home-start
    - Children’s Centres
    - Health visitors
- Service providers (many different ones listed)
- “Doing something different for self”

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What emotional support is missing? (1 of 2)

- Support after 5
- Support for family members – siblings, dads
- Specific diagnosis groups
- Well-being support
  - “Need a place to let out negative feelings and guilt / safe environment”
  - Dealing with shame and isolation
  - Counselling / therapeutic support
  - “Ask me if I’m alright”

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What emotional support is missing? (2 of 2)

- Open and honest communication
  - “Professionals need to listen and believe parents = good emotional support”
  - Regular relationship with professionals
  - “Parent battling and feeling unsupported”
- Support for all parents
  - Not just those that are assertive
  - Offer of support (pro-active)
  - Reaching vulnerable families

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Anything else? (1 of 3)

- Professionals / services
  - “Professionals need to be well-informed and able to signpost”
  - “Consistency in practice e.g. paediatrician – not dependent on individuals”
  - “Lack of trained staff / teachers – stressful for parents”
  - “Lack of trust in professionals”
- Specialist support
  - For siblings and whole family, for siblings under 8
  - For family outings
  - Parenting skills, including sleep training

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Anything else? (2 of 3)

- Emotional well-being
    - Afraid or too exhausted to ask for help
    - “Having to battle creates emotional needs and problems for parents”
    - “I’m not only a ‘parent of a disabled child’”
- Communication
    - “Professionals to listen and hear message – parent is expert”
    - “Open and transparent dialogue with parents from all involved”

Anything else? (3 of 3)

- Information
    - “Unclear how ‘system’ works, nothing offered – parent has to search or ask”
    - Lack of awareness of services and organisations
    - Schools are gate-keeping information
    - Information needs to be in a place parents can access

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Summary – What is good emotional support? (1 of 3)

- Support around diagnosis
    - Before, during (assessment) and after
    - When there is no diagnosis
- Support after child turns 5, in school
- Continuous and out of hours support
    - Through peaks and troughs
    - Weekends and evenings
    - Not just during term time

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Summary – What is good emotional support? (2 of 3)

- Consistency across organisations, practices and professionals – not “luck of the draw”
- Communication
    - Open and transparent
    - Value what parents have to say
- Specialist and group support
    - Parent to parent
    - For family (siblings, dads, etc.) and relationships
    - For specific conditions

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Summary – What is good emotional support? (3 of 3)

- Support for parent’s well-being
  - A safe place to show feelings
  - “Having to battle creates emotional needs and problems for parents; parents drained by fighting the system”
  - “Positive feedback from professionals helps to improve parental mood and well-being”
  - Someone to support with meetings, reading statements, and to speak up for you

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Summary – What is the impact of parents not getting emotional support?

- Mental health issues
- Physical health issues
- Relationship difficulties
    - Marriage
    - Within family including siblings and wider family
    - Friendships
- “If we are not well we cannot look after the kids”

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Recommendations (1 of 2)

- Ensure that emotional support is available to parents from first identification of need (including pre-natal) through assessment to diagnosis, and if there’s no diagnosis (from 0 – 25 years old)
- Focus on gaps in support after a child starts school, extend Early Support / Home-Start approach?
- Look at offering an out of hours helpline
- Train staff working with families on emotional needs of parents, disability awareness (condition specific), communication skills, positive feedback, etc.

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Recommendations (2 of 2)

- Ensure that parents are supported to meet other parents and attend groups
- Ensure that parents have access to individual support as needed (at diagnosis, when reading a statement, etc.)
- Provide or be able to signpost to support for siblings, dads and specific conditions
- Take the “battle” out of the system

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