

A pilot study to explore parental experiences of “Family Centred Care”

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Research question

- How 'family centered' do staff and parents perceive their work with disabled children and young people?

Definition



- ‘Family centered care’ has been defined as a philosophy of care where families are supported in their decision-making roles in an equal partnership with professionals, ensuring optimal quality of health care (Brewer et al, 1989).

Background of Child Disability

- UNCRC- Article 23 www.unicef.org.uk
- NHS ethos- partnership
- Aiming high for disabled children

»Every child Matters, 2007

Research design

- Qualitative
 - Themes based on the questionnaire: Measure of the Process of Care for Service Providers (MPOC-SP)
 - » Woodside et al, 2001
 - Series of focus groups and interviews in 3 different children's services
 - Thematic analysis, discourse analysis

Method

- Parents invited by their Health or Social care professional to volunteer for an interview

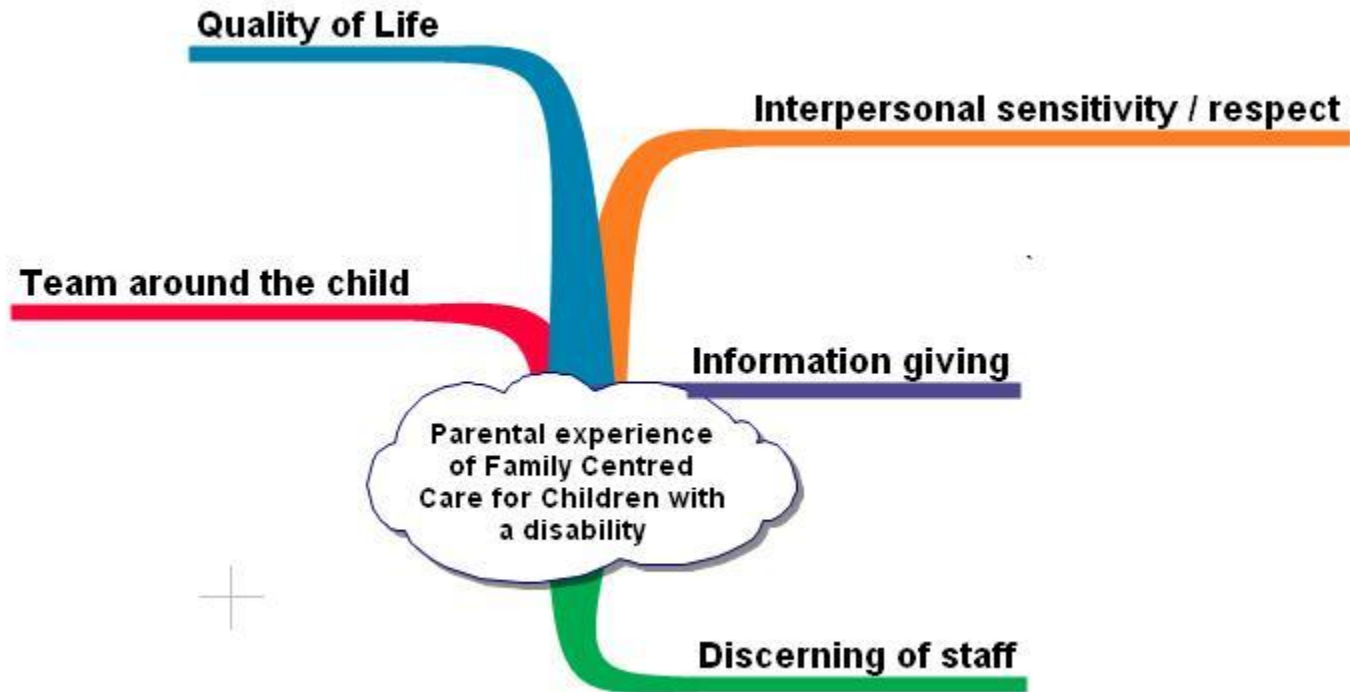
Results

10 parents – 8 interviews

Editing approach looking for emergent themes

Discourse analysis

Mind map of parental themes



Information giving

Mother : We had the odd leaflet here and there but **we never wanted to look into anything.....**

Mother : You need to accept it first...(child with Down syndrome)

Father : You can't accept it... its not accepting it at all.... It's living with it basically.....

Interpersonal sensitivity and respect

- Mother (Child with Spina bifida) the girls at the children's centre have always been, you're the parent, you know what's going on and totally agree with your judgment, it's really helpful.... They don't treat him like "he's a very special child" its never been like that, it's just, this is you and this is the way you are ...

Siblings involvement

- Mother of child with Cri du chat : Alys (sister) is eleven, she's done quite a lot of joint work with Rebecca (Speech and Language Therapist) she's come down so she knows a lot because Jack is so sensitive with his mouth....he's unbelievably sensitive, so things like Alys knows how to dab, they've taught her to dab his mouth with a wipe ...Alys does sessions with Michelle (Physiotherapist) as well, if she's off school.... the children are very involved and it's encouraged, it is encouraged. On a day off, Alys will come down with me and go to the playgroup for the day and help out with the other children as well.....

Team around the child

(Foster parent)... But what we didn't have when we took over Sarah was information about where they'd been so far, where we were at the moment and where we were going and that's something that...that's why we called the **'Team around the child'** meeting because we felt that all the different professionals were taking us in different directions and it was time to pull together and get some information written down so everybody knew...

Child First

Mother : No, we were going to do all this stuff but we still haven't joined the Down's Association because
....

Father : Yeah, I mean, you know Rhian would be grouped into one category and I just think well why, she's still, **she's just a child you know so, the disability comes second, you know, she's a child** and we want to avoid this photographic thing of Downs kids in sports or photographs and things like that...

Attributes valued by parents

- Good awareness of how what they suggest will impact on us





Unhelpful staff behaviours

- Overwhelming
- Intimidating
- Giving written information with medical jargon in
- Giving conflicting advice
- Incompetent
- Interpersonal skills
- Long waiting times for assessment
- Lack of suitable play space in waiting areas

Recommendations

- ‘Team around the child’ meetings are positive and should continue to provide a way for parents and staff to discuss progress
- Clearer processes need to be in place for parents to deal with queries or complaints
- Staff training needs to consider the attributes parents value

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