



Family Centred Care (FCC) with children with a disability- workshop

Dawn Pickering

Cardiff University

29th September 2008

Aims

- To define Family Centred Care (FCC)
- To share preliminary findings of staff and parents experiences of FCC from current pilot research study

Context

- What does family centred care mean to you?
- What qualities and attributes would you look for in a professional working with families? (Staff and parents views)

Background of child disability

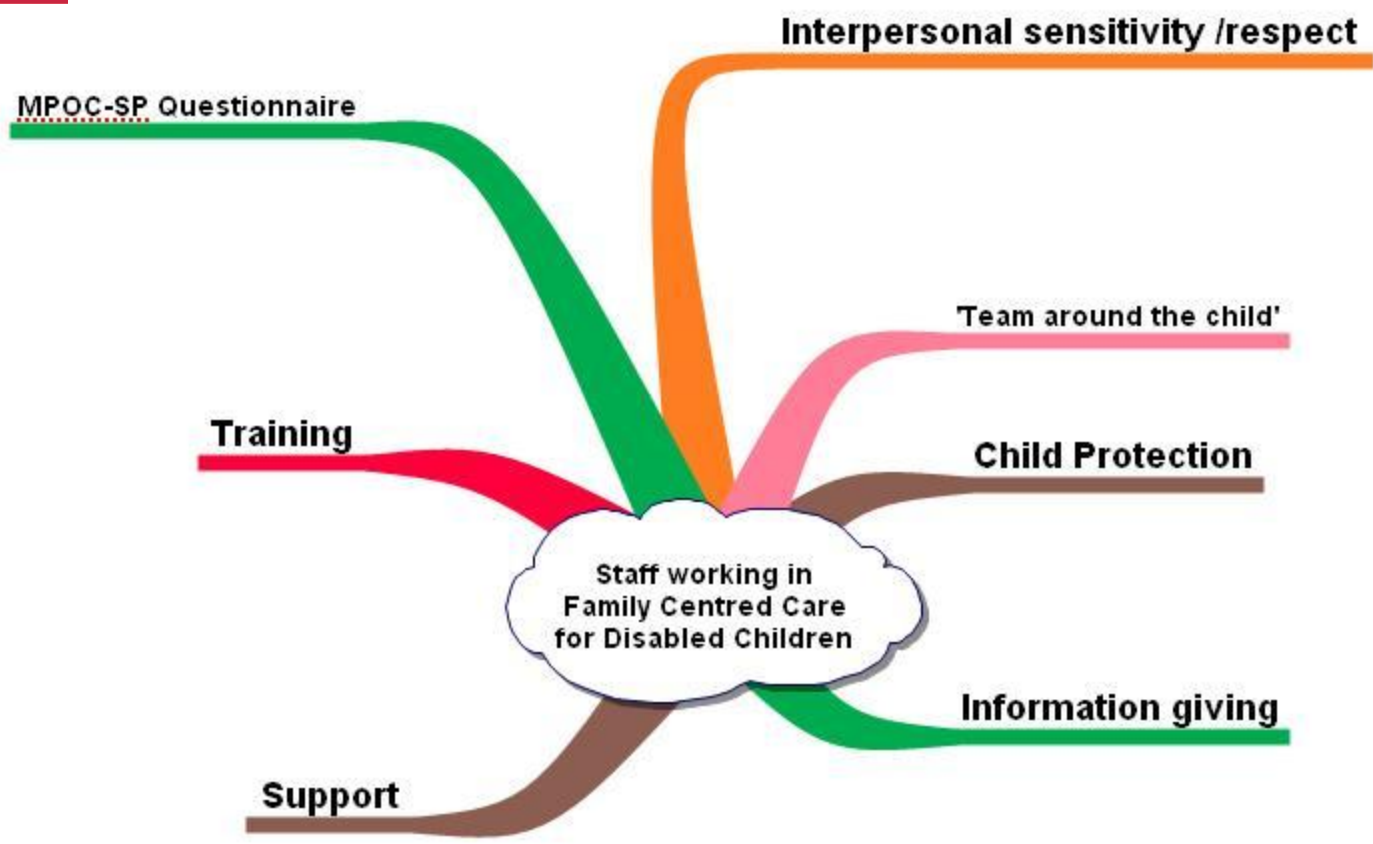
- Definition FCC- families are supported in their decision-making roles in an equal partnership with professionals, ensuring optimal quality of health care
 - » Brewer et al, 1989
- UNCRC- Article 23 'Children who have any kind of disability should have special care and support, so that they can lead full and independent lives'
 - » www.unicef.org.uk
- Knowledge and Skills Framework (2004)
- NHS ethos- partnership
 - » 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

Staff provision

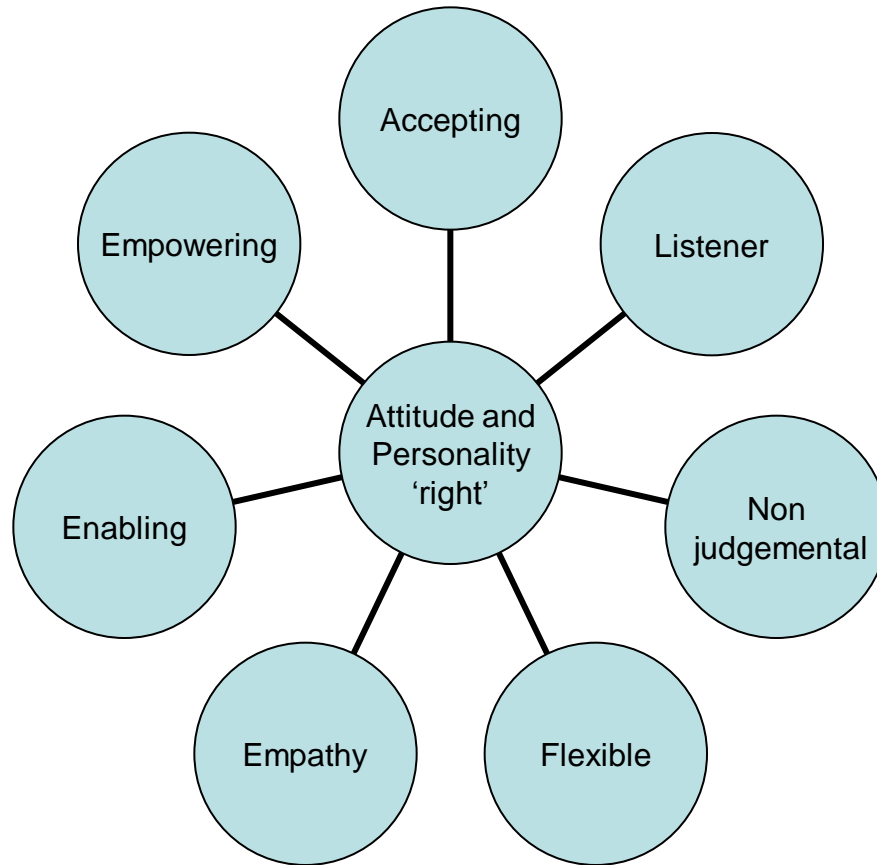
- Interpersonal sensitivity/ respect
- Information giving
- Training



Staff quotes

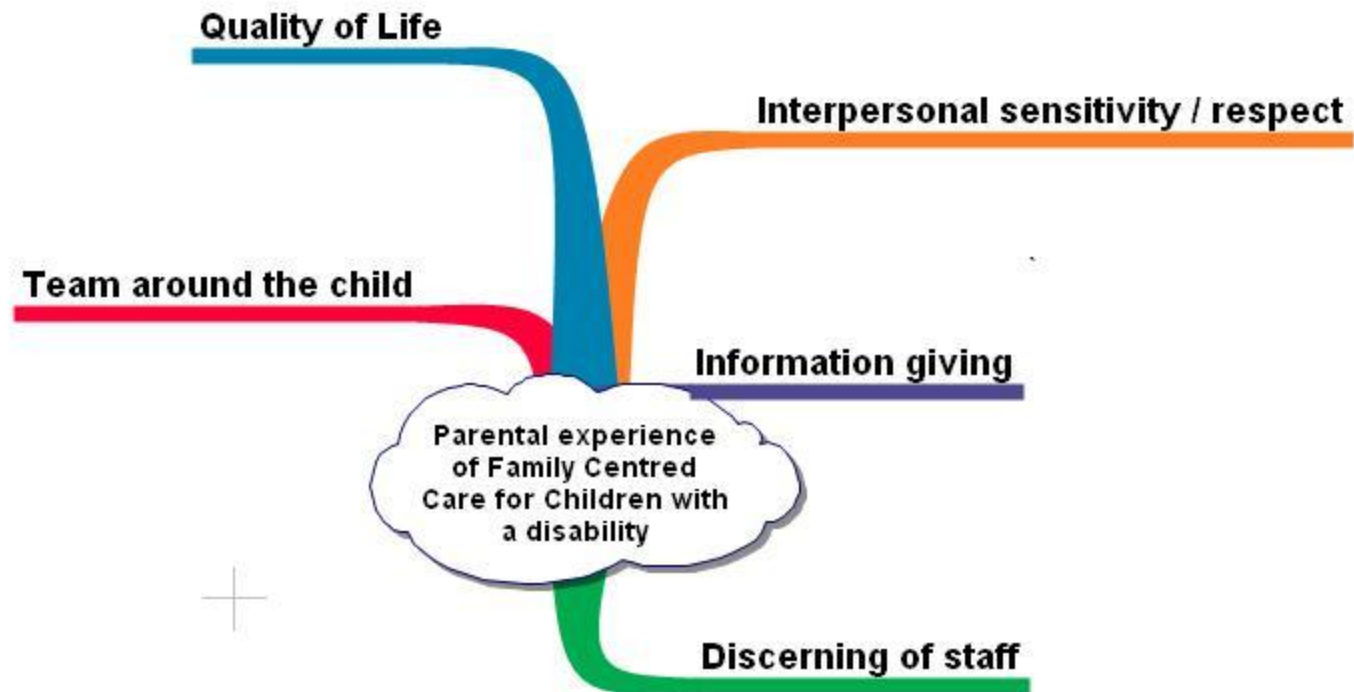
- **S2.1**
- D We use feedback very much to **empower**, because I think most of our parents they see themselves as very dodgy parents right from the start because they've got a damaged child or they can't feed their child.
- I Yes
- D So there are a lot of issues right so right from the very start we give them **positive feedback**- you are a good parent
- B I think because a lot of our children are at high risk of developing something, the parents are anxious and when you ask if they've 'worked on what I showed you last week?'I think actually it works through colleagues as well because, you know, ...'June said that you were doing such and such when she came, they were doing that and that was brilliant' I'm impressed
- I yes
- B you know, June fed this back to me, things like that you can't underrate the feedback, it must be very positive.
- D Mmm, but even if you don't have positive feedback even if they've just done it once, because they live in such chaos, which is totally acceptable, **any little bit of praise you can give is important**
- I Yes
- C Because we go in and work with the parents and the child and we actually have charts, it does depend whether the parents are literate and can read, we have different charts. They can actually see that when I leave something for them they achieve that, that's a wonderful feeling of **empowerment**, that they are actually helping to teach this child an activity and the results are there and the graph that they can see. So I find that you know there is a lot from feedback in that sense.

Staff views of qualities required for FCC



Parents experiences

- Interpersonal skills
- Information
- Future suggestions

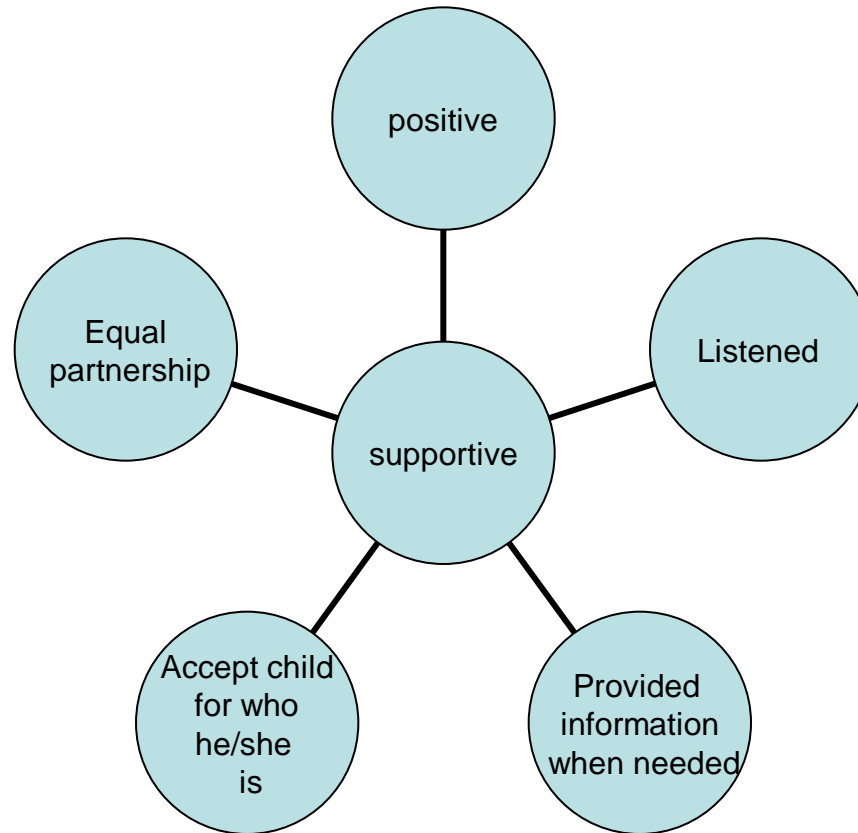


Child First

- **P2.3**

- P1: No, we were going to do all this stuff but we still haven't joined the Down's Association because
- P2: 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...

Parental views of staff behaviours in FCC



Information giving

- **P2.3**

306 P1...We had information from the hospital didn't we, that's all we had

P2: Yeah, we try and ask for information but..

P1: We had the odd leaflet here and there but **we never wanted to look into anything...**

321 P2: But when the information officer came just with her ear basically and just to explain what's available first, and what support services are there and so gently put, if you need this, I've got some information on it. Very, very good...

447 P1: You need to accept it first...

P2: You can't accept it... its not accepting it at all.... its living with it basically

P1: Yeah but you need to get...

P2: Comfortable with it...

Parental quotes

- **P2.4**
- **I So, have you received any written information about Sarah's condition?**
- P (foster parent) um with each professional that we've gone to, um we've had little bits of **information**, if its something new, for example, she had splints recently, so we've had some information on that. 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...and that's been done now

Recommendations

- ‘Team around the child’ meetings are positive and should continue to provide a way for parents and staff to discuss progress
- Staff development in FCC requires further consideration
- Clearer processes need to be in place for parents to deal with queries or complaints

Future research

- Finish analysing data
- Bigger study to gain wider representation of staff and parents in UK
- Further exploration of staff training in FCC

References

- Brewer, E.J. Jr, McPherson, M., Magrab, P.R., Hutchins, V.L. Family-Centred, Community-based, coordinated care for children with special health care needs. *Pediatrics*. 1989;83;1055-1060.
- Every Child Matters: [http://www/ Every Child Matters / Aiming high for disabled children: better support for families](http://www/EveryChildMatters/) [accessed 23.05.08]
- Department of Health, Department for Education and Skills (2004) Knowledge and Skills Framework
- McConachie, H. and Logan, S. (2003). Validation of the measure of the processes of care for use when there is no Child Development Centre. *Child: Care, Health and Development*, 29, 1, 35-45

References

- Roberts, D. (2006). Therapy without frontiers, families without tears. *Physiotherapy Frontline* 19 July 18-20
- Wales Assembly Government (2004) National Service Framework for Children and Young People and Maternity Services
- Woodside, J.M., Rosenbaum, P.L., King, S.M. and King, G.A. (2001). Family- Centred Service: Developing and Validating a Self-Assessment Tool for Pediatric Service Providers. *Children's Health Care*, 30(3), 237-252
- www.unicef.org.uk/youthvoice/pdfs/uncrc.pdf [accessed 9.9.08]