

Contrasting service provision leading to ethical dilemmas for parents of disabled children

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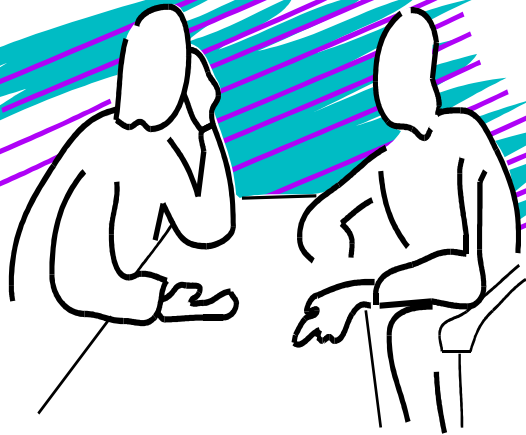
Objective of workshop

- Set the scene for the research project
- Explain the findings generally
- Outline the 4 ethical principles in care giving
- Explore a specific case study -listen to extracts of interview and read transcripts
- Discuss in small groups and report back

Research question

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

Definition



- ‘Family centred 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,
Department of Health, 2004

»Welsh Assembly
Government, 2004

Ethical approval

- Approved by Cardiff University; School of Healthcare Studies Research ethics subcommittee December 2006. Cardiff University was the Sponsor. No external funding was provided.
- This project was considered at the South East Wales Research Ethics committee in March 2007. It was considered a service evaluation that did not require ethical review by a NHS Research Committee-Ref: 07/WSE04/35.
- This project received Trust Research and Development Approval from three Welsh NHS Trusts and honorary contracts were set in place.
- The information sheet was translated into Welsh for parents

Research design

- Qualitative
 - Themes based on the questionnaire: Measure of the Process of Care for Service Providers (MPOC-SP)
 - » King et al, 1995, Woodside et al, 2001
 - Series of focus groups and interviews in 3 different children's services
 - Thematic analysis, discourse analysis
 - » Seale and Barnard, 1998, Iedema, 2007, Sarangi and Coulthard, 2000

Method

- Staff attended for focus group and given invite letters for parents
- Parents invited by their Health or Social care professional to volunteer for an interview

Results

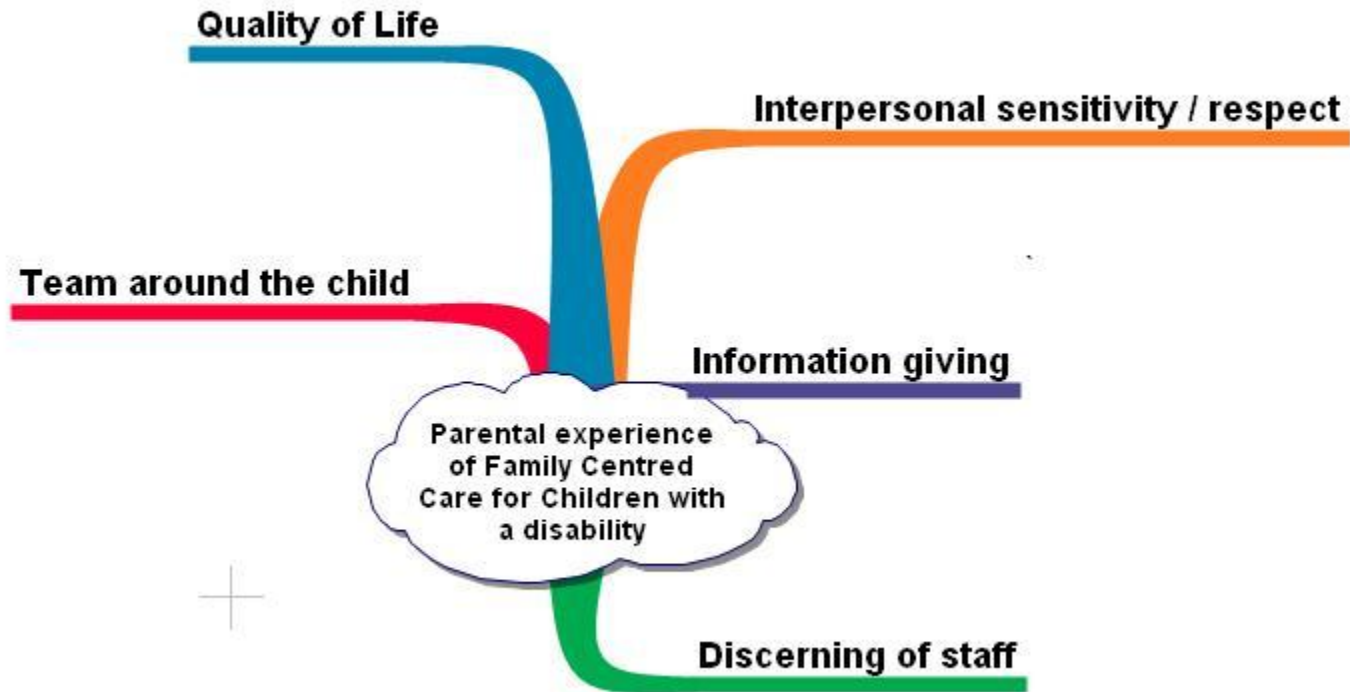
29 staff volunteered across 3 children's services

10 parents – 8 interviews

Editing approach looking for emergent themes

Discourse analysis for specific case studies

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.....

Results

- Unexpected finding- a parent who chose to keep her baby with Spina Bifida and compared the information giving process for the unborn child unfavourably to her positive experience of service provision for the disabled child

Ethical principles of care

- Non Maleficence
- Beneficence
- Justice
- Autonomy

» Beauchamp and Childress, 2001

Non Maleficence

- Do no Harm
 - Consider best interests of child and family

Beneficence

- Do good
For individual/society as a whole

Justice

- Be fair
 - Preserving life- the sanctity of life
 - Treating people equally but according to need

Autonomy

- Respect
 - Patients rights- ability to make one's own decisions
 - Confidentiality
 - Privacy
 - Dignity

Case study

- In this case study discuss the ethical dilemmas for this parent:
 - What are the issues here?
 - What are the implications for practice in both ante and post natal provision in ‘information giving’?
 - Is this a unique story or typical?

Beauchamp T.L. and Childress J.F. (2001) *Principles of Biomedical ethics*. 5th Edition New York: Oxford University Press

Department of Health, Department for Education and Skills (2004) National Service Framework for Disabled Children and Young People and Maternity Services: [Disabled Children and Young People and those with complex health needs](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089112&chk=0RgaiF)
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4089112&chk=0RgaiF
[Accessed 17th August 2006]

Every Child Matters: [http://www/ Every Child Matters / Aiming high for disabled children: better support for families](http://www/EveryChildMatters/AimingHighForDisabledChildren/BetterSupportForFamilies)
[accessed 23.05.08]

Iedema, R (2007) *The discourse of hospital communication : tracing complexities in contemporary health care organizations* Palgrave, Macmillan

- King, S., Rosenbaum, P., and King, G. (1995). The Measure of the Processes of Care: a means to assess family-centred behaviours of health care providers. Hamilton, Ontario: McMaster University
- Sarangi S and Coulthard (2000) Discourse and Social Life. Pearson Education Longman
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