

Ethical dilemmas for a parent of a disabled child

The researcher is a children's physiotherapist and as part of a research study exploring staff and parental views of 'Family Centred Care (FCC)' with disabled children, an unexpected finding raised some ethical dilemmas that are explored in this paper. FCC 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). Extracts from the interview will be used to illustrate the ethical dilemmas which arose. The discussion will focus around the challenge of supporting parents in decision making in midwifery and health care practice.

The codes of practice for Midwifery and Health Care professionals have underlying moral principles of doing no harm (Non Maleficence), doing good (Beneficence), being fair (Justice) and respecting the rights of individuals (Autonomy) (NMC, 2010; HPC, 2007). The value of a life that is compromised by a disability is seen as a challenge that healthcare professionals working with disabled children are trained to both rehabilitate and help to establish their identity as individuals.

This research project explored staff and parents experiences of 'FCC' to children with a disability. Staff took part in focus groups and parents took part in individual interviews. The interview questions with the parents were based loosely upon themes of staff behaviour in interpersonal sensitivity, respect, information giving and the family's quality of life.

The research question was 'How 'Family Centred' do staff and parents perceive their work with disabled children and young people?' Twenty nine staff and ten parents took part across 3 NHS Trusts and Social Care settings in Wales. The data was analyzed thematically using an editing approach (Seale and Barnard, 1998). Specific case studies, as the one described here, were analyzed by discourse analysis (Iedema, 2007, Sarangi and Coulthard, 2000).

The theme relevant to this paper is that of 'information giving'. The questions around information giving for the disabled child triggered the response of this parent to tell her story. The child was 1 year at the time of interview carried out in 2008:

3 minutes into interview

I: What sort of nursing did you do?

P: I did general nursing and I was going to specialize in midwifery but now after what happened that's the last thing I want to do

I: Right?

P: We had a terrible experience in the hospital

I: So you've decided that midwifery is not the route?

P: Well I don't want to be in the position the staff were in...

I: Right, OK?

P: But that's a whole different story.....'

18 minutes

'I... is the written information you've received been in a format that you could understand and has the timing of the information been appropriate for you, in terms of wanting information?

P: um, we didn't actually get a lot of information from the children's centre mainly because we already had it and they did offer and any questions, I mean in the beginning before he was born we knew this was going to be the case and we got lots of information then

I: Did you get given it or did you find it yourself?

P: We found it ourselves because we were dealing with the ...hospital, um well there was so much pressure in the beginning to have a termination, there wasn't really a lot of support for carrying on for dealing with a child who was going to have this...get rid of this child....

I: Right!

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P: So there wasn't a lot of information that came from hospitals and things, and we didn't get involved with the children's centre until after he was born so we found the information ourselves, we went and saw other professionals.....'

24 minutes

I: Well, I think as you say the incidence of Spina Bifida is still there but the actual number of children being born is less...

P: Yeah but I think that's probably because there is a lot of pressure around parents who don't know much about it to have terminations and it was months and months before they realized that we weren't gonna go down that road.

I: Yeah?

P: And there wasn't a lot of support in the hospital system

I: Right

P: if we were going to continue... there wasn't much at all

I: Right, so you were left on your own really?

P: Yeah it was sort of well if you're gonna carry on then more fool you. Then we got to the children's centre and they said oh we see kids like this all the time, not just Spina Bifida but kids with all types of disabilities and other problems and...

I: Yeah...?

P: It's just life and you just get on with it and it's a normal thing

I: yeah...?

P: It wasn't an issue for me and seeing those kids with other problems. Well, this isn't something I can't deal with, for something that's new to you might be uptight but at the children's centre it's just normal...'

48 minutes

P...well what was really good was, when we were expecting him and everybody was so negative up until he was born, from lots of midwives, doctors and specialists saying you don't know how hard this is going to be are you sure you're making the right decision and I think you should really, really, really consider.....(voices trails off, quite emotional)

I: having a termination?

P: Yeah and its was so negative, this was going to be a child who was going to be completely paralyzed from the waist down, there would be no brain function at all this was going to be dreadful.

I: So they gave you the worst case scenario?

P: Absolute worst case scenario, which is not, I know, not everybody gets that, but we did and I think everybody in this area gets that, talking to the research doctor about it and I said we were told this just most people from this area have been told all doom and gloom no positive thoughts coming from somewhere else and they've been told, oh it's fine, it will resolve itself at the other end of the scale. So after all this terrible, I mean nurses saying 'didn't they give you an option of having an abortion' and they treat you like you're a drain on the society's resources and how dare you have a child which you know is going to have problems. It was just so awful, we had to fight even for the right to keep our child and then we got to the children's centre. and they were so positive and so, well that's just yeah, that's not an issue this is your decision and if there are problems then we will work around the problems and we will find solutions and it's not awful 'you've got Spina Bifida well weren't you stupid to have a kid like that'; there's none of that at all. They thought well if you've got this then you're probably going to need this and that and the other and we'll put all that in place for you and then we'll see how it goes. Really positive, really encouraging it's like a breath of fresh air really....'

So, this mother reported how she had felt unsupported in her decision to keep her baby with Spina Bifida. Her perception was that staff made her feel as if she was making the wrong decision as it would create a problem for society to have to deal with. In contrast, the staff dealing with the child with the disability were perceived as being very positive and constructive in their advice. The issue of a child with Spina Bifida being born was perceived as not being in society's best interests due to the greater good of not creating a

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dependent person. So the Beneficence to society as a whole was perceived as more important than that individual's right to life (Beauchamp and Childress, 2001).

This story was unique and not repeated in this study. It is difficult to establish if this is an unusual or common experience in current practice. It leaves the impression that midwives and healthcare staff need to consider the impact of their behaviour of how they react when a parent chooses differently to their advice. What might seem logical medically and best for society, may not be the choice that individual wants to make. A parental right to make an autonomous choice needs respect and midwives and health care professionals must be fair in the way they treat people.

The challenge for midwives and healthcare professionals working with foetal abnormalities and childhood disabilities is not a new issue. The idea of supporting parents in their decision making is not novel and often there are conflicts in management decisions during pregnancy and for disabled children. The question remains do we support parents in their decision making or do we influence their choices in one direction that we perceive to be the best outcome?

Word count: 1502

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