

Confidential data

Case study:

Interview Parent 2

39 I: What sort of nursing did you do?

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

42 I Right

43 P: We had a terrible experience in the N.. Hospital

44 I So you've decided that midwifery is not the route.

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

46 I: Right, OK

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

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

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

352 I did you get given it or did you find it yourself?

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

357 I right

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

436 I well I think as you say the incidence of Spina Bifida is still there but the actual
437 number of children being born is less...

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

441 I yeah

442 P and there wasn't a lot of support in the hospital system

443 I right

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

445 I right so you were left on your own really

446 P yeah it was sort of well if you're gonna carry on them more fool you. Then we
447 got to T. and they said oh we see kids like this all the time, not just Spina Bifida
448 but kids with all types of disabilities and other problems and

449 I yeah

450 P its just life and you just get on with it and it's a normal thing

451 I yeah

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

.....

Confidential data

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

721 I having a termination

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

725 I so they gave you the worst case scenario

726 P absolute worst case scenario, which is not, not everybody gets that but we did
727 and I think everybody in this area gets that, talking to PG about it and I said we
728 were told this just most people from this area have been told all doom and gloom
729 and people coming from somewhere else and they've been told oh its fine, the
730 other end of the scale. So after all this terrible, I mean nurses saying 'didn't they
731 give you an option of having an abortion' and they treat you like you're a drain
732 on societies resources and how dare you have a child which you know is going to
733 have problems It was just so aw, we had to fight for the right to keep our child
734 and then we got to T. and they were so positive and so, well that's just yeh, that's
735 not an issue this is your decision and if there are problems then we will work
736 around the problems and we will find solutions and its not aw 'you've got Spina
737 Bifida well weren't you stupid to have a kid like that' there's none of that at all.
738 They thought well if you've got this then your probably going to need this and
739 that and the other and we'll put all that in place for you and then we'll see how it
740 goes. Really positive, really encouraging it's like a breath of fresh air really....