3
Mothering: Identification and Diagnosis of Impairment

There is a rich stock of folk knowledge and personal and family experience about how people first react to being diagnosed as having a fatal or serious illness and then cope with their condition. For some, the initial information is shocking and hard to believe; for others, it confirms what they already somehow ‘knew’. Most people eventually settle down and accept the diagnosis and comply with the treatment offered, while vacillating between acceptance of the new condition and a reluctance to come to terms with it: ‘This can’t be happening to me’, or ‘Why me?’ Some people sink into despair; others are stoical, optimistic and hopeful, even to the point of behaving as if the illness did not exist. […] But is there a right way to cope with information about traumatic, catastrophic or disabling losses?

(Cohen, 2001: 53)

Often the built up expectations of internalised norms regarding mothering, parenting and birth are initially dashed as the parents discover or realise that their child is different from her or his peers. This chapter is about what becoming a mother, or in some cases a father, of an impaired child means for the parents in this research, and what pressures are placed upon them that contribute to feelings of anxiety when faced with emotional and practical difficulty. I often use the term ‘parent’, but do recognise the (un)gendered significance of this term and yet do not want to dismiss the father’s role in mothering. It is clear throughout this chapter that shock, denial and disappointment are experienced in relation to the identification and diagnosis of an impairment. This is an
important building block for the following chapters as the reader begins to understand what emotions are experienced before any other process of assessment and education is negotiated.

‘Loss’ of the expected child: shock, denial and disappointment

The 24 parents in this research have 30 children between them identified with impairments. Five out of those 30 were diagnosed at birth and one, Kerry, had an ambiguous diagnosis during pregnancy. Tim had difficulty telling people that his son had Down’s syndrome; Tracy was not sure how she felt because her son was born visually and hearing impaired and at the time wondered if he should have survived at all, and Kim was simply pleased that her son survived, although she wanted another child soon after so that she could experience the celebration of the birth which she felt she had missed out on. Many of the parents have felt disappointed in the initial stages of their mothering. Even before the birth, though, pressures on mothering and normality are apparent, as illustrated in Kerry’s case; the only mother in the sample to have had an official, albeit ambiguous, diagnosis of a potential impairment during pregnancy. The mother and father may fear the death of their child, may be relieved the child is alive, may wish him or her dead (because the impairments cause the baby pain), may deny the impairment and/or experience some kind of shock. The once-expected celebration of the new baby turns into a disappointing loss.

Discovering difference

After a blood test, during her pregnancy, Kerry was told that she was at high risk of having a baby with Down’s syndrome. She arrived at the hospital to have an amniocentesis test, but could not go through with the procedure and told me,

"I thought what am I doing? If this child’s normal and they had said that there’s a percentage chance that you may abort, you may miscarriage and lose the baby. And the other thing is it proves the child is Down’s so if you don’t want the baby you still have to go through with the birth. And I couldn’t do that and I didn’t want the choice. I didn’t want to be given the choice, because the way I looked at it if I hadn’t had the injection … and I was thinking this on the bed … if I have it and it’s not Down’s and a few days later I lose it I’d never be able to forgive myself. If I have it and it is Down’s I have to decide..."