CHAPTER 2

Assessment, diagnosis and trauma

Assessment and diagnosis

The assessment and diagnosis of developmental delay is complex, may take some time and involve a number of tests and several medical practitioners. Assessment may take place before or at the time of the child's birth (e.g. if the baby is discovered to have an identifiable disorder such as Down's Syndrome, or if the baby is very premature or has associated medical problems), or it may take place at a later stage. The timing of assessments will depend on the cause of the developmental delay and may result in the diagnosis of a specific medical condition. Sometimes, however, the cause of the developmental delay may remain unexplained.

Early diagnosis

Mothers are particularly emotionally vulnerable in the period during and after giving birth. It cannot be other than an unwelcome shock to find that the hoped-for perfect baby has

not after all arrived. Instead, there may be a baby with physical characteristics that are difficult to come to terms with; urgent medical interventions may be required; or the introduction of a totally unexpected diagnosis has to be taken in and understood both mentally and also emotionally digested.

Samir

Samir was diagnosed with a genetic condition known as Beckworth-Weidermann Syndrome a week after his birth. Tests during pregnancy had not brought any sign to light of this condition, which affects one in 15,000 babies. The syndrome causes overgrowth of organs and limbs. Samir was born with a large tongue, abdominal defects, tumours and "uneven growth" of the lower limbs.

Samir's early care was provided by children's hospital services and four different departments were involved: Speech and Language Therapy, Feeding Clinic, Genetics and Ophthalmology. He needed an operation on his tongue to reduce its size, because it affected his breathing and feeding. Samir's mother was understandably very shocked by his diagnosis; in fact, she became depressed and overwhelmed by worry about the future. On his release from hospital, Samir was placed in foster care. Although his condition did not necessarily mean that he would be cognitively delayed, at the age of nine months he had only just begun to explore with his hands and to put them into his mouth. It was important that his carer stimulated him by talking, smiling and cuddling him as well as by introducing opportunities for him to socialise with other babies in playgroups. Samir's mother could not look after him and he remained in foster care.

Emma

Emma suffered lack of oxygen during the process of her birth. It was later demonstrated that she had been developing normally *in utero* and that the lack of oxygen, which caused brain damage, was due to the negligence of the medical professionals involved. Emma

was diagnosed with cerebral palsy. All aspects of her development were severely affected by her condition and her life expectancy was reduced because of her complex difficulties.

Later diagnosis

Sometimes, however, it is not at birth but later that delay in development becomes obvious. For instance, a baby may not reach out for toys, roll over or sit unsupported within the expected timeframe. These may turn out to be early signs of delay in motor development and sometimes also cognitive development.

In other cases, development may appear to be proceeding quite normally until the age when infants would be expected to start to develop speech and language. Children who go on to have a diagnosis of autism spectrum disorder (ASD) are most commonly initially identified through a delay in their language development, which may be picked up between approximately 18 months and two years of age. A child may then first be seen by a speech and language therapist. If she is worried that he has a developmental disorder, which pervades many aspects of his development and not only his language, she will probably refer him to a multi-disciplinary child development team for a more thorough assessment.

For parents and carers, assessment and diagnosis can be a very stressful process and a difficult time. When a child's speech and language development is delayed, parents and carers will often be told by friends and family that children all develop at their own rate and there is nothing to be worried about. It can therefore come as a shock to be told that the child has a lifelong condition, which will manifest itself in a number of ways, with communication, play and imagination all possibly affected.

Variation in how well diagnosis is made

It is to be hoped that assessment and diagnosis are handled sensitively by the professionals involved, but of course, in stressful

and painful situations there is always variation in how smoothly the procedures go.

It can take time to digest and process the news that a baby or young child has a serious condition. An adoptive mother of a young child newly diagnosed with an autism spectrum disorder used to have a recurring dream in which her child spoke to her and played with her "like a normal child". This dream seemed to be an expression of her deep wish for her child to be well and to develop normally. It took a long time for her to adjust to the reality of her little girl's developmental difficulties.

Appointments and testing

Any parent or carer of a young child whose development is not proceeding as hoped will have to bear the anxiety and uncertainty inevitably associated with this. They will also have to have enough stamina to deal with the practical demands of looking after a child who may need numerous medical appointments, tests and assessments.

It is interesting but upsetting to see how difficult it can be for professionals to think about the whole child who is also part of a whole family. I have written elsewhere about the way in which children with developmental difficulties are sometimes thought about in separate "bits", as if to think of them as a whole child is too challenging, and perhaps too painful (Bartram, 2009). As we saw above, in the case of Samir, different "parts" of him were attended to by different hospital departments. Whilst there are no doubt sound medical reasons for this, having to relate to so many professionals, who unfortunately do not always successfully relate to each other, can put a strain on parents and carers. Those who do not feel strong enough to co-ordinate their child's medical appointments can easily feel overwhelmed and disempowered.

In *Evidence Based Paediatrics and Child Health*, Drs Salt and Gringas

report that the number of tests ordered for a three-year-old child with moderate developmental delay ranged from 0 to 15 and included 26 different investigations (2004, p. 117). Whether you are the parent of the child where no test was ordered, or of the child where 15 tests were ordered, or anywhere in between, it is likely that this will place a strain on you. Depending on what is entailed by the test, probably the child too will be placed under strain. Some children become very distressed when brought for appointments, as they have come to associate seeing professionals with stress, or even physical pain.

Emotional trauma

The word "trauma" comes from the Greek word meaning "to pierce". The idea of a traumatic experience therefore is one which "pierces" our normal self-protective coping mechanisms, and overwhelms us. The psychological effects of these experiences cannot be relied on to stop when the experience stops, but may continue to reverberate until they are alleviated by some special attention or intervention. Whether at the time of assessment, diagnosis, or later as life continues, children and families where there is developmental delay and persistent disability are vulnerable to emotional trauma. One parent described to me the moment when the head teacher of her child's school caught up with her at the bus stop and told her that she thought her daughter was autistic. Had this ever occurred to her? The mother said that this moment remained fixed in her mind, repeating itself over and over again, and always accompanied by the sense that she had been assaulted, left wounded and that she was falling into a black hole. At anniversaries or times of unreached milestones, trauma, which had receded, may be re-awakened.

Sometimes trauma is not a dramatic event, but a quiet accumulation of indigestible disappointment and pain. This can be

true for children and young people as well as for their parents and carers.

Case study: Carrie

Carrie had struggled all her life to keep up with her peers in a mainstream setting. She had a facial disfigurement, and thought and behaved in many ways like a child three or four years younger than her classmates. She told her therapist that she wished there was an x-ray machine that could look into her brain and see exactly what was wrong with her. Her daily experience of looking, acting and feeling different had a cumulative effect on her sense of herself and her value. She could not shake off the idea that she was made "all wrong".