

the news had been given badly or were unhappy with these contacts, were deterred from complaining because 'The medical fraternity stick together', and were concerned that any action might have an effect on future contacts with the doctors on whom they might be dependent for ongoing care.

At every step we were kept informed. They told us when they were carrying out tests, and what the test results were as soon as they were known. But it seemed like an eternity between the two. We were so anxious, and all the time the feeling of helplessness persisted, disabling us from answering even the simplest of questions like "Would you like a cup of tea?" When we did summon up the mental energies to ask questions, we were given honest answers. I say 'we', in fact I would creep out of the side ward we had been placed in to find a passing nurse or doctor who might have some more news. I did not want them to tell my wife, to increase her distress, I wanted to bear it all.

#### **Professional perception of fathers**

The fathers felt that because they were regarded as 'different', the hospital staff were not trained to deal with them. They were constantly watching for others' reactions conveyed by words and body language.

A nurse constantly attended my wife, and gave me kindly glances. Any medic who came anywhere near our room must know something, and I pounced upon each of them. When there was news to give, they told us together, but all the time you expected more. Were they withholding information?

#### **Professional prediction**

Many contacts, medical and social, offered gloomy forecasts of the effects the child would have on family life. A General Practitioner warned that 'the mother may become mentally unstable and may attempt suicide or harm the baby'. Another was warned that his marriage would fail.

This must all be a dream - this thought ran through my mind again and again. This cannot happen to us!. In this turmoil, I was conscious of the supportive attitude of the hospital staff, and that every effort they made was an endeavour to uphold us, to help us to endure the pain and distress that fell upon us as the reality of our baby's disability dawned upon us.

#### **Information seeking**

In all cases, fathers sought additional information initially from books, but later from other families and professionals.

In spite of what we had been told by the Paediatrician, it was not enough. A thirst for a greater and a deeper knowledge became all consuming. This search became a driving passion. I wrote to anyone and everyone who might be able to throw more light on our baby's disability. When I finally made contact with an appropriate Parent support group, I scoured their membership lists for other parents nearby who had similar children. Once I realised that we were not the only family in the area with this type of child, I accepted with a degree of peace, the knowledge I had gained.

Hornby (1991) recommends networking amongst families. Various practical examples of this exist (Carpenter and Carpenter, 1989). In the context of this small-scale research, the sensitivity of this process was highlighted. Whilst acknowledging its implicit value, it was found that families needed more than 'one feature in common' (Byrne, -Cunningham and Sloper 1988) in order to make the contact positive and effective.

As in any set of personal relationships there are those that are richer and more rewarding than others. With some families our only point in common was that our children had the same disability, and this led to a fairly factual exchange of information; but even that was helpful. With other families there were interests in common other than with our children and time spent with these families was for the same reasons one might spend time with any set of friends. What is unique about friendship with other families is the depth of understanding: they are more than the sincere, empathetic professional. They have been there too - through the endless hospital appointments, the perplexing behaviour patterns, the unanswered questions. This in no way diminishes the invaluable contribution of professionals, but to live with a child with a disability twenty-four hours a day, brings lessons that no professional course of training can ever hope to teach.

#### **Source of support**

Extended families were found to be a major source of support to the fathers.