

Family Support

The Contribution of Early Intervention Services

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Robert and Louise eagerly anticipated the arrival of their first child, and when Clare was born they were elated. Their joy lasted for only a few short moments. Clare's physical disability was obvious - only one ear, her chin depressed into her neck. The paediatrician advised an emergency tracheotomy.

Numbed with shock, Robert and Louise agreed to the operation. During the operation, Clare lost consciousness for 15 minutes. In spite of this she survived. As feeding was clearly going to be a problem, a nasogastric tube was fitted.

During the next week, Clare began to gain weight. Louise noticed that Clare's tongue was exceptionally small. The paediatrician confirmed this and told her that the implication was that Clare would never feed properly. No one counselled Robert and Louise at all during this week. Doctors engaged them in conversations around medical issues; nurses were kind in their ministrations to Clare, and talked to Robert and Louise, but only on care matters.

When Clare was three weeks old Louise noticed that the baby startled whenever she approached her and that Clare did not visually track her face even when she was very close to her. Louise reported this to the nurses, and tests were carried out. She was told (without her husband present) that Clare had a significant visual impairment. Louise asked where she could get help and advice about her child. The doctors shook their heads; they did not know.

Both extended families visited Robert, Louise and Clare frequently. From an initial poor prognosis, it became evident during Clare's

first month of life that she was beginning to thrive. Robert and Louise were desperate to talk to someone about Clare and to discover what they could do constructively to aid her development.

Robert's sister happened to know of someone working in special education. Perhaps he could help. Indeed he could; he had a friend working in a regional service for Multi-Sensorily Impaired (MSI) children. He contacted this friend. Within a day the head of the MSI service had visited Clare and her parents in the hospital. She has kept in regular contact and has taken the parents to visit a Family Centre specialising in the care and support of children and their families with Multi-Sensory Impairments.

After three months in hospital, Clare was finally allowed home for a one-day visit. Prior to this no professional had visited the home; no one accompanied the parents on this occasion. Within two hours of being at home, the portable machine the parents had been given to keep Clare's air passages clear failed to work. The family made an emergency dash back to the hospital.

This story is true. It is the sort of saga one would have expected to hear before Early Intervention programmes became standard practice from the late 1960s onwards. If only it were; this story happened this year in the second largest city in the United Kingdom. To this day, those parents have not been given any counselling to help them to come to terms with the shock, grief and despair they have endured in these last few months. The words of Wyman (1986) ring out from this situation: '...our child is still a child, a child with special needs for whom no miracle cures can be awaited: just herself, just himself, with potential to be explored, love to be given or awakened and a dignity and life to be safeguarded.'