

Fathers: The Secondary Partners

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Abstract

The following is an account of a research project exploring the recollections of seven fathers at the time of the birth of their children with Down's syndrome. It discusses the disclosure of diagnosis and subsequent contacts the fathers made both professionally and socially during the period following, both in the hospital and at home.

This is combined with the personal recollections of one father, not part of the original study, whose child was born with special needs. The implications for both professional practice and fathers are highlighted.

Whilst there is an acknowledgement that the project was small scale, the conclusions will raise challenging issues for further discussion both among professionals and individual members of families.

Introduction

In 1990 a small-scale investigation was carried out into the reactions of nine families to the fact that their new-born babies had been born with Down's syndrome and into their feelings and reactions in the weeks immediately following the births. Down's syndrome is a genetic condition which can be diagnosed within the first few days of life, therefore, it is usual that the disclosure of diagnosis is made before the mother and baby leave the maternity hospital.

The children and their families were known to the researcher through her work as a member of a team of teachers devising programmes for pre-school children with possible special educational needs. This work takes place in the home setting and aims to enhance the skills of both parents and children.

The nine children in this study were born in 1986-87 and were the only children with

Down's syndrome born and nurtured by their natural parents within the Local District Health Authority during the period. (Since all the children with possible special needs are referred to the Pre-School Service, all children with Down's syndrome born in the area are therefore known to that Service.) The paediatrician at the local maternity hospital stated that during the last five years, seven children with Down's syndrome have been rejected at birth by their parents. However, this was not the case with the cohort that formed this research sample.

The size of the research sample was determined by two criteria. Firstly, the demographic focus of the group and the need for the results of the research to be relevant to the development of the researcher's service.

Secondly, the size of the group had to be manageable within the working caseload of the researcher. As such, this was a practitioner-led research enquiry, carried out in the spirit engendered by Lawrence Stenhouse who argued that practitioner research was vital but also that small-scale studies contribute to an accumulated body of knowledge (Stenhouse 1975).

it was decided to carry out the study using face-to-face interviews, and arrangements were made during the course of the researcher's routine home visits to speak to the parents of these nine children. An assumption had been made by the researcher that both partners would be present but, in the event, only the mothers took part although in some cases the fathers were in the house. The interviews lasted for up to three hours.

Despite the growing research into the optimum method of disclosure (Cunningham 1984, Cunningham and Davis 1985, Byrne et al 1988, Hornby 1991, Jupp 1992) and the availability of support services (Lacey and Lomas 1993) the project concluded that there was little co-ordination between professionals