

# **PARENTS' VIEWS OF HEALTH AND EDUCATIONAL SERVICES FOR PRE-SCHOOL DOWN'S SYNDROME CHILDREN**

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## **INTRODUCTION**

It has been argued that the early years of development of the severely and moderately mentally handicapped have little effect upon their attainments in later life (Clarke and Clarke, 1974; 1975). Piper and Pless (1980) have noted that far from promoting long term benefits, intensive early training may not even produce immediate advantages for retarded children. There is, however, a growing body of evidence which suggests that in certain circumstances, the nature and quality of early experiences and early stimulation can affect the intellectual and psychosocial development of the mentally handicapped (Bowlby, 1951; Rutter, 1972; 1980). Several researchers in this field have found that early stimulation is crucial to the development of Down's Syndrome children in particular (Brinkworth and Collins, 1973; Brinkworth, 1975; Connolly and Russell, 1976; Smith, 1976; Cunningham and Sloper, 1977; Ludlow and Allen, 1979; Sandow *et al.*, 1981). As a result of these findings increasing attention is being paid to the contribution parents may make to the early development of their handicapped children and to pre-school education in general (Bricker and Cususo, 1979). Given that early stimulation and parental involvement appear to be factors in the development of Down's children, it seems important to ensure that the health and education services currently available provide the appropriate support, advice and information from the parents viewpoint. Whilst a great deal of evidence exists regarding the problems of families with handicapped children (Pilling, 1973) little is known about what the parents feel about the services provided for them, whether or not the services meet parental needs and adequately inform them about the level of their child's development and progress (Lloyd-Bostock, 1976).

The study reported here describes parents perceptions of, and satisfaction with, the services available to them and their pre-school Down's Syndrome children. Attention is focussed upon those services and types of professional assistance which have some bearing upon the early stimulation of these children.

## **METHODS**

This study constituted a retrospective descriptive survey of parents use of and satisfaction with the services available for families with pre-school Down's Syndrome children.

The sample population comprised the parents of all the Down's syndrome children who were born in and were still currently resident in Nottinghamshire and were aged 6 months-7 years at the time of the study. The sample was identified from the Handicapped and Observation Register kept at the Child and School Health Unit, Nottingham. All births, hospitals and domicilliary, within Nottinghamshire county are notified to this department within 36 hours. The notification of births forms have a section for information for the Handicapped and Observation Register and in this section congenital malformations are required to be described.

Forty eight of the 66 families (77%) responded to an initial and follow up letter and agreed to be interviewed about the appropriateness of services and their level of satisfaction with those they had used. The sample was evenly distributed in relation to children's sex (23 girls, 25 boys). A structured interview, which lasted approximately one hour, was carried

out by one interviewer with each family (usually with the mother; i.e. in 54% of cases [N=26]). The questions asked derived from three sources, namely: Cunningham and Sloper (1977); Carr (1975) and Barnado's 1981 Project. Questions were asked about the availability of information, advice, and the emotional and practical help received from the health professionals the parents had come into contact with (e.g. health visitor, specialist health visitor, G.P., paediatrician) and the educational services they had used (e.g. schooling for the under fives, educational psychologist and peripatetic teacher (teacher counsellor)).

## RESULTS

### The Health Professionals

- (i) *The Paediatrician* provided most parents with their first contact with expert advice about their handicapped child. Nearly half of the parents were given some form of information about Down's syndrome by their paediatrician (21; 46%). As table 1 shows, the type of information made available most frequently related to the services available, such as the local Mencap Group. Only one fifth of the total sample of parents (10/48; 21%) were informed about the possibilities regarding progress and development of Down's children by the paediatrician. Over one third of parents (16/48; 35%) expressed a desire for more information from the paediatrician on a range of topics including what their child could be capable of achieving. Nearly half of all parents (22/48; 48%) attached little or no importance to their visits to the paediatrician.

**Table 1**

Types of information given to parents by paediatricians

Information	Parents	
	N	%
Services	13	41
Progress/development of child	10	31
Health Problems	8	25
Literature on Down's Syndrome	1	3
Total	32*	100

(\*The paediatrician may have given more than one type of information to some of the 21 parents who indicated they had received information of any sort from this source).

- (ii) *The Health Visitor*. Almost all of the families had been visited by a health visitor (47/48; 98%). Of these, just over a third (16/47; 34%) indicated that they would have liked more information from her on general care matters, possible health problems and the availability of services. Although parents were largely happy with the health visitors contribution, 60% (N=28) attached little or no importance to her contribution in helping to bring up their handicapped child.

Only six of the families had been visited by the new specialist health visitor (for the mentally handicapped). These parents pointed out that the specialist provided a great deal of information pertinent to their needs and they found her visits more useful than those of the 'ordinary' health visitor who had been to see them.

### Educational Services and Professional Assistance

- (i) *The Educational Psychologist*.

Under half the children in the sample (N=21; 44%) had been assessed or 'ascertained' at home by the educational psychologist between the ages of two and four years.

**Table 2**

Parents' views of the usefulness of the educational psychologists' assessments

<i>Level of usefulness</i>	<i>N</i>	<i>%</i>
very useful	2	10
fairly useful	2	10
not very useful	1	4
not at all useful	16	76
Total	21	100

Nearly all parents were aware that the assessment was carried out to decide appropriate placement at school or nursery, but as table 2 shows, parents perceived the assessment to be of little use to them. Of the fifteen parents who could clearly remember the child's assessment, almost a third (N=6; 30%) said that the psychologist had not told them anything at all; over half (N=11; 50%) had only been told the name of the school their child would eventually attend and 15% (N=3) had been informed of the child's score in the tests or the areas in which they had performed particularly well or badly. The majority of parents (N=15; 71%) expressed the view that the assessment could have been more helpful if:

1. results had been relayed in more detail and had included information about how far behind or ahead the child was developmentally in different areas so that adjustments could be made accordingly

and

2. more advice about the variety of different schools available to their child had been given.

(ii) *Teacher Counsellor or Peripatetic Teacher*

The majority of the families (N=43, 90%) had been visited by a teacher counsellor and of these, 90% (N=37) considered her visits to be very important in helping them to bring up their handicapped child. The initial source of contact of parents with the counsellor was varied and ranged from friends, health visitors, social services, and other mothers to self-help groups. Of the 41 families who had seen a teacher counsellor more than once, the majority indicated that she had given them a great deal of advice and information relevant to the syndrome (N=35; 93%). Her role as a teacher was especially appreciated since she brought toys, played with the children and taught them educational and social skills as well as giving them special exercises. The counsellor also acted as a liaison with other services by putting parents in touch with self-help groups; dealing with the difficulties in obtaining attendance allowances; advising on schools; providing literature and discussing the future of the child. She was perceived as the families most valuable resource in respect of nurturing their child's development.

(iii) *Schooling for the under fives*

Almost one fifth of the mothers in the sample (N=9; 19%) had taken their child to a mother and toddlers group when he or she was about one year of age. Approximately three quarters of mothers had used playgroups or nursery schools (N=39; 70%). Parents reported that the groups appeared to help the child a great deal socially, allowing him or her to get used to being with other children, making them more adventurous, less dependent and providing a wider selection of toys. They were not however thought to provide much educational assistance.

**Overall**

As table 3 shows, teacher counsellors were the most frequent source of information about Down's Syndrome, though paediatricians (in 46% of cases), health visitors (in 38% of

cases) and general practitioners (in 21% of cases) also featured as important in this respect. Table 4 indicates that parents were most appreciative of the services offered by the teacher counsellor and were least satisfied with those provided by the educational psychologist.

**Table 3**

Services which had given parents information relevant to Down's Syndrome

<i>Service</i>	<i>Parents who had used the service and been given information</i>	
	<i>N</i>	<i>%</i>
Teacher counsellor	42	98
Paediatrician	21	46
Health visitor	18	38
General Practitioner	10	21

**Table 4**

Parents' views of the services they used

<i>Service parents most appreciated</i>	<i>N</i>	<i>%</i>
Teacher Counsellor	37	66
Health visitor/ <i>Specialist health visitor</i>	7	13
Paediatrician	5	9
General Practitioner	3	5
Under five schooling	3	5
Educational psychologist	1	2
Total	56*	100

(\*parents may have given one or more responses in this category)

## DISCUSSION

In view of the fact that recent research has suggested the importance of the contribution parents can make (Bricker and Cususo, 1979), in addition to professional health and educational help, in stimulating the early development of Down's Syndrome children, some of the findings of this local study may give cause for concern and others, for encouragement.

### Health Professionals

If parents are to feel confident and act effectively in nurturing their handicapped child's intellectual and social development, they must have access to information and guidance on the subject. Their first point of contact with expert advice after their child is born is likely to be the paediatrician and it is notable that almost half of the parents in this study attached little or no importance to their visits to the paediatrician. Furthermore, one third of parents actively expressed a need for more information from this source on many aspects of their child's development, including his or her potential in educational or social terms. Given that only one fifth of parents received information about Down's Syndrome from their general practitioner, it appears that any such need will probably not be met by the G.P. This situation may be substantially improved by some paediatricians and G.P.'s being made more aware of parents wishes and their anxiety and frustration over the level of information passed on to them.

Parents were generally happy with the contact they had with their health visitors, but the few who had been visited by the specialist health visitor were particularly impressed by her contribution and she will probably feature in the future as a source of extremely useful information. Parents perceived her to meet many of their needs and welcomed her visits. Her advice and guidance would complement any which is given by both paediatricians and G.P.'s during the child's very early years.

### **Educationalists**

The teacher counsellor, who visited children from the age of three months, was perceived as the parents' most valuable resource and source of advice and information. Parents were particularly appreciative of the teaching aspect of the counsellor's role and their specific interest in this area is in accord with a desire for information about the development of a wide range of skills in their handicapped children. Although the majority of families in this study had already been visited by a peripatetic teacher, it could be argued that the seemingly haphazard way contact with her was initially made, through for example friends, other mothers, self-help groups, the social services and health visitors, was rather less than satisfactory.

Whilst praise for the efforts of the teacher counsellor were almost 'universal', the educational psychologist was severely criticised by the majority and only one fifth of parents indicated that their visit to the psychologist had been of any use whatsoever. Parents wanted to know in detail exactly how their child was progressing both intellectually and socially, so that they themselves could be involved in making changes or adjustments necessary to aid development. Given their interest in promoting the educational potential of their child it is not surprising that parents also wanted, but did not in the main receive, information and advice about the many schools available. It is clear that parents felt the service provided by the educational psychologist to be inadequate, especially in relation to the above aspects.

Parents experience of organised pre-school activities suggested that they provided little which contributed towards their child's intellectual progress. Play groups, nursery schools and the like, were however perceived to offer considerable social support to the parents themselves and also assisted in the social development of their children.

In conclusion, parents were, with the exception of the psychologists input, largely appreciative of the majority of the services and professional help made available to them. Teacher counsellors clearly played a crucial role in the stimulation of early development in Down's Syndrome children. The findings of this study of the views of parents from Nottinghamshire do however suggest that there may be scope for further dissemination of information about educational potential and development from paediatricians, general practitioners, health visitors and most particularly from educational psychologists. Given parental commitment and the various gaps in communication which exist, more research is needed into ways in which parents' contributions to the development of their handicapped children could be effectively harnessed, implemented, co-ordinated and evaluated.

### **SUMMARY**

This study describes parents views of the health and educational services provided in Nottinghamshire for Down's Syndrome children aged 6 months-7 years. Parents were generally satisfied with services, but were particularly pleased with the teacher counsellors, who appeared to play a central role in encouraging early development of the children. The assessments made by the educational psychologists were not thought to be helpful and there appeared to be scope for further dissemination of information about educational potential and development from this source, as well as from paediatricians, G.P.'s and health visitors.

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