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FATHERS OF SPECIAL NEEDS INFANTS AND TODDLERS ENROLLED IN EARLY INTERVENTION PROGRAMS: PATTERNS OF INVOLVEMENT

A Dissertation Presented

By

SANFORD IRVING ROTH

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taught me what it means to be the parent of a special needs child.

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Finally, I must thank my parents, Leonard and Ceila, for always having confidence in me no matter what I have done. My parents have been, and always will be, the models by whom I have guided my life. It is to my parents this dissertation is dedicated.

ABSTRACT

FATHERS OF SPECIAL NEEDS INFANTS AND TODDLERS ENROLLED IN EARLY INTERVENTION PROGRAMS: PATTERNS OF INVOLVEMENT

by

Sanford I. Roth, Ed.D., University of Massachussetts

Chairperson: Dr. Carolyn P. Edwards

A sample of fifty fathers with children under six years of age who were currently or had been enrolled in an early intervention program were interviewed. The primary research goal was to determine what activities fathers participated in which were specifically related to their special needs children and the "patterns of involvement" of the fathers in these activities. Also, an analysis was made of the appraisal-focused coping strategies used by the fathers to manage the stresses associated with having a child with special needs.

The results indicated four primary patterns of involvement: (1) <u>fathers highly involved by choice</u> who were motivated to attend as many home-visits as was possible and were highly invested in doing follow-up therapy, (2) <u>fathers involved by necessity</u> who were at almost all the home-visits because their wives worked during the day but who had surprisingly little involvement with follow-up therapy, (3) <u>fathers who were moderately involved</u> who attended only a limited number of home-visits and were generally taught by their wives how to do follow-up therapy, and (4) fathers with low involvement (traditional fathers) who had almost no involvement with the home-visitors, and when they did do follow-up therapy it seemed to be under the direction of their wives.

The data suggest that fathers with higher levels of involvement were much more likely to have first-born special needs children. It was hypothesized that fathers of first-born children were more involved as a result of having to only focus their time on this one child and perhaps also because they felt a special investment in their first child having special needs.

The primary implication of these findings is that early intervention programs could use the results of this study as a means to develop strategies which take into account the needs, concerns, and interests of fathers in a more planned way. The results of this study indicate that fathers differ from each other in important ways, and these differences need to be recognized when working with families.

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CHAPTER I

PROBLEM AND BACKGROUND

Introduction

Over the past twenty-five years, the provision of educational services to special needs children under the age of six has grown at such a rapid rate that "...early intervention is now 'big business' employing thousands of diverse professionals and paraprofessionals" (Garwood, 1981, p.ix). Along with this growth in the quantity of services, there has also been a growth in the models of service delivery. From the earliest Head Start models to the transdisciplinary approach of more recent programs, the early intervention profession has never lacked for a variety of philosophies. As diverse as these models may be, what they all have in common is inclusion of the child's family as part of the program. While most of the earliest models of early intervention programs had no special role for fathers, the need to involve fathers in all aspects of the programs is now recognized.

The recent inclusion of fathers in early intervention program models is a reflection of the recent social and economic changes which have brought fathers back into more central roles in their children's lives. Since the beginning of the nineteenth century in America, parenting young children has been equated with motherhood (Demos, 1982; Davis, 1976) whereas before that time fathers had a more prominent role in child rearing.

The return of greater paternal involvement in child rearing may be traced historically through a study of changes in child custody laws. Before the beginning of the 19th century, men, for a variety of reasons, predominated in parenting and "...provided the best examples of good character and right behavior" (Demos, 1982; p. 428). As long as infants were being breastfed, mothers were in charge of their daily care of infants, but as Demos points out:

> Once infants were past the age of breast-feeding, their fathers came strongly into view; and girl-children, no less than boys, required moral supervision from a man. It was chiefly for this reason that the common law affirmed the overall rights of child custody to the father in cases of a marital separation. (p. 428)

During the first fifty years of the 19th century, decisions about which parent should have custody of children turned completely around, and by 1847, a New York court held that "...all other things equal, the mother is the most proper parent to be entrusted with the custody of a child" (Demos, 1982, p. 429).

The primary reason for this dramatic turn-around in child custody laws occurred because the industrial revolution and subsequent urbanization separated a father's work place from his home (Pedersen, 1980). Before the industrial revolution, most men worked as farmers, while a smaller number worked as skilled tradesmen or artisans. In these occupations men spent most of their time in and around their homes and were in constant contact with their children. Under these circumstances fathers included their children as a natural part of their work life, and their children "..were thus a visible presence, year after year, day after day" (Demos, 1982; p. 429).

By the mid-19th century, as men gave up their work as farmers, artisans and craftsmen to work in factories away from home, American women became solely responsible for almost all childcare. As men spent more and more time away from their families, their duties as fathers became secondary to their roles as family providers.

Because of recent changes in American culture, men are once again becoming more involved in their children's lives, and as a result are being given more consideration in child custody cases. In 1970, California passed the first no-fault divorce law and set a trend which was followed by the entire nation. One of the principal features of no-fault divorce is the equality granted between the spouses regarding the custody of children. In deciding who shall have custody, the "...preference for the mother (for children of tender years) has been replaced by a sex neutral standard which instructs judges to award custody in the 'best interests of the child'" (Weitzman and Dixon, 1980, p. 364). Thus, many men are now finding themselves in the position (often for the first time in their lives) in which they are the primary caregivers for their children.

Because of these recent changes, today's fathers can not be stereotyped as incompetent with children or resistant to becoming more involved with them. Men, in large numbers, are choosing (as well as being forced into) greatly expanded childcare roles. The old views of father as aloof and distant and as being primarily the sole breadwinner are giving way to what Fein (1978) calls the "emergent perspective" of fatherhood which:

> ...proceeds from the notion that men are psychologically able to participate in a full range of parenting behaviors, and furthermore, that it may be good both for parents and children if men take active roles in child-care and childrearing. (p. 127)

As noted by Pleck (1984), the rate at which this new perspective is emerging is by no means rapid. For a variety of reasons, the shifting of the typical American male's role is occurring slowly and in many ways is still one in which the primary responsibility of the father is to earn a wage. This view persists even when the wife is working. Nonetheless, there are many examples in contemporary society where there are significant variations of men's roles resulting from current social and economic pressures on the family.

This change in family roles makes it necessary for us to change our views of families in ways which will give us a better understanding of the complex negotiations for new roles and responsibilities families face. A theory of the family which has recently been developed is one in which the family is seen as a system "...in which the actions of one member affect the other members" (Rapoport, Rapoport,and Strelitz, 1977; p.62).

From a system's perspective, the changes or influences which one member of the family is experiencing are seen as having important affects on all family members. Research by Shereshefsky and Yarrow (1973), for example, suggest that the degree to which a wife adapts to pregnancy is related to the support given to her by her husband. In a study of mother-father-child interactions (using natural observations and structured play situations) Clarke-Stewart (1977) found that having the father present decreased the amount of mother-child play time, a situation she feels might affect a child's intellectual competence, in that such competence is part of a system of family influences, going from mother to child to father, and back again to mother. And finally, Pedersen (1975) found that mothers who had their maternal skills evaluated positively by their husbands were independently rated as more effective in feeding their infants.

The conception that families operate through systems of influences has also been supported by recent investigations on the significant effects children have on their parents (Bell and Harper, 1979). Rather than viewing children as passive recipients of influence from their parents, children are seen as active participants in the family system. In particular, the work of Thomas and Chess (1977) suggests that children's temperaments can have long lasting and significant effects on how the family system operates. Whether or not a child has an "easy" or "difficult" temperament can greatly influence how well the family functions.

The Problem

The cultural changes in fathers' roles, along with the recognition that a better understanding of how families function may be attained through a system's perspective, has recently created an interest in studying fathers who have special needs children. The focus of this new research on fathers has been on several aspects of how fathers adapt to their roles as "fathers of special needs children."

One approach taken in the research has been to investigate how fathers adapt to the stresses associated with having special needs children. The ability of fathers to adapt successfully to stress has been studied in relation to variables such as the fathers' income levels, the extent of their social support networks, and the ways they have used specific coping strategies to reduce stress.

To gain an understanding of how having a special needs child has affected fathers, several researchers have investigated how fathers of special needs children adapted to their roles compared to fathers of normal children. The goal of this research has been to determine what, if any, are the negative consequences of having a disabled child. Researchers have compared the two groups of fathers in terms of such factors as their self-esteem, psychological adjustment, marital relationships, and types of interactions with their children.

In another type of study, researchers have tried to determine the various roles fathers take on when there is a special needs child in the family, for example, are fathers primarily the family "breadwinners", "disiplinarians", "protectors", etc.?

The findings of these studies suggest that while fathers of special needs children are under considerable stress and have a difficult time adjusting to fatherhood compared to fathers of normal children (Cummings, 1975; Wagner, 1979), fathers of special needs children use a variety of coping mechanisms to reduce stress (Radcliffe, 1975), and are similar to fathers with normal children in the the ways they define their paternal roles (Mitchell, 1979; Dimperio, 1975; Gallagher, Scharfman, and Bristol, 1984). Thus, researchers have suggested that while having a special needs child may have a negative affect on fathers, these fathers enact the role of father in ways similar to fathers without special needs children.

Unfortunately, none of the researchers who have studied fathers of special needs children have investigated the ways in which fathers of special needs children have participated in activities <u>specifically</u> related to their children's special needs (e.g. trips to hospitals, special medical care, etc.) or the detailed ways in which fathers have tried to cope with having a disabled child. As a result of this, the general impression researchers have given of "fathers of special needs children" is that all of these fathers have adapted to their roles and coped with the stresses of having a disabled child in similar ways. They have not yet defined the range of parenting styles and coping strategies of fathers of special needs children, even though common sense suggests that not all fathers are similar in the ways they define their roles or adapt to stress.

When researchers have studied the types of activities fathers have participated in or their coping strategies, they have done this only in a general way. For example, they have classified the fathers' roles in categories like "moral leader" or "breadwinner" of the family, rather than looking specifically at what the fathers do and how they feel, and they have studied only a limited repertoire of coping strategies. Because of this, it has not been possible for researchers to distinguish differences among fathers and thereby create typologies which describe how these men have differentially enacted their roles as fathers of special needs children.

Coping with the problems of special needs children who are in early intervention programs most often requires parents to devote extra time to the care of their children. Not only must parents spend extra time being involved in the many activites of the early intervention programs, but they must also devote extra time to the physical care of their children (e.g. putting on braces, providing special diets), and they must make additional trips out of the home for medical care and a variety of therapies. Since these extra activities are almost always the responsibility of one or both parents, mothers and fathers must make important decisions regarding who will participate in these activities. In the sociological literature on the "transition to parenthood" several studies have emphasized the importance of parental decision-making about how childcare responsibilites are divided between the parents (e.g. Cowen et al, 1978; Entwisle and Doering, 1980; LaRossa and LaRossa, 1981).

Of particular relevance to the present study is the work of LaRossa and LaRossa. In their in-depth interview study of how upper-middle-class white parents made the transition to parenthood, the LaRossa's found that parents were often in conflict over child-care arrangements because of a lack of the scarce resource of time. Time was considered a "scarce" resource by the LaRossa's because the couples of their study put a high premium on their free time:

> ...no parent in our sample indicated that he or she would not be bothered if his or her free time were cut drastically. In other words, on the value continuum from "no value" to "high value," all of our subjects were bunched at the "high" end. This is not surprising. The United States is quickly becoming both a career-oriented and a leisure-oriented society, and the upper middle class (which our sample represents) is at the forefront of this movement. Free time -- or, more accurately, "down time" from children, -- means time to pursue a career and time to participate in the variety of leisure activities manufactured in a postindustrial economy (p. 215-216).

The free time which the parents of the LaRossa's study valued so much is, of course, not inherently valuable (as the importance of free time varies among cultures) but is a reflection of how the parents choose to organize their lives. When parents make decisions regarding their use of time for child-care arrangements, they are also making value judgments about the relative importance of the time they spend with their children. When parents are confronted with the problems of a special needs child, it is not unreasonable to speculate that the value of their free time may increase because of the extra time needed to care for their child.

When free time becomes a scarce commodity, parents are more likely to be in conflict over its use. If husbands and wives are not in agreement over whose free time will be used up for child-care, they will tend to engage in conflict behavior in order "manage the conflicts of interest." As the LaRossa's studied their interview data they became impressed by:

> ...the conflicting goals of both husbands and wives and the amount of conflict behavior in marriage. Couples had set up child-care arrangements which created a scarcity of valued free time. More often than not, it was the wife who "came out on the short end of the stick"; more often than not, if someone had to sacrifice it was she, regardless of whether she was employed. But wives did not sit idly by and let themselves be exploited. On the contrary, they were sensitive to the division of baby care, and, though they did not push for equality of responsibility for the children, they did view marked imbalances as illegitimate and worthy of note (p. 218).

The findings of the LaRossa's study, therefore, suggest the importance of determining the responsibilities delegated to fathers which are specifically related to their special needs children. This is potentially important information as it would be an indication of other aspects of the family relationship which are of great interest. Lein (1984) and

LaRossa and LaRossa suggest that an understanding of the tasks taken on by a family member reflect such factors as the balance of family decision-making power, the self-image of family members, the relative importance of the tasks being performed, and the structure of the family. Since fathers of special needs children are often required to make many more unique and memorable decisions regarding the use of their free time relative to fathers of normal children, this information may take on even more importance.

What is now needed is a research study which investigates the variety of tasks fathers participate in which are directly related to the special needs of their children and the ways fathers cope with the stresses associated with having a disabled child. By knowing how frequently fathers participate in activities which are related to their special needs children and how they cope with stress, one could gain a better understanding of fathers' roles in families where there is a special needs child. The relevant research questions related to fathers' participation in these activities are: what activities related to the special needs of their children do the fathers become involved in, what are the "patterns of involvement" (typologies) of the fathers in these activities and how do the fathers of these patterns cope with the stresses associated with having a special needs child?

An assumption underlying these questions is that the patterns of involvement are related to specific socio-cultural conditions which either facilitate or inhibit the fathers' use of their time to participate in activites they consider to be important to the amelioration of their children's problems. By studying the variety of ways fathers arrange their time schedules and thereby invest energies in activities related to the special needs of their children, it should be possible to attain a better understanding of the factors which propel fathers into these roles and the ways they cope.

A study of how men balance their time commitments between work and the family is an area of great importance, because the ways families adjust to stress and cope with problems are, to some extent, dependent on the presence or absence of the father. Whether or not a father "makes" time to be with his family or never seems to have time to be with his family, is a complex question which has relevance for fathers with or without special needs children.

It follows that a study of the ways fathers participate in activities related to their childrens' special needs must take into account how fathers make use of or create free time in relationship to their work schedules. The amount of free time a father has available which allows him to participate in special needs activities both inside and outside the home is, to a certain degree, constrained by the degree of flexibility in his work schedule. If a father must spend a significant portion of his time during the day at work and has little or no flexiblity to adjust his hours, the extent to which he may participate in early intervention programs and other activites is limited.

Research questions related to fathers' work schedules and their patterns of involvement are: to what extent does a father's work schedule affect his participation in activities related to his special needs child and what factors are related to how much a father takes advantage of or creates "free time" to become involved in these activities?

Another factor which must be considered in how fathers use their free time is related to the "passage of time" and how, as children grow older, fathers make adjustments in the ways they particpate in various activities. In particular, an important factor which needs to be investigated is how, as the special needs children go through times of transitions and/or pass developmental milestones, the fathers make adjustments in the ways in which they become involved in special needs activities. As children pass (or fail to pass) milestones in growth, as they enter and leave special education programs, and as the severity of their children's problems improve or worsen, how do fathers make changes in way they allocate their use of time and what variables account for these changes?

In conclusion, the purpose of the present research study is to investigate the roles of fathers in families where there is a special needs child under six years of age and to investigate the coping strategies the fathers use to manage stress. In response to changing family needs and social policies, fathers are now being included in early intervention programs, and human service professionals are suddenly being faced with the responsibility for understanding the fathers whom they are now serving.

While many of the early intervention strategies which have proven effective with the mother-child relationship should also be effective when fathers become involved, there is a need to implement new approaches which take into account the changing roles of today's fathers. Since a father's relationship to his child and the time constraints he is under may differ from those of his wife, what have proven to be effective approaches in working with mothers, may not work when fathers are involved as well. The challenge which faces human service professionals who work with fathers of young children is the need to re-think programs, so they take into account the needs, concerns, and perspectives of fathers as well as mothers.

CHAPTER II

REVIEW OF THE LITERATURE

While much research has been done over the past two decades on families of special needs children (Farber, 1959; Solnit and Stark, 1961; Gumz and Gubrium, 1972; Holyrod and McArthur, 1976; Gath, 1978; Waisbren, 1980), these studies have generally neglected to include the father. The few studies which have included both the mother and father (Farber, Jenne and Toigo, 1960; Tallman, 1965; Burke, 1973;) suggest that fathers do not adapt as well as mothers to having a retarded child and that the impact of having a retarded child is greater on the father when the child is a son. There is also a general consensus in both the research and clinical literature that fathers of special needs children need greater support from the mental health profession (Bell, Trieschman, and Vogel, 1961; Grunebaum and Strean, 1964; Tuck, 1971; Cummings, 1976).

Researchers have only recently become more interested in studying fathers of special needs children in greater detail. This should come as no surprise, since it has only been within the last decade that fathers have taken on greater responsibilites in the rearing of their young children. Current literature on fathers of special needs children, while still small, provides valuable insights into how fathers are affected by these children. Recent studies include: Dimperio's (1975) study of the psychological adjustment of fathers of young retarded children, Radcliffe's (1975) study of the sources of stress on fathers of retarded children, Cummings' (1976) study of the psychological impact of retarded and chronically ill children upon the father, Mitchell's (1979) study of aspects of the relationship between fathers and their Down's syndrome children, and Wagner's (1979) study of the needs and concerns of fathers with seriously ill children. While these studies cover a variety of different areas, what they all have in common is some focus on how the fathers adapt to the role of being the father of a special needs child. The three aspects of adaptation discussed in these studies are: (1) the degrees to which the fathers adjust psychologically, (2) the coping strategies which fathers use to adapt to the stresses associated with having a handicapped child, and (3) the extent to which fathers make use of their support systems for help in adapting. An understanding of each of these aspects of the adaptation process is necessary to gain a full appreciation of how having a special needs child affects fathers.

Psychological Adjustment of Fathers of Special Needs Children

Two of the studies which have much in common both in terms of their research goals and methods of instrumentation are the studies by Dimperio (1975) and Cummings (1976). These researchers were interested in measuring and comparing the psychological adjustment of middle-class white fathers of retarded (both studies) and chronically ill children (Cummings study only) to a comparison group of fathers with normal children. In Cummings' study the children were between the ages of 4 and 13, while in Dimperio's study the children were between the ages of six months and six years.

In both studies, psychological adjustment was measured by the use of self-administered questionnaires, and the adjustment scores of the groups of fathers with special needs children were statisticaly contrasted to adjustment scores of fathers of normal children. Test measures in the Cummings study included self-esteem, prevailing mood, interpersonal satisfactions in relating to family members, and child rearing attitudes. Test measures in the Dimperio study included self-concept, locus of control, and parental adjustment.

The findings of Cummings' study indicated that the personality characteristics of the fathers with special needs children differed significantly from those of the comparison group of fathers. The cluster of scores on the personality scales of fathers of the mentally retarded children were "...strongly suggestive of a constricted male accentuating his compulsive tendencies in order to suppress his aggressive sexual desires" (Cummings, p. 250). Cummings also found that the personalities of the fathers with chronically ill children were negatively affected relative to the comparison group, but not to the same degree as the personalities of the fathers of retarded children.

Like Cummings, Dimperio found fathers of retarded children to have significantly lower scores on some of the personality measures as compared to the fathers of the normal children. In particular, Dimperio found the fathers of special needs children to be negatively affected in the areas of their emotional reactions to their children, marital-family relationships, and personal social adjustments.

While both Cummings and Dimperio found that fathers with special needs children had adjustment problems related to these children, they both asked whether or not this necessarily carried over into the fathers' overall functioning. My analysis of their findings allows me to conclude that the stresses these fathers felt in relationship to their special needs children did not necessarily have negative consequences for their general mental health. In Cummings' study, fathers' self-esteem scores and Interpersonal Satisfaction cluster scores were most "emphatically" lowered only in relationship to their special needs children but not in relationship to their wives, other children, or other adults. Dimperio found no significant differences in self-concept scores between the two groups of fathers. These findings, therefore, suggest that while the fathers do seem to have adjustment problems in relationship to their special needs children, these problems do not significantly affect their general feelings of self worth or overall adjustment. Dimperio suggests:

> The differential effects of a retarded vs. normal child on fathers seem to relate primarily to those aspects of psycho-social functioning which directly involve the fathers' relationship to or contact with the child, rather than a pervasive detrimental influence on general personality function. Thus a father may feel depressed about his retarded child, in conflict with his spouse over treatment of the child, and constrained in social activities because of the child, without being pathologically depressed in a clinical sense, suffering from serious marital disharmony, or being significantly withdrawn or socially isolated. (p. 63)

If indeed the fathers were able to manage the psychological stresses associated with having a special needs child as suggested by these research findings, what were the coping mechanisms the fathers employed in order to do this?

Coping Strategies Used By Fathers of Special Needs Children

In his study, "Sources and Intensity of Stress for the Role of Father of a Retarded Child," Radcliffe (1975) interviewed 12 middle-class white fathers who had just brought their retarded children into a clinic for evaluation and possible placement into an an institution. One important goal of Radcliffe's research was to investigate the coping strategies the fathers used to cope with deviancy stress (the stress associated with the diagnosis of retardation) and chronic stress (the stress associated with the long term care of a retarded child).

Radcliffe found that when fathers were first presented with the diagnosis of retardation, they used the coping strategies of "denial", "logical explanation", and "withdrawal" in order to control stress. Upon first learning that their children were retarded, the fathers had a tendency to deny the reality of the diagnosis, especially if their children did not have physical manifestations of a problem. Second, as a means of supporting their denial, fathers would begin to offer logical explanations for their children's problems, suggesting, as one father did, that a reason for his daughter's not talking had to do with problems of her "voice box" rather than her retardation. Third, all of the fathers coped with the initial diagnosis through various degrees of withdrawal from the situation, ranging from going for walks, spending more time at work, to complete withdrawal through divorce. Thus, in order to protect themselves from psychological harm upon hearing of their children's retardation, the fathers made use of three coping mechanisms. At some point, however, the fathers had to accept the "reality" of their childrens' retardation, and begin to deal with long-term problems.

In order to cope with these long-term problems Radcliffe found that fathers, as suggested by Lazarus (1966), used the coping mechanisms of cognitive maneuvers and action tendencies. The two types of cognitive maneuvers which fathers used were, "structuring the meanings" of their situations in order to make them more bearable (e.g. explaining their childrens' delays as messages from God), and "redefining" their own behaviors as fathers to make them conform to positive self images (e.g. making the act of institutionalization something which was "good" for their children). The one type of action tendency which Radcliffe found the fathers to be using, was the "pursuit of adequate services and/or diagnosis" for their children. The presence of the fathers at the clinic was itself an indication they were trying to reduce the levels of stress they were experiencing.

In Radclffe's opinion the fathers in his study were "...effectively coping with a chronically stressful situation" (p. 108). In the instances where fathers took action by seeking professional help for their childrens' problems, it seems obvious that they were using an important strategy for effective coping. However, it is not so obvious how the fathers' use of cognitive maneuvers could lead to effective coping.

By making use of cognitive maneuvers, the fathers were able to control the meanings of their experiences in terms which they defined and understood personally. If the problems of their children seemed to be out of their control, at least they could compensate for this by mentally adjusting the situation so that it was not as overwhelming. Once the situation had been "adjusted" this may have then served the fathers by reducing anxiety, increasing their self-esteem, and removing guilt. In an important sense the fathers were adjusting "reality" in "...service to the adequacy of their emotional functioning" (Radcliffe, 1975, p. 108). Thus, for example, the fathers might redefine their problems as messages from God, tests of their parenting, or they might look upon their escaping to their jobs as being good for the children because it meant they were making more money for their families. By redefining their situations, the fathers were able to gain some control over a difficult situation and explain their behaviors in terms of how these behaviors helped to maintain their egos. Judgements as to whether or not the fathers' redefinitions were logical, seem to be "reality-based" or were actually harmful to their children are important for clinical purposes. The point I am stressing here, however, is that _cognitive maneuvers_ are important means by which fathers cope whether they are logical or not.

Coping Strategies and Psychological Adjustment

To a large measure, I believe Radcliffe's study sheds some light on the question of whether or not the fathers' psychological adjustment problems related to their special needs children carry over into their general functioning. It seems that while fathers of special needs children are troubled by the needs of their children, they are able to use a variety of coping mechanisms to maintain their general mental health. While it is true that their self-concept and/or adjustment scores, when compared to fathers of normal children, are significantly lower, the fathers' _own perceptions_ of their behaviors and feelings of self worth are often positive. By defining their circumstances in ways which make them manageable, the fathers are able to make good adjustments. What may seem like an unmanageable situation to an "outsider" has been "subjectively rearranged" by the fathers to such an extent that it becomes manageable and does not significantly affect their general psychosocial functioning.

What this suggests in terms of future research, is the need to explore in more depth the personal meanings "handicap" has for fathers. By taking into account the points of view from which fathers understand and frame their actions, it should be possible to obtain a much richer and deeper understanding of what it means to be the father of a handicapped child. This is what Bronfenbrenner (1979) is suggesting when he discusses the ideas of Kurt Lewin:

> ...of greatest relevance for the scientific study of behavior and development is reality not as it exists in the so-called objective world but as it appears in the mind of the person; in other words he (Kurt Lewin) focuses on the way in which the environment is perceived by the human beings who interact within and with it. (p. 23)

It is my hope that my own research in this area will be a step in the direction of understanding the complex meanings fathers of special needs children attach to their personal landscapes.

Services and Support for Families of Special Needs Children

As I have previously mentioned, the focal point of Cummings', Dimperio's, and Radcliffe's research was the extent to which the fathers adapted to their roles as parents of special needs children. To adjust to being the parent of a special needs child, a father must rely on his psychological strengths and on certain coping strategies. However, the abilities of a father to draw upon these personal resources is related to the amount and appropriateness of the support he receives from others (e.g. his wife, friends, parents, and human service agencies). Without considering the ways in which a person is able to use his existing support network as part of his adjustment process, researchers in this area are making the mistake of viewing adjustment as being exclusively related to the characteristics of the individual.

In their review of factors that affect the abilities of families to adapt to special needs children, Gabel, McDowell and Cerreto (1983) consider the types and quality of services families are receiving as being important to the adjustment process. Such services as medical care, diagnostic evaluations, in-home educational training, and relief care for parents, act as supports to the families as they cope with the the problems of their children. Without adequate support, not only from medical and social service agencies, but also from extended family and friends, families and individuals with special needs children, "...are thought to be at risk for developing problems" (Gabel, McDowell and Ceretto, 1983, p. 485).

In view of the importance of the support system to the success of adapting to stress, it is interesting to speculate upon how the passage of The Education of All Handicapped Children

Act (PL 94-142) in 1975 might have affected the psychological adjustment of fathers who participated in the studies of Cummings, Dimperio, and Radcliffe. At the time of these studies, the fathers and their families had access to a much smaller number of supportive services relative to what has become available since passage of PL 94-142. Since passage of PL 94-142 significant federal, state, and local funds have become available for supportive services to families with special needs children. Prior to PL 94-142, if children with special needs were receiving educational services at all, they were most likely placed in an institution or in a segregated class for "deviant" children. When professional supports were available for the families, they were almost always provided to mothers but not to the fathers:

> ...fathers are being less adequately provided for than are mothers in the development of supportive mental health services to the parents of the handicapped. (Cummings, 1976; p.253)

Actually, Radclffe found that one of the major sources of stress for the fathers in his study occurred when they were not able to locate adequate services for their children. Having a child in need of help and not being able to get adequate support is a real cause for emotional distress which would tax anyone's ability to cope. I cannot help but wonder to what degree the paucity of services at that time contributed to the differences in measures of psychological adjustment between fathers of special needs children and fathers of normal children. If there had been more services available to the fathers of special needs children, in what ways would this have interacted with their adjustment patterns and modes of coping?

Early intervention

A more recent study that offers insights into how the availability of services affects fathers' abilties to cope is one by Mitchell (1979). Mitchell's research was an exploratory study of the psychological adjustment of middle-class white fathers of Down's syndrome children and of the interaction patterns of the fathers and their children. Mitchell was interested, like Cummings and Dimperio, in comparing psychological adjustment between fathers of special needs children and fathers of normal children. Since Mitchell was also interested in comparing interaction patterns, he made behavioral observations of the fathers and their children in their homes. This information is important, for it tells us what the fathers were actually doing with their children. Whether or not the fathers were "well adjusted" according to paper and pencil measures may or may not be relevant to the kind of job they were doing as fathers. By evaluating the nature of the father-child interaction it becomes possible to find out if there is a significant relationship between the fathers' adjustment scores and their enactment of the father role.

Mitchell used behavioral observations and psychological status to compare a group of eight fathers of Down's Syndrome children to a group of eight fathers with normal children. Unlike the other studies reviewed here, these special needs children and their parents had been involved in an early intervention program. The eight fathers of the Down's syndrome children and their families were involved in the Down II Early Intervention Program at the Developmental Evaluation Clinic at Children's Hospital and Medical Center in Boston. This program is typical of recent service delivery models which offer a variety of services to young children and their families. The comparison group of fathers were recruited through a variety of strategies; the main criteria for selection was that their normal child could be matched in developmental age and socioeconomic status with a Down's syndrome child.

Data for this study were gathered on the fathers' psychological status, their daily involvements with their children, and interpersonal interactions with their children at bed time. The psychological status of each father was measured, using the following three instruments: an adaptability scale, a psychological inventory and a global personality questionnaire. Information regarding the fathers' daily involvements with their children and participation in out-of-home activities was gathered through the use of daily logs. Finally, four behavioral observations were made in the homes at the time the children went to bed. In the first two home visits the observers recorded the activities of the family in a narrative form. During the next two home visits a checklist of 25 target behaviors and five affective states of the children were recorded.

The results of Mitchell's study stand in contrast to the findings of earlier research with fathers of special needs children. Mitchell found no significant differences between the groups on the adaptability or personality scores. While the comparison group received slightly higher scores on the scales, none of the differences reached significance at the .05 level of confidence. He did find differences between the two groups in the spousal-self ratings; the mothers of the Down's syndrome children were rated as more involved in selected care-giving activities. The most interesting findings of this study were based on the analysis of the home observations which indicated the extent to which the fathers in the two groups differed in their daily involvements with their children.

Mitchell's analysis of his observations in the home revealed that the two groups were more alike than different (both had similiar ratings regarding parent-child interactions). Analysis of the father-child interactions at bedtime indicated only two differences between the groups: the fathers of Down's syndrome children spent significantly more time teaching their children and more time watching television with them than did the comparison fathers. Mitchell interpreted the additional teaching activities of the fathers of Down's syndrome children as indicating that the fathers did not take their children's development for granted and used this extra time to stimulate their delayed children. I might add that this extra teaching may have reflected "homework" given to the fathers by the intervention program as part of their children's educational plans. Interestingly, the fathers of the Down's Syndrome children rated themselves lower on the teaching self-rating scale than did the comparison fathers. Even though they were doing more teaching, the reality of their chidren's slow progress may have made the fathers feel somewhat inadequate as teachers.

From the point of view of how coping strategies are used by fathers of special needs children (Radcliffe, 1975), the extra teaching time engaged in by the fathers of the Down's syndrome children may also be looked upon as an <u>action tendency</u> coping strategy. By becoming engaged in teaching activities with their children, the fathers were doing something for their children. It should be remembered that Radcliffe only identified the one <u>action tendency</u> strategy of "searching for help" as the way in which fathers were doing something for their children. In Mitchell's study, the fathers did not have to devote their time and energies to looking for help, because it was already available, therefore, they could devote their time to other means of acting on their childrens' problems.

While Mitchell does not offer explanations for his finding of extra television viewing time for the fathers of the Down's syndrome children, it seems to me that by watching more television with their children, the fathers were engaged in an activity that was automatically successful. If they felt inadaquate as teachers, then watching television with their children provided them with the opportunity to spend time with their children in a situation which was "fail-proof".

In summary, the findings of Mitchell's study suggest that the fathers of the Down's syndrome children:

> ...are not very different from fathers of normal children, at least when they are receiving supportive services. Certainly these fathers are required to respond in some way to the increased stress and demands placed upon them by the special needs of their children. The proper question is, have their reactions been adaptive or maladaptive. The many measures used here suggest that...these fathers of mentally retarded children have adapted reasonably well...The Down syndrome fathers recognized the importance of increased stimulation in helping their children make the most important progress in the crucial early years. They were supported in the assumption that this stimulation would have lasting benefits by the early intervention program at Children's Hospital. (p.128)

Mitchell's study was limited to a small group of fathers, and it did not document the ways in which the fathers were involved in the intervention program. It is possible that the eight fathers who volunteered for the study were the most involved fathers in the program and thus were not a representative sample of all fathers of Down's syndrome children receiving early intervention services. Perhaps those fathers having the greatest difficulty adjusting, or those fathers who did not think the intervention program was effective would not let researchers into their homes for the purposes of observation. Any future research in this area needs to take into account the "levels of involvement" of the fathers with early intervention programs.

The Fathers' Support Network

An important contribution which Mitchell makes to the literature on fathers with special needs children is his finding that the ability of the fathers to adjust to their stress is somehow related to the support they are receiving from the early intervention program. While I believe this suggestion points in the right direction, it falls short of recognizing that the fathers' abilities to cope with their stresses is related to the entire support network which they have available to them. While for some fathers the early intervention program may have been an important source of support, for other fathers, another element of their support network may have been of much more importance to them. It is necessary, therefore, to investigate the extent, importance, and personal meanings of the entire support system which fathers use as they cope with the problems of having children with special needs.

In his study "Needs and Concerns of Fathers in Families Where a Child is Seriously Ill," Wagner (1979) investigated the types of support which fathers sought and received as they tried to cope with their seriously ill children. Wagner, using a structured interview, asked a group of 49 fathers questions regarding the types and quality of support they received from their "external support systems" (i.e. hospital staff, clergy, friends, and relatives) and from their immediate families (i.e. their wives). All of the fathers came from middle-class intact nuclear families where the children had been diagnosed as seriously ill at least six months prior to the interview.

While the ages and variety of problems (e.g. leukemia, cancer, burns) of the children in Wagner's study are not necessarily representative of children typically found in an early intervention program, I have nonetheless decided to included this study for review, because I believe the ways the fathers of the seriously ill children have made use of their support systems, would be similar to how fathers whose children were in an early intervention program would make use of theirs. Possibly, the findings of Wagner's study have relevance to fathers with similar problems.

The first group of questions Wagner asked the fathers, focused on the types of support the fathers received from their external support systems, and their evaluations of the quality of that support.

Not surprisingly, the fathers of this study most often cited hospital staff members as being the most helpful support persons. The fathers reported the staff as being helpful by knowing how to put the fathers in touch with sources of financial help, by being familiar with and knowledgable about the illness and by teaching the fathers what to do to help their children. What seemed most surprising to Wagner was the extent to which the fathers were disappointed in the support they received from their friends and extended families. While the fathers reported turning to friends and relatives for help, they most often found them to be well meaning but ineffectual as support. Both friends and relatives wanted to "make everything all right" for the fathers, and this made the fathers feel that all they received was bad advice and misunderstanding. Because the fathers did not receive the type of support they needed, they had a sense of "abandonment" from their friends and disappointment in their extended families.

Other persons or agencies cited by the fathers as being helpful were their bosses (when they excused them from work to attend to their children), parents who had similar problems, agencies such as the American Cancer Society, and members of the clergy whom the fathers had known prior to their children's illness'.

When Wagner asked the fathers how they felt their wives experienced the external support networks, he found that fathers perceived their wives as having different experiences with their support network.

The fathers believed their wives had received as much or more support as themselves from the hospital staff, because their wives actually needed more support and because they may have been better able to ask for help. Those fathers who reported themselves as being able to ask for help were satisfied with the support they received. However, some of the fathers felt that the hospital staff gave their wives "emotional" support while they were only given "factual" support.

When fathers were asked, "With whom do you most often discuss your concerns", 80% of the fathers reported talking primarily to their wives, 12% talked to no one, and the remaining 8% talked to a family member other than their wife, to a friend or to a professional. Most fathers reported that they did not talk with anyone else about their problems. These findings point out the importance of the communications between the fathers and their wives. Since fathers reported disappointment with the support they had received from most members of their external support networks, the importance of their wives as primary support persons becomes apparent. Without adequate and satisfying support from their wives, the fathers were essentially without support.

Looking back to Mitchell's assertion that fathers benefited from the support they received from the early intervention program, Wagner's findings suggest that perhaps it was not the early intervention program which was the primary support of the fathers, but their wives. It may have been that the fathers of the Down's syndrome children who were so well-adjusted had particularily good relationships with their wives, who in turn had particularily good relationships with the early intervention program. In other words, the effects of the interventions need to be considered within the context of the family "system" and the complexities of how support may be "filtered" in a variety of ways, depending on the particular circumstances of individual fathers.

Wagner's suggestion that fathers use their wives as primary sources of support in coping with their seriously ill children, is consistent with the more recent findings of other studies (Lieberman, 1982). Liebrman reports on a study he did with Sherman on the sources of effective help within a group of parents who had experienced the death of a child. The findings of this study suggest that:

> Under extreme stress such as child loss it is rare to find individuals without usable social resources. Overall amount of help provided does not have an impact on the person's marital relationship or well-being: the crucial factor is who provides the help. The spouse is central. (Lieberman, 1982; p. 771)

Wagner's study (like that of Mitchell's) supports the position that paternal coping in response to children with special needs, is a function of both the fathers' inner resources and the support they receive from their "external" support systems and their wives. Future researchers in this area need to take a more in-depth look at the complexities of the fathers' support systems with particular emphasis on the role of the wife. It is important not only to identify important persons in the fathers' social networks, but also to investigate the ranges of reactions which fathers have in response to these persons, and to identify some of the dynamics of what makes for effective coping by the fathers.

Summary of Literature Review

In summary, my review of the literature suggests the following information regarding fathers of special needs children:

1. In terms of psychological adaptation to the stresses of having special needs children, fathers are negatively affected by their children, but this does not necessarily carry over into their general psycho-social functioning. The negative aspects of the adjustment may be offset by the availability of supportive early intervention services. The degree to which fathers are affected by early intervention programs needs to be investigated in relation to the types of involvements the fathers have in the programs and their relationships with their wives.

2. While research findings suggest that fathers cope well with the problems associated with having special needs children, the criteria for what constitutes "good" coping is not clear. The coping mechanisms which fathers use are suggested by Radcliffe, but the small size of his sample and his method of data analysis only yield a limited number of examples of how fathers cope.

3. An important element of the coping process is the personal meanings which fathers attach to their stresses. Probably no two fathers react to the same stress in the same way. In an important sense, an understanding of the coping process must include recognition that the perception and experience of stress is mediated through cognitive redefinitions of the stress by the individuals experiencing the stress.

4. Research results present only a general picture of how fathers make use of their entire social support system. While fathers seem to limit themselves to seeking support only from their wives, it is not clear to what extent they make good use of other members of their support system to "supplement" the help they receive from their wives. Also, the complex interconnections between different persons and groups in the fathers' support network are unknown.

5. Researchers do not report consistent correlations between such variables as fathers' ages,

income levels, occupations, family size, sex of their children, and how the fathers adapt to their children or become involved in early intervention programs.

6. The literature is limited to the extent that the populations studied consist of moderately to severely retarded children and seriously ill children of middle-class white fathers. Caution must therefore be used when generalizing research findings to other groups. The term "father of a special needs child" should not just refer to a limited group of men. Rather, it should encompass fathers who have children from a wide range of disability groups, and of varying demographic characteristics.

7. The literature does not differentiate fathers of special needs children from each other. While common sense would suggest that not all fathers of special needs children are alike in the ways they adapt to the stresses associated with having a special needs child, there have not been any studies which suggest the ways fathers differ from each other. An important contribution to the field would be a study which described differences among fathers and suggested reasons for these differences.

CHAPTER III

GOALS AND METHOD

Goals

The present study is an exploratory study of fathers with special needs children under six years old who have been, or are currently enrolled in an early intervention program. A review of the literature in the field indicates a need to investigate the following questions:

1. What activities do fathers participate in which are specifically related to their childrens' special needs?
2. What are the patterns of involvement of the fathers with respect to their participation in these activities?
3. How do the fathers of these patterns cope with the stresses associated with having children with special needs?
4. What variables (e.g. income, education, sex of child) or other factors seem to account for the differences among the patterns?

The framework of the present study is based on the notion that to achieve an understanding of the father's behaviors, thoughts, and feelings regarding their children, a research method should be used that is flexible enough to be adapted to a wide range of fathering styles. A research method which meets this requirement is the in-depth interview. This is a method which allows the researcher to probe for data during each interview, based on the particular circumstances of each subject.

Method

The research instrument

An in-depth interview method was used to collect data on fathers of special needs children. I chose to use a qualitative approach for two reasons. First, a complete understanding of how fathers cope with their special needs children cannot be measured in objective terms. As researchers such as Radcliffe (1975) and Pearlin and Schooler (1978) have suggested, an important way in which fathers cope is by making cognitive redefinitions of their situations. An understanding of the intense feelings fathers must experience as a result of having to cope with their special needs children is perhaps only accessible through the use of a qualitative research approach:

> ...qualitative methods enable us to explore concepts whose essence is lost in other research approaches. Such concepts as beauty, pain, faith, suffering, frustration, hope and love can be studied as they are defined and experienced by the real people in their everyday lives (Bogdan and Taylor, 1975; p. 5).

I felt that a qualitative research strategy, such as the in-depth interview, would enable me to collect data which accurately captured the unique perspectives of my subjects.

The second reason I used an in-depth interview is that some of the inconsistentcies of research findings on fathers of special needs children may be due to the use of research designs which have prematurely tried to find cause-and-effect relationships between variables, without grounding the research in an adequate theoretical framework. By using in-depth interviews I felt that I could study fathers from a broader perspective, and thus be able to conceptualize their behaviors, thoughts and feelings in a more complex manner than has been done before.

Interviewing the fathers allowed me to attain an understanding of how these fathers interacted with their children and made use of their social networks. Learning how the fathers viewed themselves as actors, how they rationalized their behaviors and how they used available resources became apparent through the interview method. The major strength of the in-depth interview technique was that it allowed the subjects to tell their own stories. Their view of the world formed the framework for the interview.

An obvious feature of the in-depth interview method is that each interview with a father consisted of individualized questions. Since no two fathers had the same experiences with their children, it was necessary to ask questions which were relevant to individual situations. What is important to understand, however, is that even though my questions were different, I was still obtaining compatable information from the the fathers. This means that while my measurements were not "phenomonally equivalent" they were "conceptually equivalent" (La Rossa and La Rossa, 1981). In order to discover the personal meanings fathers attached to their experiences, I had to ask "personal" questions.

While interview questions were varied, depending on the circumstances of each subject, the interview format was similar for all interviews. The interviews followed a chronological order of events in the fathers' lives. I chose to interview the fathers according to a chronological ordering of events for two reasons. First, since I was interested in finding out what "special needs activities" the fathers participated in and their patterns of involvement in these activities, the chronological format allowed me to make this determination at all periods of their childrens' development. Second, the chronological framework allowed me to have greater control over the flow of the interview. By focusing my questions on the unfolding of events, I was able to do an effective job of guiding the interviews, while at the same time providing the fathers with a structure they could easily understand. The interviews included the following areas: (1) biographical information (e.g. work history, schooling, personal interests); (2) extent of social network (e.g. parents' place of residence, frequency of contact with relatives and friends); (3) occupational information (e.g. flexibility of working hours, enjoyment of work); (4) relationship with wife (e.g. shared interests, areas of conflict, divison of child-care); (5) relationship with other children in the family (e.g. activities, child-care responsibilities); (6) experiences with the birth of the special needs child (e.g. prepared childbirth class, difficulty of labor); (7) the child's history (e.g. nature of problem, special care needed); (8) involvement of the family in the early intervention program (e.g. how referral was made, the types of activities the father has participated in); (9) the types of support the father has received (e.g. the most supportive persons, the number of people who have been supportive), and (10) the child's future from the father's perspective.

The initial questions in the interview were focused on biographical information. Knowledge regarding the fathers' experiences prior to the birth of their special needs children was especially useful for several reasons: it helped in the overall interpretation of their responses; it saved time and confusion when discussing their special needs children, because I would not have to stop the interview to obtain background information, and it was a non-threatening way to begin the interview. Once I had obtained enough background data, I questioned fathers in approximately the chronological order in which events occurred regarding their special needs children. Throughout the interview I framed my questions in as neutral a manner as possible, so as to not encourage the fathers to give responses which they felt were socially accecptabe to me.

Subjects

Fathers for this study were recruited through three early intervention programs in Western Massachusetts which provide therapeutic services to families of special needs children between the ages of birth and three years. Each of the programs have similar service delivery models, in which in-home and center-based services are provided by an interdisiplnary team of professionals (e.g. educators, social workers, physical therapists). I made visits to each of the program sites where I observed program operations and talked to staff members regarding their philosophies and approaches to working with families. While I found that each program had a slightly different philosophy of service delivery, I did not feel these differences were so great as to significantly affect how fathers became involved with activities related to their special needs children.

While interviews were conducted with 50 fathers, data from only 46 fathers were analyzed, because four of the interviews could not be coded: three because the fathers' responses were too ambiguous and one because the father's native language was not English, and I could not sufficiently understand his responses.

Included in the sample are biological fathers who at the time of the interview were residing with their families and who had children under the age of six who were currently or had previously been enrolled in one of the early intervention programs. To recruit a representative sample for the present study, the center directors contacted as many fathers who met study criteria as was possible and then provided me with the names of those fathers who had agreed to be interviewed. The only fathers not recruited for the present study were fathers, who for reasons of confidentiality, the directors felt I should not interview (e.g. retarded fathers, fathers whose children were near death). Surprisingly few of the fathers who were asked to volunteer for this study refused to participate, as 50 of the 53 fathers contacted agreed to be interviewed.

Procedures

Initial contact with the fathers was made by telephone calls from program staff members who had some familiarity with the family. Once a father granted permission for an interview, I was given his name and telephone number so that I could make arrangements for an interview. Upon calling the father I identified myself as the graduate student who was interested in talking to him, and I asked the father if he was still interested in being interviewed. When the father agreed to the interview I let him decide on the place and time of the interview. By letting the father set his own terms about the time and place of the interview, I hoped to give the father a sense of security in the arrangements. I correctly anticipated that most of the interviews would be held in the fathers' homes in the evenings, but I also met fathers in such locations as their places of work or restaurants.

At the time of my phone contact with the father I asked that the interview be held in private. I requested the privacy to insure consistency in interview conditions across interviews and to create an environment in which the father felt free to discuss topics he might not talk about with other persons present.

When I arrived for the interview, I introduced myself and spent some time getting to know the father. Before I began an interview I requested permission to tape record the interview and in no case was permission denied. The interviews were tape recorded so that transcriptions of the interviews could be made for purposes of analysis. At this time I also explained the confidentiality of the interviews and requested permission to conduct the interviews. At the end of each interview the fathers were requested to fill out a "background information" questionnaire which provided me information about the characteristics of the fathers and their families. (See Appendices D and E for forms.)

Shortly after the completion of the interview I wrote an account of the interview, including information such as my impressions of the father's reactions to the interview, a description of the father and his home, observations of his interactions with his wife and/or child, or any unusual or interesting events which occurred during the interview. These data were used to supplement the interview data, giving "flavor and life" to my interpretations of the data.

Data analysis

When all the interview tapes had been transcribed there were approximately 1650 pages of typed transcripts. The data were analyzed using the general guidelines suggested for the in-depth interview method by Patton (1980). This is a method of analysis which requires that the emergent "...patterns, themes, and categories of analysis come from the data...rather than being imposed on them prior to data collection and analysis" (Patton, 1980; p. 307). This method suggests that the key element of the analysis is to organize the data in such a way that the natural variations of the research subjects are allowed to emerge in ways which are accurate reflections of their differences. The primary purpose of this type of analysis is to describe the data so that it is possible to make interpretations about the nature of the fathers.

As Patton indicates, there is no "right" way to organize qualitative data. It is a process which depends on the creativity and insights of the researcher in arriving at a description of the subjects in a way which suggests causal linkages between the data and process variables. In the present study the qualitative analysis of the data was accomplished through coding themes in the data which emerged as a result of the fathers participation in a variety of activities related to their special needs children, while taking into account demographic variables, coping strategies, and the ways fathers made use of their support networks. The exact content of those themes, as is consistent with qualitative research methods (e.g. Bogdan and Taylor, 1975) were not known until after the transcripts were analyzed. The details of the procedure used for the analysis of the data are described in the following chapter.

Characteristics of the sample

In all, 50 fathers were interviewed. The mean age of the fathers was 31.7; their mean income was $18,400; the mean number of years they were married was 8.04, and the mean number of children in their families was 2.14. Three of the fathers (6%) did not finish high school; 24 (48%) had only finished high school; four (8%) had degrees from community colleges (Assoc.); 11 (22%) had undergraduate college degrees, and eight (16%) had graduate degrees (e.g. M.A., M.B.A., Ph.D.). Thirty three (66%) of fathers had wives who did not work; 10 (20%) had wives who worked part time, and seven (14%) had wives who worked full time. The children of these fathers had a mean age of 2.67; 29 (58%) were males and 21 (42%) females; 22 (44%) of these children were first-borns and 28 (56%) were later-borns. The disabilities of the children included: developmental delays, hydrocephalus, Down's syndrome, cerebral palsy, neuro-motor diseases, visual deficits, spina bifida, clef palate, epilepsy, heart disorders, and rare genetic disorders. The severity of these problems ranged from mild to severe. (Summaries of the the sample characteristics are presented in Appendices A and B.)

CHAPTER IV

STUDY RESULTS: PATTERNS OF INVOLVEMENT

Introduction

The initial focus of my data analysis involved searching for natural variations in the fathers' responses which would allow me to "...identify the attributes or characteristics that distinguish..." them from one another (Patton, 1980; p. 307). My goal was to determine what were the "analytic typologies" which best described the fathers' participation in activities related to their children's special needs.

I hoped that important themes would emerge from the data which I could use as the basis for classifying fathers into typologies which were accurate descriptions of their thoughts, feelings, and behaviors. I hoped that this information could then provide professionals in the field with information that would be useful in designing more effective intervention strategies with families of special needs children.

As I read each interview for the first time I focused my attention on the father's participation in activities which were specifically related to their childrens' special needs (e.g. doctors appointments, trips to clinics, participating in support groups). I found, for example, that the fathers differed greatly in the extents to which they became involved in activities associated with the early intervention programs. I was struck by how little some men participated in the programs compared to how much other fathers were involved. For some fathers, the early intervention program was something they knew little if anything about, yet for others, the program seemed to be a focal point of their lives.

Therefore, the starting point for my analysis of the data was to investigate the "special needs activities" in which the fathers became involved.

Analysis of Involvement

My analysis of the activity data involved the following five steps: (1) determining the number of activities the fathers participated in, (2) categorizing the activities, (3) determining the "key" activities which differentiated among the fathers, (4) devising scales to measure the relative involvement in the "key" activities and (5) determining "patterns of involvement" (typologies) based upon the scales.

Determining the number of activities

In order to determine the "special needs activities" which the fathers participated in, I reread the interviews and coded them according to the types of involvements the fathers reported. The coding took the form of color-coded "signal dots" which I placed in the margins of the transcripts at those points in the interviews where a father described his participation in an activity which was related to the special needs of his child.

In order for an activity to be included in the coding, it had to be _specifically_ related to the special needs of the child. Excluded from the coding were such routine activities as a father's participation in diapering, attendance at pediatric appointments, or playing with his child, unless these activities were directly related to the child's special needs. Thus, for example, only if a child had a skin condition which required special care during diapering, or if "rough-play" was requested by the therapist would these activities be coded as being related to the child's special needs.

After tabulating the results of the coding, I found there were 15 mutually exclusive types of activities which I grouped into the four categories to be discussed in the following section. The following list includes _all_ activities, even if an activity had only one instance of occurrence. The types of activities which the fathers reported participating in included:

Type I -- Involvement With Home-visitors

1. _Home-visits_. An important component of all the early intervention programs was the home-visit. A home-visit was a regularily scheduled visit by a staff member of the early intervention program (the home-visitor) to the child's home. The home-visit was intended to be a time where the home-visitor provided both parent training and direct service to the child. Home-visits were most often scheduled on a weekly basis, but also occurred less frequently.

2. _Center-visits_. In some instances parents were asked to bring their children to the early intervention programs for the therapy sessions,

rather than having them at home. This occurred in instances when there were limited funds, when the home-visitors did not have the time to visit the homes, or if there were special circumstance which made it better for the therapy to occur outside of the home. The services provided at the center-visit were exactly the same as at a home-visit.

3. Taking the child to playgroups. All of the programs, in addition to the home-visits and/or center-visits, had playgroups which met on a regular basis. These playgroups were designed to be times for the children to socialize with each other, as well as to allow home-visitors to work with the children in a classroom setting. In all programs, the parents were responsibile for transporting their children to the centers.

Type II -- Participation in Follow-up Therapy

4. Follow-up therapy. As part of each child's intervention program, the parents were given training in therapeutic activities to be done with their children. Parent training almost always occurred at the time of the home-visits, and the parents were expected to follow-up on the training during the following week(s). Depending on the child's needs, the amount and type of follow-up varied greatly among children.

Type III -- Other Activities of the Programs

5. Evaluations. When a child was enrolled in an early intervention program, an initial developmental evaluation was done in order to determine the child's needs. The evaluation usually included two sessions, one for the evaluation and one for a report to the parents. The evaluations and follow-up reports occurred either in the parent's homes or at the early intervention centers. Also, usually on a yearly or as needed basis, there was an updated evaluation on the developmental status of the child.

6. Parent discussion groups during playgroups. While children were involved with the playgroups, the early intervention programs set aside special times for the parents to meet so they could discuss

special topics or items of personal concern. These were optional meetings, because a parent could either stay with his/her child in the playgroup instead of participating in the discussions.

7. Parent support groups. The early intervention programs offered parents the opportunity to meet in the evenings with other parents of special needs children. In certain circumstances the support groups were not sponsored by the early intervention programs, but parents were referred to the groups by the programs. The focus of these groups were discussions by the parents on the needs and concerns they had regarding their children. The groups were both for couples and/or just fathers or mothers.

8. Social events. Each of the early intervention programs sponsored a variety of social events in which the families were invited. These event's included Christmas parties, open houses, and picnics.

9. Special projects. Oftentimes the early intervention staff needed help on special projects and therefore requested assistance from the families. Included in these types of projects were fundraising, moving of equipment, clean-ups, and the making of equipment.

Type IV -- Activities Not Related to the Programs

10. Taking children to special appointments. Almost all of the children in the study sample were in need of special care which required their parents to make trips to hospitals, specialists (e.g. neurologists and orthopedists), and clinics. These appointments usually occurred on an infrequent or emergency basis, but in some instances they were regularily scheduled over long periods of time.

11. Extended stays in hospitals. Some of the children were in need of extensive hospitalizations in out of town locations. When this occurred the parents had to make arrangements to be with their children for either part or all of their visits. The need for these stays arose, for example, because of surgery, special testing, or illness.

12. Meetings with public school officials. When children turned three years of age they were no longer

eligible for early intervention services. At these times the parents had to meet with public school officials to determine if there was a need to transfer the children into mandated special education programs. If it was found that the children were in need of public school services then the parents had to participate in the process of creating an Individualized Educational Plan (I.E.P.) for their child. This meant that the parents had to attend a variety of meetings in order to have their child properly placed and enrolled. If the parents disagreed with the plan offered by the publc schools, then they also had to become involved in an appeals process.

13. Child advocacy. The provision of services to special needs children often became a political issue in which parents became activists for the rights of their children. Parents could become involved in this political process through such activities as lobbying, joining special interest groups, or attending rallies in support of legislation.

14. Informal parent support. In addition to the parent groups offered by the early intervention programs and other human service agencies, parents sought out, on their own, the advice and support of other parents of special needs children. The parents met either as groups or as individuals on either a regular or short term basis.

15. Routine care. Some children, because of their special needs, had to have their parents provide them with special care on a daily basis (e.g. catheterization, special medical treatments, care of braces).

Categorizing the fathers' activities

Once I determined what the activities were, I then had to devise a system of categorization which could serve as a tool for defining the patterns which distinguished the ways fathers became involved in these activities (i.e. patterns of involvement).

In devising a system of classification I made the assumption that typologies of fathers could be created through an investigation of the clusters of choices they made in becoming involved with the special needs activities. Since the use of time is such an important factor in American culture, I felt that a classification of how fathers became involved in the array of identified activities would provide important insights into differences among fathers.

Creating the classification system involved an inductive process whereby I tried several different strategies for classifying the activities before I finally found the one which seemed the most appropriate. The problem which I faced was one of "convergence" (Patton, 1980), where the system of classification had to somehow make the data "fit together". In order to make the proper "fit" I had to go back and forth from my data to the classification system to determine if the system accurately clarified the data by bringing out the differences which existed among the fathers.

Patton suggests that a qualitative research classification system be designed in such a way that it meets the criteria of "internal homogeneity" and "external heterogeneity". With respect to the present study, this suggests the following: (1) fathers who are grouped together within a particular pattern should show similar behaviors and attitudes as fathers of special needs children (internal homogeneity); and (2) fathers who are compared between groups should be obviously different (external heterogeneity).

Patton also suggests that a complete system of classification has not been devised as long as there are a large number of cases which are not assignable to a pattern. In the final analysis, the classification system should be reasonably inclusive of all the existing data.

The classification system which I finally arrived at (and which I felt most closely met Patton's criteria) was one in which I divided the activites listed above into four general types: (1) Type I (Involvement With Home-visitors) were those in which the fathers became involved with the home-visitors either at the father's home or at the early intervention program where the children participated in therapy and/or playgroups (activities #1-#3 listed above); (2) Type II (Participation in Follow-up Therapy) was the one activity where fathers did follow-up therapy with their children (activity #4 listed above); Type III (Other Activities of the Programs) were those which included all other involvements with the early intervention programs (activities #5-#9 listed above); and Type IV (Activities Not Related to the Programs) were those which were not related to the early intervention programs (activities #10-#15 listed above).

By analyzing the data according to the fathers' patterns of participation in these four types of activities, both the resulting differences between patterns and the similarities within patterns suggested that I had found the "analytic typologies" which best described this study sample.

What seems to make this system work is its general adherance to a chronological unfolding of events. The potential involvement of a father within an early intervention program (activities #1-#9) usually occurs at a time *after* extensive trips to hospitals and visits to doctors during a "crisis period" when children's problems are often first identified (activities #10, #11, and #14), but *before* the time when children become involved with public school programs (activites #12 and #13). This system of classification, therefore, highlights important developmental and transitional stages of the children's lives which, as it turns out, have particularily important significance for the fathers.

During periods of "crisis" when a child's special needs first became identified (prenatal, perinatal, or postnatal) or when medical complications would occur, many fathers viewed their roles (and willingness to commit their time) very differently from when their children became enrolled in the early intervention programs. During times of crisis fathers were able to find almost all the time they needed to participate in activities related to their special needs children. Once the "dust had settled" and the children were referred to early intervention programs, many fathers did not make time to become involved with the home-visitors or do follow-up therapy activities. Later, as their children made the transition out of the early intervention programs and thus moved into the preschool stage of development, many fathers then began to make time to become involved in these types of activites and looked upon their roles in new ways.

Determining the key activities

Since, of the four types of activities, only Involvement With the Home-visitors (Type I) and Participation in Follow-up Therapy (Type II) stood out as being especially significant in differentiating among fathers, these were the two activity types which served as the primary basis for creating the typologies. When, for example, all the the early intervention activities were categorized together for the purposes of creating patterns, the resulting typologies did not distinguish the fathers from each other. Furthermore, my attempts to use Type IV activities (those not related to the early intervention program) as a basis for classifying fathers did not prove useful.

It was only when I created the typologies in terms of the father's involvements with home-visitors (Type I) and follow-up therapy (Type II) that important differences emerged from the data. Once these difference became apparent, it was possible to clarify and refine the typologies by investigating how the fathers became involved in the other two types of activities (Type III and Type IV)

Involvement with home visitors. Of all the activities the fathers participated in, none seemed to provide as much understanding of the fathers as did their involvements (or lack of involvements) with the home- visitors. Even as I was conducting the interviews I became sensitized to how important the fathers' contacts with the home-visitors were to the present study, and when I began to organize the data, I would most often begin my analysis by looking at the ways the fathers became involved with the home-visitors.

The fathers' involvements with the home-visitors seemed to be a reliable indication of the their roles in the family structure and the viewpoint from which they conceptualized their willingness to commit their time and energy to the amelioration of their children's special needs. Involvement with the home-visitors required a unique type of commitment from the fathers, and this seemed to tap into basic differences among them.

Involvement with the home-visitors almost always occurred during the hours between 9 a.m. to 5 p.m. when fathers were normally working, although occasionally visits were scheduled at times convenient to the fathers. Therefore, if fathers were to become involved with the home-visitors, they almost always had to make special arrangements in their work schedules or else take advantage of scheduling flexibilities or unusual circumstance which provided them with "free-time" coinciding with the times of the visits. Thus, a key factor of my analysis was the flexibility of the fathers' work schedules which provided them with opportunities to participate in home-visits and trips to the early intervention centers if they so desired.

A surprisingly large number of fathers in this study had many opportunities to make arrangements to meet with home-visitors at times which did not conflict with their work schedules. Fathers who worked four-day weeks, fathers who worked second shifts, and fathers who were salesmen with irregular hours are examples of fathers who could have made arrangements to meet with the home-visitors if they wanted to. What became important in the creation of the "patterns of involvement" were the ways fathers made use of their flexible times. The availabilty (or potential availability) of free time did not necessarly mean that fathers took advantage of this time to meet with the home-visitors. The expressed (or inferred) reasons fathers used to account for how they made use of their free time became valuable data in achieving an understanding of the ways fathers framed their roles as parents of special needs children.

Participation in follow-up therapy. The second activity I used as a basis for creating the typologies was the fathers' involvements with follow-up therapy. I found, as in involvements with the home-visitors, participating in follow-up therapy required a type of commitment which highlighted differences among fathers related to family structure and to the ways fathers viewed their roles in relation to their children. In particular, I found there were three reasons to create a separate coding category for follow-up therapy.

First, as I read the interviews, I sensed that for a number of fathers, doing follow-up therapy was an especially important activity. It was a type of activity which seemed to "raise the passions" of a number of fathers. I was impressed by their persistent commitment to becoming involved in follow-up therapy and the detailed knowledge they had regarding the nature of the follow-up routines. It seemed that this direct contact with their children was a way for some of the fathers to do something for their children which could not be accomplished in any other way. In all other types of activities the fathers could be involved without having to do "hands-on" work with their children. Unlike such activities as home-visits, participation in evaluations, or transporting a child to appointments, follow-up therapy required that the fathers learn specific skills to be used when interacting with their children.

Second, follow-up therapy could be done at any time of day or on weekends and was therefore, not an activity which was dependent on work schedules. If fathers could not attend home-visits because of conflicts with work or if they could not squeeze visits to doctors offfices into their routines, they could not easily excuse themselves for not doing follow-up therapy.

Third, involvement with follow-up therapy seemed to be a good indication of whether the fathers were "traditional" or "non-traditional" in their orientation to fatherhood. Doing follow-up therapy is similar to doing the routine childcare activities traditionally done by mothers. The patterns of how the fathers became involved with follow-up activities provided important information which distinguished the fathers from each other.

Other activities of the programs. The fathers' involvements in other activities of the early intervention programs did not provide data used in the creation of typologies. These activities all required relatively short-term commitments, as fathers only needed to take time off from work once or twice (e.g. to attend an initial evaluation) or could attend activities planned in the evening (e.g. social events).

While fathers, in general, showed some interest in social events or special projects of the early intervention programs, for some of the fathers, participation in parent support groups was a partiularily important activity which had special significance to them. I also found that the ways the fathers talked about their participation in these support groups offered insights which helped to clarify how they were able to adjust to the stresses of having a child with special needs.

Activities not related to the programs. In addition to becoming involved in the activities of the early intervention programs, there were many other opportunities for fathers to become involved in activities related to the special needs of their children. Included in this group are activities #10-#15 listed above. These are the activities fathers generally became involved with either before or after their child was in the early intervention program. With few exceptions, these activities required short term time commitments, and were often related to "crisis" situations or times of transition for the children.

Since with only one notable exception, all fathers participated in crisis situations this was not an activity which could be used to differentiate the fathers. It would have taken rather unusual circumstances for a father not to become involved in these times of crisis. When children were hospitalized or had to be taken to clinics for treatment and/or diagnosis, almost all fathers made time to be present.

When children had to leave the early intervention programs at age three, some fathers who had no previous involvement with the early intervention programs suddenly showed interest in this transition and wanted to meet with home-visitors. In analyzing the typologies based upon home-visitor and follow-up activities, an important factor which helped to bring the typologies into focus was the fathers' involvements with these transition activities.

Measuring frequency of involvement in activities

Once I had determined the types of activities, the categories of activities, and the relative importance of the activities, my next task was to devise a means to measure differences among fathers based on how often they became involved with home-visitors and how frequently they did follow-up therapy activities. I felt that a measure of frequency of participation was important because "involvement" is relative, and a high degree of differentiation among fathers could be achieved by using a measure of frequency of participation.

To measure the relative involvements of the fathers I constructed two "level of involvement" scales. These are linear scales which range from "low" to "high" involvement, and reflect the relative amount of involvement of the fathers with home-visitors and doing follow-up therapy. My goal in constructing these measures was to create ordinal scales as a means of differentiating the ways fathers became involved in the activities keyed to each scale.

<u>Home-visitor scale</u>. To devise a useful means for creating the home-visitor scale I read through all of the interviews and put red "signal dots" alongside all excerpts where fathers discussed their participation in the three activities included in the home-visitor scale (i.e. home-visits, center-visits and taking the child to playgroups). Upon completing the coding, I cut-out all of these excerpts and collated this information so I could search for patterns which emerged from the data.

As already mentioned, an important factor which emerged from the coding was how often the fathers met with the home-visitors. Upon reading over the excerpts I felt the following six-point home-visitor scale covered the continuum of responses the fathers reported:

Home-visitor Scale

1. The father reports no involvement with home-visitors.

    -- The father states he was never home when the home-visitor was there, or if he was there, he did not participate in the session. The father reports he never took his child to the early intervention program.

2. The father reports minimal involvement with the home-visitor.

    -- The father reports being involved in one or two home-visits and/or trips to the early intervention program. If the father does not give a specific number, the vagueness of his answer will be taken as minimal involvement.

3. The father reports some involvement with the home-visitor

    -- The impression is given that the father was involved in home-visits and/or trips to the early intervention program which occurred from time to time. The impression is also given that the involvement was by no means a regular occurence.

4. The father reports moderate involvement with the home-visitor.

    -- The impression is given that while the father was involved in many home-visits and/or trips to the early intervention program, there were also many which he missed.

5. The father reports much involvement with the home-visitor.

    -- The impression is given that the father was involved in a great many home-visits and/or trips to the early intervention program, and while he may have missed some visits, he attended many more than he missed.

6. The father reports involvement with almost all of the home-visitor's sessions.

- -- There is a clear impression that the father attended almost every home-visit and/or trip to the early intervention program, missing only a small number.

Fathers were considered to be "high" in involvement with the home-visitors if they were scored as a 5 or 6 on the scale, "moderate" if they were scored as a 3 or 4, and "low" if they were scored as a 1 or 2.

The intervals of the scales are not based upon strict frequency counts nor are they uniformly graded from low to high. The intervals between the levels are a reflection of what I felt were the "natural break points" in the data which helped to differentiate typologies of fathers. When coding the data I had to make judgements as to how to score the fathers, and I found that, in particular, there were several interesting problems in coding the data.

First, in some of the interviews it was not clear how frequently the fathers were actually involved with the home-visitors. Sometimes their answers to my questions were vague, sometimes my questions were worded somewhat ambiguously, and in some instances the fathers could not remember how often they became involved. In rare instances I did not ask questions about frequency of participation because the interviews took other directions or the father was difficult to interview. In all of these situations I had to judge frequency of involvement by making inferences based on other information the fathers gave me. In four cases, the information was too ambiguous and I did not include the interviews in the data analysis.

Second, in some instances I found that fathers reported being at a certain number of home-visits at one point in the interview, but at other points they either contradicted themselves, or it became clear that while they may have been home, they did not participate in what was happening.

Third, some fathers reported being at home-visits as a matter of chance (e.g. a bad back kept them out of work) and indicated they had no interest in what was going-on, whereas another father may have been at the same number of sessions, yet he went out of his way to make a special commitment to being present.

A final type of problem occurred because fathers' situations changed over time. Some fathers, for example, were highly involved with the home-visitors when they were unemployed, but when they went back to work, their level of involvement decreased. When this, or any type of problem occurred, I had to make a judgement as to which score was most representative of the father's involvement.

I should add that while the above problems caused difficulties in scoring the data, at the same time they provided special insights into how fathers enacted their roles. By having to struggle with ambiguous data, the subtleties of motivation, and the changing work patterns of fathers, I was able to attain important insights into factors which influenced involvement.

Follow-up scale. In constructing the follow-up scale, I used a procedure similar to the one used with the home-visitor scale. The responses were coded, collated and analyzed for rates of participation. Similar problems occurred in the design and coding of the follow-up scale, as with the home-visit scale.

After analyzing the data related to the fathers' involvements with follow-up therapy activities, I found the following six-point follow-up scale covered the continuum of responses reported by the fathers:

Follow-up Scale

1. The father reports no involvement with follow-up therapy.

    -- The father states he has never done any follow-up therapy.

2. The father reports minimal involvement with follow-up therapy.

    -- The father reports doing follow-up therapy on only one or two occasions. If the father is vauge about the extent of his involvement with follow-up therapy, this will be taken as an indication of minimal participation.

3. The father reports some involvement with follow-up therapy.

    -- The father reports doing some follow-up therapy, but by no means on a regular basis. In all liklhood the father did the therapy with his wife, who seemed to be in charge.

4. The father reports moderate involvement with follow-up therapy.

    -- The impression is given that the father did follow-up therapy activities on a regular basis. While he may have done these with his wife, he seems to have had a good working knowledge of what he was supposed to do.

5. The father reports <u>much</u> involvement with follow-up therapy.

    -- The impression is given that the father had a great deal of experience doing follow-up therapy with his child. He is able to explain what the therapy is, and understands some of the reasons for the therapy.

6. The father reports <u>great</u> involvement with follow-up therapy.

    -- The impression is given that the father did a great deal of independent follow-up therapy. He reports upon the specific success or failure of the therapy. He may also report devising his own therapeutic interventions.

Fathers were considered to be "high" in involvement with follow-up therapy if they were scored as a 5 or 6 on the scale, "moderate" if they were scored as a 3 or 4, and "low" if they were scored as a 1 or 2.

As in the case of the home-visitor scale, I had to overcome problems in scoring the data so as to arrive at the most approriate scoring for each father.

Patterns of Involvement

The final step of my analysis of the activity data was to arrive at a final grouping of the fathers into "analytic typologies" based on the two "levels of involvement" scales and the complementary data of the father's involvements with the other activities. As in all other steps of this analysis, I followed an inductive process to arrive at the typologies. It was a repetitive process in which I would identify the beginnings of patterns, test them for completeness, consistency, and logic and then revise them as needed.

In the final analysis there were four typologies which described differences among fathers. In assigning fathers to these four patterns, I found that all fathers could be matched to a pattern. Since all the fathers fit so well into the typologies, I feel they capture the flavor of the interviews, and are a useful way to summarize the data.

The typologies to be described in the following four chapters are as follows:

(a). Pattern of Involvement #1:

-- Fathers Highly Involved By Choice

(b). Pattern of Involvement #2:

-- Fathers Involved by Necessity

(c). Pattern of Involvement #3:

-- Fathers Who Were Moderately Involved

(d). Pattern of Involvement #4:

-- Fathers With Low Involvement (Traditional Fathers)

In the descriptions of the patterns in the following chapters, information which could possibly identify fathers has been changed to protect their confidentiality.

CHAPTER V

FATHERS HIGHLY INVOLVED BY CHOICE

Introduction

The pattern of fathers highly involved by choice with their special needs children includes the ten fathers who were scored "high" on the home-visitor scale and "high" to "moderate" on the follow-up scale. All of these fathers made use of their free time to meet with the home-visitors as often as possible, and they were also committed to following-up on their children's therapy programs.

I am calling these fathers "involved by choice" because their involvement with the home-visitors and their carrying out of the follow-up therapy activities was not mandatory. Had these fathers not become involved, in all likelihood, their wives would have been there to insure service delivery to their children. The fathers, therefore, were at the home-visits because they wanted to be there, not because they had to be there:

> ...so when I found out that there was definitely something wrong with him, I really knew that I couldn't, you know, that I had to get involved because it would be easy to, especially with Kurt since it was so mild. It would be easy to say, "Well, he's O.K. He'll be O.K." I knew that I had to get involved and help him as much as possible.

These fathers made strong commitments to be at the home-visits, to take their children to the early intervention centers for therapy and/or playgroups and to do follow-up therapy as a routine activity. They saw themselves more as "equals" with their wives and did not delegate the responsibility of involvement with the early intervention programs to their wives. In contrast to all of the other patterns of involvement, these fathers took on as much work as their wives did.

The paternal role played by these fathers highly involved by choice is quite different from the "traditional" model of fathering, where the father has little, if any, involvement with young children. These fathers are examples of men who have stepped outside the traditional definition of the role of father; for example one father said:

> ...In my particular case, I really feel family oriented. I really enjoy my kids. I want to be with my family when everything, anything happens.

Not only do they enjoy being with their children, they also take on many of the responsibilities of providing for their daily care:

> ...well at first I was extremely nervous, you know, with doing different items. But I was anxious to do it. But I was scared because I didn't know if I was doing it right. I started off with the changing of the diapers, I enjoyed that after a while. Then taking care of changing up...Then when he started eating solids I got trained to feed him and just partaking and doing my little bit with him and relating to him, holding him, playing with him, rocking him to sleep, I enjoyed all that so very much.

The fathers highly involved by choice reported a high degree of satisfaction in the "collaborative" relationships which they have established with their wives. Their enjoyment and satisfaction of participating in the early intervention programs seems to be an extension of the types of relationships they have with their wives. All of these fathers seem to derive satisfaction out of the time they spend with the home-visitors, but this can not be separated from the fact that they do this as partners with their wives.

Just as their meetings with the home-visitors were optional, so too were their involvements with the follow-up therapies. The follow-up activities which were included as part of a child's therapy program were only "suggested" activites, and parents could carry them out to varying degrees. The fathers involved by choice were the only fathers in this study who chose to become involved in the follow-up activities on a regular basis:

> I thought it was really great. I thought at the time, we didn't, I don't know if you could ever imagine what it would be like if somebody told you that your baby's blind, that you have to bring up a blind baby, because I felt like the blind leading the blind. I didn't know what to do. I didn't. I hadn't the foggiest idea of how you bring up a blind baby. So when we met the woman from the program and a few of these ladies that had come down, I thought it was great. They just sat down with us and told us, "This is how you, how we found what works best." And, you know, it seemed like it was all common sense, nothing hard about it, it was just all common sense. You know, there was something that you probably wouldn't think of how to do to a blind person, especially a baby that doesn't (pause) how can he reach for something if he doesn't see it. So you work with the things that he can hear.

This excerpt illustrates how these fathers learned to act as facilitators of their children's development. At first they may have felt like they were "the blind leading the blind", but they all acquired the necessary skills to effect developmental changes in their children. These fathers seemed to have a sense of control about their children's immediate problems and unlike the fathers of the other patterns who tended to leave this type of work to their wives, these fathers took this on themselves:

> ...But, oh we used to have fun when they came over, you know, we (pause) she had all these color charts and all different types of toys for Larry to play with, and when he was first blind they used to give him like crinkle paper, I don't know what kind of paper it is, but it made a lot of noise when he touched it. Whatever, it was his favorite toy. You try to take that away from him and it was (pause). We just worked together like that.

For each of the ten men of this pattern, their presence at home-visits and their commitments to doing follow-up therapy were by no means "chance" occurrences, but reflected conscious efforts on their parts to become involved in their children's special education programs. These fathers were cast in the role as "equals" with their wives and the availabilty of time to participate in the home-visits or to take their children to the centers was a commodity the fathers valued highly. The time they used to meet with the home-visitors or in doing the follow-up therapy was time well spent.

Involvement With Home-visitors

Since, with only two exceptions, home-visits and trips to the programs occurred during daytime work hours, the fathers highly involved by choice had to have time available to them during these hours if they were to meet with the home-visitors. Without having the option of being able to make time or to take advantage of circumstances which made them available, the fathers would not have then been in a situation where they had to decided whether or not to use this time to meet with the the home-visitors.

Analysis of the data revealed the following four conditions which provided these fathers access to the home-visitors: (1) three fathers had flexibilities in their daytime work schedules which allowed them to arrange, on a regular basis, to take time off from work to be with the home-visitors; (2) two fathers attended home-visits because the home-visitor came when the fathers were off work after 5:00 p.m; (3) two fathers who worked on shifts which allowed them to be home at the times of home-visits; and (4) two fathers were unemployed during the time period when the home-visits were made.

For the three fathers who arranged time off from work to be at the home-visits, their involvement reflected especially strong commitments. Their involvement consisted of them <u>making</u> time during their usual working hours, whereas for each of the other fathers of this pattern, the times of the home-visits and trips to the early intervention centers fit into their routines without them having to rearrange work schedules. While this does not mean the three fathers who made the free time were more committed, it does reflect an especially strong desire to be at the home-visits. It should be noted that these were the only fathers in the entire sample who rearranged their schedules to meet with the home-visitors every week. For these fathers, the time spent with the home-visitors was suggestive of their strong desires to be involved in the special education programs.

Typical of the fathers who took time off from work is Father #3. Father #3's daughter, Sharon, was referred to the early intervention program by the family pediatrician when she was 18 months old. The doctor felt she was not developing at a normal rate, and he was concerned that since her rare genetic condition made her look different, she might develop emotional problems.

However, when it was time to start Sharon in the program, Father #3 and his wife were not convinced it was what they really needed. Prior to their involvement in the early intervention program, they had learned how to take care of their daughter's special problems by themselves and felt they did not need someone to come into their home to tell them how to "...stimulate their child." But the home-visitor made an appointment to come to their home, and as can be seen in the following excerpt, Father #3 was highly interested in being at the sessions:

> S: You made sure to be home, that was your idea?
>
> F: Yeah. I said, "I'm going to be there." And she talked to us and Barbara [his wife] was more standoffish than I was, because it was like, you know, "Who is this person coming into the house?" I was, "Let's see what she has to say. Maybe Sharon does need it. She's needed help in other areas so maybe she can help us."

After the first home-visit it was decided that Sharon would benefit from a playgroup with other children. In the following excerpt Father #3 explains how he could arrange time-off so he and his wife could begin to take Sharon to a weekly group with other children:

S: Who took her there?

F: I did.

S: What time did she go?

F: Let's see. No, at the time Barbara and I did, we both did. I took time off from work. I'm on salary so it worked out good. I think we went over for -- what was it? -- 10:00 to 11:00 in the morning for about an hour. And so we both took her over and we'd get involved with getting her in with the other kinds in the playgroup. They'd have one person watch the kids while the parents -- the mothers and me -- went into a room to talk.

From these two excerpts it is seen how Father #3's involvement was made possible by the opportunities which were available to him to take time off from his job as a supervisor. The strong motivation which impelled his involvement was, in part, facilitated by his flexible schedule. Like the other two fathers who could "make time" to become involved in the home-visits, there is a sense about Father #3 that he highly values the time spent during his involvements. Certainly, unless he felt that his time would have some positive benefits, he would not have been motivated to take off the time from work.

In these excerpts it is also seen how, typical of other fathers involved by choice, Father #3 always spoke about his involvements with the home-visitors in terms of both himself and his wife. Even when Father #3 first started to go out with his wife they focused their relationship on her child by a previous marriage. When Father #3 would visit her, he said he would always "...bring a box of pampers with me." Raising children was a joint effort they seemed to share in equally.

The sense of "we" which these fathers highly involved by choice had with their wives is seen in the following comments from Father #40 when he discusses how he and his wife reacted to their child's problems:

> ...how should *we* be working with this. Should *we* be working with this differently than a child that didn't have those problems? How can *we* let her hear us? How can we let her (pause) how can *we* know she is expressing herself the way she wants? Just a lot (pause) you are wondering what she wants because she is hungry, she is still crying but most of it was even harder because she couldn't hear. *We* tried to talk to her. (emphasis added)

Father #40 had the opportunity to attend the home-visits because he had a work schedule which allowed him to be home at the time of the visits. Father #40 could be at the visits, because it just so happened that the visits were regularily scheduled at times when he was not working, and he chose to use this time to become involved with the sessions.

Father #40 works at a factory where he is sometimes on a four-day-a-week schedule. Because of this he often had Fridays off and was able to be at all of the visits which occurred on Fridays. Father #40 had a physical handicap himself, which was similar to his daughter's. When he and his wife had decided to have children, they both knew there was a good chance their offspring might inherit his problems, but as is seen in the following excerpt, this was not an important consideration in whether or not to have children:

> Well, she wanted children and she wanted children with me and she had said -- she is really understanding -- I am lucky in that sense because she said, "Well it is a chance we are going to take and she'll be treated and be brought up the

same way if she does have the problem" She accepted it right away.

Perhaps because of some guilt, he felt about his daughter inheriting his handicap, for Father #40, using time off from work to attend the home-visits was especially important. In the following excerpt, he let his wife know he wanted to be included as much as possible:

> S: Whose decision was it to schedule the home-visit for a Friday?
>
> F: Mine. I love working, now I am back on five days for a short time, but I love working four days because, like I tell Ruth [his wife], and she does it automatically anyway. Any appointments, unless emergencies, any appointments that can be made, make them on a Friday so I can be there.

As is seen here, one reason Father #40 loves to work four days is so he can use this time to be at appointments. For Father #40, a high priority use of his free time is helping his daughter, and he wanted to make certain he was included in the sessions if it was at all possible.

Father #40's free time, however, was often limited because of changes in his shifts, so he tried to maximize its use whenever he could. Father #40 made sure his wife did not squander away time which he could be a part of, and as is seen in the continuation of the previous excerpt he wanted to be as involved as he could:

> S: You told her that?
>
> F: Yes, and she knows it now. She works the same way. She loves having people help her. I like to get as involved as I can.

S: Why did you want to get so involved?

F: Well, I wanted to try to do for them, not because they are handicapped or anything [his second child also has a special need], but I wanted to do it for my whole family as much as I can. I feel if I am there maybe there is a question that I want to know that Ruth wouldn't ask so I want to be there. I want to hear firsthand what is going on, too, and I want to.

S: What if you didn't have Friday off?

F: Then I would just, I would be just harping and nagging at my wife all the time, "Did you hear what happened there? What did they say? Did they say anything else or something?" And I, of course, because I harp sometimes.

In this excerpt it is seen how Father #40 wants to be there <u>firsthand</u>; he is not content with second hand information. If he can arrange to be directly involved then that is his preference. It is also seen how intensely interested he is in finding out what happens when he is not present. Like the other fathers highly involved by choice, Father #40 wants and <u>needs</u> information from the home-visitor which will assist him and his wife in their job of helping their daughter.

The ways in which Father #40 and his wife trade off and share in their "helping" roles is seen in the following excerpt, where Father #40 talks about how he and his wife work out arrangements to make sure that the information given to them at the home-visit is well utilized:

S: So who does those things with her at home?

F: I do at night and my wife does during the day. She will do it at night also so we both work her; it is not a one-sided deal or anything. No, I want to get as much involved as I can, too. As a matter of fact I think I nag her a little...I will because I make sure that I can be there as much as possible.

This excerpt is so typical of these fathers, who seem to have an intense desire to be on the scene working hand-in-hand with their wives. What becomes apparent about these fathers is their self-motivation to become involved. They never give the impression they are being coerced or cajoled into becoming involved. They are highly invested in what happens to their children and want to be a part of the process which creates change for their children. For Father #40 it is important to realize that because he worked according to an alternative work schedule, he was able to have an outlet for his needs to be at the sessions.

Two of the fathers highly involved by choice had almost no restrictions on their use of time to become involved with the home-visits. Unlike Father #40 who had to always be making special arrangements to be present at the visits, Fathers #21 and #22 had the opportunities to become involved in the home-visits because they were unemployed. While Father #21 was unemployed for the entire time his son was enrolled in the early intervention program, Father #22 started work several months later.

Time was not as scarce a commodity for Father #21 as it was for the other fathers involved by choice. Father #21 dropped out of high school in the 10th grade and had been in and out of work ever since. When his son, Larry, was born, Father #21 was unemployed, and he only worked occasional weekends for the entire year when Larry was enrolled in the early intervention program.

Larry's birth had been a difficult experience for Father #21 and his wife Susan. Larry had to go into intensive care because of many complications and Susan needed to stay in the hospital for weeks because she was in a great deal of pain. The stresses which Father #21 felt because of all the difficulties surrounding the birth of his son were almost too much for him to bear, but eventually he and his wife pulled through it all and brought their son home.

When Larry finally came home from the hospital he was found to be totally blind and was therefore referred to the early intervention program by his pediatrician.

Since Father #21 was out of work he "...made it a point" to be at all of the home-visits. When I asked him why he wanted to be there, he replied as follows:

> For one thing, because I didn't have anything better to do. I wasn't working -- I didn't mean anything better to do -- obviously when it comes to my son I wanted to be there just so I could see what they were doing. So I didn't want to miss it. I mean they would do things like have him sit up when he was first learning how to sit up and shake a bell around his head and see if he reacted to it. For the longest time, he didn't even react to that. You know, it seemed like he just leaped and bounded right into good health. Except for his breathing; he does have asthma.

In this excerpt, Father #21's first response was, "...he didn't have anything better to do", but he quickly retracted this and said he was there because of his son. Although he most certainly was there because he honestly wanted to help his son, it was "easy" for him to attend the visits because he had so much time available to him. Perhaps he really did not have anything better or more important to do, because facilitating his son's development was a high priority for him. Unlike most men, Father #21 had lots of time available to him during the day, and he was able to make use of this time to be at the home-visits without having to make special arrangements. He most certainly could have been doing something else, but there was not much pressure on him to use his time in other ways.

When there is more time available to men, such as in Father #21's case, it must certainly be more "natural" for them to use this time to be involved in such activities as the home-visits. Of course, there is no guarantee that all fathers will make use of this time as much as he did, but just having the "option" available makes it more likely that at least some extra time would be spent with the home-visits.

Like Father #21, Father #22's time was not taken up by other responsibilities because he was also unemployed, and he had "...the time to be home." But as is seen in the following excerpt, from the time his twin daughters were born, he was an "involved" father:

> And right in the bassinets at the hospital, or in incubators -- the glass incubators -- I think I tended to go over and talk to Nancy [the special needs infant] more than Jodie, and with two kids, Dad's got to have one and Mom's got to have one when you go somewhere and I always tend to pick up Nancy and she tends to pick up Jodie.

Perhaps because he "had" to be involved Father #22 saw himself as being a "team mate" with his wife. But in the following example, where Father #22 is talking about what was going on in his house before I arrived, he seems to enjoy and thrive on the type of sharing relationship he had with his wife:

> And like tonight before you came, Jodie had her riding horsie out here and she was on it for a while and Nancy was sitting with me and she comes over and starts to tug on Nancy and pull her hair and grab her shirt and wants her to come and ride the horsey. So my wife brings the horsie over and I sit her up on it and roll her back and forth and Jodie just beams...

In the following excerpts, it is seen that just as Father #22 enjoyed the play times with his wife and children, he also enjoyed the home-visits and made use of the time to learn about his daughter's problems. Father #22 was far from being a "passive" participant at the home-visits. As this excerpt indicates, he had a good working knowledge of his child's special needs:

> S: Again, you were here for all of those home-visits?
>
> F: Most of them, yes, which was great. Yes, I got to know the girls too and they're really nice people, got really impressed. For a state program, you get conditioned not to expect much from a state program. The calilber of the people they have is (pause) I don't think you could buy the service.
>
> S: What kind of things did they do?
>
> F: The developmental therapist would work with various games and so forth to develop skills like passing little balls into boxes and things like that. They got us in touch, or had a physical therapist come and that's to get Nancy's muscles working in the right ways so they wouldn't get severely stiff and if they stay in that position after a while they become deformed. It is essential to keep the muscles moving. They may not move themselves because they

> are so spastic at times. You've got to keep the movement of them so they can be usable when she's at a point when she can use them herself, 'cause you can lose the muscle, basically.

Because Father #22 was unemployed he had the chance to be at the home-visits and learn what he could do. But several months after the home-visits began, he started a new job, and from that point on he was only able to attend "very few" of the visits. On one occasion, however, the physical therapist came in the evening,

> S: Why did she come in the evening?
>
> F: Well, I think she likes to do that, number one, on occasion. I think she does do that and she had little things she wanted to get me to start doing as far as roughhousing with the kids and things like that. There are some lttle things that (pause) hanging Nancy by her feet and swinging her, things like that.

An interesting question raised by Father #22's changing work status is the effect on him of having the initial option to be at the sessions. Had he not be able to be at the home-visits for the first several months, would this have affected the way in which he intervened with his child? How much did his availability influence the ways in which he became involved? Unlike some of the other fathers highly involved by choice, who either made time or requested time to be at the sessions, Father #22 just happened to be home because of circumstances, and it appears he benefited from the experience. Had the home-visitor been able to come more often in the evenings, it seems safe to assume Father #22 would have liked those arrangements.

The problem of having a home-visitor come at inconvenient hours, as in the case of Father #22, did not happen for two of the fathers because the home-visitors rearranged their schedules to accommodate to the needs of the fathers. As illustrated in the following excerpt, Father #7 was able to be at the home-visits because he and his wife requested that they be made when he arrived home from work:

> S: And did you make arrangements for her to come at 5:30?
>
> F: Uh, huh. That was our preference, and that was fine with her.
>
> S: Had they made other arrangements before that to come in the afternoon?
>
> F: No, no, no. It's always been like this. And she comes every two weeks except for vacations.

For Father #7, involvement in the home-visits was a continuation of a pattern of involvement he had established even before his child was born. Father #7 participated in all of the prenatal visits to the obstetrician, and when it was found that his son had to have many special tests out-of-town, he never missed a single appointment.

Since Father #7 had done research in the field of special needs children when he was an undergraduate, he was especially knowledgeable about his child's problems and the technical details which were discussed in doctor's offices. From the very beginning of his "fatherhood", Father #7 made "time for involvement" a high priority.

The other father highly involved by choice who attended home-visits after working hours was Father #12. Father #12 had the opportunity to be at monthly home-visits because they were scheduled in the evenings when he was free. The following excerpt shows that these meetings were especially important to him:

> ...I know right now, for the next two-and-one-half years, he'll have the early intervention program working with him and they'll guide him and they'll guide us how to work with him. That to me is very important I can't really pick out his weaknesses, you know. I'll hold him up, I'll see that his legs are flimsly and I'll take him. I'll try to get him working his legs and I'm not sure if that's right or not. I don't know what I should be doing for him, whereas they come along and they explain as we go along what we should be doing with him.

Because the early intervention staff members had the flexibility to schedule their visits at "odd" hours, both Fathers #7 and #12 had the opportunity to become involved in the programs. In each case, the father made use of this time to learn what he could do to help his child through his own personal involvements. Time was available because the "system" was adjusted to meet their needs, rather than the fathers having to adjust their schedules to the routines of the early intervention programs.

Involvement In Follow-up Therapy

In the previous section I presented data which indicated the circumstances by which the fathers of this pattern were able to have free time to meet with home-visitors. However, as mentioned before, these fathers were also motivated to use the information they received from the home-visitors to facilitate their children's developmental patterns. The fathers who were highly involved by choice believed that through their own personal efforts, they could be of direct assistance to their children. It is important to note that only the fathers highly involved by choice reported doing follow-up therapy and their own stimulation activities on a regular basis, and they did so with a high degree of interest and enthusiasm.

Unlike participation in home-visits, engaging in follow-up therapy activities does not require unusual work schedules. Follow-up therapy, in almost all instances, is something which may be done at any time of day. In order for a parent to do the follow-up therapy, they must simply be motivated to find any time period to do it in. For the fathers highly involved by choice this was not a problem, as each of the ten fathers reported consistent involvement in working directly with their children. Just as they made time to meet with the home-visitors, they made time to see that the recommendations made by the home-visitors were carried out.

Typical of these fathers who engaged in routine follow-up stimulation activities are Fathers #44 and #17, both of whom have children with Down's syndrome. Both of these fathers seemed to feel they could make an important difference in the ways their children were developing.

For example, Father #17 discusses some of the things he does with his son:

> ...I've sort of devised my own games that I play with him.

> Some of them are things that have been recommended and some are of my own devising. Well, I like to name body parts and he lkes this a lot, "Hair, ears, chin and teeth." The interesting thing is that he is trying to say it. You know, where you go, "Hair", and he goes, "Ahh...". And maybe its just the fact that we were parents, but we see a slight difference in his version of "hair" and "ear". But he likes it a lot. I sometimes bounce him on the bed or mattress and he loves that. I don't think it helps him too much, but it gives him a lot of satisfaction. I've started to try and have him put a little bit of weight on my lap, which is recommended...

In this excerpt, Father #17 makes use not only of recommended interventions, but goes on to try his own. Father #17 had a sense that his involvements would be good for his son, and in the following excerpt, it is also seen how he even had some disagreements with the early intervention program about what would be best for his son:

> ...there is a little difference of opinion between the program and some of the things we've read about whether or not it is good to imitate the sounds that he makes. They say it is a good idea. Some of the things I've read say it is not a good idea. And I was doing it for a while, but I stopped doing it because what my wife said made sense; thay you don't want them to talk baby talk, you want them to make our sounds...It's better for his own long-term development if he imitates us. So I've stopped doing it.

Whether or not Father #17 is correct in his assessment of the situation, what is important to note is his sense of responsibilty for doing the interventions and that he felt capable of deciding how to modify them according to his own observations. Father #17, like other fathers of this pattern, feels his "hands-on" interventions will help his child.

Father #44 was enthusiastic about spending time with his daughter. He particularily enjoyed taking her downtown in his infant backpack carrier so he could show her off to everyone. When I asked him about the kind of progress his child had made since coming home from the hospital he replied as follows:

> Oh, a lot. Andy has been making progress on her own ever since we brought her home. When we brought her home she started lifting her head up right away. And I think it's more of us focusing energies, we're just focusing energies. "O.K. Andy, clap like this" (he claps). All right, we're diverting energy that she would use to hold her arm up than putting it for something else. The school, and the books and the manual, they just give us ideas to implement.

When I asked Father #44 how often he did the activities he read about in the manuals, he replied as follows:

> We work them in every day. When we first got the manual, I read it. I said, "O.K. work it into play." You know, I work it in subconsciously. I'm not conscious of what I'm doing, but I'll sit here and sing a little silly song with Andy and "Clap our hands, all right?" and she will go (he claps his hands). Or, you know, I'll put her arms out into the crawl position -- just playing with her -- I'm doing the excercises in the book. All I have to do is see a picture and then I know.

In these excerpts, Father #44 gives the impression that his involvement was "natural". From his point of view, he works the excercises into his normal routines so that they can occur frequently and he really does not have to make special time to do the "work", because he does it whenever he might be "playing" with her. Like the other fathers of this pattern, Father #44 is an active participant in facilitating his child's development, and perhaps, seeing a good future for his child is additional fuel which tends to motivate him:

> ...Andy is going to be in the kitchen with me learning tablespoons, cups, how to cut, how to use a knife. When she is eight I want her to be able to cook something, you know, not be afraid of the stove. I want her to be able to use her

> talents. I think we're going to develop Andy. We're going to blossom her out really well. Just the combination of me and my wife is the right combination. We click, you know, me and my wife disagree, but we click.

In this excerpt, Father #44 clearly sees a positive future which he feels he can shape. The work which he is putting into his child now, will pay off in the future. His vision of what is possible, must certainly make the time he spends with his daughter worthwhile. Father #44 is convinced that he and his wife have the combined strengths to help his daughter overcome the "limits" imposed upon her by Down's syndrome.

CHAPTER VI

FATHERS INVOLVED BY NECESSITY

Introduction

The fathers involved with their special needs children by necessity includes the three "non-traditional" fathers who were scored "high" on the home-visitor scale but only "moderate" to "low" on the follow-up scale. These fathers participated in almost all of the home-visits and trips to the early intervention centers because they were the daytime primary caregivers of their children and had to meet with the home-visitors if their children were to receive early intervention services.

By staying home with their children, the fathers involved by necessity took on a highly non-traditional style of fathering, and their small number is a reflection of the cultural norm of women being the primary persons responsible for childcare. These fathers, like the fathers highly involved by choice, participated in the routine care of their young children, expressing satisfaction with their roles and confidence in the jobs they were doing:

> ...I used to play with him quite a bit. Hold him quite a bit. Being of course a six-month-old, he slept quite a bit...I used to have to change...but although I did take a class on how to change diapers and how to give him a bath before he left the hospital, I don't think it was anything that difficult for me, really.

and from another father,

> It was great [taking care of his daughter]. I loved it. I'm

> a very unorthodox male...I got very close to her...I found it very rewarding to see the different stages of development with her and to be a part of the whole thing. Not that my wife wasn't. She had her at night.

Of the three fathers involved by necessity, Father #45 saw himself as being the most "non-traditional", and felt that his involvement in the early intervention program was a reflection of his being "different". This is particularily clear in the following excerpt, where he talks about his participation in the discussion groups which went on during playgroup:

> S: What did you love about the discussion group?
>
> F: I love people. I'm gregarious by nature, and...I found it sort of amusing to be the oddball, and they [the mothers] thought it was funny too, because their husbands wouldn't come and do this, you know. I just don't fit, I don't fit the stereotypical male, which is probably why Jane [the home-visitor] gave you my name. [laughs] Because I do spend a lot of time with the group and Jane.

Father #45 was proud of his involvement, and several times during his interview he made reference to his perceived uniqueness.

Like Father #45, Father #37 was also aware he was in a different situation than most other men, and he too compared himself to other fathers with special needs children when he was at the discussion group:

> I was in a different situation. I had the kind of job where I could be a little bit more involved. One of the women [in the discussion group] was saying that her husband completely ignored the son, and I felt that was kind of strange. How could a father ignore something like that? A couple of the girls mentioned that the husbands just didn't have the time to be involved.

Unlike the fathers highly involved by choice who attended the home-visits as "partners" with their wives, the fathers involved by necessity were much more likely to participate in the home-visits alone. It was only at times when a father's schedule "overlapped" with his wife's schedule or when one of the parents was unemployed that they could meet with the home-visitors together. On those occasions when this type of arrangement occurred two of the fathers reported leaving the sessions to do other things.

All three of the fathers involved by necessity reported having significant conflicts with their wives. One of the fathers had to attend counseling sessions to resolve marital differences, while another father separated from his wife for several months. Not surprisingly, for two of these fathers, the issue with their wives was a difference of opinion on the use of their time. Since all three of the couples were on rather hectic schedules at times, the use of "free time" became a bone of contention:

> ...I had problems trying to balance my artistic priorities with my financial responsiblities and with the relationship it didn't help because, it was more or less taken as a selfish act on my part. Nothing that wasn't resolvable. There was no great schism. It was a little bit of a strain. She had to go back to work, and she didn't want to.

Involvement With Home-visitors

For all three of the fathers of this pattern, involvement with the early intervention programs came about because of the ways they had arranged their routines to accomodate to their wive's work schedules.

Father #4 had time to meet with the home-visitors, because he was unemployed and took care of his child during the day while his wife worked. For Father #4 the decision to stay at home was not necessarily made because it was something he most wanted to do, "...it was largely practical...she had a job; somebody had to be here to take care of Cathy".

Fathers #37 and #45 had time to be at the home-visits on a regular basis, because they had coordinated their work schedules with their wive's work schedules, and it just happened that they were often home during the day:

from father #37,

> ...I was on a rotating shift, every two weeks I'd change shifts. So, if I was working third shift, it would work out well, because I could babysit up until the time she came home at ten or eleven. If I was working first shift, I'd be home in time for her. Second shift was the only problem and what would happen then, we'd have the grandparents take care of him then.

from Father #45,

> ...if she worked evenings and I worked evenings, that meant a babysitter, and number one, we didn't want our daughter to be with a stranger. We wanted one of us to be with her. So it just worked out that if I stayed home days and took care of her, she could be with her at night...

It is important to note here that the fathers involved by necessity, did not have a choice as to whether or not they would attend the home-visits. Because the home-visitors came during the day, they had to be home if their children were to receive services from the early intervention programs. These fathers were thrown into their "highly involved" roles with the early intervention programs because of economic and "chance" circumstances. They did not have to make the special commitments to become involved as did the fathers highly involved by choice.

The fathers involved by necessity had an abundance of time to become involved in the early intervention programs. Since they were home anyway, they did not have to make special arrangements to find times to become involved. But for two of the fathers, the time they had available for the early intervention programs had to be "balanced" against other uses of their time which they needed. In effect, the fathers seemed to feel that because they were putting in time to care for their children, they <u>needed</u> their "free" time for other purposes.

This need for extra time created problems for Father #4 who told me he was applying to graduate school and needed extra time to study:

> ...you know, my wife gets home from work and she doesn't particularily want to take care of Cathy the whole evening, because she has been working. And I have been taking care of Cathy all day, I don't particularily want to take care of her. So dividing up the time that we are both here is (pause) can be difficult...we don't really resolve it; we just sort of go on week to week hasseling it out.

For Father #45, caring for his child during the day and working at night made him feel that he was "...burning the candle at both ends". The extra pressure which Father #45 felt because of the demands on his time was a factor which he felt affected his marital relationship and the quality of time he could give to his special needs child. This is illustrated in the following excerpt in which Father #45 discusses his frustrations over trying to do too much at once:

> ...I think that when you see a child with special needs, that you immediately feel that you should be doing more for that child. As it was, having a problem balancing all that I am doing with child rearing and then seeing one that may need a little extra, I mean; obviously you're talking about extra time as a whole.

Perhaps because these two fathers spent so much time with their children, they saw this as creating certain problems in their lives which the fathers highly involved by choice did not experience. The latter made special choices to become involved in the early intervention programs, while for the fathers under discussion, involvement in the programs was yet another responsibilty added on to their daily care of their children.

Becoming involved with the home-visitors for these fathers became a routine activity, like taking their children to the grocery store, rather than being a special commitment derived from a sense of urgency to effect change in their children. There were times when their wives were home during the home-visits that Father #45 (like Father #4) would become involved in other activities when the home-visitor arrived:

> S: So sometimes you and your wife were both there?
>
> F: And at other times it was just me, and on occasions it was just her. It depended. There were times when I had other things to do that, you know, taking care of the home or something, repairing windows or something like that.

Thus, even though Fathers #4 and #45 were home at the times of the visits, they left the sessions in order to do something else. Perhaps because they had committed so much time to child care, they looked on these times as opportunities to "break their routines". What is important to note is that unlike the fathers highly involved by choice, who reported taking advantage of all opportunities to be with the home-visitors, the fathers involved by necessity did not appear to have the same sense of urgency to learn how to work directly with their children.

Sometimes, instead of having home-visitors do therapy in the home, all three of these fathers had to take their children to the early intervention centers for the therapy. At these times the fathers could observe their children in the therapy groups and talk with other parents (usually all mothers). All of the fathers reported using this time to talk to other parents, where they would compare experiences such as the following, reported by Father #37:

> ...we'd talk about how they were different, how the development was different or the same and what areas they were behind in and what we were doing to help them, and how the other family members felt about it, whether the child had older brothers and sisters. If they helped out in that.

Involvement in Follow-up Therapy

Although the fathers involved by necessity met regularily with the home-visitors, they did not report extensive involvement in follow-up therapy activities. Unlike the ten fathers highly involved by choice, who were very interested in following-up on the therapy sessions, the three fathers involved by necessity were surprisingly much less interested in doing the therapy. While they certainly seemed aware of what kinds of follow-up therapy needed to be done, they did not seem to put a lot of importance on their doing the follow-up therapy. This attitude is illustrated in the following excerpts:

from Father #45,

> S: To, like to what extent did you do some of those activities that she...
>
> F: Uh, not as much as I could have. My wife did them more than I did, but it was obvious that, you know, being busy and such, that I couldn't always do it. But my wife did it quite a bit.

from Father #4,

> S: Have you usually tried to do some of those activities?
>
> F: Yeah, I don't always get them all done; it depends. You know, I sometimes got, you know, I try to get the list out and look it over, or pick out a specific thing to do. Other times it's just, if something that we are just happening to be doing. I'm doing it or otherwise I'm not. You know, some suggestions she doesn't really (pause) Kitty really doesn't get into them.

What is noticeably different between the fathers highly involved by choice and the fathers involved by necessity is the extent to which the former are interested in doing the therapy. The fathers involved by necessity have a much more subdued interest in affecting change in their children. They are, of course, highly invested in seeing their children improve, but they do not see themselves as the agents of change. The data suggest they see their wives, doctors, and the home-visitors as the people most responsible for the changes which occurred in their children. They see their roles as more "distant" than do the fathers highly involved by choice; they see themselves as having to be at the sessions, but not as the persons who should do the work. In a sense, they see their responsibility as being one in which they "deliver" their children to the therapy sessions but leave the therapy to someone else.

It should be noted, however, that since there are only three fathers in this group, it is not possible to suggest all fathers who are involved because they have to be are not as invested in the therapy. What the data do suggest is that their presence at the sessions with the home-visitors does not mean they will routinely do the follow-up therapy activities. The fathers highly involved by choice made special commitments to be at the home-visits, and thus came into the sessions with a much different attitude than did the fathers involved by necessity.

For two of the fathers involved by necessity, time was a scarce resource because of their dual roles of caregivers and wage earners. Perhaps because of this pressure, they were not as invested in the therapy and follow-up work. Since they had so much time pressure, they had to spread themselves out more thinly than they would have liked. For Father #45 there were times when time demands on him were so great that he remarked to me, "...How much can a man do? I'm going to school full time and working, you know, it was just a rat race."

The following excerpt shows how important time was to Father #4 as he reacts to my question about his participation in parent support groups:

> S: Was that something (pause) had you wanted to be involved in those groups [parent support groups]?
>
> F: Uh (pause) Not a whole lot. I mean for me (pause) my time is so constrained in a lot of ways. I feel like, you know, free time is a scarce commodity so I don't (pause) that's not a high priority thing for me to do.
>
> S: And what do you mean by a scarce commodity?
>
> F: Well, I don't have a lot of it and, when I do have it, I have plenty of things to do...I think it's crazy to have kids and be a graduate student at the same time -- but it's mostly a squeeze on time.

In both of these excerpts, the fathers are expressing concerns not heard from the fathers highly involved by choice. Because of their commitments to work and childcare, two of the fathers involved by necessity had to contend with pressures which may have affected the ways they became involved with the early intervention programs.

CHAPTER VII

FATHERS WHO WERE MODERATLY INVOLVED

Introduction

This pattern includes the nine fathers who were scored "moderate" on the home-visitor scale and "moderate" to "low" on the follow-up scale. These fathers only met with the home-visitors on several occasions and did not commit themselves to becoming regular participants in the sessions:

> ...I was here probably for the first 3 or 4 or 5 meetings...And, you know, I wanted to be there. And the home-visitor was surprised that I would. And, you know, I wanted to be there; I wanted to know what she is doing.

and:

> ...At first, I was very curious, then once I saw what she was doing and he was doing, I'd say, "Well, you don't really need me here," you know, and I'd go about my own business. There's only so much you can do.

Unlike the fathers highly involved by choice who shared responsibility for participating in the early intervention programs on an almost equal basis with their wives and the fathers involved by necessity who met individually with home-visitors on a regular basis, the fathers who were moderately involved only met with home-visitors on an irregular basis and saw themselves as "supporters" of their wives. One moderately involved father said:

> ...And I wanted to be here [at the home-visits] in case, well, I think that I was stronger through the whole thing than my wife was...his condition does not bother me like it bothers her. I think it bothers her less and less now.

In the families of the moderately involved fathers, the wives were primarily responsible for becoming involved with almost all aspects of the early intervention programs. Information the fathers received about their children's programs was almost always obtained through their wives. For example one father said:

> ...Yeah, it was no problem. My wife pretty much kept me posted. That was to make sure that nothing got lost in between.

When fathers who were moderately involved met with home-visitors, the data suggest they did so for one or more of the following reasons: (1) to "fill-in" for their wives when their wives could not meet with the home-visitors, (2) to satisfy their curiosity about what the home-visitor was going to do when she first started making visits and thereby giving their "stamp of approval", (3) to lend support to their wives whom they perceived as being anxious about what was going to be happening, (4) to be updated on their children's progress and (5) to discuss their own needs and concerns.

For the fathers highly involved by choice, the time used for involvement with the home-visitors was a precious commodity. For the fathers involved by necessity, time to become involved with the early intervention programs was available in great abundance, and they often experienced this time as cutting into their free time. But the fathers who were moderately involved, because of their infrequent participation, never reported concerns about having too much or too little time to meet with the home-visitors. These fathers invested only modest amounts of time to be a part of the early intervention programs, and they seemed content with this arrangement.

Although these fathers were by no means as involved with the home-visitors as the fathers in the previous two patterns discussed, all but one of them were somewhat "non-traditional" in their views of fatherhood. The fathers of this pattern reported that they participated in the daily care of their infants and toddlers and they seemed to take pride in the types of care they provided:

> ...Oh, I know I spoil her somewhat. Every night I rock her to sleep. In fact, last night my wife tried rocking her and she won't rock for her, only if she knows I'm not home she will. If she knows I'm home, she won't sleep until I rock her. And I enjoy being with her for that while. And when I come home that's all she wants, she's a real daddy's girl...I like to lay on the floor and play with her. I really enjoy having her around. When I run to the store, I'll put her in the car seat and take her with me.

and from another father:

> I think that, in general, women have been associated with parenting more than men over the years. And say a hundred years ago it was extremely much so. Fifty years ago it was a little bit changed, and now as part of the social change men are being recognized more as an important parent along with the mother.

Both of these fathers view themselves as "involved" fathers who have equality in the household/childrearing areas, although by their own reports, they do much less actual work than their wives do. The moderately involved fathers seem to be "caught" between two roles. They see themselves as "involved" and perhaps even "non-traditional" fathers, but their actual roles lie somewhere between that of the "traditional" and the "non-traditional" father, as illustrated in the following excerpt:

> ...Our feeling is -- with me and my wife -- is that we both are equal parents parenting our child. I have to work 40 hours at a job, but other than that we try and budget things half and half in the decision making and things like that.

One father in this pattern, who was not nearly as involved with childrearing tasks as the other fathers, had an acute awareness of his inability to enjoy his role as a father. In the following excerpt, it is seen how he is caught in the bind of wanting to participate as he thinks he should, but is also aware of the difficulties this poses for him:

> ...let's put it this way, I'm a lot better with doing work than I am with dealing with small kids. Even today, I'm fine with getting jobs done, but as far as taking care of them and getting them dressed and undressed, and all this; I'll do it if I have to do it, but I don't enjoy doing it, and I don't do a good job at it, you know. I get keyed up, the kids get keyed up, so why the hell do it?

These fathers are not as involved with the early intervention programs as the fathers in the previous two patterns, but their interests in and commitments to time spent with their young children is greater than that of the fathers to be discussed in the next chapter: those with low involvement.

Involvement With Home-visitors

The fathers who were moderately involved did not report having difficulties using their "free time" to meet with the home-visitors, because they did not seem to be interested in using their time for this purpose. Each of these nine fathers, however, did create time to meet occasionally with the home-visitors.

Analysis of the data revealed five conditions which provided these fathers the opportunity to meet with home-visitors: (1) one father took time off from work; (2) two fathers asked the home-visitor to come in the late afternoon after they got off from work; (3) one father, who was a salesman, could schedule his own time; (4) three fathers could occasionaly "fill-in" for their wives because of flexibilities in their work schedules; and (5) one father worked second shift and was home mornings.

Father #32's son had severe colic for over seven months, which put a tremendous strain on him and his wife. His son, John, cried for over 20 hours a day, and it was exhausting to stay up with him for such a long time. Father #32 and his wife had to provide each other much support during those seven months to get through this ordeal.

After John's crying stopped, the pediatrician noticed that his development was delayed and referred him to the early intervention program. When a home-visitor came to evaluate John, she felt that he should be in the program and would need weekly visits. In the following excerpt, Father #32 talks about his initial involvement in the home-visits:

S: So were you here for any of those visits?

F: Maybe a few with Abbey [the home-visitor] as it was

> always during the day and I was at work. I think maybe for, for the first couple...

S: How come you were there? How did you get off work?

F: I asked for it. I had a pretty good working relationship with my boss and I explained to him. He knew about the whole situation the first 7 1/2 months, and there were many times I would just go home from work and just be totally exhausted from being up all night with Johnny or whatever. So he knew that there were times. He knew that we were having our problems, so I would just say to him, "Well, his therapist is coming today," and she would be coming from say one to two, "could I just come back late from lunch" or something like this or, "She was going to be coming in the morning so could I take an early lunch hour" and he would let me know.

Clues as to why Father #32 was motivated to use his lunch hour to be at the first few home-visits are suggested in the following excerpt where it is seen how he had been especially sensitive to his wife's needs during their ordeals:

> ...I wanted to come home and help her and more or less take over, if that is the word you want to use, but just give her a break, because I would come home from work at times (pause) and he might be sleeping in the playpen or something and she would be laying there on the couch totally exhausted. I would walk up to her and put my arms around her and she would just start crying...

It seems the strains on Father #32, but especially the strains on his wife, motivated him to want to be at some of the home-visits to support his wife. Participation in the home-visits for Father #32 may be seen as a means for him to continue the kinds of support he had been giving his wife. He saw his role as needing to let his wife know he was behind her, but because of his "breadwinner" role in the family, he did not feel he had to become a regular participant.

Another reason which seemed to motivate Father #32 to attend the home-visits was to ease his own anxieties about his child. In spite of extensive testing, the doctors could not determine the etiology of his child's problems. He seemed to need to know the cause of his son's problems, and perhaps he felt that the home-visitor would provide him with some answers, for example, he said:

> ...I think if she was to have an answer and if somebody, like I say, to sit us down tonight or whatever and tell us what the future holds would be a load off our minds.

The support which Father #32 felt he needed to give to his wife and the anxieties he felt about his child's status are concerns also experienced by Fathers #2 and #16 who asked the home-visitors to come to their homes after they got off from work at mid-to-late afternoon. They each attended a limited number of visits and expressed no interest in higher levels of involvement.

Father #17's daughter was an enigma to doctors for many months. Her development was delayed, and she had a great deal of difficulty crawling. For months, Father #17 and his wife Martha had gone back and forth between doctors and hospitals trying to find out what was wrong with her, but nobody seemed to have an answer. As in the case of Father #32, the pediatrician finally recommended the family become involved in an early intervention program. As is seen in the following excerpt, Father #17 felt a strong need to be at the initial visits:

S: Did the home-visitor ask if you'd be home?

F: She just said "What's a good time" and we pretty much said "around 4-4:30." In fact she had expressed then -- because I was here probably for the first 3 or 4 or 5 meetings -- that a lot of the families she had worked with the father either wasn't interested or just wouldn't be there. And she was surprised that I would. And, you know, I wanted to be there, I wanted to know what she is doing . I told her, especially since I'm (pause) I don't like state agencies so I wanted to know what she is up to. See, I don't like lawyers, doctors, dentists, undertakers. I don't like professionals. I'm always leary of them.

S: Was your wife, was she glad you were there?

F: Yeah.

S: Did she ask you to be there, or was this your decision?

F: No. My decision. But see, I'm, I think, I'm guilty of being a very calm person. Almost too calm at times. And inside she is a bag of nerves. So I think we offset each other. She used to break down and cry at anything very easily. She's kind of toughened up to it now. Whenever something happens, I always tell her, "Relax; worrying about it won't change the world; it won't do anything." So she always yells at me; sometimes she says, "How can you be so calm?".

Father #17's use of time to be at the first 3-5 visits served the purpose of giving his "stamp of approval" to the early intervention program and was also a way of supporting his wife. He wanted to make sure he could trust the people who were supposed to be helping his child, and he wanted to "balance off" his wife's worries.

It is also seen here that Father #17 sees himself not so much as an equal partner with his wife, but as having a role "complimentary" to hers. He sees his role as letting his wife know he approves of the program and supporting her in her role as the primary contact with the program. Once he has done this, he apparently he no longer feels the need to be present. The time he feels he can give to being a participant in the home-visits is limited. Perhaps, too, he wanted to begin to get answers about his daughter's cloudy future because he said:

> ...So we don't know. They don't want to predict what she'll be like, because it would be like predicting the weather. So they have no idea, but (pause) her nervous system (pause) they don't know if it will ever catch up or not. They don't know why it is delayed. And they don't know if it'll reach a plateau or if it'll just keep going. They have no idea.

Father #2's son has a neuromuscular disease which, unfortunately, is a terminal illness. The future faced by Father #2 and his wife is uncertain:

> ...we don't know exactly what his life expectancy is. If the disease keeps progressing worse, as it has been over the last year or two years, then things don't look too good for him. If it was more gradual, he would have a life expectancy of late teens -- so that aspect of his condition is one of the most frustrating.

Because of the severity of his son's problem, Father #17 was aware of the strain which this put on his wife, and he worries about her a great deal:

> ...She has a very close relationship with my son. I'd say that my feeling is that they are too close in a way, because if anything happened to him she would be really deprevated. Say if he was to die in a year or two, she would be devastated; whereas, if she has some sort of outside interest, some type of serious part-time job or something that would give her some positive input outside the family, that would be good.

When the home-visitor started coming to Father #2's, home she made her visits in the morning when he was at work, but as he noted she did come in the afternoon, "...every so often -- or as requested -- to meet with me to keep me updated." When I asked Father #2 whose idea it was for the afternoon meetings he reponded as follows:

> F: It was her idea [the home-visitors].
>
> S: It was her idea.
>
> F: Yes, and ours.
>
> S: So was that easy for you to do?
>
> F: Yeah, it was no problem. Cindy [his wife] pretty much kept me posted. That was to make sure that nothing got lost in between.
>
> S: How did she keep you posted?
>
> F: She would tell me when Jane [the home-visitor] came and what they did. You know what Jane said, you know Jane said, "Well maybe we ought to contact so and so." And she'd say "What do you think?" and I'd think about it.

In this excerpt it is seen that Father #2 only attended an occasional home-visit, and perhaps, as he suggests, one reason he did not have to attend the visits is that he always knew what was happening from the reports of his wife. But in the following excerpt it is also seen that Father #2 needed to be at these occasional visits because they gave support to him as he tried to cope with the stress of a child who was slowly dying:

> ...Janet [the home-visitor] has a lot of perception; she knows that parents want the best for their son, but we're not exactly (pause) we're not all geared to deal with other agencies and other people that are dealing with special needs children, and doctors. She really has instructed us on what type of questions we should be asking doctors, what type of things we should be doing that would be best for our child. She showed us in a way that was very perceptive on her part. She was able to read us well, and to know exactly how she could guide us in the right direction.

It appears that Father #2 needed to participate in the home-visits not only to support his wife, but to meet his own needs for support and direction.

Father #34's third child, Jason, was born with an unusual congenital birth defect. Because of the nature of the syndrome, Jason has many facial anomolies which will always make him look different. When Jason was born, Father #34 reported that he quickly had to face up to the reality of having a son who did not look like a normal child:

> ...we have this kid who doesn't look normal and I guess, now we accecpt it with no problem, but back then....your first impulse is how am I going to deal with it. I know that I spent a lot of time saying to myself how am I going to deal with a kid that doesn't look like all the other kids. I kept thinking of a freak. I kept thinking of the kid that you see in the shopping mall and that kind of thing...

Since Father #34 is a salesman, he had the opportunity to schedule his time so he could be home at odd hours. When his son started in the early intervention program, the father was able to arrange his time to be at the initial consultation and at several of the home-visits. Father #34 attended the home-visits when his presence was requested by the home-visitor to allow her to update him on his son's progress:

> S: Did you have a lot of contact with Judy [the home-visitor]?
>
> F: Yeah, I had a lot of contact with Judy. Every time Judy would make some progress with Jason, we would have a meeting at our house. Judy really enjoys Jason. She enjoyed him when she worked with him and enjoyed coming to our house a lot, and I would come home early, once again, and I would catch Judy in the afternoon, and we would sit down and have some tea and chat about his progress.

In this excerpt, one can see how the focus of Father #34's involvement was one where he was updated on progress, not one where he particpated in the therapy sessions. But unlike the other moderately involved fathers previously discussed, Father #34 felt his wife was in control of the situation:

> ...as soon as she [his wife] realized that he was healthy -- and he was healthy -- I think...the next thing she was dealing with was helping Kenneth out and getting herself on track that he was going to need a lot of help. She started to convince me at that point how much help he was going to need. She really accepted it well after the first week...you didn't have any choice in the matter; it had to be that way. We started going to the hospital in Boston, and that's when it -- when things started to go good for us when we went down there.

From the beginning, in spite of some rather severe problems, Father #34 took what he called an "upbeat" point of view. Since his son was making good progress, and his wife had confidence in the quality of services from the early intervention program, Father #34 only needed to "check in" with the home-visitor on occasions to make sure he had a good picture of the way his child was progressing. In the following excerpt, Father #34 discusses the content of his occasional visits with the home-visitor:

> They were filled with a lot of questions. Even as close as my wife was to the situation all the time, she still had as many questions. I had probably more than she did...But the meetings were very upbeat. They were all positive. I don't remember Judy giving us any bad news at all. I remember Judy always telling us what she was working on. She always had a time table for which she wanted to accomplish. She always knew where she was going. She wasn't scattered-brained. She gave us a good feel. We felt that we were getting a good, fair shake from her services.

From this excerpt one can see how confident father #34 seemed to be about his situation. In contrast to Fathers #32, #2, and #17 who appeared to have deep anxieties about their wives and children, Father #34 seemed very secure. Yet, from these fathers' somewhat opposite mental states there resulted similar patterns of involvement. What these fathers have in common is a type of involvement which leaves the majority of the work to the wives, and these fathers, for a variety of reasons, only feel a limited need to "touch base" with the home-visitors.

Three of the moderately involved fathers participated in a limited number of visits by assuming the role of "surrogate" mother. Two of the fathers substituted for their wives during the summers when they had time off from teaching; while one father, who was a student, could fill in during time off from school.

Typical of these three fathers is father #6 whose son had a mild developmental delay which affected his movement patterns and caused him to be late in his language milestones. Right from the time his son was born, Father #6's wife was concerned that something was wrong with him, but the pediatrician felt that he would outgrow his problems. Finally, she convinced the doctor to refer her son to an early intervention program and this resulted in a recommendation that he receive therapy for his motor delays.

On several occasions, Father #6 just happened to be home at the time of the home-visits, but when this occurred he would take his younger daughter out of the house on walks, so that the sister would not interfere with the therapy. The only times when the father actually did become involved were those occasions when he had to take his son to a playgroup which the father described as "wishy-washy".

Father #6 apparently felt there was no real need for him to become more involved. In the following excerpt, in response to my question about his attending parent support groups, one can see how Father #6 views his child as being essentially normal and therefore not in need of any extra help from himself:

> ...I'll be honest...I suppose since last September when I started going to school again, life had been pretty busy. The semester ended and there really wasn't time. If it had been something that I was sure was going to help Mark, then I'd have made time somewhere. But in terms of something for me to do because I have a problem dealing with Mark -- a support group type of thing -- I haven't felt it necessary...in some ways I probably let my wife do a little bit too much of the worrying...I know Mark has some problems and I don't deny that ...and I guess I see him in most ways as a pretty normal little boy. So I think if he had what I would consider real problems or <u>real</u> physical disabilities that were noticeable -- <u>real</u> noticeable and that he really had to, if he was in any way paralyzed, something that was really a big thing -- then I would need some type of support group for people to talk to. But I don't see Mark in that light. I know he is less than perfect, but I don't think he's so less than perfect that it's just not a big thing to me.

In this excerpt, Father #6 states that if the problem were more obvious, then he would "have made time somewhere," meaning that as far as he was concerned he did not need to invest his time, because it would not pay back the benefits. But he does realize his wife is worried about the problem and that maybe he is not supporting her enough. Perhaps, in ways similar to the other moderately involved fathers, his filling in for his wife is a way of showing some support for her; however, in spite of his awareness of her needs, he still allocated only a relatively small amount of his time to help her out. The role of primary caregiver is part of his wife's role, and he feels that more involvement on his part would only occur in more extreme circumstances in which there was a more obvious need. It is also possible that if he became more involved, it would have been an admission that his son had a more severe problem, and this was something he just did not want to believe.

Involvement In Follow-up Therapy

Not surprisingly, the fathers who were moderately involved were not highly invested in doing the follow-up therapy activities, although one of the fathers was scored at a "moderate" level of involvement. Since their wives were primarily involved with the home-visitors, they were the ones who did the follow-up therapy. In spite of the fathers' concerns for their wives, or their own anxieties about their children's futures, they did not become greatly involved in follow-up therapy.

Father #6 was primarily worried about his child because of his delay in speaking. Because his son was "cute and normal looking," the father did not feel he had to worry a great deal about his son's motor problems, especially after the son started to talk. The following excerpt illustrates how Father #6 left the major responsibility of doing follow-up therapy to his wife:

> ...a lot of the stuff was done in the evening after our baby had gone to bed, you know, and I just wasn't home...right now the only thing we're supposed to be doing in terms of stimulating him for his physical abilities is just to be kind of rough with him. Not push him and hurt him by any means. Roll him around, just be physically active with him. Earlier, my wife did most of this at night...All along, I think I've rough played, swinging him and that, but I would have done those things anyway...

Once Father #6's child began to talk he saw this as an indication his son was doing fine and did not really need interventions. Father #6's point of view contrasts to Father #32's who was initially very enthusiastic about the follow-up interventions, because he felt they would be just what his son needed. Father #32 talked about his excitement when the home-visitor taught him what he could do to help his son:

> ...and she [the home-visitor] really wanted us to practice with him and work with him and we would. And I really liked to be there as much as I could, because then when I knew he liked a certain thing, and when she wasn't around -- if it was just me or the both of us -- then I would practice with him and help him, hopefully thinking that this is going to help him get out of his delay.

Unfortunately, Father #32's son never "got out of his delay". In spite of intense efforts on the part of the home-visitor and the family, Father #32's son did not show the kind of progress the father originally hoped for. When this occurred, Father #32 became quite upset, and withdrew somewhat, leaving most of the follow-up therapy to his wife. He said:

> ...I still help out, but I think I have gotten to a point where I probably don't help out as much as I should any more...we can put him in a room with a bunch of toys, and he

> can play with these toys, and he really, he gives the impression that he doesn't need me to do this toy for him anymore, or show him how it works because he is trying to figure it out for himself...

In this excerpt, Father #32 views his role in the follow-up as one in which he "helps" his wife. From his perspective, his role is to assist his wife because she is the person primarily responsible for working with the early intervention staff. When he began to feel his help was ineffective, he started to withdraw, leaving almost all of the work up to his wife. To some extent, his involvement was "conditional" in that he needed to see some progress in order to want to continue. Whether or not his son made progress, his wife still had to carry on, and this made the father feel guilty because she was "...with him more during the day".

In the case of Father #2, a lack of progress on the part of his son may have contributed to the father's low motivation to do follow-up. Since his son has a degenerative neuromuscular disease, there is a stark reality to his difficulty in helping his son progress. This is seen in the following excerpt:

> Well, instead of working toward a goal of him improving and getting better, we both know that he is getting worse, and there is nothing we can do to prevent it. We can, we use the stander by the table that you see here and you do things to help him develop normally and to slow down the muscle weakness. But that is the most we can hope for...So just going through the motions doesn't really help.

Perhaps if his son had shown more progress as a result of his personal efforts this father would have been more interested in doing the follow-up activities.

CHAPTER VIII

FATHERS WITH LOW INVOLVEMENT (TRADITIONAL FATHERS)

Introduction

The fathers with low involvement make-up the largest pattern of fathers in the present study, consisting of the 24 subjects who were scored as "low" on the home-visitor scale and either "moderate or "low" on the follow-up scale. None of these fathers made time or took advantage of flexibilities in their work schedules to meet with the home-visitors more than once or twice, nor did any of them report extensive participation in the follow-up therapies recommended for their children, although several did mention doing occasional therapy, usually at the direction of their wives.

Even when many of these fathers had opportunities to participate in home-visits, they did not take advantage of these situations. For example, one said:

> I could have if I really wanted to. I have for special functions when they've asked me to be there for special things.

The fathers with low involvement allowed their wives to shoulder almost all of the responsibilities for working with the early intervention programs. Involvement of these fathers with the early intervention programs was limited to participation in only one or two home-visits, doing occasional follow-up therapy, some attendance at social functions (e.g. Christmas parties and clean-ups), and participation in short-term parent support group meetings

My designation of these fathers as being "low involved" does not necessarily mean these fathers were "absent" from the lives of their children, nor that they did not "care" about or "love" their children. On the contrary, the data indicate that almost all of these men, by their own reports, became involved with their children in a variety of satisfying ways:

> ....it's just keeping him on an even keel, making sure that he is always moving ahead. You know, providing him with little things different at home. Little distractions. Like I brought a couple of boxes in tonight with some frames and stuff and they all go crazy when I bring something home. He loves music, so we play music every once in a while. Keep him animated, when I see him picking up on something, I just carry it along.

The data do indicate, however, that all of these men had little, if any, involvement in the activites supported by the early intervention programs. When the fathers of this pattern did become involved in activities related to the special needs of their children, they were almost always related to "crisis" situations (e.g. hospitalizations of their children, traumas at birth), and/or to transitions of their children into early childhood education programs.

Unlike the first three patterns of fathers who have taken on somewhat "non-traditional" fathering roles, these fathers have assumed more "traditional" childcare roles with their young children and have left the majority of the childcare responsibilities up to their wives. Their lack of involvement in the early intervention programs is consistent with the more limited roles they have generally assumed with their children:

> I was reasonably active [with his daughter], but by virtue of the fact that I worked all day and whatnot, active in the traditional father role I would say...I was your typical father who worked all day but who still found time to play with the kids at night when I came home.

and from another father:

> I thought it was great. I liked being a father, but taking on some of the responsibilities I didn't care for: babysitting, changing diapers, getting up in the middle of the night, that kind of stuff. After my son got older where I could take him out with me, I've been taking him out ever since...

In other words, it does not seem that these fathers decided specifically to avoid involvement with the early intervention program, but they view this program as simply another childcare responsibility which should be taken on by their wives:

> Yes I did some [therapy], I didn't do that many of them, I was -- I didn't have the patience. You have got to have a lot of patience to do that. But I did some of them, but my wife was involved more.

and:

> ...I should have gotten more involved with them [the therapy exercises], but with my work and sleep, and I would always have some excuse I have got to do this. Not because of my daughter or anything. It was just that -- I guess I didn't want to get involved with therapy. I wanted her to get well, but I didn't want to do anything to help her...

These fathers see their wives' as the "homemakers" and themselves as the "breadwinners" to a much greater extent than the fathers of the three patterns previously discussed.

Involvements With the Home-visitors

The fathers with low involvement did not make time to meet with the home-visitors, and even in those circumstances when time was available, they were not motivated to use this time to participate in home-visits or take their children to the early intervention centers.

Father #30 was home for several of the home-visits, because he worked on third shift for a time, but the following excerpt shows that he really does not seem to be very interested in the sessions:

> S: In what way did you get involved?
>
> F: Actually, it was only because the teacher wanted me to. I really wouldn't have done it on my own. You know, you just sit on the floor when you're with him, and with them and just, uh, you know, put some things in front of him to see if he'll try to grab it or, you know, if he'll just walk away. Then talk to him to see if he'll pay attention, you know, things like that.

As I have suggested above, the fathers' lack of interest in the "home-visits" and follow-up therapy, apparently reflected the role structure which existed in their families. Being involved in child-care related activities was not seen as a primary responsibility by these men. These fathers seemed to feel that they were just not needed at the visits.

The "distance" the traditional fathers put between themselves and the home-visitors is particularily evident when Father #31 talks about his "presence" at home-visits. In the following excerpt one can see how Father #31, even though he was home at the time, went into an adjacent room so he could "eavesdrop" on the therapy sessions:

> S: ...as a father, were you given fair involvement in the program...that you were included or had the opportunity?
>
> F: Yeah. If I had wanted to come, I could have taken the time. And I did occasionally. And I took the time to be here to kind of watch from the other room when Andrea [the home-visitor] was here; to watch him and see how he was progressing and then listening to what the critique was on how he did and how he didn't do. And this particular toddler program down here I've been to twice and my wife fills me in on it. It's more of a playtime for him. I was never restricted from going down there, but then again I was confident that I didn't have to because I was seeing the results. Not that I wasn't interested either, but that is one of the first things that we discussed at the end of the day. I will come in the door on a Wednesday, "How's school?"...

A key element that emerges from this father's rationale of why he did not become more involved is his perception that since he was "seeing the results" of the therapy, there was no need for him to be there. As long as his wife and the therapist, working together as a team, were achieving progress for his son, he felt that he only needed to be updated on the progress. Seeing that his son was indeed overcoming his difficulties served as a convenient rationale for Father #31's view of his role. In a sense, there is a self-fulfilling prophesy at work for these fathers. Since they see their wives as the primary agents of change for their children, as soon as they see any progress being made as a result of the early intervention program, they accept this as evidence that they are not needed, because their wives are doing just what was expected. It is also clear that, like the other traditional fathers, Father #31 is highly invested in his son's progress and is very much tuned into what is happening to him.

While Father #31 seems to distance himself from the therapy because he perceives his son as making adequate progress based upon his wife's interventions, Father #38 distanced himself because of his lowered expectations for his child, and because his child was not "strange" looking. Since his wife was primarily involved in all of the therapies Father #38 could justify his distance by viewing the "reality" of his son's special needs as a lowered priority. In a sense, Father #38 has framed his involvement in a manner similar to Father #31, but with a twist in his logic. Father #31 sees some progress and views this as an indication that he is not needed, while Father #38 has no need for his son to excel, so he does not need to become as involved. In the following excerpt, Father #38 discusses what it would be like to have a special needs child (since he has two special needs children, his "distancing" becomes especially interesting):

> ...I mean, this may, it sounds kind of odd but it would not distress me that much to have a child that's not normal or whatever you want to call it. It's not that big of a tragedy to me, you know. It's, I mean if I had a child that had cerebral palsy or something like that, the only time it would really bother me is if there was suffering, you know, the child was suffering or if the child had to have a lot of care 24 hours a day, or something like that. Or it the child was strange looking. Maybe that, maybe even that wouldn't bother me that much. My kid doesn't have to go to MIT or Yale and become a great person or something...I'd just be happy if he just grows up and feels successful himself, you know, whatever he wants to do. It doesn't

> bother me that much, but I think that a lot of people in my family or a lot of people around us, they think it's the most horrible thing in the world.

It is only when things go wrong that the traditional fathers are motivated to become more involved with their children's special needs. When I asked Father #5 whether or not he attended his child's evaluation by the home-visitor, he told me that this was something his wife did. When I then asked him if he could have taken off from work if he wanted to, he replied as follows:

> If I wanted to, I'm sure I could've, but at that point in time we were both settled into what we had to do and we did it.

When I then asked Father #5 why he had taken time off from work to take his child to Boston for special tests, yet he did not take time off so he could participate in the early intervention program activities, he replied as follows:

> F: As far as Boston goes, it was one of those things trying to get more information about genetics and what could have caused it and so on. We were pretty well rooted in what Down's was. After that, as far as the evaluation goes and so on, I see the evaluations anyway.
>
> S:. I see, uh huh.
>
> F: So there's no real need for me to be right there when it's being done. Extra body around for what?. You know. The evaluations, as you well know, are written up; a copy is sent to everybody and we get one too. So I see it anyway.

In this excerpt, father #5 equates his presence at the home-visit as simply being another "body" who is present. From his point of view, it seems that since he would be getting a report anyway, there was really no need for him to accompany his wife.

Whatever information he needed, he could get indirectly. For the fathers with low involvement, trips to hospitals for emergencies or special tests were very different than the "routine" visits of the home-visitor. They were special occasions which warranted the fathers' attentions and times in which they would not hesitate to readjust their work routines to be present. When special occasions came up these fathers could find almost all the time they needed to attend to their children, even it it meant setting up an office at the hospital as is seen in the following excerpt from Father #31:

S: Did you take time off from work?

F: No, I was able to work around it. The time I have during the day is my own. In sales, in management I have two people that answer to me that are out in the field...I find that I can handle most it it by phone...so I explained things to them and my company was just super...Hell, I had an office at Children's, I had a phone.

S: You did your work right there?

F: Yeah, they saw me using the phone out in the lobby and said, "What are you doing?" "Making calls to make sure everything is going all right."...

Because many of these fathers believed involvement with the early intervention programs was "womens" work, they did not feel the need to take time off for this more "routine" activity. Father #39 expresses an underlying feeling that what went on in the early intervention program was not for men:

S: O.K. And your wife took him to the center; did you ever get a chance to go to the center while he was in that play group?

F: No.

S: Had you ever wanted to go?

F: Well, not really, because from what I understand, it's all the mothers, anyway. I probably would have felt a little bit out of place.

S: O.K. Now, so you didn't. Now why is that you didn't take time off to come to the sessions with the home-visitor.

F: I just felt it wasn't absolutely necessary for me to be there.

S: And why wasn't it.

F: Good question. I just never felt that it was. It was something that the home-visitor was working with my wife there. I picked up whatever was necessary later on.

Like many of the other fathers with low involvement, Father #39 felt that because he could "pick up" whatever he needed later on, there was no need to be present.

Involvement in Follow-Up Therapy

When the fathers with low involvement did become involved in the follow-up therapies, in almost all instances they did it in conjunction with their wives, and they gave the distinct impression that they were following the leads of their wives. Since these fathers were not present at the "home-visits", they had to learn second-hand from their wives what they were supposed to do. While not all of the fathers were enthusiastic about doing the exercises, some fathers, like Father #47, worked closely with their wives and seemed to have a good understanding of what they were doing:

F: ...My wife would take him during the day and I would be working. I would come home and we would discuss what they did at the clinic and she would tell me what they instructed her to do certain things with Tommy to try to get him more coordinated; play with him more often. But we would sit on the floor at night and watch television and play little games with him and help him along.

S: Did your wife instruct you in what those games were?

F: Yes.

S: Can you give me an example?

F: At first it was "sitting up", a lot of it, when we first started, was balance; getting him coordinated. He had a problem. He'd get up and he'd fall down. He had a tendency to take a few steps and lose it: just fall down wherever he stopped. What they wanted us to do initially was to build up his coordination first to get him where he could stand on one leg or stand there with his hands spread out without tipping over one way or the other and bend when he picks things up...

More typical, however, of how the fathers with low involvement regarding the follow-up therapies is Father #43 whose child was diagnosed as having hydrocephalus. Soon after her birth, Father #43's daughter's head size became very large, and it was apparant she had a problem. After a shunt was put in place to drain the fluid, she was referred to an early intervention program and a home-visitor began therapy. Because the shunt had mitigated his daughter's medical problems, and the therapy of the home-visitor was effective, Father #43 felt his daughter was "cured". When I asked him who carried out the exercises, he replied as follows:

F: We both do. My wife probably 90% of the time.

S: So when would you usually get involved with them?

F: Like at night. After supper, you know, we would be playing in the living room.

S: So how did you know, what you were supposed to do?

F: My wife told me, right.

S: And how did you like doing them?

F: Good. Good, I uh, I think a lot of them were things that she would have learned eventually anyways, but it was just, they say, she was supposed to be doing this at this certain age.

S: How important did you think they were, these exercises.

F: I think they were important, but I really don't know if, uh, you know, eventually she would have done them anyway. I'm not trying to say that, you know, it was a waste of time, because it certainly wasn't, but it was just something where I think more kids would develop on their own level anyway. And she eventualy would start doing it.

In this excerpt one sees how Father #43 is somewhat skeptical about the value of the follow-up, and he does not seem to be motivated to become too involved in the exercises. From his point of view, his daughter is going to be developing normally, so why should he be spending his time doing the follow-up.

While Father #43 limits his involvement in the follow-up therapy, because he feels his daughter has made progress, Father #36 is not involved because he has not seen any progress for his son but says he feels that because his wife was involved with the therapy, this has been very important to her. Father #43 said:

S: What kind of progress has he made since he's been in the program?

F: I haven't seen any, honestly (pause) for him (pause) I've seen a lot of progress for my wife.

S: What kind of progress have you seen in your wife?

F: Just her whole attitude has changed (pause) she has a very positive attitude about it (pause) which is great (pause) I love to see her when she is positive. She feels strongly that we are working toward a goal, period, whatever it is, we are working toward a goal (pause) and she benefits by it.

In this excerpt, Father #36 is expressing his concerns about his wife, in much the same manner as the fathers who were moderately involved. For Father #36, the real value of the early intervention program are the effects that it has had on his wife. While he has become frustrated over the progress of his son, and prefers to not invest his time in follow-up therapy, he still highly values the therapy time because of the support it gives his wife.

What is apparent from the data, is that these fathers do not seem to feel their direct involvement with the follow-up therapy will be a significant factor in changing their children. While they may feel their wives' efforts will be useful, they do not see the need to act themselves because it seems to be redundant, or they do not see themselves as persons empowered to make changes. Unlike the fathers highly involved by choice who made a point to work with their children and who were determined to effect changes in their children through their personal efforts, the traditional fathers did not mention how effective they might be.

Father #39's child was severely delayed, but the father had almost no involvement with the home-visitor even though he was at home during many of the home-visits. In the following excerpts, Father #39 discusses his frustrations over his lack of control in directly helping his child but sees that he will be able to have a hand in determining the kind of living conditions his child will have in the future:

> S: What's been the hardest thing for you personally?
>
> F: It's the type of thing, you know, if he needed a pair of pajamas, because he was cold, I could go out and beg or I could go out and work, and I could supply the pajamas, you know. But he's got a problem that I can't do anything about. That bothers me. It's just kind of an inability on my part to do something about it, you know therapy and stuff, I'm sure it helps, but that just is a, you know, it's not the problem. It won't solve the problem. It's hard to accept anything that I can't do anything about. I've always been able to do something, whether it meant working 24 hours or, you know, whatever was necessary to do something, you can accomplish if you try.

From Father #39's point of view, his interventions would not be effective, and this certainly could be a contributing factor to his non-participation in the therapy. But in spite of his inability to change his child, he feels he can do something about having a hand in determining the financial security of his child should he and his wife die:

> We're trying to work something out now in terms of a special trust fund, I guess it would be a financial burden for whomever it is [if he and his wife die]. Maybe we could financially ease that burden, this is money set aside specifically for his upbringing...just as long as I'm around, you know, I'll do what's necessary, if I'm not, then somebody else will have to.

By focusing in on the future, Father #39 is able to have a sense that he can do something to help his child.

Involvement in Activities Not Related to Early Intervention Programs

In order to attain a fuller understanding of the fathers with low involvement I must discuss their participation in activities not related to the early intervention programs. I do this to avoid the impression that these fathers were not interested in helping their children. While these fathers were not involved in the activities of the early intervention programs, they were motivated to support their families in a variety of other ways.

Support in Crisis

In many instances, the time around the birth of a special needs child is a difficult period. It is a time when the children's problems are often first identified, and families are under stress. In some instances, problems arise later on and often require frequent trips to hospitals and clinics over long periods of time.

During these times of crisis the data indicate that fathers with low involvement were all able to make time to be with their children and wives. These were special situations which were often life-threatening and which required all of their attention. Perhaps this is to be expected, for only a father who was under extreme stress or who was very insensitive would not become involved in such situations.

While the types of the crises varied from father to father, all fathers responded in ways which insured that their children were provided with the best care, and they made whatever adjustments were needed in their work lives. Typical of the fathers who had to make many extended trips to and from hospitals is Father #19, whose daughter was diagnosed as having a neurological disease which often causes deformities due to the growth of lesions in the brain. When the family pediatrician noticed there were problems he could not diagnose, he recommended that the family see a specialist. When I asked Father #19 about his participation in visits to doctors he replied:

> I wouldn't say that I went, I rarely would go to the pediatrician. But when we start to go to the specialist, I go.

In this brief excerpt, Father #19 succinctly summarizes his motivation for involvement; only when there is a special problem, does he make the time. Over the course of the next six months, his daughter was in and out of doctors' offices and hospitals where unsuccessful attempts were made to diagnose her problems. Finally, Father #19's daughter's name was put on the waiting list of a major medical center, and when a space became available, this meant an immediate change in his plans, as described:

> S: So you went and took her to the hospital?

F: I left work at three o'clock one day, they called up, well, they called Martha [his wife] at one o'clock and said, "We have a bed available." So I left wherever I was, I was at the Morley Company and we took her. My other daughter went with us to the hospital and Mary [his special needs child] was admitted...

S: So, then, you weren't working then, you were just staying?

F: I took some time off. I took a week off.

After a week's stay in the hospital a diagnosis was finally made and his daughter then needed 30 days of special treatment. This meant that he had to work during the week and make special trips back and forth to the hospital to be with his family. Finally, when it was felt that the child could come back home, it was recommended that she become involved in an early intervention program. As one can see in the next excerpt, Father #19 did not want to become involved with the program:

F: ...I had nothing to do with it, very little, you know, other than what Martha would relay to me over the dinner table or after dinner or whenever.

S: Now why was it that you didn't have anything to do with them?

F: Uh, well, because I felt that, uh, in a sense, the life-threatening or the worst kind of medical conditions had been dealt with as well as we could deal with them, and I wanted to get on with my life, in a sense, getting back to normalcy. And it seemed like this was a good resource, you know, that could help her developmental situation. Also, I think very much, I felt that Martha was at ease and felt that she was in a good environment. And again, just like a placebo, that, in itself, has a certain value, and this is not on any group. I know they did a good job, but, I mean, just to think that they did a good job is helpful.

In this excerpt, four factors are apparent about Father #19's feelngs about the early intervention program.

First, involvement with the program is not a crisis situation. It is a more routine type of activity which does not require his attention. Once he perceives that his actions have helped to eliminate a crisis situation, he feels that his "job" has been done.

Second, as he suggests, his non-involvement in the program is an indication his life is back to "normal". Father #19 was a very hard working man who put in long hours on his job. Once his child was out of the hospital, this meant that he could return to his usual work habits. While he was highly invested in resolving the crisis, he felt that once it was over, his "normal" role was to return to work, leaving the childcare to his wife.

Third, he recognized that his wife was pleased with the program. This meant he could rest assured that his child was in good hands, and his wife did not necessarily need his support. He was willing to give his support in the more obvious crisis situation but not in the daily routines.

Finally, whether or not the program was actually doing any good was secondary to the fact that his daughter was just in the program. Like Father #36 who saw the program as being beneficial to his wife, so did Father #19. If his wife felt that it was helpful and this gave her a sense of ease, then he was content in his role.

Transition from Early Intervention Programs

While most of the fathers who participated in the present study had children who were under the age of three, eight of the fathers with low involvement had children above the age of three. At age three, under the laws of the Commonwealth of Massachusetts, a child is no longer eligible for services from an early intervention program. When a child who is part of an early intervention program reaches age three, a determination must be made as to whether or not the child is eligible for services from local public schools. If it is decided that a child still needs to receive special services, arrangements are made to "transition" the child into an appropriate public school program.

Such a determination was made for six of the children of fathers with low involvement, and in four of these cases, the fathers became actively involved in the placement process. As is seen in the following excerpts, the fathers had varying experiences with the public schools:

> ...The most difficult, or the most time-consuming, the most frustrating, if that's the way you want to put it, is trying to get her into the school system, which leads to mainstreaming. There's several programs available, and you had to be interviewed by this one, be at that one...That was a pain in the neck.

and from another father:

> Well, we heard so much about problems parents have in the publc schools...All you are doing is trying to fight for your child's rights to go to school. I heard that some parents have had problems. We have been fortunate, we haven't had any problems.

As in situations where there was a crisis, the data suggest that "transition" times were occasions when the fathers with low involvement were more likely to become involved. This seems to be consistent with the "traditional" role of fathers, where they see themselves as becoming involved with "protecting" their families from the outside world. These are not routine events which their wives can handle alone but are special times which require their attention.

What is especially interesting about the fathers' participation in the times of transition, is the sense that the fathers were able to feel as if they had some control over their children's lives. While the fathers may have relegated control over the daily progress their children were making to their wives or may have felt unable to be effectual with therapy themselves, they seemed to feel that they could be effective in dealing with the "system".

In the case of Father #19 it is especially clear how he gained a sense of control over his child's future when he describes how he and his wife rejected the school system's decision regarding his daughter's placement. In the following excerpt Father #19 tells how he refused to put his child into the public school's special education program, because he felt it was inappropriate:

> ...so at that point in time they said, "Yes, Martha [his child] is a special needs child and what we're going to do is, we're going to put her out in the "Siberia" we have on the west side of town, next to the college, in the back where

> all the trees are, and you can't see the building. We put all the handicapped kids there so nobody will see them and we are going to have her go to the pre-school there. Martha is going to be one of the "healthy" kids. We're going to consider her as a role model for all these other kids." So we said, "No, we're not going to take the program." So we enrolled Martha in another school as a three-year-old.

In this excerpt, Father #19 certainly indicates that he feels a sense of control over his daughter's future. In this particular situation, he was highly motivated to spend as much time as was necessary to insure a proper placement for his daughter. While in many other situations, he was more than willing to have his wife take care of his daughter's needs, in situations such as these, he took the lead away from his wife.

Although Father #29 had almost no role in the early intervention program, he wanted to make sure his child was receiving the services she needed from the public schools. This meant he had to go before the school board and negotiate with them for the types of services his daughter was to receive. Fortunately, as in the case of several other fathers of this study whose children turned age three, he had the support of the home-visitor to assist in the transition, and Father #29 also brought along a friend to act as an advocate:

> ...and like, the home-visitor helped us the first time that my daughter went in, and set up the program. And she went down with us that time, and we brought another fellow with us that worked with us. He is going to school too to be a social worker.

When I further asked Father #29 about his experiences he provided me with a detailed answer about how he viewed the transition. What is interesting about his remembrances of this time period, is his view of how he learned to fight for his child's rights. In effect, he learned how to fight the system so as to get the best for his child, and he could thereby view himself as an effective person. When it came to helping his child through therapy or involvement with the home-visitor, father #29 did not feel there was much he could do, but as illustrated below, he felt he could have some control over his child's future through his involvement with the schools:

> ...so he [the advocate] went with us that time, and sat in on the board, brought up his points that he wanted to set up a program like they said, "Well, physical therapy is going to be 15 minutes a day" and the home-visitor said, "No, she needs more than that, she needs an hour a day." So they wrote it into the program. You know, we would make sure that everything was written down: what they said was going to be in the program was in it...I think we are prepared you know, to fight now that we have gone two years, you know, into having our daughter into the school. I know what to expect sometimes. You know, if you go in there expecting that you may have a rough time and it goes smoothly they you have prepared yourself. If you go in there and you say we are going to have a really easy time and they come on like bulls, then you know that you would be shaken...

Father #29 also felt his daughter might need special care for the rest of her life, and he believed it was up to himself and his wife to see to it that "...she gets the right kind of environment when she gets out of the house." One of the major roles that Father #29 sees himself as playing, is one in which he has a hand in shaping the kinds of care his child gets from other people, whether it is the schools or future placement in a special facility.

CHAPTER IX

STUDY RESULTS: COPING STRATEGIES

Introduction and Background

A consistent theme which I found throughout my review of the literature was a focus on the ways fathers coped with the stresses associated with having special needs children. Coping, within the context of these studies, was seen as a way in which fathers attempted to deal with the problems they encountered. This viewpoint is consistent with how Holyroyd and Lazarus (1982) conceptualize coping as, "...efforts to manage environmental and internal demands and conflicts among demands" (p. 24). Rather than building "fortresses" around themselves so as to cut themselves off from their problems, the fathers in these studies were seen as trying to come to terms with them. The difference between "total retreat" from and "confrontation" of a problem is the difference between defense and coping.

The point of view I take in my analysis is one in which I see the fathers as actively attempting to come to grips with their childrens' problems as opposed to defending themselves against the problems. Of course, it is not always clear where coping ends and defense begins. As Haan (1982) points out:

> ...a self-protective maneuver, undertaken with awareness, could be a sensible coping response in a situation of dangerous oppressiveness. Whether an action is coping or not can be decided only within context. Thus, coping does not insure a successful outcome because not all situations permit just or reasonable solutions (p. 256).

Whether or not individual fathers of the present study are engaging in defensive behavior as opposed to coping behavior will have to be decided on a case by case basis, but it is expected that most fathers will be motivated to help their children and will not resort to totally defensive strategies.

Researchers on coping strategies have suggested that there are a variety of ways in which individuals cope (Lazarus, 1966; Pearlin and Schooler, 1978; Folkman and Lazarus, 1980), and they have devised a number of systems for classifying coping patterns. To integrate these different approaches, Moos and Billings (1982) have devised an interesting framework for the classification of coping responses which I have used as a basis for analyzing the data of this study.

According to Moos and Billings, coping strategies may be organized into the following three categories: (1) appraisal-focused coping, (2) problem-focused coping, and (3) emotion-focused coping. These groups represent the general types of coping strategies which individuals use to manage stress. The research findings of Folkman and Lazarus (1980) suggest that people tend to use a combination of all three types of coping strategies to manage the stresses of daily life, but such factors as the context of the stress, who is involved, and how stress is appraised affect which strategies are most likely to be used. In general, no one strategy is better or more appropriate than any other; what becomes important to individuals is the success of their particular "...efforts made to master, tolerate, or reduce external and internal demands and conflicts among them" (Folkman and Lazarus, 1980; p.223).

Folkman and Lazarus suggest that an analysis of how people cope with stress must take into account the dynamic aspects of how stress is appraised. From this perspective, the appraisals of stress and the coping efforts to manage stress are seen as being in a constant state of flux; as coping efforts are made and situations change, individuals need to reappraise the situation based on the new relationship of the individual to the environment. Since all coping efforts to reduce stress are, to some extent, dependent on how stress is appraised, the present study has as its focus, an analysis of how fathers of each pattern appraised the stresses associated with having special needs children and the appraisal-focused coping strategies they used to manage stress.

Appraisal-focused Coping

Appraisal-focused coping strategies are those devices the fathers used to define problems is ways which made them easier to manage. When the fathers were confronted with the stresses caused by having children with special needs, they had to make on-going interpretations (appraisals) of their circumstances and then take problem-solving actions based on these appraisals. As their children changed, the fathers had to then make adjustments in their appraisals, and perhaps take new problem-solving actions based on these new appraisals. The ways fathers became involved with the early intervention programs and other activites related to their childrens' special needs were, in part, dependent on how they appraised stressful situations. The point of view which I am suggesting here is consistent with symbolic interactionism theory:

> All situations consist of the actor, others and their actions, and physical objects...a situation has meaning only through people's interpretations and definitions of it. Their actions, in turn, stem from this meaning. Thus the process of interpretation acts as the intermediary between any predisposition to act and the action itself. (Bogdan and Taylor, 1975; p. 14)

In terms of the present analysis, the appraisal-focused coping strategies are viewed as important tools used by fathers to define their problems, and their involvements in activites are seen as the actions resulting from their unique definitions of the circumstances they were experiencing.

Examples of appraisal-focused coping strategies are: (1) trying to make a logical analysis of the situation (e.g. "my son's problem was due to a lack of oxygen at birth"); (2) cognitively redefining the situation so as to make it more tolerable (e.g. "at least my child is alive", "at least my child is a worthwhile person"); (3) avoiding or denying all or part of the problem so as to make it more bearable (e.g. "my child's delay is only temporary", "my child really doesn't have a problem").

Appraisal-focused strategies were used by fathers to help them make sense of their situations and ultimately of their roles as fathers. When fathers made choices as to which activities they participated in, they made these choices based, in part, on their appraisals of three types of stress: (1) harm-loss (i.e. the damage which had already occurred to their children, (2) threat (i.e. harm or loss which had not yet occurred to their children but might occur), and (3) challenge (i.e. the extent to which the fathers could master the problems), thus:

> The degree to which a person experiences psychological stress, that is, feels harmed, threatened, or challenged, is determined by the relationship between the person and the environment in that specific encounter as it is defined by the evaluation of what is at stake and the evaluation of coping resources and options (Folkman and Lazarus, 1980; p.223).

For the purposes of the present study, there are compelling reasons why it is important to understand how fathers of special needs children made use of appraisal-focused coping strategies. Parents who have special needs children are greatly affected by the attitude of the community towards children with special needs. The problems of having a child with special needs cannot be separated from the ways people in American culture value individuals with handicaps. A problem most all parents of special needs children must cope with is the appraisal of their children's worth by members of society. In American culture, persons with special needs have long been considered to be "devalued" persons (Wolfensberger, 1972) who are stigmatized (Goffman, 1963) for being different, and this stigma is especially painful for parents of disabled children:

A society's negative evaluation of a child places severe

> strain on the child's parents. Parental aspirations for the child and the realization of cherished goals can be thwarted by social obstacles as well as by the disability itself. In addition, parents are forced into conflicting roles as providers who desire the best for their children and as members of a society that views the child as socially unworthy. (Fewell and Gelb, 1983; p.178)

If I am to understand the ways in which fathers made decisions regarding involvement in the lives of their special needs children, I must make my analysis in relation to the social meaning of having a child with a disability. The ways fathers attributed meaning to their children and the ways they became involved with them are a reflection of how the fathers have adjusted to cultural values regarding special needs persons. The task of finding meaning, which all fathers of the present study had to face, is summarized by Berger and Foster (1976) in their discussion of parents who have a retarded child:

> Another common effect of the child's retarded status is to create for parents the necessity of finding "meaning" for the child's stigma. This task has several dimensions: (1) constructing an explanation for the retardation, (2) interpreting the stigma to a variety of persons and/or organizations, (3) assessing the current and likely future impact of the child on the ongoing familial patterns, and (4) deciding whether changes in relatively stable family patterns will be required, and, if required, whether they will be possible.
>
> The task of finding meaning for the stigma involves both value and reality components...The issues are inseparable. Reality issues have value components and value issues have reality components (p. 5).

What becomes important here is not necessarily the "actual", or real stress which exists for the fathers, but how the fathers "perceive" (or "appraise") stress. In order for the fathers to feel justified in making the types of commitments they made, their behavior had to be congruent with their appraisals. Since the fathers had to make some investment of their time and energies in the medical and educational interventions already discussed, the patterns of involvement are, in part, a reflection of the types of subjective and objective appraisals they made of stress.

Ultimately, all of the fathers became involved in activities so as to have some control over the future. For the group of fathers highly involved by choice, involvement meant extensive "hands-on" contact with their children, while for the fathers of the other involvement patterns it meant involvement via a more indirect route. In either case, the fathers "painted pictures" (i.e. made appraisals) which were used to guide their decisions and control their emotions regarding their use of time.

Magnusson (1982) discusses how individuals react to some situations as stressful because of their "partly unique appraisals of surrounding stressful circumstances" or because of unforseen future events:

> ...The basis of an individual's anxiety or stress reactions in psychosocial situations is, then, his anticipation of future harm. The anxiety and stress are not in the situation per se but in the appraised anticipation of harmful outcomes. Forming situation outcome and behavior outcome contingencies has adaptive value for the person in that it enables him to control and influence the environment to some extent. The information provided by the situation forms the basis for his predictions about the outcomes of alternative behaviors and makes possible for him to prepare himself and to act appropriately (and least within his own framework of action). (p. 237)

The fathers in the present study used appraisal-focused coping strategies as tools to create personal meanings which formed the framework for their patterns of involvement. Their behaviors may be seen as resulting, in part, from their appraisals of past harm and their predictions of possible harm in the future (e.g. negative developmental outcomes for their children or possible injury to their parental status).

Analysis of Appraisal-focused Coping Strategies

In the present study I investigated the ways fathers of special needs children made use of the apprasial-focused coping strategies as suggested by Moos and Billings. It should be noted that there is some overlap in the different types of appraisal-focused coping strategies. For example, when a father makes a positive comparison between his child and another child with a special need, it is possible that the comparison is a reflection of the father's denial that his child has a special need or the severity of the difficulty.

This overlap occurs because the different kinds of apraisal-focused coping strategies to be discussed are not mutually exclusive types but are rather processes of thought and behavior which reflect general types of strategies which vary with specific circumstances. What is of ultimate importance is not the precise classification of the strategies, but how they reflect and affect the perceptions, feelings and behaviors of the fathers.

None of the fathers in the present study reported a consistent use of all the appraisal-focused coping strategies. Some fathers used many strategies while others made a more limited use of them. Each father had a unique pattern of coping which was adapted to his particular circumstances. What is of importance is not the number of strategies employed but how they became important to the individual fathers.

It should also be noted here, that because of the qualitative nature of my data collection, the analysis of the data is by no means exhaustive. My analysis of the data to find the appraisal-focused coping strategies reported by the fathers in the interviews is only suggestive of the range of strategies which the fathers actually used. In reality, it must be assumed that in an interview I was only able to elicit responses which are indicative of each father's general pattern of coping. Future researchers will need to take a more systematic approach to fathers' coping patterns to enable them to define these patterns more accurately. Such an approach has been taken by Folkman and Lazarus (1980) in their study of the diversity of coping strategies in a population of retired persons.

In spite of this limitation, there emerges from my data, styles of coping (both within and across involvement patterns) which offer interesting insights into how and why fathers became involved with the activities related to their childrens' special needs.

Analysis of the data with respect to the appraisal-focused coping strategies was done through a simple coding procedure. As I read each interview I placed differently colored-coded "signal dots" in the margins at those points where I felt the data indicated that a father was using one or more of the appraisal-focused coping strategies. I then cut out these excerpts and sorted them according to the types of appraisal-focused coping strategies used and the pattern of involvement. Unlike the difficulties I had in creating the typologies of fathers, the coding and categorizing of the coping data were rather straightforward.

While I did encounter some problems in categorizing particular strategies, I found that it was not difficult to identify prominent appraisal-focused coping strategies used by the fathers.

Varieties of appraisal-focused strategies

Analyses of the interview data were only done for Involvement Patterns #1, #3, and #4, because Pattern #3 contained only three fathers, and there was an insufficient data base to do a separate analysis of the appraisal-focused coping strategies used by these fathers. Analyses of the interview data for Patterns #1, #3, and #4 revealed that fathers of these patterns made use of the following five types of appraisal-focused coping strategies: (1) "valuing their child"; (2) "positive comparisons"; (3) "denial and/or "avoidance"; (4) "fate"; and (5) "lessons in living".

Valuing their child. An appraisal-focused coping strategy used by only three of the fathers in the present study I am calling "valuing their child". This is a coping strategy which rather dramatically highlights the parental dilemma of finding meaning in a special needs child. For many fathers, having to admit that their child did indeed have a special need, meant they had to learn how to place the same human value on their child as they would have if the child had been born normal.

In order to overcome the "shock" of having a child born who was not normal, the fathers had to come to terms with their children's "differentness". While most of the fathers in this study found ways to attribute positive social value to their children through indirect means of thinking, only three fathers seemed to be directly aware of the stigma they faced as parents of special needs children, and they "created" this unique type of appraisal-focused coping strategy to manage the stigma.

Positive comparisons. The most common appraisal-focused coping strategy used was that of "positive comparisons". This is a strategy in which the fathers compared their problems to those of other parents of special needs children and concluded "other people have it worse off than me", or compared their children's current status with their past status and concluded "I used to be a lot worse off".

In this type of appraisal-focused strategy, fathers adjustd the relative "badness" of their situation by moving ahead in the "pecking order" of problems: they are comforted in believing somebody else had it worse off than themselves. This strategy may also have reduced the degree of stigma they felt was being attributed to their children by making the stigma seem greater for other peoples' children.

By making the positive comparisons, the fathers were adjusting their perceptions of just how bad off they really were relative to others. By finding somebody who was worse off, the fathers were making their burdens seem a little lighter. Whether or not there was any objective reality to these comparisons is irrelevant, since all that mattered to the fathers was that they believed them to be true.

For almost all the fathers in this study, the data suggest that positive comparisons were a key strategy which enabled them to reduce stress. In reading over the excerpts it almost seemed that the fathers had an "instinctual" need to find someone else who was worse off, even if that meant comparing themselves to how bad-off they used to be. It almost seems as if the fathers were on the prowl, trying to find another parent to compare themselves to. If the fathers did not find those parents in a support group, then they could find them in hospitals, in stories their wives told them, or at parties where there were other special needs children. By making these comparisons, the fathers were "redefining" their problems in ways which seemed to reduce the levels of stress they must have been experiencing.

Denial and/or avoidance. The appraisal-focused strategy of denial and/or avoidance was used by fathers to reduce the "objective" degree of their childrens' disabilities. Included here are such strategies as denying that their childrens' problems are as bad as everyone else thinks, focusing in on only one or two of the milder aspects of their childrens' problems, engaging in wishful thinking about why their children had their problems, not believing doctors' evaluations, denying the problem even existed, and removing themselves from the situation to avoid confronting the problem.

The use of denial as a coping strategy varied greatly among fathers. There were some fathers who seemed to deny only slightly the reality of their children's disability, while other fathers seemed to express the feeling that their children did not have any disabilities in spite of the fact that they were enrolled in an early intervention program and their wives were very concerned. To whatever degree denial was used as a coping strategy, it served the purpose of "adjusting" reality so the father's conception of his child's "true" problem was one which he could accecpt.

The use of denial and/or avoidance did not necessarily result in a father becoming less involved with his child. Indeed, the data suggest that for many fathers (especially the fathers highly involved by choice), the use of denial was a means by which a father could remain involved or even become more involved. By cognitively adjusting the severity of his child's disability, a father could create a situation which he felt he could do a better job of managing.

Fate. For a small number of fathers, blaming fate as the cause of their child's disability was a way they could more safely understand their situations. If fate was the cause of their problems, then they could remove the blame from themselves. In their appraisals of the cause of their child's special needs, the fathers found it convenient to look outside of themselves for the causes. This coping strategy took the form of such statements as: "There was nothing I could do about it," "It was predetermined," "It was just one of those things, it was a fluke of nature." In a way, this view is a rational acceptance of one level of reality, for example in Down's syndrome.

Lessons in living. The final appraisal-focused coping strategy used by fathers in the present study was one in which they came to see that because of their childrens' special needs, they learned important lessons in living. For the fathers who used this strategy, the meaning of their child's disability included "side benefits" to them as people. These fathers came to see that no matter what else happened, their child was the source of improvement in their own lives. The fathers learned that in coping with the stresses associated with their child's special needs, they had learned valuable lessons in what it meant to be a human being; for example, in their increased understanding and acceptance of the difficulties of others.

CHAPTER X

COPING STRATEGIES OF FATHERS HIGHLY INVOLVED BY CHOICE

Fathers "Valuing Their Child"

The two fathers of this pattern who made use of the appraisal-focused coping strategy of "valuing their child" were Fathers #17 and #12.

When Father #17's son was born with Down's syndrome it was a great shock to him and his wife. Father #17's first reaction was to institutionalize his son because:

> ...When something horrible happens to you, your first intuition is to see what you can do to have it go away.

But fortunately for Father #17, a social worker notified the early intervention program about the birth of his son, and a staff member appeared at the hospital to talk to Father #17 and his wife the next day. What Father #17 remembers as being particularily helpful about this first visit, was that he was given the name of another father with a Down's syndrome child whom he could talk to. In the following excerpt, Father #17 tells why his talk with this father was so important:

> F: ...so it was extremely beneficial for me to sit down with a man who had been put in a similar situation two months before. He told me something that changed my whole way of looking at the situation, which was; there's a long waiting list of couples to adopt Down's syndrome babies. That's a concept that I had never considered. At that time I was still thinking that I'm never going to smile again, this is the worst thing that could ever happen.
>
> S: So why was that an important concept?

> F: Well the fact that other couples would want this son of mine made me realize that there was some value to him. And that was really important. And that was the beginning of my getting close to my son. Up until that point I was a little stand-offish, "What should we do about this? Maybe if there is somebody out there who wants to adopt him, maybe we should let them." And sometimes I had these feelings that it would be best for everybody if we grabbed him and beat his head against the wall and beat the life out of him. And that was the beginning of me making up my mind there must be value.

This rather dramatic and moving passage shows how Father #17 made the important appraisal that his son was someone who was worth spending time with. Certainly, if he never felt his son had value, his time with him would have been a difficult and "hard" time. By coming to terms with his feelings of distance, Father #17 laid the groundwork for becoming highly involved with his child. Father #17 needed to find a way of perceiving his situation which would allow him to become close to his child.

But this one meeting was only a beginning for Father #17. He still needed to do more appraising of his situation before he felt comfortable with his view of his child, himself and his family. A theme which recurred over and over again in his interview was his need to find meaning in having a Down's syndrome child. Father #17 needed to make sense out of his child's "differentness". In order for him to want to spend time with his child, he had to redefine constantly who his child was. Eventually, Father #17 began to perceive his child as being more "normal" than he was different. This perception comes out in the following passage, where he discusses his reactions to a picnic held by the early intervention program:

> S: What was your experiences when you met these other couples?
>
> F: Uh, one impression I had was that they [the children] didn't look too different from normal children. I was expecting that I would see a bunch of freaks ...
>
> S: What do you mean you expected to see freaks?
>
> F: I expected -- I was saying that slightly tongue and cheek -- I expected to be startled by how different these children were from normal.
>
> S: The Down's children who were older?
>
> F: No, these were not just a lot of Down's children. But a lot of different kinds of handicaps. And I was struck by how much like my perception of normal children they in fact were.
>
> S: So how did that affect you?
>
> F: It made me realize that my son was going to have a lot of things like a normal baby and a normal child.

Seeing his child as being more like normal children was a means Father #17 used to attribute social worth to his son and must have served, in part, as a basis for motivating the father to take a hand in shaping his child's future. By viewing his son as a socially valued person who could achieve many of the same goals as a normal child, Father #17 reduced the threat of future harm to himself and his child while at the same laying the groundwork for setting goals he could help his son attain.

The second father who came to terms with his child's differentness by directly attributing value to him was Father #12. When Father #12's son was born and there was a suspicion of Down's syndrome, it was something that neither he nor his wife wanted to believe possible. Perhaps like any parents, they did not think it could happen to them. In the following excerpt, Father #12 recounts his reactions and his need to deny the possibility that his child had Down's syndrome:

> ...so we [his wife] went through all the signs that the doctor said were signs of Down's syndrome. He said that one of the things that they look for is a crease that runs horizontally across the hand. I said, "I've got that." Uh, eyes kind of slanted, we looked at him, his left eye slanted more than his right, her family has a trait. It's like about the toe. The big toe being separated from the other toes, kind of operating independently, well, Ellen's toes do that. So you know, he's got Ellen's feet. Well these different things that he kept pointing out to us saying, well, "Hey, these are family traits that he has; they can't be Down's syndrome."...

But the chromosome test came back positive, and these parents had to start dealing with the reality of having a Down's baby. Fortunately for Father #12, his pediatrician made an immediate referral to the early intervention program, and an appointment was set up with the home-visitor. This was an important visit for Father #12, because he was given the name of another couple with a Down's child whom he visited with his wife. What was significant about his meeting with the other couple was that he had the opportunity to meet an older child with Down's syndrome, and it was there that the mystery of Down's syndrome began to unraveled for him. He suddenly had a sense of his child's future, and this was just what he needed to "get the ball rolling" with his own child:

> ...It was around this time that they took and gave us a couple of people to contact who had Down's syndrome children in the area. So we contacted people; went over and saw their 18-month-old Down's syndrome child acting very

> much like a normal child and I was saying, "My God, she's acting normal, she's taking toys away from my older son, she's doing all this." I said, "Our son's going to be all right, you know. Once we get over the heart problem, this is what we are going to have to face," and I said, "It doesn't look that bad." It was at that time that Down's syndrome didn't seem as bad to me. My feeling was that through all this, finding out that he did have Down's syndrome and really not knowing too much about it, I said, "I don't care what his problem is, I want to keep him home. I don't want to put him in an institution or nothing, especially after having him for seven weeks and really getting to know him."

Like the other highly involved fathers of Pattern #1, Father #12 perceives the future as something he can shape. Before he saw another child with Down's syndrome, he did not know what to expect, but seeing what was potentially possible for such a child acted as a target for him to shoot for and also added value to his child. By viewing his child as being like a normal child, he is actually saying that he has begun to value his child just as he would if the child were normal.

When Father #12 talked about the future, his thoughts indicated a complex mix of emotions. He "knew" that his son could progress like a normal child yet he also knew he was different and that this might be a problem for him. In the following excerpt, the uncertainty of the future weighs heavily on his mind:

> ...You see that they can lead perfectly normal lives. They come up; they grow up like perfectly normal kids; they are just behind. The gap seems to get bigger as time goes on, you know, that's just the only thing. But that doesn't seem to be much of a problem to deal with. The biggest problem I really fear for Stewart is his relationships with others. You know, I myself having been in a school system, and seeing these retarded children, have been very critical of them when I was in school. This is basically how kids

> are; if anyone is different, they get down on their case. They really make fun and laugh, you know. I really fear these problems with Stewart and the emotional strain it's going to have upon him, especially when he's knowing that he is different; he's really not normal.

In this excerpt, one can see how Father #12 fears that his child will not be valued by others in the same way he has learned to value him, yet he is aware, himself, that his child is "not really normal". The complexity of the conflicts engendered in coping with a special needs child is evidenced by Father #12's bind of being caught up in both the "normal" and "not normal" worlds of his child.

For these two highly involved fathers of Down's syndrome children there is a strong need to face up to the ambiguities of their situations . Their strong desire to effect change in their children is marked by a painful awareness of the limits and potentials of their children. Although society has stigmatized their children, these fathers have resisted the blind acceptance of this "decree" and have made appraisals which empower them to act as agents of change for their children.

Use of Positive Comparisons

Four fathers who typify the ways in which the fathers who were highly involved by choice made use of positive comparisons are Fathers #3, #7, #22, and #44.

The home-visitor recommended to Father #3 that he and his wife should take their daughter, Sharon, to a weekly playgroup.

When Father #3 and his wife brought Sharon to the playgroup, they met with other parents while Sharon played with the other children. While Father #3 seemed to enjoy talking with the other parents of special needs children, he was the only father present, and he felt that his needs were not being met by the discussions. He was a father, and he felt he needed a different type of support.

In response to Father #3's needs, and perhaps the needs of other fathers, the early intervention program began a fathers' support group which met several times over a six month period. For Father #3 this was a particularily important experience, because it gave him the opportunity to compare notes with other fathers who were in similar situations. In the following excerpt, Father #3 is particularily perceptive in realizing that he was comparing his child to the children of the other fathers and how important these "comparisons" were to himself and the other fathers in the group:

> F: ...each one of us had a child with a different handicap. And obviously there was one handicap that was worse than another one. And I came out of there feeling that what Sharon had isn't really all that bad.
>
> S: You felt other people had worse?
>
> F: That other people had worse. And yet it was the other way around. They all felt the same way, "I don't know if I would be able to handle what you are doing." So it was kind of, there wasn't one father there that had the "worst handicap". Well, it wasn't necessarily all that bad, because each of us was "Jeez, I don't know if I could handle that," and they were saying the same thing about Sharon. Not about her but about the situation. And we talked about it and we said well,

> actually it is probably because we aren't in the situation. None of us have ever had a handicapped child before, and it was just voom! It was thrust upon us. It was there, and without thinking we handled it. So, if given another situation, say my child had Down's syndrome, O.K., it would have been the same situation. I'd just pick up and carry on.

What is particularily interesting here, is how Father #3's perception that other fathers were worse off than he was serves as a means to congratulate himself about how well he has done as a parent. Being one of the highly involved fathers, he had put much time and effort into working with his child, who had a rare disease which required much special care, and caused her to look different. Perceiving his problems as easier to manage than he had previously realized served as an incentive for him to work harder; for, after all, he was "lucky" to have things as "easy" as he did. Rather than saying, "Well, my situation isn't all that bad; I really don't have to work as hard as I thought," he does just the opposite.

In making this comparison Father #3 realized that even if his child had a different problem he would have become just as involved. Father #3, like the other fathers highly involved by choice, had a marked tendency to appraise situations in ways that helped to facilitate his involvement. For the fathers highly involved by choice the severity of their childrens' problems did not seem to significantly affect the degree to which they became involved. These fathers made the appraisal that "the future had hope," and they wanted to take a direct hand in shaping events.

While Father #3 compared his child to the children of other fathers with special needs children, Father #7 (who never attended parent support group meetings) compared his child's past problems to his current problems. Father #7's son was born with a number of acute medical problems which greatly affected his developmental pattern. While the etiology of his problems were unknown, doctors felt that he showed autistic-like tendencies. From the following excerpt one can seen how Father #7 was able to put his current situation into a perspective which was both manageable and filled with hope for the future:

> Well, essentially what we are is parents of a kid with clear developmental delays -- that's not even true -- with relatively clear developmental delays that absolutely nobody up until now has been able to tell us what it means. And some people say, "Jeez! This must be real hard," and it is real hard. But my answer to that is that "It is real hard, but it's a lot easier than dealing with somebody when they're three months old," and they tell you, "Well we can guarantee horrific consequences of developmental delay." And I think what we have done internally is that on the 23rd of each month, not consciously, but we kind of think, "How much is he this month as compared to last month". By and large he has been on a pretty good curve...

In this excerpt, one can see Father #7 re-appraises (or reframes) his situation into one which has positive overtones. Unlike Father #3 who relieved his stress by comparing his child to those of other parents, Father #7 has done the exact same thing except that he is comparing his child's present status to his past status as a special needs child. Instead of saying, "Look how well off we are compared to other parents", Father #7 is able to look back and say, "Things are a lot better now for us than they used to be. Boy! Are we lucky." As the severity of his child's problems decreased and the prognosis for the future improved, Father #7 could look back, compare his "new" son with his "old" son and appreciate the gains his child has made.

It seems that Father #7 has made some powerful psychological adjustments which make his involvements seem worthwhile. Since he was so involved in his child's early intervention program, his ritual of making "monthly updates" of his child's developmental gains may be seen as the "reinforcers" he used to motivate himself to continue his high level of involvement.

The positive comparison Father #22 uses is slightly different from those of Father #3 or Father #7. Rather than comparing his child's problems to other children's or to how "bad-off" his child used to be, Father #22 compares his situation to how bad-off he could have been ("count your blessings").

When Father #22 was told that one of his twin daughters had cerebral palsy, he found the term "cerebral palsy" to be frightening. His initial reaction was one in which he could only envision a horrible existence for his child. But as he learned more about it, he found that it was not as "scary" as he thought:

> ...That's another thing about cerebral palsy. There is such a wide range. It can be totally flat on your back and not being able to do anything, not even raising your head. It can also be not able to move one arm. There's a wide range. And you just don't know the potential so why get totally upset about it. She may have a great potential. We still haven't had potentials yet. She's doing great.

In this excerpt one can see how, typical of the highly involved fathers, Father #22 is able to frame his situation in such a way that will empower him to make changes for the future. Father #22 feels that his daughter's potential has yet to be determined, and since there is such a wide range of outcomes, he is betting on a good one for her. Like the other fathers in this group, his positive vision of the future is a key factor in understanding his motivation to continue doing the follow-up therapy. As long as there was hope, he could do something to make the positive outcome happen.

For Father #44 the opportunity to make positive comparisons occurred when he observed his daughter with Down's syndrome in the early intervention program's playgroup. In the following excerpt, Father #44 discusses his impressions of the other children he saw there:

> F: Some of them, I rate them, I put them up against Andrea [his daughter], you know, even though they may be 2-3 year-olds. You know, there was a boy there who's a two-year-old, has Down's syndrome, he didn't even know how to walk. I said, "Gee, Andrea, she's getting her legs together and stuff. She's going to do well in this program".
>
> S: So you saw the kids she compared pretty good too?
>
> F: Yeah she rates up there pretty good. That makes, you know, well O.K.; she has Down's syndrome [whispers], but when I look at this and compare to "this and that" she is doin' fine.

In this excerpt, it seems that Father #44 almost cannot resist making a comparison between his child and the others. And as is the case with almost all of the fathers, his child holds up very well by his measure.

Denial

Two of the fathers highly involved by choice used the appraisal-focused coping strategy of "denial" to come to terms with their special needs children. By denying some aspect of their childrens' problems, Fathers #7 and #44 possibly reduced the amounts of stress they were experiencing. In effect, a denial of the "true" extent of their childrens' special needs may have allowed these fathers to cope, and perhaps increased their motivations to want to engage in problem-solving activities in helping their children. Perhaps if Fathers #7 and #44 had "faced-up" to the actual extent of their childrens's disabilities, they may not have been as motivated to put efforts into helping them. By creating positive prospects for the future, they gave themselves a reason to become involved.

Because of his academic training Father #7 was the most knowledgeable and articulate about his child's problems. He seemed to have a limitless amount of information about the details of his son's developmental history, and his observations of his child's development were very fine grained. Yet, like the other fathers of Pattern #1 he too had to make sense out of his child's problems and appraise them in such a way that made his heavy investments of time seem worthwhile. In the following excerpt, one can see how Father #7 cleverly frames his son's developmental pattern as one which barely puts him in the range of normal:

> ...no one is willing to make a definitive statement about anything, except to make the definitive statement that they think there is zero chance that he has severe retardation. Maybe we are talking about normal. If we are not talking about normal we're probably talking about the low end of the possibility of an I.Q. in the 80's...

Since Father #7 is knowledgeable about I.Q. testing, it must be assumed that he is well aware that the "standard" cut-off point for retardation is around 80. So when he suggests an I.Q. of about 80 as a minumum, it is his way of hoping for a positive future, possibly denying the severity of the problem and attributing value to his son. Father #7, like the fathers of each of the involvement patterns uses "denial" as a means to manage stress; because Father #7 is highly involved does not nececessarily mean he "accepts" his son's delays to their fullest extents. If Father #7 felt his son's I.Q. was below 80, perhaps this would have been too difficult for him accept and would have dampened his hopes for the future.

In Father #7's opinion, his son is "normal" and this is of the utmost importance to him. This is especially clear in the following excerpt:

> ...So the sense about him is that he takes in more and knows more than he will often let on. And I don't know why that is. The general summary about him, the best way that I can summarize it best; you have the sense that he wasn't there for the first three months of his life. If you --if he were three months younger he'd have almost a normal development, that is, his curve would parallel a normal curve. You push down the "x" axis three months.

By "forgetting" about those first three months, Father #7 is able to consider his son to be normal and in the process is also attributing value to him. Whether or not he is accurate in his perceptions is beside the point as far as his coping is concerned; he needs to have those three months set aside.

While Father #7 seems to be denying the extent of his son's delay, he is also very aware of his son's delays and weaknesses, but he chooses to not fixate on them. For Father #7 denial may therefore be seen an a tool which he uses as a means of "selectively attending" to the strengths of his son rather than to his deficits. By focusing his attentions on what his child is able to do, Father #7 attributes value to him and this may, in turn, make it easier for him to become more involved. Father #7 has a sense of hope about his child which is a balance between his son's limitations and possibilites.

When Father #44 began to talk about his daughter's special education program, he told me about the information given to him regarding Down's syndrome, but he also conveyed a sense of denial about his daughter's problems. Like Father #7, Father #44 sees his child as "normal", and this undoubtedly helps to fuel his interest in her development. In the following excerpt it almost seems that Father #44's daughter does not really have Down's syndrome:

> S: What kind of information has the home-visitor passed along to you?
>
> F: Well, she talks about things, you know, Down's syndrome babies are --because people are still lumping them in the group as retarded. They're not retarded; they just have an extra chromosome. That's all. You know, some of them, like Audrey, Audrey is bright. She's on the ball. She's borderline.

> S: When you say she's borderline, what do you mean?
>
> F: Uh, between being Down's syndrome and between being normal. She's walking that line. To look at her you wouldn't know she has Down's syndrome. To see her development you wouldn't know she has Down's syndrome. They took a blood sample and did a chromosome check and she has the 23, you know, she has one with three. And that's -- as far as I can see and as far as Carrie can see -- that's the only difference, you know, she is a little slow in other things.

This excerpt makes it painfully clear that Father #44 has minimized his daughter's problems. He has a strong need to see her as a person of considerable potential, so that he and his wife will be able to "...blossom her out someday."

Fate

Only Father #3 needed to use the powers of "fate" as a partial means to cope with the stress associated with having a special needs child. In the following excerpt, Father #3 talks about how fate had intervened in his life:

> And my abnormal gene had to come into contact with her abnormal gene in order for Sharon to be what she is. So when you talk about genes, you know, the odds are something you don't want to go to Las Vegas with. O.K. we could have ten more kids and never have a problem...everything is just. Like we don't have any control. It's all laid out for us. Regardless of what we do this is going to happen, this is going to happen, this is going to happen. It's really weird.

Viewing his child's problem as a product of fate allows Father #3 to reappraise his situation in a positive way. When his daughter was first born, Father #3 reported feelng sorry for himself and vented out his emotions:

> ...I went through a period of time the same day Sharon was born. I went over to the hospital. I was over there till midnight and I came home, went down the basement; I had a nice shop bench. And I totally proceded...the bench was huge and I just picked it up and threw it -- just totally tore the basement apart, like, "Why me?"...

His finally coming to appraise his child as a "rare" or special person because of the "hands of fate", must have made it easier for him to cope. If he had resented the "odds" working against him rather than for him, the task of coping would certainly have been much harder.

Father #3's positive view of his situation may be looked upon as part of the fuel that allows him to want to take the time to be with his child. Like the other fathers of Pattern #1, his reframing was an important component of the way he perceived his situation and one which provided a reasonable rationale for his use of time to help his child. Since he was committed to spending so much time with his daughter, his reframing of her problem made the time with her "special".

Another related way to interpret Father #3's view that fate was responsible for his daughter's condition, is to assume that he used this belief to relieve himself and his wife the responsibility and guilt of causing his daughters problems. By putting the blame on fate, Father #3 removes that burden from himself and his wife. Once he has reduced his guilt to a more manageable level, he is able to mobilize himself to take actions which will help his child. Father #3 does not want to let himself "wallow" in self-pity. He is a man of action who needs to view his world in a way that will make his actions seem effective.

Lessons in living

The final coping strategy used by a Pattern #1 father, is the one used by Father #17 who felt that by having to learn to cope with his child with Down's syndrome he became a better person. Just as many of the fathers came to realize that "things could have been worse", Father #17 coped by turning what he called a "seeming tragedy" into a positive lesson in living:

> ...but gradually in August and September the knowledge about a child with Down's syndrome was beginning to have a larger affect on my life which I think was a good thing. I started to become more compassionate for people in general. I started to look upon people's behavior patterns not in terms of good or bad, like or dislike, but in terms of people are the way they are for certain reasons, and very often they can't help it. And maybe for people -- somewhat, at least, given the problems -- being compassionate is a more appropriate reaction than anger. And I've tried to adapt that to my professional and personal life. And in the last six months it has been very emotionally gratifying and liberating to do that, to free myself from the self-imposed requirement to like or dislike.

In this excerpt one can see how Father #17 was able to "generalize" the ways he had learned to reappraise his relationship with his son to relationships with other people. A "side benefit" which he attributes to his son, is the "growing up" he did in learning to understand what it means to have a Down's syndrome child. This perception of Father #17's must have made the time he spent with his child seem even more worthwhile, for it meant that not only was he helping his child, but he was growing as a person in the process.

CHAPTER XI

COPING STRATEGIES OF THE FATHERS WHO WERE MODERATELY INVOLVED

The Strategy of Positive Comparisons

Typical of the fathers who were moderately involved (Pattern #3) who used positive comparisons as a coping strategy are Fathers #2, #15, #16, and #34. As was true in all the other patterns, positive comparison was the most common form of appraisal-focused coping strategy used.

For Father #2, using "positive comparison" did not serve him as well as it could have. Because of the extreme nature of his child's special need, coping strategies were hard to come by. Father #2's son was the only child in the present study diagnosed as having a terminal illness. Indeed, there was not much Father #2 could do for his child. In spite of his working with his child, he always knew that no matter what he did, the disease process was progressing. In the following excerpt, Father #2 discusses his attempts to help his son:

> S: So, have you had specific training [therapy for his son]?
>
> F: She has showed us things. The type of exercises that we would do for him don't really help, because he needs to initiate the action himself with his own muscles. So just going through the motions doesn't really help.

For Father #2 the future was all too clear, and he found it difficult to visit friends who had normal children, because this put him into a position where he had to compare his child to theirs, and the comparisons were anything but "positive". He told me:

> F: Our friendships with other parents is good, except that other parents with normal children -- and it has put kind of a little damper on it. I can't say exactly; maybe we kind of feel a little bit jealous when they come over, and the kids are running around...
>
> S: Damper? In what way?
>
> F: Well I don't know, I feel a little jealous if they come over with their kids, and they're running around perfectly normal. Scott is in a standing brace and can't move.

In this excerpt, one can see how hard it is for Father #2 to compare his child to normal children. All the comparisons he makes with his friends' children are "negative". Yet, in spite of the relatively "low" position he finds himself in with his own child, after attending several parent support group meetings, he was able to read into the problems of other people positions which made him feel relatively better off. This is seen in the following excerpt:

> S: So, how many of these parent meetings have you been to?
>
> F: It was quite a few altogether. Some of the parents had children that were a lot worse off than Scott as far as Down's syndrome children -- things like that -- and some had children that were a little bit more mild than that. It was a good mix of parents that had a lot of the same problems that all parents of special needs children deal with.

It is seen here how Father #2 interprets Down's syndrome as being a problem "worse" than the one his child has. Even though Down's syndrome is not a terminal disease, Father #2 had the need to feel that these parents were indeed worse off than he. In this making this comparison with Down's syndrome children, Father #2 may subtly be attributing value to his child. Since his child was not retarded in his intellectual development, as are children with Down's syndrome, Father #2 may have been thinking, "At least my child is not stigmatized by being retarded."

But so unlike most all of the other fathers, Father #2 also states that children were a little bit more "mild" than (presumably) his child. But no matter how hard he tried, he could not escape his anxiety over the future. It is perhaps much to his credit that he could frame Down's syndrome parents as having it worse off than he did. At least he could find somebody else to make a positive comparison to. In the end, however, he states that other parents had the "same problems" as he did, and he seems to gain some comfort by realizing that his problems are just like other parents' problems. If he was not better off than they, at least they were in the "same boat".

When I then and asked Father #2 what he saw as the biggest need of other parents in the groups he attended, he clearly projected his own anxieties onto the group in the following way:

> I'm trying to think of what type of problems most parents talked about. I think that the big thing that sticks in my mind; everyone seemed to feel a little bit guilty, like they weren't doing enough for their child. That maybe there is something more they could be doing to help a little bit more. So there was a lot of (pause) certain amount of anxiety over, "Am I doing everything that I can?"

What becomes especially clear because of Father #2's concerns, is the power of the positive comparison. When a father has a difficult time making such a comparison, this may be an indication of difficulty in coping. By not being able to make a positive comparison, Father #2 is put into a position in which he sees himself as being worse off than other people, and this may have serious consequences in his adjustments. Of course, in the case of Father #2 it is perfectly understandable why this is true. Because of the real nature of his child's problem, there are few positive comparisons to make.

Unlike Father #2's child, Father #15's daughter had made wonderful progress over the years. At the time of our interview, his daughter was in an integrated preschool and was doing well. This progress stood in stark contrast to her past history when, as a baby, her early development was severely delayed, as she had several medical problems which had put her health in jeopardy.

Sometimes during the summer months, when Father #15 was free of his duties at a State University, he had taken his daughter to the early intervention program's playgroup. When I asked Father #15 about his experiences in the playgroup, he remembered how the problems of the other other children had brought back memories of his child. This is seen in the following excerpt:

> ...The fact is, you know, these Down's syndrome kids often develop very vigorously and project personalities and be good at language, and have a lot of the things Kitty [his daughter] did not have. So it was interesting for me to see that. To see that Down's syndrome is not a total

> demolition of the personality, but is focused in certain ways.

Seeing the Down's syndrome children was a surprise to him, because he could see they had certain abilities his daughter did not have when she was young. But fortunately for him, she grew out of her problems, and when he looked at her present status, he compared her to where she used to be in the following way:

> ...But the overall prognosis is good. The early concerns, especially if you think back to those early days just after she was born or to all the other times she was manifesting different developmental problems and look at her now, things really look good. In fact, so good that we couldn't have imagined or hoped that at any of those times that she would be the way she is now.

One can see how the Father #15 envisions a future which, in many ways, is less demanding than he might have ever expected. Father #15's daughter had made excellent progress as a result of her participation in the early intervention program and he could look forward to seeing his daughter progress normally. When Father #15 reminisces about his problems of the past, he makes comparisons which comfort him.

If Father #15 could make positive comparisons because he saw a good future for his child, when Father #16 talked about his child's future, he was not able to see one which held definite signs of hope. Although he felt effective in seeking help from doctors and the early intervention program, one can see that he was less than optimistic about the future from the following excerpt:

> S: What is her developmental level coming in at?

F: Probably a year and two months. Uh, yeah, that is only a year behind but that is also half her life. So we don't know. They don't want to predict what she'll be like because it would be like predicting the weather. So they have no idea, but (pause) her nervous system (pause) they don't know if it will ever catch up or not. They don't know why it is delayed. And what we don't know is if it'll reach a plateau or if it'll just keep going. They have no idea.

Father #16 and his wife were able to compare their problems with their daughter positively to the problems of other children only after they attended a parent support group meeting offered by the early intervention program. As Father #16 reports, the home-visitor felt they would benefit from talking to other parents with special needs children. At first, as is seen in the following excerpt, he and his wife did not feel they were ready to meet with other parents:

S: Why didn't you want to do that [meet with other parents]?

F: I don't know. I don't know. Maybe we felt we just didn't need it, I don't know. But the good thing about the home-visitor is she never forced anything on anybody. You know, she would just kind of invite us casually and then we finally said, "Let's go to one of these things and hear them out." We went on from there.

After Father #16 and his wife decided to go to a series of meetings, these seemed to be important experiences for them. At these meetings, they were not only able to get a new perspective on their own problems, but they could see that they could help other parents by demonstrating how they had learned to talk about their problems. Most importantly, as is seen in the following excerpt, listening to other parents discuss their problems provided them with an opportunity to put their lives into a more manageable perspective,

> S: What did you hear other parents saying?
>
> F: I think the thing you appreciate about the early intervention program is when you talk with other people, you realize how lucky you are because there is always somebody that has it worse than you. And as much as we might have felt bad, and that included going to all the hospitals, we saw a lot of people that had much more severe conditions...to us the problem isn't all that bad because we understand it. And yet we see somebody with a Down's syndrome baby and we don't know what it would be like raising one of them...

In this excerpt, Father #16 is making use of the most common form of coping strategy found in the present study. Fathers of each of the involvement patterns often saw themselves as being "lucky" because somebody else had it worse. Feeling that "other people are worse off than you" seems to be a "basic" comforting device for these fathers. They seem to need to feel that although their children have special needs which are causes of concern, they (the fathers) are <u>not</u> at the bottom of the pecking order of misery. Misery, for these fathers, does not love equal company.

It is interesting to note how Father #15, like Father #2 (the father whose child was terminally ill), chooses to compare his child to those children with Down's syndrome. By "positively" comparing his child to Down's syndrome children, Father #15 is attempting to protect himself from the stigma of parenting a retarded child. For many fathers of this study, Down's syndrome children became the "targets" of comparison, perhaps because they are a group of delayed children who are highly visible to the public. Father #15, in choosing to compare his child to Down's syndrome children, thereby disassociates his child from this "stigmatized" group (the "mongoloids") and also reduces the ambiguity of his own situation.

At the time of the interview, Father #34's son, John, had made so much progress as a result of being in the early intervention program that he only needed a minimal amount of special services. John was born with an unusual chromosomal anomoly which gave him an unusual appearance and left him with several serious medical problems which may never be fully resolved. Because of the seriousness of these problems, the future always holds the possibility that his son may suddenly die.

Because of his son's facial deformities, Father #34 reported a strong concern over how well his son will be accecpted by other children in public places, and eventually in school. In the following excerpt, he discusses an experience he had with his son on a vacation:

> ...What bothers me is the kids. The kids are stopped dead in their tracks, and they look at him, and they run away and they tug at their mother's coat and they point at him, you know, all that kind of stuff...But, yeah, it bothers me and it will probably bother me forever to a certain degree. It doesn't kill me, but it really bothers me when I see a kid, you know, and the kids don't know any better. My kids would probably do the same thing when they see a Mongoloid kid or a kid in a wheelchair; it is only natural. I'm trying to brace myself for kindergarten and all the problems.

In spite of the uncertainty of the future and his son's apearance Father #34 also felt that other parents had worse problems, and this seemed to give him some comfort. Father #34 was able to reframe his situation positively in a way which seemed ease his burdens as follows:

> ...and all of a sudden you start running across a parent. Like one of my own customers, I ran across a couple of guys who have kids that are totally crippled and I start relating that to my situation and I come home and I says to Pauline [his wife], "Jeez, Bobby Jones, he has a kid over at Shriners hospital. The kid has never walked a day in his life and he's sixteen." We know that John is going to walk. So that kind of therapy that we created in ourselves is bringing us out of this thing.

It is interesting to note how Father #34 recognizes that the comparisons he was making were a form of "therapy" which was helping him to cope. He was sensitive enough to his own needs to recognize that he needed to find a frame of reference which would help him to cope. Later in the interview, Father #34 repeated his awareness of the importance of making positive comparisons when he discussed how taking his child to a group where there were other special needs children helped his wife:

> S: Did your wife ever talk about those groups?
>
> F: Yeah, they were like a support thing. They were like (pause). There was a lot of learning, particularily, I remember. She is a great observer. The two mothers who had Down's syndrome kids seemed to be having the most problems. She would use that as a vehicle a lot of times to make herself feel better. But not look at it, she felt really bad about that. But she could walk away from that and think that "My problem is not all that bad. These kids were going to end up with open heart and heavy things."...

Denial

The strategy of denial was used by Fathers #6, #32, and #42. Denial of their children's problem may have helped these fathers to cope in any one of three ways: (1) to reduce the ambiguity of having a child who was not "normal"; (2) to reduce the threat of future harm; and (3) to provide a framework which reduced the need for these fathers to become involved in the remediation of their children's problems.

In the cases of Fathers #6 and #42 the denials seem to be part of their rationales for not being more involved with the early intervention programs. Denying certain aspects of their children's special needs allowed them to feel they were not needed to help, because, "there was not really a significant problem." For Father #32 denial of the problem was complexly woven into the difficult times he and his wife were having accepting their son's delay and finding a specific diagnosis. By denying that their son really had a problem, they hoped that someday he would be normal.

Father #6's son was mildly delayed in his motor milestones and speech development. At the time of the interview the son had started to talk, and his motor delay was improving, but he still needed services from the early intervention program. Throughout his interview, Father #6 kept referring back to his perception that his son was just a "normal little boy", and he seems to wonder what the early intervention program is all about.

In the following excerpt he talks about his son:

> ...to look at him he is normal, for that matter. To me he is just plain normal. I don't think he has (pause) I know he has (pause) he will have some difficulties, but he's not (pause) there's nothing gross about him...if somebody told me they had a child with a disability I would think of a physical disability, you know, either a Mongoloid child, or I don't know a blind, a deaf...

In this excerpt one can see, because Father #6 seems to feel his child looks normal, he has a difficult time thinking of his son as being anything but normal. In a sense, Father #6 is making a comparison between his child and other children who "really" have special needs, and his son comes out so far on top that the father essentially proclaims him to be normal. The extent to which he sees his son as "normal" is seen in the following excerpt, where Father #6 talks about his wife's support group at the early intervention program:

> ...my wife goes to a mother's group of about a half dozen mothers that have children with some type of disability, and I guess on a scale of 1 to 10 my son is a 1 and everybody else is a 10. Some of the children are from very big problems.

Just how real his denial is becomes appearent in the following excerpt where Father #6 declares that he does not deny his son has a problem:

> ...I know my son has some problems, and I don't deny that, and I'm not practicing self denial. But he's (pause) he seems to be reasonably intelligent, he's cute, he's affectionate and he's fun to have around, and I guess I see him in most ways as a pretty normal little boy...

In this excerpt, one can see how torn Father #6 is between accepting that his son may have a problem (perhaps a learning disability) and yet not accepting it. The fact that his son is enrolled in the early intervention program and that his wife is anxious about him provide sufficient evidence to suggest that the son does have problems. As is true for any parent who uses denial as an appraisal-focused coping strategy, for Father #6 this "defense" is complexly woven into the fabric of how he looks at the world and how he takes problem-solving actions.

Like Father #6, Father #42 also saw his son as being a normal child, and because of this, he may not have been as motivated to become involved in the early intervention program activities. A contributing factor to the "non-acceptance" of the existence of a special need in the children of both Fathers #6 and #42 is the relative mildness of their children's problems. Because their children did not look "different", or manifest extreme developmental delays, it was difficult for the fathers to acknowledge the problems. Hence, "relative" denial of the problems became a means of coping. I use the term "relative" because it was impossible for the fathers to totally deny the problems; their children did manifest some problems; they were receiving some special services, and their wives were very concerned. Denial, therefore, became a subtle factor which influenced the fathers' behavior. On the one hand, they could discuss with great sincerity their children's problems; yet below the surface there existed shadows of doubt which came up in the form of denial.

The existence of denial in the case of Father #42 became appearent in an important passage where he was rambling on about his son (Father #42 tended to talk a great deal, responding to my questions in long soliloquies.) Like Father #6's son, the exact nature of Father #42's son's problems was not known.

From both of their descriptions, I inferred their children had mild learning disabilities showing up mainly in their speech but with some difficulties in their motor development. In both cases, nobody could tell the fathers exactly what was wrong with their children. In the following excerpt, Father #42 discusses the possible etiology of his son's problems:

> ...it's still very vague what it is. It's basically that they think that there's a (pause) in his nervous (pause) in his brain sending signals, you know, interpreting, getting the information and sending it out to the brain and sending it out to parts of the body. There's something, you know, it comes in but it just doesn't go back out again, and as far as what's causing that, nobody can be really sure.

From this excerpt, one can see how vague an understanding the father has of the problem. Yet even at the time of our interview when his son was five years old and out of the early intervention program for two years, Father #42 had difficulty understanding his son's speech. So it was clear that his son did have a problem, even if nobody knew what was causing it.

In the next excerpt, which is a continuation of the previous excerpt, Father #42 recalls to me how he only recently realized that his son has a problem. What is fascinating about this excerpt is that his son had been in special education programs for almost his whole life, and yet it was just occurring to the father that his son really did have a problem. Apparently, underlying the moderate level of involvement Father #42 did have with the special education programs, was a skepticism as to whether or not his son actually had a problem. Father #42's denial becomes apparant in the following long excerpt:

> ...I never wasn't really all that concerned, because I'd see him every day and everything else, and it didn't seem to be that bad. And one day, it kind of woke me up a little bit. I was riding, going to town with Karl [his special needs son] we were going shopping...and Karl and his sister Judy were in the car, and this wasn't too long ago. This was, oh, maybe six months ago. And I was winking to Judy or something and I was trying to teach her to wink. I said, "Karl, can you wink?" I said, "Close your eyes," and he couldn't close his eyes. I go, "Aye-ya-ya," you know, it started really bringing it home. I said, "Wow!" Because I didn't know he couldn't. I'd say, "Karl, close your eyes!", and he couldn't close them. He tried, he's grunting and groaning and he's squeezing his face, and his eyes just couldn't close. He's five years old, you know; he's almost five years old; if he can't close his eyes, I figured that there is something drastically wrong with him. There is something really wrong here, and I don't know if -- it didn't really come home to me until just recently, as far as that -- do you know what I mean?...

Father #42 needed "hard" evidence that his child had a problem, and his denial, as in the case of Father #32, is possibly related to his need for "somebody" to tell him what was wrong with his child. To cope with the ambiguity of not knowing what the future might bring, Fathers #42 and #32 seemed to use denial to reduce ambiguity and eliminate the stigma of having a disabled child. By "eliminating" aspects of their children's problems, these fathers could increase their self-esteem and gain a kind of "control" over the future that their direct interventions could not allow them to do.

Father #32's search for answers to the causes of his son's problems seemed to be related to some underlying hopes that his child was not really delayed or retarded. When the family pediatrician had suggested to him that his son might be retarded, this sent shock waves through the family, as may be seen in the following excerpt:

> ...he mentioned the possibility of retardation; and my wife was beside herself. She called me at work; she asked me to go over to her parents. And she was talking to her mother and father about it, and she called me at work and I was totally baffled and shocked at how could he say this if he doesn't actually have any proof, and my father-in-law called up and said "What symptoms does he have?"...and he questioned it, and it was just a big vicious circle...

Throughout his entire interview Father #32 centered his discussion upon three themes: the frustrations of not seeing his son make enough progress, the lack of a specific diagnosis and an uncertainty of what the future would bring. Father #32 did not seem to be able to find anything positive about his situation; "positive comparisons" were out of the question. He felt that doctors, and even the early intervention program had given him nothing to look forward to. In the following excerpt, his frame of reference which appeared throughout the entire interview is accurately characterized:

> Either way, you know, if someone, instead of giving us false hopes saying, and this is what they've been telling us, "We really don't know. We can't tell you." I'd rather have somebody say, "No, he's definitely not going to be like this the rest of his life", or whatever. Or if they put a time limit on it even and said "That within two years", you know, "on his fourth birthday, you're going to be able to do this, this, and this with him", or, "You'll be able to see this difference", then I would feel relieved. If they would tell me that he's never going to be able to do these things, I'd feel relieved also, because I want to know, you know.

From this excerpt one can see that Father #32 has a difficult time seeing anything ahead that is even remotely satisfying to himself. The future is a jumble of confusions where nothing he has done or the the advice of "experts" has seemed to help him. It is possible that Father #32 and his wife were not willing to accept their son's delays and were buying time to allow themselves to accept the reality that their son may not be normal.

At the time of my interview, Father #32 and his wife had decided to remove their son from the early intervention program, a decision which they apparently felt would give them more control over the future. In their opinion, the early intervention program had not helped their son, and they needed to do something else for him. The following excerpt expresses these feelngs:

> S: Has he enjoyed the group [at the early intervention program]?
>
> F: Well, not really, because and we have really talked about this, and since then, she, we, have decided that we are going to take him out of the group because we don't really feel he's getting the type of stimulation he needs by going to the particular group that he was in...We had serious doubts about whether the Program was really helping him, and just as of, like a couple of weeks ago, I think maybe as of last week, Maggie [his wife] called and not only cancelled the group but also cancelled the early intervention program too. Until, we just have to do some talking here. You know, the two of us, meaning her and myself, have to just sit down and just have to look at what, where our son is right now. We still know that he is still delayed, and we can give him enough stimulation...

In this excerpt, Father #32 and his wife seem to be having a difficult time coping. All the help they have turned to has failed, and they finally have decided to try "going it alone". While they recognize their son as "still" being delayed, the adjustment pattern (and acceptance of a more severe developmental delay) is much more difficult. Unfortunately, because of the type of problem their child has, they were locked into a position where nothing seemed to get better, and as the next excerpt shows, even after he had tubes put into his ears (to improve his hearing), the operation did not work the miracles they thought it might:

> ...Maggie would think, "Well, we know he's having problems with his ears why don't we just get the operation?" We sort of delayed the operation, thinking to ourselves it was going to be more of a nuisance because of the fact that he had the tubes put in you couldn't get water in there ever again and stuff like this. And we didn't really, we hoped deep down that it might solve some of his problem, but we didn't, it's just another thing that somebody's telling us, giving us a hope that it's going to solve it. And as it turned out, I can say, "It has helped", We have noticed a big, big difference, as I say, in just his hearing and the things he's picking up. But I guess maybe we're looking for miracles to happen. We can't expect...the tubes were put in and they've only been in now for like a month. We can't expect the fingers to snap like that and he's going to be walking and stuff like this.

What is significant in this excerpt is Father #32's clinging to the idea that a "miracle" might still be worked. In their search to find out what was wrong with their son, Father #32 and his wife had denied that he actually was delayed. In important ways, in spite of all their difficulties, the denial eased some of their anxiety, and also gave them the time they needed to come to terms with the "real" nature of their child's problems.

Fate

The one father of Pattern #3 who used the appraisal-focused coping strategy of "fate" was Father #41. What is particularily unusual about his use of fate as a coping mechanism is the pervasiveness with which he casts his lot into the hands of fate. By feeling that he was "bearing his cross" at the hands of fate, Father #41 found meaning in being the parent of a child with Down's syndrome. Because Father #41 sensed that developmental limits had already been defined for his child, he may have used this to justify his "moderate" level of involvement. This perspective of Father #41 contrasts greatly with that of the Pattern #1 fathers who had children with Down's syndrome. These latter fathers sensed, that even though there were limits to how far their children could develop, they could "challenge" the limits by making therapuetic interventions. Had Father #41 felt that he too he had more control over the future, he may have been inclined to become more involved.

Father #41's sense of the power of fate extended even back to the birth of his son, as illustrated in the following excerpt, where he tells how his sister-in-law, Abbie, had a vision of a problem birth for his wife:

> Now Abbie has had things happen in her life, which you would almost call psychic. I don't know if you want to get into that. It's very strange. The night before [his son was born], I mean that night, when I was working, they went to a

> bar, she was going to have a ginger ale or have a drink, whatever. All night long, Abbie had a feeling, and she doesn't lie, she's a smart girl too, she's very smart. She had a terrible feeling that she could not stand to be around Bonnie [his wife]. Something is wrong...She wouldn't tell her that. They come home, the lights went out, all power in the house went out, there was no black-out. Abbie got away from her. Well, they waited for the lights to come back on, they got away from her and drove home. Then I came home, that all happened. We went to the hospital. The baby was born. This is going to sound very strange, just before the doctor went up to Abbie (who they know, they know each other by first names), Abbie was looking out the window, and of course, it was sort of dark, it was early morning, and she sees a vision of a retarded baby. She turns around, and there's the doctor saying, "The baby's retarded". And she was saying, "Oh my God." ...

In this excerpt, Father #41 seems to be putting the "blame" for his son's problems on fate, and in so doing he is perhaps relieving himself of guilt. For Father #41, his son's condition was meant to be, and for him, this was very important. It not only removes the burden from his back, but he is also setting himself up as being a "special" person who was chosen to care for this needy child. Indeed, as is seen in the following passage, Father #41 has reframed his role as a father as one in which "chance" has called upon him to carry out a special task:

> ...as you go through time you start to realize how much of a special parent you are and what your job is. When people meet you, I think that there's a respect -- there's a bit of respect from people who meet you -- and they find out that your son is retarded. They look at you and say, "Wow, how do you do it?" And I say, "I do it fine, how do you do it? How do you handle two normal kids? How do you handle three normal kids?" They romp, they scream, and run around three times as much as my son does, "How do you do it, I admire you!" And they turn around and say, "But your son is retarded, he's Down's syndrome!" I say, "Yeah, he is but he's healthy." We haven't had any real out of the ordinary things happening...so that's part of being a special parent.

In this excerpt, Father #41 also is using normal children as his standard of comparison for his child, and as might be expected, his child comes out "lower" on the scale. But even here he sees the passivity of his son as something positive, and he thereby frames his job as a parent as easier than if he had a normal child. Father #41 also "counts his blessings" because his son is healthy and feels his situation could be worse. Father #41 also appears to be proud of his role as parent of a special needs child in that he perceives other people as looking up to him because of the "burden" he is carrying.

In the following excerpt, Father #41 frames his son's future in tragic terms, because he feels his son's "differentness" will always cause the son pain:

> ...He is in a world of his own, and it will remain that way. Little by little, I mean, he will be out in the world, and he will be saying, "How come people don't want to play with me," you know, pretty much. Maybe people will play with him more than I think, but not to what I have observed of other Down's syndrome people.

Throughout his interview Father #41 emphasized how different his son was. He was very concerned that his son would never be normal, and there was not much he could do to affect the future. The only time Father #41 could see his son as being more like "normal" was when he visited the early intervention center and observed other children in his son's playgroup. Like so many of the other fathers of this study, Father #41 used this time to compare his son positively to the other children:

> F: Well, the first time we went down, I walked out and thought I was holding about as normal a baby as I

could.

S: What do you mean by that?

F: We saw a girl who was totally out of control with her limbs and stuff and she was blind...and I said, "My God"...Then I saw another boy who was a paraplegic; his legs were missing from the knees down, he's got one arm and the arm he does have has three fingers...but when I saw that, I said, "Oh my God." Here's Dirk [his son] sitting on the floor playing and I'm saying, "He looks normal!" And then I saw other kids who were normal, the parents were all messed up. They couldn't handle normal childhood...I was saying, "See, there are problems all over and they affect each other just as bad. So we're in no different boat than anybody else. You might think you are. You might feel alone, but you're not."

Thus, even though Father #41 equates his child as being "normal" compared to the other children, in his final analysis he still feels that he is in the same boat as the other parents who have it just as "bad" as himself. If fate had dealt him a difficult hand, at least he was not alone.

From all of these excerpts one can see how Father #41 uses the coping mechanisms as powerful tools to help him manage stress. Perhaps more than any father in the present study, Father #41 felt a strong need to see himself as a special person. It was a theme which appeared several times in the interview. In the following excerpt, Father #41 summarizes how having a Down's syndrome child has affected him and made him special:

F: I think having, especially being the first one, but even in anybody's life, having a special child, retarded, blind, limbs missing, whatever, changes a person dramatically. And I think it gives him a lot of courage and a lot of strength and a lot of guts. You know, if they really accept it, and they don't go around saying, "Woe is me, everyone have pity on me." If you don't do that and you really accept it and work at it, I feel that, at least in my case, that I haven't been afraid to tackle anything, no matter what the job is...

S: And do you think a lot of that came from your experiences with your son?

F: Yeah, yeah, I do. I really do. I feel like I'm a special person...But, I think that on the whole I've taken it very well and I feel, uh, "Hey, this is my job!" I consider it to be a -- everybody has their quote-unquote cross in life -- and I consider this to be my job. This is what I was meant to do and that's it; that's the bottom line...

CHAPTER XII

COPING STRATEGIES OF FATHERS WITH LOW INVOLVEMENT

Use of Positive Comparisons

For the fathers who showed low involvement (Pattern #4) "positive comparisons" was the most frequently used form of appraisal-focused coping strategy. Like the fathers of the other patterns, it was also helpful for these fathers to reframe their situations in ways which made the stresses associated with their children's problems seem easier to manage. Whatever the level of a father's involvement, there still seemed to be a "basic" need to make comparisons so that the stresses associated with their children's problems became relatively easier to manage. What is particularily interesting about the use of the "positive comparison" is the wide range of circumstances in which it proves to be useful.

Typical of the fathers with low involvement who used "positive comparisons" are fathers #18, #38, #39, and #47.

Father #18 is a factory worker who often put in long hours and rarely had an opportunity to meet with the home-visitor. When he discussed his role as a father, he made it clear that his wife was "...the one raising them [the kids] ...and she is doing a heck of a job".

Father #18 reported that a major factor in his ability to cope with the many complications which occurred at the time when his child was born with spina bifida was related to the support he received from his wife and family members who lived nearby. It seemed that at a moment's notice there was always somebody there to offer him support in times of need. Father #18 felt he was a lucky man, not only because of the support he received, but also because his son had made so much progress. By seeing that his son became relatively better off because of the assistance offered by the early intervention program, he could see the future held good tidings for his son in spite of physical limitations. In the following excerpt, Father #18 summarizes the process he went through in coping with his son's problems:

> ...dealing with it at first was the toughest, trying to accept it, not knowing what it was going to bring. You know, because everyone wants to see their boys, especially, running playing ball, and all this, you see it on TV all the time. Like the old saying goes, "It can never happen to me," and when it does you just don't know how to accecpt that. But it has a lot to do, I feel, that with the way my wife took it, and the way everybody in the family took it and everythng else, and just having to realize, you know, this is it, this is the way it is going to be. And as his progress got better and better, I believe it made it easier for all of us to accept that...

In this excerpt Father #18 emphasized that having a special needs child was something he felt could have "never happened to him" and yet it did. The shock of having a child with spina bifida was something the father and his wife were totally unprepared to deal with. Yet, over time, adjustments were made, such that Father #18 felt he could accept what happened. Two key factors which allowed Father #18 to adjust were the visible progress he could see happening as a result of the interventions and the ability of his wife to adjust to her role as the primary caregiver of the child; he could see that the hard work his wife was putting into their child was paying off.

As his son progressed, Father #18 could compare how his son was doing, relative to how he thought he might have done in the "worst case" scenario. By seeing progress beyond what was expected (no matter what the actual progress was) Father #18 could make a "positive comparison" of "past to present". As may be seen in the following excerpt, the progress which Father #18's son achieved because of involvement in the early intervention program plus the efforts of his mother who was "raising him", served as one basis for the father's ability to cope:

> Well, he's doing so well; he's doing excellent. He's doing much better than most kids with his birth defect. When he was born, they said he wouldn't walk, and now you can't stop the kid, he runs like crazy. Fortunately, like I say, he's doing excellent...

Father #18 had a sense that the future held positive prospects for his child. Like other fathers of Pattern #4, he could see that the efforts of the home-visitor and his wife were working, and as a consequence of this, he may have felt justified in his primary role as the family "breadwinner". Because of the work of others and his financial support as a husband, Father #18 could justify his family role by seeing that his son was doing well and everything was falling into place.

Father #38, like Father #18, believed that his son had made much progress which, of course, pleased him. In Father #38's case there was no specific diagnosis of his son's problems other than that he was delayed in development. Because of the vagueness of the problem and the lack of any physical manifestations of a problem, Father #38 had not been overly concerned about his son's delays. In the following excerpt, Father #38 discusses his view of his son's problem:

> ...it's kind of funny because I'm really the only one who's not that excited about it, you know, I mean, this may, it sounds kind of odd but it would not distress me that much to have a child that's not normal or whatever you want to call it. It's not that big of a tragedy to me, I mean if I had a child that had cerebral palsy or something like that, the only time it would really bother me if there was suffering or if the child had to have a lot of care 24 hours a day or something like that, or even if the child was strange looking. Maybe that, maybe that wouldn't bother me that much. My kid doesn't have to go to MIT or Yale and become a great person or something. I'm not that, I'd just be happy if he just grows up and feels successful himself, you know, whatever he wants to do. It doesn't bother me that much, but I think that a lot of people in my family or a lot of people around us, they think it's the most horrible thing in the world.

In this excerpt, it is seen how Father #38 has minimized his son's problems by <u>comparing</u> him to a "theoretical" child who has severe manifestations of a problem. Because his child is normal looking and does not require special care, Father #38 is not "bothered" by the problem. Father #38 has set a "standard" of concern whereby his son falls well within a boundary in which he does not need to become upset. By not expecting his son to be the best, he has not set himself up for disappointment in case his son does not "excel".

What is also apparent in the excerpt, are the rationales Father #38 uses to justify his lack of involvement with interventions for his son. Because he has set lower standards for his son and does not see his son as having needs for special physical care, he has essentially eliminated reasons to become more involved. The "positive comparison" which Father #38 uses, is an important element in his appraisal of his need to become involved in his son's care. In the following excerpt, Father #38 compares his son to children who have more severe problems and concludes that he does not have to be all that bothered:

> ...They say special needs kids [and] they automatically have a vision of some kids on crutches or a kid in a wheelchair. Nobody thinks that there's degrees of it; it could be slight...Like my brother-in-law came up here a year or so ago; he had heard that Jason was a special needs child, and after he'd been here awhile he took me aside and he said, "Jesus, I was expecting some kid drooling or with his mouth open, or just a blank stare" -- he was just so surprised. So I think maybe people who do have kids who are severely handicapped have a different (pause) maybe their concerns are, rightly so, more intense. Like I said, it would bother me if my child were in pain or if my child had to have really special care 24 hours a day or something like that. Then I imagine it would probably be on your mind all the time...

From this excerpt, one can see how Father #38 has carefully minimized his concerns by comparing his son to "imaginary" children who are much worse off. By making his child's problems relatively less "disastrous" than they might be, Father #38 may feel justified in not becoming more involved with the home-visitor.

The way Father #38, like several other fathers of Pattern #4, has used the positive comparison, contrasts to how the fathers of Pattern #1 used this same strategy. These latter fathers used the positive comparisons as part of their rationales for <u>more</u>, not <u>less</u>, involvement, because this allowed them to feel their interventions might have a greater chance for success. When Pattern #1 fathers could see that their children were were relatively better off than they had first thought, this seemed to become one basis for motivating them to become effective change agents for their children.

In the case of Father #39, whose son's problems were much more severe than either Father #18's or #38's, the small progress which his son did make was used as the basis for making a positive comparison. Even though the fathers of Pattern #4 were not involved in doing the extensive therapy which was helping their children, they were aware of progress, and many compared their child's current status positively to their past status. By being able to see their children as "progressing", the fathers could define their "reality" in relative terms which gave them some hope.

When Father #39's third child was born, his son seemed to be "just like the other kids" with no problems. By the time his son was six months old, however, both Father #39 and his wife suspected a problem, even though the doctors said his son was too young to determine if there was a problem. Finally, when Father #39's son's development seemed to stop, it was recommended that he be taken to a neurologist, and the neurologist told him what to expect for the future, as follows:

> ...He looked at Jamie for ten minutes, fifteen minutes, put a tape around his head, measured his head to find out the circumference of his skull; he sat there and he said, "Well,

> he's never going to walk, he's never going to..." and he just blatantly, you know, "This car comes with these hubcaps," you know, "You can have AM or FM stereo", a very cold, matter of fact, which I wasn't prepared for...The guy knew what he was talking about. He pegged it in ten minutes.

In spite of this rather grim prognosis, Father #39 began to see his son make some progress and he found this to be reassuring. In the following excerpt, Father #39 talks about his son's progress:

> ...I think that he is doing well, as well as I would expect by my standards. He's reaching for objects, he's attempting to see things differently. He's trying to walk, talk, (not walk) he's trying to talk. I can see him trying to vocalize things. I see some progress and that's important. I don't care if the progress takes thirty years, in my eyes there's progress. Or I know that, if this is all there's going to be, that's fine, as long as he's happy.

Father #39 expresses a point of view which is the essence of the "positive comparison" when he says "...in my eyes there's progress". What, in effect, he is doing here, is adjusting reality through a setting of his own "standards". In order to feel that his son is doing well relative to some standard, he has created his own standard rather than using the "standard standard" which would certainly place his child in a lower position. This is similar to the type of comparison made by Father #38 who set a standard of concern based upon an "odd looking child who drooled and was in a wheelchair." In an important way, Father #39 is able to protect himself from harm by viewing his child through the lenses of his own choosing. He uses "positive comparison" as a subjective tool which allows him to see his child in more positive ways.

Since Father #39 is realistic enough to know that his son may never progress beyond where he currently was, he already had the answer to this potential harm worked out in advance, as evidenced by him telling me that everything would be fine as long as his son was "happy". In effect, Father #39 was setting himself up to make a "last ditch" positive comparison in case his son should not even live up to his current standards when he could feel that because his son was at least "happy", things were not all that bad. It seems that Father #39 was able to carefully protect himself from even the worst situation by making use of the "positive comparison" coping strategy.

Father #47's second child was referred to a high-risk follow-up program because his wife had a condition which placed her children at risk for problems. When it was felt by clinic doctors that Father #47's son's development was delayed, they referred the family to the early intervention program. When I asked Father #47 how he felt about the referal, he replied as follows:

> I don't know if I was hurt or happy that he was involved in this program. I think I was hurt in the way of (pause) "Oh God, there is something wrong with my child. Is it something that we did or something that we didn't do?" But as the program went on and I met the home-visitors, I realized how beneficial that program was to a child and what they do for a child...

What is especially interesting about this family's involvement with the early intervention program, is that the home-visitor noticed that Father #47's first born son who was four years old might also have had a problem which had not been identified. Upon the initiation of the home-visitor, Father #47's eldest son was taken in for a special evaluation where it was found that he had spina bifida. For years, Father #47 and his wife had been extremely frustrated over their attempts to toilet train their son as illustrated in the following excerpt:

> ...We would take him every night and put him on the potty and sit with him and talk to him. We tried threatening him. We tried rewards, "Here's a piece of candy if you go potty". Some of the times it worked and 99% of the times it didn't work. We didn't know what to think (pause) whether we were doing something wrong or whether he was just outright lazy. The doctors had told us there's nothing wrong with your child...

When the doctors finally diagnosed his older son's problem, the father's reaction was similar to when he learned that his first child had a problem:

> ...I really tried to come up with an answer about <u>how</u> this came about. Was it my fault? Was it hereditary? Was it because of my wife's problem? Was it because I drank beer? Many a night I would lay there in bed and think about this and try to come up with my own answer.

Suddenly having two children with problems put a strain on Father #47 and his wife, but it was a strain which he felt helped to bring them closer together, because they had to work extra hard in order to be successful as parents. In response to the concerns of Father #47 and his wife, the home-visitor arranged for them to attend a parent support group. It was at this group where Father #47 was able to put his seemingly large problems into perspective as seen in the following excerpt:

> ...I was hesitant at first going to this, you know, sit down and talk to a bunch of strangers that I never knew before,

> you know, spill my guts to them, no way. But as I sat there and I listened, and I heard all the other people talk, I had to turn around and say, "Well, you know, God we are lucky, we don't have it that bad. There's a lot of children out there a lot worse off than our son, and we can be thankful that he is not one of those"....There was another couple there with a child that had CP, which is a lot more extreme than either of my sons' problems. I listened to the husband talk, and I felt that he could overcome it and they've got much more of a challenge to work with than we do. And I said that it can't be all that bad. It made me feel more at ease with the problems than I did before I went to these classes...

In this excerpt, Father #47 makes it clear how important the "positive comparison" was to him. Father #47 had put a lot of time and energy into dealing with his oldest son's lack of bladder control. It was a concern which seemed almost to haunt him. Throughout his interview, Father #47 talked about how difficult it was trying to come to terms with his first son's bladder problems and then having to deal with a second child with special problems. However, when Father #47 met another man who told how he had overcome seemingly worse problems, Father #47 realized that he too could overcome his problems, because his were relatively easier to deal with than the other parent's. Father #47 looked upon the parent support group experience as a challenge for him to resolve his relatively easier problems.

Denial

Three of the Pattern #4 fathers who made use of the appraisal-focused coping strategy of denial are Fathers #23, #27, and #28. These three fathers are representative of the variety of ways in which Pattern #4 fathers made use of denial.

Father #23 used such an extreme form of denial that he almost totally avoided dealing with his child's problems. Of all the fathers in the present study, Father #23 used the most intense form of denial. For Father #23, denial (and in this case avoidance) of his daugter's problems was a general type of response which he used in dealing with many other types of interpersonal stresses. Throughout his interview Father #23 repeatedly talked about himself as a person who was at odds with the world. He saw himself as a victim of other people's capricious decisions. He reported when he was a young boy he was mistakenly labeled as having special needs, and as a result was misplaced in a special education class where they treated him as if he were not intelligent. In the following excerpt, Father #23 talks about his intelligence and how it helps him to deal with problems,

> You see, people who are intelligent always have problems. People who are not intelligent don't have problems. So I contend that I am not intelligent, and then I don't have these problems.

Indeed, it does seem that Father #23 does not have problems, because he has an extraordinary way of blocking them out of existence. In the following excerpt, Father #23 makes it clear that, to some extent, he is aware of his need to avoid problems:

> ...It could be that I'm a Picses. Picses are known to be -- they go in both directions at the same time. What I've always done is whenever I have a problem or something's really aggravating I just ignore it. If something's really bothering me, I ignore it, and the next day, or two days later, I'll come up with a solution to the problem.

In this excerpt, Father #23 clearly states that his way of dealing with problems involves avoidance (and to some extent denial). Although he suggests that he will come up with a solution in the "next day or two," an analysis of his interview data indicates that in actuality he ignores problems for much longer periods of time.

When Father #23's daughter was born, she had many complications at her birth, and he was angry at the staff who delivered his child, saying to me:

> I think the staff were a bunch of bumbling idiots...They put some sort of monitor on her belly that made no visual or physical checks. They put a monitor on my wife's belly and that was supposed to tell them when the baby was due, and for twelve hours nobody made a visual check once. No nurse, no doctor. They kept on, "Oh, you're not ready yet."

For the first year after her birth, Father #23's daughter had to be taken back and forth to hospitals and doctor's offices for special treatments and checkups. During this entire period Father #23 reported that:

> F: ...I mean the first year I ignored her because she was sick and everything else and was back at both doctors. I never saw her but she was doped up all the time...

and later in the interview:

> S: You were still working your full load?
>
> F: I was working at the gas station probably 12-14 hours a day, and the station was not able to pay me enough salary, so I got myself an outside job...
>
> S: So did you spend any time like going to the doctors?
>
> F: No. I, ah, was (pause). We had a choice, go to the doctors together, or have you go to the doctors by yourself. And I'll make some money so we can eat. Ah, that's just the way it worked out. I don't feel guilty about it at all. I can't stand doctors.

In these excerpts it is seen how Father #23 had little, if any, contact with his child for the first year of her life, in spite of the fact that she had serious medical problems which eventually required an operation. Father #23 is the only father in the present study who did not become involved in trips to doctors offices or hospitals. His avoidance was so great that he did not even become involved in times of great need. Father #23 always seemed to be busy at work and rarely had time for his family. While there is certainly a reality to his need for money, in Father #23's case, the data suggest that his lack of free time was as much related to his need to deny and avoid problems, as it was a need for money.

When I asked Father #23 if he felt his wife needed some support during these times, as may be seen in the following excerpt, he sidestepped my question and eventually talked about his own problems, not his wife's nor his child's:

> My daughter's problems kept my wife's mind fully occupied, and I didn't, I wasn't aware of everything that was wrong or right. I didn't understand three quarters of what she was talking about, because she really got into the medical terms. She wouldn't speak English. She just spoke medical terms...And they'd go on and on with the Latin terms and everything else. "Whew, I'm not even in the same room with you people. You can keep going if you want, fine. The kid will be O.K. in the long run. I know you guys are going to look after her, but I don't know what you're doing, and I don't really want to get into it too deeply. I mean, I've got my own medical problems if you don't mind...I don't mind my own guts hanging out, I've had it, but I just -- babies when they get hurt or sick like that, I have trouble. I can't stand dogs and babies sick or hurt...If they're a little bit older, maybe my other daughter's age, you get a cut, I look at it, "Yep, you need stiches. No you don't need stitches. Get over here. Stand still. Don't cry,

> I'll put some ice on it. I'll bandage it up. No problem." But when at her age, I -- it bothers me too much -- I just don't know how to handle babies that well.

In this long passage, the extreme degree to which Father #23 avoids and denies becomes clear. Father #23 builds up a rationale for avoidance by suggesting that his daughter will be all right in the long run, and since other people are looking after her he does not feel a need to become too involved.

Father #23 had built up such a strong sense of avoidance that it should come as no surprise that he was hardly involved in any aspect of the early intervention program. Even when he attended social gatherings of the program, he tried to avoid contact with the other people there, for example, as he described one such gathering:

> I grabbed a handful of food and sat in the corner with my oldest daughter...I ran into another guy that was sort of bewildered like me. The women seemed really enjoying the kids. They all got together, they all understood everybody's problem. "Oh, hi, Judy. I haven't seen you since Tuesday." " What are they having this party for?" the other guy said. "What's this? What's going on? Who are these people?"

While Father #27's denial of his daughter's problems was not nearly as extreme as Father #23's (just described), he did not look on his child as a person who "really" had a special need. From the time his daughter came home from the hospital, Father #27 did not feel she needed any type of special attention. While she had Down's syndrome, she did not have the physical problems associated with Down's syndrome (e.g. heart problems, respiratory distress). Perhaps just as he would have with any new baby, Father #27 left all the care of his daughter to his wife.

It seemed to be especially important to Father #27 that he treated her "...like any one of the kids. She gets yelled at and spanked just like anybody else" and treating her like everybody else also meant that he did not have to become involved in any of the follow-up therapies recommended by the home-visitor. Indeed, Father #27 viewed his child as somebody who was just like everybody else. Father #27 reported that his daughter did not look like a typical Down's syndrome child, and he felt that if she were in a wheelchair or had some type of physical disability, he would have been more concerned.

In the following excerpt, Father #27 summarizes his perceptions of his child:

> ...I don't particularly look at her as somebody with Down's syndrome. I just look at her as a small person running around that doesn't talk. Like I said, I treat her just like all the rest of the kids.

Since Father #27 has several other children, I asked him how they felt about having a sister with Down's syndrome, because I was curious to find out how he explained her differentness to them. In the following excerpt, one can see how his perception of his daughter as "being normal" accounts for his not telling them their sister has Down's syndrome:

> S: They don't even know? Do you plan on telling them some day? Explaining it?
>
> F: Oh, sure...Sooner or later they'll ask, "Well, how come she's getting special attention? How come everybody is picking her up at the door while we've got

> to walk down the street?" you know. If she had more physical disabilities, then, you know. To look at her, I think it's a riot when we take her to the grocery store, people look at her, and they haven't the faintest idea that she's got Down's syndrome, you know.

More than anything else, Father #27 wanted his child to be seen as a "normal" child. His denial of his child's Down's syndrome is a way in which he could attribute value to her. He wanted to feel that people in the community looked upon his child as someone of value, and one way he did this was to see her as someone just like everyone else.

Father #27, as may be seen in the following excerpt, enjoyed being a father, and his denial of his child's problems may have also been a means to bring greater enjoyment and satisfaction to that role:

> S: Do you, with your wife in school, do you do more childcare?
>
> F: He, he, he, don't bring that up. I've always -- when you say childcare -- we've always kind of split as far as that goes. I kept teling my wife, I don't need you for nothing, you know; I can take care of kids, no big deal...
>
> S: Have you always done that?
>
> F: Ah, well, I didn't do it as much with the first one. She did, she had 99% of the care and so forth. Which was not that we sat down and said, "Listen, I'm going to take care of the kids, you're not." It's just the way it worked out. When more kids came along, there was more to do, then we could say, "You go do the wash today." Then, you know, after awhile you started doing it. Nobody told you to do it, you just picked up and did it. Whatever had to be done, somebody did, you know...

An appreciation of how important the "normalcy" of his daughter is to Father #27 is seen in his contrasting perceptions of two parent support group meetings he attended. The first meeting took place when Father #27's daughter was enrolled in the early intervention program. On one occasion Father #27 had to take his child to the program in order for her to attend playgroup, and when he did this, he also attended the parent discussion group which went on while his child was playing. In the following excerpt, Father #27 describes this group:

> S: So what happened in that group?
>
> F: Oh, sure, there was a bunch of women, they were talking about this and that, and you just sit there and drink coffee.
>
> S: How did you like being the only man in that group?
>
> F: It didn't bother me, but you know. I, maybe it's my training in business such as it is, I tend to listen before I open my mouth, and I wish I had a tape recorder of some of these women. I think they lock them in a cage and let them out once a week. You know. You know, "Ain't you got nothing better to talk about?"...

When I went on to ask Father #27 what it was that bothered him, he talked about how the mothers were trying to get free services from the State and how much he disliked this. I then went on to ask him if he ever attended any parent group meetings that he did like, and he then told me about a meeting he attended in his daughter's current program which was paid for by the public schools. In the following excerpt, it is clear that what Father #27 liked better about the new group was the attitude of the other parents, who like himself, "accepted" their children's problems more than some parents did and saw them as normal children:

> ...They talk about the kids, but they all seem like they accept it more. Like they really -- they're not talking about someone -- somebody made out of eggshells, sit them on top of the thing, afraid to touch. They're talking like they're normal kids. Which is, as far as I'm concerned, the way they should be talking about them. You know?

Father #27 reports a much greater liking for the second group probably because it was a group of parents whom he felt looked upon their special needs children more like he did. They saw them as "normal" children, who were not fragile. This is an image which is congruent with the need of Father #27 to have his child be valued like any other child.

The third example of a Pattern #4 father who used denial is Father #28, whose daughter had a severe case of hydrocephalus. While his wife was in labor, an ultrasound test indicated that the child's head was too large to pass through the birth canal so the baby was delivered by a Caesarian section. As a result of the operation, his wife had to stay in the hospital for a full week, and Father #28 took off from his job at a paint shop in order to be present and take care of his older daughter. Father #28 took off this time even though he thought he would not be paid:

> Well, I got a real good boss, O.K. and I shouldn't have gotten paid for it, but he called up the owner and he said, "Pay him." So I got paid for all the times I have to leave early and like when my wife was in the hospital, I was out for the first week until she came home, because my first child was here and I had to take the whole first week off and I got paid for it.

The first week at the hospital was a difficult one for Father #28 and his wife, because they were not sure of the extent of their daughter's damage:

> ...I had gone back into the labor room where I was met by the other doctor, the neurosurgeon, and he told me that the baby had hydrocephalus and that he didn't know how much damage was done to the brain and what to expect for the future. Basically, that's all that I was told that night.

Later, when the actual extent of the damage was evaluated, the results were far from encouraging. Father #28 was told that only 10% of his daughters brain was functioning due to damage done by the fluid build up. When Father #28 talked with the doctors about the options for his daughter, he was told not to have a shunt put in to drain the fluid so that his daughter could be left to die. This hit Father #28 and his wife like a "ton of bricks," and after seeking a second opinion decided to have a shunt put in.

After the shunt was finally in place and his daughter could come home Father #28 felt that the operation had gone "perfectly":

> ...it came out perfect, no infection, no nothing and her head hasn't grown since she's had it. She's happy, to me she's a perfectly healthy baby. She smiles, they told us that she was blind, she's been seen by an eye doctor; she is not blind. They said that she can't hear, and she can hear. In my opinion, she's a fine happy baby. You know, well, she's nine months now and she cannot crawl, you know, she has trouble; she can't sit up yet. She's not as advanced as a nine-month-old baby should be, but she's perfectly happy.

In this excerpt, Father #28 seems to have made a well balanced appraisal of his child. He recognizes her limitations, but he also has a sense of her strengths. What is particularily important about his assessment of his child, is his emphasis on her "happiness." To Father #28, what became most important was his feeling that his daughter was happy. In his attempts to cope with a child with severe brain damage, he sought to find a glimmer of light which he could hang on to, and this was his daughter's happiness.

At the time of the interview, the future for Father #28's daughter was still uncertain; she was nine months old, but functioning at a three-month-old level. With this much uncertainty to face in the future, Father #28 said that he was "...taking it as it comes." By not worrying about the distant future, Father #28 could focus in on the present and appreciate his child's easy-going temperament. When I asked Father #28 how much he was enjoying his daughter he replied as follows:

> F: It's great, you know, to me, she's just a normal regular, healthy baby. She's great.
>
> S: What is your wife's view?
>
> F: Same way. Exact same way, you look at her, you go, "She's just a healthy, happy baby. You know, a little slow, but that's it.

In this excerpt, one can see how denial plays an important part of Father #28's coping process. In spite of his recognition of her severe delay, both he and his wife see her in the "exact same way" as a healthy, happy baby. Father #28 has chosen to selectively screen out aspects of his child which would be causes of concern. In a seeming healthy and productive way, he has focused in on those aspects of his child which are postive, and he temporarily denies the existence of her problems. By reducing the "future" to the next day, and emphasizing his daughter's health and happiness, Father #28 has increased the value of his child as someone to love and care for.

A Father "Valuing His Child"

Only Father #29 of Pattern #4 talked about how he had to readjust his thinking so that he could see that his child had value in spite of her special needs. Father #29 had to reframe the value of his child so that in the eyes of community members she was "not sick" and had the same rights as anyone else. What makes this coping strategy particularily interesting is Father #29's lack of committment to taking care of his child. In spite of the low investment he made in his personal relationship with his daughter, Father #29 was keenly invested in how other people valued his child.

Father #29 worked as a career State employee and had dedicated his life to this work. He worked long hours on different shifts and describes how he had missed much of his first child's growing up:

> It was very hard to do things as a family except on my days off, because I worked nights...I'd get out of work at about three o'clock in the morning. I'd sleep until one in the afternoon some days, and I didn't have that much time to spend. I spent time with her, you know, change her diapers and fed her and everything like that. Um (pause) I guess it was the joy of watching her grow, you know. Even though I (pause) we talked about it and I missed a lot, because, you know, the job, the hours that I've had and everything. You miss so much. It seems like -- here she is six and I can remember when she was just sitting in her little chair on the floor and not doing anything.

Several months after his second daughter was born, it was discovered that she had suffered brain damage and would need to be followed by an early intervention program. When I asked Father #29 how he felt about his child being in the program he responded as follows:

> ...I probably shoved it aside, thinking my wife will have to live with it or something like that. You know, my wife will be home most of the time, I will only be home at night, something like that.

Indeed, as events unfolded, Father #29 was rarely at home and had very little to do with the early intervention program or follow-up activities. Yet, in spite of his low involvement and seemingly lack of pleasure in raising children, he was concerned over how society might view his child. In the following excerpt, Father #29 talks about how he had to change his thinking about handicapped people:

> Well when you are younger, you see somebody who was handicapped with C.P. or Muscular Dystrophy or something walking down the street and you would make fun of them. You know, once you have a child of your own, and you see other parents with children that are handicapped you understand that handicapped people have as many rights as anyone else.

Father #29 was helped to reach this conclusion through his wife's experiences in a parent support group. Like so many of the other fathers, just hearing that other parents were in the "same boat" helped him come to terms with his anxiety. By feeling that his daughter had the same rights as anyone else, he was protecting both himself and his daughter from being looked down on by society.

Even though Father #29 had come to see his daughter as being a person of more worth, he was still concerned about the reaction of strangers when he took his child out in public. Father #29 felt anger when people seemed to devalue her in public, for example, he said:

> ...I don't care if somebody looks at me or what. I'll look right back. You know, and they ask, "Is your daughter sick?" "No, my daughter is not sick. She has cerebral palsy, but she is not sick." You know, I put a lot of people off now-a-days...our generation though has gotten to the point where handicap is not a disease. It used to be years ago...Now there has been so much, you know, so many birth defects of so many kinds, that people are starting to think that sometimes it is more of a norm than not being the norm.

What also seems to be related to Father #29's anger is his own frustrations of not being able to look forward to a bright future for his child and the burdens this will place on him. Father #29 seems to feel sorry for himself, and when he compares his misery to that of other people, he comes out on the bottom:

> ...It used to bother me when you have got somebody and they've got two kids and they're out there jumping and running around the yard and the guy looks up and says, "Hey, I know what you feel like." I mean you go and break a kids leg and then you know what I feel like...I says a divorce is something you go through; you have a child and your wife is going to leave and she is going to take the child -- I says that is rough -- but when you have a handicapped child you have that child every day of your life. You know -- if she is going to be the type of child -- that if she isn't going to be able to get out on her own -- my wife and I are going to have to take care of her for the rest of our lives...

Although in this quotation one can see how Father #29 has difficulty in coping with his daughter's problems, by looking upon his child as someone of value, he is making his "burden" in life easier to bear. Father #29 is a man who has difficulties enjoying his role as a father, but at least when he takes his child out into public, he wants to be proud of her and to have people look upon her in a positive way. In order to achieve this end, Father #29 has had to make the important adjustment of seeing his child as a person of value.

CHAPTER XIII

MAJOR FINDINGS, INTERPRETATIONS, AND POLICY IMPLICATIONS

This chapter summarizes the findings of the present study, offers intrepretations of these findings by the researcher and suggests policy implications for early intervention programs.

Findings

Patterns of Involvement

One of the primary goals of this study was to investigate the ways fathers of special needs children became involved in activities specifically related to their children's special needs. The in-depth interview data were analyzed to discover the typologies of how fathers became involved in these activities. Analysis of the data revealed that the frequency of the fathers' involvement with the home-visitors and doing follow-up therapy with their children were the key criteria which distiguished variations among the fathers.

The interview data were scored using two six point scales in which the fathers were scored as "high" (scores of 5-6), "moderate" (scores of 3-4), or "low" (scores of 1-2) in terms of the frequency of their involvements with the home-visitors and doing follow-up therapy.

Analysis of the fathers scores on the two scales suggested four involvement patterns: fathers highly involved by choice, fathers involved by necessity, fathers moderately involved, and low-involved (traditional) fathers.

Fathers highly involved by choice. Pattern #1 consisted of the ten fathers who were scored as "high" on the home-visitor scale and "moderate to high" on the follow-up scale. These fathers were able to become highly involved with the home-visitors because they arranged their schedules to be present at the times of the visits or took advantage of offers by the home-visitors to arrange their schedules for the convenience of the fathers.

All of these fathers were highly motivated to attend the home-visits and to do the follow-up therapies recommended by the early intervention staff. These fathers seemed to place a priority on using their "free time" to be at the home-visits. For example, one father of this pattern who worked a four day week made sure his wife scheduled the home-visits on his one day off to insure he could be present.

Each of the fathers of this pattern of involvement assumed non-traditional childcare roles with their young children with special needs. They reported great enjoyment and satisfaction with their involvement in the daily care of their children. Like almost all of the fathers of the present study, however, the fathers highly involved by choice worked full time. My designation of these men as non-traditional fathers does mean they have given up their exclusive roles as family "breadwinners". To some extent, their non-traditional role was one in which their emotional involvement with their children was as much an indication of their "non-traditionalness" as was their participation in routine care.

The fathers of this group saw themselves as being equals with their wives in the amelioration of their children's problems and had a sense about them that through their direct efforts, they could act as facilitators of their children's development. When these fathers looked to the future, they had a marked tendency to envision positive changes for their children which occurred as a result of their interventions. Their sense of empowerment to effect change was matched by an optimism that their efforts would be rewarded by their children making progress. Even the one father of this group whose child was severely delayed could only see positive things happening for his daughter. Like the other fathers of this pattern, he was confident in his abilities to work towards the growth of his child.

Fathers involved by necessity. Three of the fathers were scored as "high" on the home-visitor scale, but only "moderate to low" on the follow-up scale. These three fathers comprised Pattern #2, fathers involved by necessity. All of these fathers were highly involved in home-visits and trips to the early intervention programs, because their wives worked during the day and as a consequence, they were responsibile for seeing to it that their children participated in the early intervention programs.

The involvement of these men in the early intervention program activities came about because of necessity; had these men not been present at the therapy sessions, their children would not have received services. For the fathers of this pattern, involvement with the home-visitors became a routine part of their caregiving responsibilites and not a special commitment as in the case of the fathers who were highly involved by choice. Perhaps because so much of their time was taken up by childcare activities and they had to continually coordinate their work schedules with their wives' work schedules, these fathers reported significant conflicts with their wives over their use of free time.

While the fathers involved by necessity were at almost all the home-visits, they were surprisingly unmotivated to do the follow-up therapies: they left this responsibility to their wives. Also, the fathers of this pattern were rarely involved with the home-visitors when their wives were present. On those occasions when their wives were home at the times of the home-visits, these fathers were apt to leave responsibility of particiation in the sessions up to their wives. Perhaps because they did not have as much free time as they would have liked, and they looked upon these occasions as opportunites to do other things.

The fathers of this pattern, in staying home to take care of their children while their wives worked, assumed highly non-traditional childcare roles. These fathers were aware of how "different" they were from traditional fathers, but they attributed their roles as much to the flexibilites of their jobs and the economic realities of needing two incomes as to their desires to be at home with their children. Unlike the fathers who were highly involved by choice, the fathers involved by necessity did not take advantage of every opportunity to be at home-visits or do follow-up therapy. Although they were "non-traditional" fathers because they were primary caregivers for their children, they still saw their wives as being the family member who was primarily responsible for carrying out the goals established by the home-visitors.

Fathers who were moderately involved. Pattern #3 fathers consisted of the nine fathers scored as "moderate" on the home-visitor scale and "moderate to low" on the follow-up scale. All of these fathers were motivated to attend only a small number of the home-visits and had a limited involvement with follow-up therapy. These fathers were interested in attending the home-visits for one or more of the following reasons: to "fill-in" for their wives on those occasions when their wives were unavailable (i.e. to "help out" their wives), to give their "stamp of approval" to the home-visitor when she first started making visits, to satisfy their curiosity about what the early intervention program was all about, to give support to their wives whom they may have sensed were anxious about involvement in the programs, and to be updated on how well their children were progressing and thereby ease their own anxieties.

When these fathers did participate in the follow-up therapy, they did so at the direction of their wives who taught them what was supposed to be done. The fathers' knowledge of their children's progress was communicated to them by their wives. These fathers who were moderately involved did not feel a great need to make special arrangements, on a regular basis, to be at the sessions, although they did adjust their routines, if necessary, to be at some of the home-visits. These fathers left almost the entire resposibilty of involvement with the early intervention programs up to their wives.

The fathers who were moderately involved expressed an interest in assuming somewhat nontraditional childcare roles even though they left much of the resposibility up to their wives and were the primary wage earners in their families. These men seemed to be caught between conflicting desires to be both "traditional" and "nontraditional" fathers. These fathers took pride in describing how often they helped out their wives in doing such chores as changing diapers, washing dishes and dividing up housework, yet they still felt it was up to their wives to do a majority of these activities.

Several of the fathers who were moderately involved expressed anxieties about how their wives had been affected by their childrens' disabilities. For these fathers, it was apparent that they used their free time to participate in the home-visits to support their wives and offer them assistance in coping with the problems presented by their children. These fathers seemed to be especially sensitive to the concerns of their wives, and they needed to know that the home-visitors were providing their wives with the help they needed.

The fathers of this pattern were not highly invested in becoming involved in the follow-up therapy. Since they left the majority of the follow-up therapy to their wives, they did not see themselves as being the primary persons who were going to help their children. While these fathers wanted their children to make progress, they felt it was up to their wives and the home-visitors to do the work which would help facilitate their children's development.

Three fathers of this pattern did not feel their children had made significant progress, and as a consequence they did not have a sense that the future was going to be one they liked. One of these fathers even had his child taken out of the early intervention program.

Fathers with low involvement. Pattern #4 consisted of the 24 fathers who were scored as "low" on the home-visitor scale and "moderate to low" on the follow-up scale. These low-involved (traditional) fathers had almost no contact with staff members of the early intervention programs. Their participation in the early intervention programs was limited to one or two home-visits (e.g. when they were "accidentally" home at the time of the home-visit, participation in the initial evaluation of the child at home), occasional contact through social events or clean ups, and for a limited number of fathers, participation in short-term parent support groups. For the fathers of this pattern almost total responsibility was left to the wife. For many of these men, participation in the early intervention program was viewed as "women's work", and it was something they did not want any part of.

The fathers with low involvement did not create free time in their schedules nor did they take advantage of opportunites to participate in home-visits when they did have the time. Since these fathers did not feel the need to be at home-visits they made almost no effort to arrange their schedules to be present when the home-visitors came to their homes. Even when it just so happened that they were home at the time of a home-visit, they almost always removed themselves from the sessions, or were "reluctant" participants.

The fathers of this pattern saw themselves as the family "breadwinners" who did not want to become involved with the home-visitors or be responsible for doing the follow-up therapy. While there were other reasons which removed fathers from participation in the home-visits (e.g. conflicts with their wives, inflexible work schedules, lowered expectations for their children) these men, unlike the men of the other three patterns, saw themselves as traditional fathers who did not need to become any more involved with the early intervention programs.

Although the fathers with low involvement, like most of the fathers of the present study, were somewhat optimistic about their childrens' futures, they did not view themselves as the persons who would be directly responsible for the changes. Most of the fathers of this pattern expressed the view that it was their wives, acting in conjunction with the home-visitors, who were the persons most responsible for causing changes in their children. Many of these fathers felt their wives were doing an "unbelievably" good job of meeting the needs of their children, and as a consequence, implied they were not needed. Several of the fathers of this pattern attributed the improvement of their children to "natural" developments which would have occurred without the involvement of the home-visitor. These fathers felt the early intervention program served primarily as a "support" to their wives who needed the comfort of another woman. Two of these fathers even felt the early intervention program was like a "placebo" for their wives; because their wives felt it was helpful that was all that really mattered.

The designation of these fathers as "low" involved is not meant to imply these men were absent from their children's lives. These fathers, with only one or two exceptions, all reported enjoying their roles as fathers and expessed interest in spending time with their families. These fathers, however, while participating in some routine childcare activities, did not express the same interest or commitment to these activities as did the fathers of the other three patterns. In almost every instance, these fathers reported it was their wives who were primarily responsible for most all childcare activities of their young children with special needs. While these men were supportive of their wives' participation in the early intervention programs, they did not see the need to become directly involved themselves. For the fathers with low involvement it was only "normal" that their wives were the primary persons who were involved with the early intervention programs.

All of these men reported involvement, however, in many "crisis" situations which occurred because of their children's problems (e.g. hospitalizations, times of diagnosis of the special need). During these times of crisis the fathers, with only one exception, were all able to arrange their schedules so as to be supportive of the families no matter how "inflexible" they reported their work schedules to be. Once the crisis was over, however, they returned to their "normal" pattern of leaving childcare responsibilities to their wives.

Many of the fathers of this pattern also reported participating in the process of "transitioning" their children out of the early intervention programs and into public school preschools. Some fathers of this pattern who showed no interest in any of the activities of the early intervention programs suddenly became very involved when their children entered the public school system. These fathers felt it was their responsibility to attend meetings with school officials to make sure their children received appropriate services from the public schools.

Appraisal-focused coping strategies

A second major goal of this study was to investigate the ways fathers made use of appraisal-focused coping strategies to manage the stresses associated with having special needs children. Appraisal-focused coping strategies were considered to be important by this researcher because they were seen as being important indicators of how the fathers thought about themselves, their children, and their situations.

In American culture, people with disabilities are considered to be "different" and are often stigmatized because of these differences. Fathers who have children with disabilites must somehow come to terms with this type of stigma and then take some form of action to ameliorate their children's disabilities. To do this, parents must make three types of appraisals: appraisal of harm done in the past, appraisal of future harm which might occur and appraisal of the challenges needed to gain mastery over events. The activities which fathers participated in relative to their disabled children were, to some extent, a reflection of these kinds of appraisals. The specific appraisal-focused coping strategies which fathers reported using to manage stress were viewed as open windows which allowed the researcher to view and understand the complex meanings the fathers attached to having a child with special needs.

Analysis of the data revealed that fathers made use of five types of appraisal-focused coping strategies: valuing their child, making positive comparisons, using denial and withdrawal, deferring to fate as a cause of events and learning lessons in living. It was found that while there were similarities in the ways fathers of all the involvement patterns made use of the coping strategies, there were also important differences among the patterns.

Two of the Pattern #1 and one of the Pattern #4 fathers were seen as using the strategy I have called "valuing their child". Of all the strategies used, this one tapped into an important need of most all the fathers to find value in a child with a handicap. To some extent, all fathers of this study had to deal with our cultural norm which considers people with handicaps to be of lesser worth. The three fathers who used this strategy were seen as directly confronting this dilemma. These three fathers managed stress by realizing that the "tragedy" of having a child with special needs was not a tragedy. These fathers verbalized to me what was perhaps on the minds of many other fathers; having a child with special needs meant that there was a need to question a system of values which stigmatized a person for being different. Because these fathers suddenly, and quite unexpectedly, found themselves to be in a position where they were threatened by these values, they may have used the strategy of "valuing their child" as a means of protecting themselves from lowered self-esteem.

For fathers of all the patterns, making a comparison between their child and another child with a special need or making a comparison between their own child's past and current developmental status was an important means for managing stress. When fathers made these types of comparisons they almost always felt that other children had much worse problems than their children's or that their children were relatively worse off in the past -- therefore, these comparisons were "positive".

The use of the positive comparison was seen as a way the fathers could control the meaning of the present situation and possibly reduce the threat of future harm. When fathers met children or parents whose problems were seemingly worse than their own, this provided the fathers with an opportunity to create a viewpoint mitigating some of the relative psychological harm they must felt had already occurred to them because their children had a disability; the positive comparison seemed to make the fathers feel relatively better off than they had previously thought.

While the fathers of all the patterns made use of the positive comparison strategy, the ways it was used differed among the patterns. For the fathers highly involved by choice, positive comparisons were seen as a reflection of how these fathers, feeling their were not so bad off, could sense that their interventions had more chances for being successful. For several of the fathers who were moderately involved, the use of the positive comparison was not as effective as it was for most other fathers. The former fathers seemed very anxious about their children or wives, and they had a difficult time making any comparisons which were "positive". For the fathers with low involvement, the positive comparisons were often seen as part of their rationales for not being more involved; since "things could be worse" they did see a great need to become more involved.

When fathers made use of "denial" and/or avoidance, the data indicates there were wide variations in the degrees of denial and avoidance. For some fathers, denial was almost complete (i.e. they felt their children did not have problems) while for some fathers it was more limited (i.e. they only denied one aspect of their child's problem).

Denial seemed to serve the the fathers who were highly involved by choice in two different ways. First, the fathers' denial of some aspect of their children's problem may have suggested to them that there was a greater liklihood that their efforts to effect change would be more fruitful. When these fathers denied aspects of their children's disabilities, they were perhaps not as overwhelmed by the work still needing to be done. In a sense, these fathers were "motivating" themselves to become more involved. Had these men accepted the "total reality" of their children's problems they might not have been so eager to become involved because the problems may have seemed to great to overcome.

Second, by using denial, the fathers highly involved by choice may have seen progress made by their children in more relative terms, such that even small progress could seem great. By looking at the changes which had occurred, and perhaps ignoring progress not made, the fathers were looking ahead to positive futures for their children based on progress already made.

When denial was used by the fathers with low involvement, this served as a means for them to justify their inactions towards directly effecting change in their children. By denying the severity of their childrens' problems these fathers found a way of thinking about their children's futures which was congruent with their "inactions". Since they felt their children's problems were not all that great, they may have then felt more justified in not becoming more involved.

Interpretations

The focus of this interpretation of the data centers on an analysis of what variables or factors seem to account for the the differing levels of involvement. The fathers of Pattern #1 are a group of fathers whose interest and motivations to effect change in their children lives differ considerably from those fathers of the other three patterns. While the fathers of

Pattern #2 were highly involved in the home-visits, they did so out of necessity and not necessarily to work directly with their children via follow-up therapy activities; so although these fathers were "highly" involved, their motivations differed greatly from Pattern #1 fathers. For the fathers highly involved by choice interpretations need to be made to suggest possible reasons accounting for their high levels of motivation relative to the rest of the fathers in the present study.

One possible avenue for explaining their high levels of motivation would be to suggest that they did so because of their personality types or certain character traits. Using this type of analysis it could be hypothesized, for example, that fathers highly involved by choice became involved because of strong internal needs to personally take control over life events. It might be assumed, for instance, that these men have what has been called an "internal locus of control" (Rotter, 1966). Individuals with an internal locus of control have been described as believing that, based on previous experiences of success or failure, they have the ability to control the outcome of life events, whereas individuals with an "external" locus of control believe they have less control over events. People with an external locus of control do not feel empowered to influence the course of life events. Compared to external locus of control individuals, internal locus of control people seem to be better able to cope with their environment.

From the point of view of this argument it might be suggested that the fathers highly involved by choice were "predisposed" to become highly involved because of past experiences which have suggested to them that they can have important influences on future events which matter to them. Because they feel they have control over events, this manifests itself in the ways they deal with their children. Their high levels of involvement with the home-visitors, and their active participation in the follow-up therapies may then be seen as being reflections of their sense of needing to have control over life events.

A weakness with this type of argument is that, like other personality traits, locus of control theory is a "general" theory and is not necessarily situation specific. A father's general sense of having control over life events may not be relevant to the <u>specific</u> problems related to coping with a handicapped child. While having a handicapped child may challenge a father's sense of control, it is probably true that the ways he deals globally with the control of events may have no relevance to how he copes with his child, especially if he feels that this type of "control" issue is the responsibility of his wife. It is also true that there are many ways a father can gain control over life events surrounding a handicapped child which do not involve "hands on" contact. For example, three fathers, all of whom are "internals" may use different avenues to gain control of their child's future. One father may feel that by working extra hours, he is contributing to care, another father may only feel in control when he is working directly with his child or a third father's real work demands may not leave enough time for him to work with his child, even though he has a desire to do so.

Any explanation of the differing levels of involvement based on personality traits, like that of the locus of control theory, may be challenged on the basis that such theories are general explainations which may not be appropriate in such a specific situation as coping with a special needs child.

Another way to interpret the differences among the groups would be to suggest that the fathers highly involved by choice and to a lesser extent the fathers involved by necessity and the fathers who were moderately involved, were more "androygenous" than the fathers with low involvement, and hence were more involved because of this "equality" with their wives and a view of themselves which is less traditionally masculine.

The data do indeed suggest that fathers of the first three patterns had a tendency to view themselves as somewhat nontraditional fathers who were taking more active roles in their childrens lives and that Pattern #1 fathers saw themselves as being the "most" equal with their wives.

The fathers of the first three patterns reported more interest and enthusiasm in "sharing" with their wives and did not define their roles in traditional masculine terms. While in most all instances -- as is true in the general population --

these fathers were still the "breadwinners" of the family, they have defined their roles as fathers from a broader perspective. To some extent these men have been affected by recent changes in cultural expectations of men, and their involvement with the home-visits and follow-up therapies is a reflection of this change. In contrast to this, the fathers of Pattern #4 still see themselves as more of the traditional father who leaves the major daily childcare responsibilities to his wife. These fathers, everything else being equal, see themselves as the family "protectors" who only become involved when the family is threatened. In times of "crisis" and when their children leave the early intervention programs and their families must deal with the administrators of public schools, these fathers are more likely to feel a need to "protect" their families from the "outside" world.

In all liklihood the fathers of Pattern #4, and to some extent the fathers of Pattern #3, did not see the early intervention programs as an "outside" threat to their families. Almost all of the families who participated in this study were middle-income families whose backgrounds were similar to those of the home-visitors. By working with the families in the homes and forming close working relationships with their wives, the home-visitors may not have appeared as threats to the fathers. Also, none of the three early intervention programs in this study had a single male staff member. Thus, many of the more traditional fathers may have viewed the early intervention program as nonthreatening because they were "female" oriented and not meant for men anyway. The fathers of Pattern #4 may only have felt insecure about their chidren's need for protection when they encountered potential problems from the publc schools which were clearly "outside" of their homes, and in most instances were headed by males.

Another explanation for the higher levels of involvement of Pattern #1 fathers may be attained from an analysis of the characteristics of the sample (see Appendices A, B, and C). A comparison of the characteristics of the fathers highly involved by choice to the other three patterns suggest reasons why a differences may exist between Pattern #1 fathers and the rest of the study sample.

An analysis of the characteristics of the study sample indicates that the fathers of Pattern #1 as compared to the other three patterns were younger, had fewer and younger children, had been not been married as long, had slightly higher levels of education and all but one of these fathers' special needs child was first-born. Thus, it could be hypothesized that Pattern #1 fathers had much higher levels of involvement than the fathers of other patterns because they were younger men who were in the process of defining their roles as fathers, and as a consequence of having a <u>first</u> child born with special needs, they were compelled to put more time and energy into this one child. It should also be noted that while the fathers of Pattern #1 were somewhat better educated than the fathers of Patterns #3 and #4, the difference do not seem to be so great as to suggest their higher involvements were only due to social class differences, for example, 60% of Pattern #1 fathers as compared to 48% of the Pattern #4 fathers and 56% of Pattern #3 fathers attended college.

I would suggest that a significant factor which may account for the high level of involvement of the Pattern #1 fathers with home-visitors and follow-up therapy is due to their first born child having a special need. I feel there are several reasons for this.

First, since these first-born children were <u>only</u> children for at least nine months the fathers had more time available to spend with that child. Having only one child in the family obviously means that whatever time the father has available to be with his family, it can be focused on that one child. The first child typically gets more attention from both parents than a later-born child just because there is less competition for the use of that time.

Second, if a first-born child has a special need, it is not unreasonable to assume that a father might be more motivated to spend extra time with this child, and especially so his wife is in any type of distress. Research by Pedersen et al. (1980) has found that when a child is born through a Caesarian section, fathers are more likely to become involved in the care of the child because of the extra strain this puts on the mother. Because meeting the baby's demands is more difficult for the mother, the father reacts by becoming more involved. In a similar manner, a mother may be required to do many extra tasks with a special needs child which eventually results in her needing more support from her husband. Since, for Pattern #1 fathers the special needs child was the only child, this may have meant they could devote more energies to this one child.

In the case where the special needs child is a later-born child, it also seems that a father may need to offer extra support to his wife, but in this situation the support offered by the father may come in the form of extra time being spent with the children who do not have special needs. When the mean size of Pattern #1 families (1.7 children) is compared, for example, to that of Pattern #4 (2.5 children) it is seen that Pattern #4 fathers have larger families and their time must be spread over more children. Thus, one way these "lower" involved fathers may support their wives is by taking care of the older children so their wives may provide the special needs child with extra care. Thus, while the fathers of Pattern #4 may report not being involved in as many activities of the early intervention program, they may have been involved in activities related to their older children.

Third, the research findings (e.g. Cowan, Cowan, Coie, and Coie, 1978) suggest that parents have a tendency to become more traditional in their parental roles once a child is born, no matter what beliefs the parents held before the birth of the child. Thus the fathers of Pattern #4 who have been married for an average of 9.5 years as compared to Pattern #1 fathers who have been married for an average of only 4.7 years have had many more years to become more "traditional" in their orientations to parenting. In these more traditional roles, the fathers of Pattern #4 have fewer responsibilites for their infants and toddlers with special needs, just as they would have if these children had been born without special needs.

Third, because almost all of the children of Pattern #1 fathers are first-borns, it is possible that these fathers are more concerned about defining their roles as fathers than are fathers with later-born children. None of the Pattern #1 fathers had expected their first child to have problems, and all of their fantasies of what it would be like to be a first time father were shattered by the reality of having a child who was different. Because of this, these men may have needed to spend extra time with their children in order to define their roles more clearly. The fathers whose special needs children were later-borns, already had a great deal of experience in defining their roles as fathers, and hence their roles were less ambiguous. The fathers of Pattern #1 may have been more motivated to become involved with home-visitors and follow-up therapies as a way of learning what it means to be a father under those "unusual" and unexpected circumstances.

Finally, another possible factor which may have been motivating the fathers of Pattern #1 was a perceived threat to their egos because of having their first child be one which was not "perfect". In an important way, having a first child born with a special need may have special significance for a father's sense of "potency" and inability to father a normal child. The intense interest and investment of time which these fathers of first born children felt may be a reflection of their needs to do all they could to show the world they could help correct a "mistake" which had been made. By becoming involved in the "hands-on" activities of the follow-up therapy, these fathers may have been acting on a need to "prove" their manhood.

Policy Implications

This study may be seen as raising questions about the ways early intervention programs provide services to two-parent families. The findings of this study suggest the need to examine policies regarding how the needs and perspectives of fathers are taken into account when designing interventions for young children with special needs. This study has broad implications concerning the relationship of early intervention service delivery models and the needs of familes with respect to how programs may best integrate services into the total family system.

Although this study is exploratory and does not present data with respect to mothers' points of view, it does suggest the need to call into question policies of special education programs which do not offer services aimed at including fathers.

The results of this study indicate there are many fathers interested and willing to become involved in the amelioration of their children's special needs. Of the 46 fathers included in this study, 50% were consideredd to be "non-traditional" fathers who saw themselves as needing to be involved in making decisions about their children's special education programs. It is to the credit of the three early intervention programs who offered me support to do this research project that they were able to provide opportunties to these fathers to become involved by offering parent support group meetings in the evening, having home visitors rearrange their hours so as to be available in the evening after fathers left work, or by asking the families if there were times during the day which would be convenient for the fathers.

In my discussions with the staff members of the early intervention programs I found that only one of them provided parents with short-term support groups for couples. This particular program arranged short-term support group meetings in the evening so fathers could attend with their wives. The interview data suggest these meetings were particularily valuable for the fathers for three reasons, and as a consequence should be used by more programs.

First, these meetings gave the fathers the opportunity to meet other parents who were in the "same boat" as themselves. Several fathers reported to me that it was only after seeing and talking with other couples in similar situations that they were able to get a better perspective on their problems. By meeting with these other couples the fathers could see that they were not isolated, and there were "peers" who understood their needs. Even though many of the home-visitors talked to the fathers about their concerns, in may instances it was the reassurance of another couple with similar problems that proved especially valuable to many fathers.

Second, as I have reported in this study, the most common form of appraisal-focused coping strategy used by the fathers was that of the "positive comparison", where fathers gained a sense of relief in knowing there were other children who were worse off than theirs. Almost all of the fathers in this study who attended support group meetings, reported how "good" it was to find a father who had problems worse than his. By attending a support group meeting, the fathers found themselves in the position of being able to compare their special needs child to other special needs children, and this almost always resulted in the fathers being able to "spot" a family whose child had worse problems than theirs regardless of whether or not the other child "really" was worse off..

Third, the parent support group meetings provided the fathers with the opportunity to get first hand advice from other parents of special needs children. At these meetings, fathers received advice about who were the best doctors to see, about how to manage their children; and from parents of older children, they learned what to expect in the future.

Thus, a primary implication of this study is to suggest the need for early intervention programs to provide fathers with opportunities to meet with other parents who have children with special needs. By providing a forum for the discussion of personal needs and concerns, an important consequence of these meetings is the realization by the fathers that not only are they not isolated, but there are people "out there" who have problems worse than their own. The results of this study suggest that this is a crucial feature of the process of understanding what it means to have a disabled child, and every effort must be made to provide fathers with the opportunity to make these types of comparisons. Since men's social networks are much more limited than women's (Lein, 1984), fathers may not be in the position to make the same kind of contact with other parents of special needs children, and it may be even more important that early intervention programs provide fathers with the opportunity to increase their social support networks.

A second implication of this study is that early intervention programs need to try and be as flexible as possible in scheduling home-visits and evaluations so as to take into account the work schedules of the fathers. With only a few exceptions, the home-visitors provided services only during the 9 a.m. to 5 p.m. workday which meant that fathers who did not have flexibilites in their work schedules could not attend the visits even if they wanted to. To be sure, the data clearly indicate that for many of the fathers who participated in this study, even if times had been arranged in their behalf, they would not have taken advantage of these opportunities. But for many of the fathers of the first three involvement patterns, had the home-visitors been more flexible there is a strong liklhood that they would have taken advantage of the opportunity.

In general, I believe the findings of this study suggest that early intervention programs make it a policy to assess the ways fathers may be involved in programs if given the opportunity. A clear implication of this study is the need for human service professionals to make more differentiated assessments of the ways in which fathers may become involved in special education programs. The findings of this study suggest that special education policy cannot be based on a model of fathering in which fathers are simply seen as "breadwinners" and mothers as the providers of childcare. Indeed, the data suggest that fathers are diverse in the ways they become involved in activities related to their children's special needs, and interventions could be designed which take into account the patterns by which fathers become involved in these activities. By appropriately offering fathers options through which they may participate in the early intervention programs, there will in all liklihood be a much higher rate of father involvement.

In particular, it seems that fathers with first born special needs children are especially motivated to become involved in the amelioration or their children's problems and special efforts need to be made on behalf of these men. While the findings of this study suggest that these fathers will go out of their way to work with the home-visitors, perhaps only a relatively small extra effort to adapt to the fathers' individual needs may provide these fathers with even more opportunities for involvement.

In the present study, it was also found that fathers who had little or no interest in participating in any activities of the early intervention programs were nonetheless highly invested in becoming involved in activities related to "times of crisis" (e.g. a child's sudden hospitalization, at the time of diagnosis of a probblem) and "times of transition" (e.g. when the child enters public school, when the child is evaluated by the program). These are sensitive periods for fathers in which motivation to become involved is high, and they will make even radical adjustments in their work schedules to make time for involvement. I found that even fathers who reported their work schedules to be highly "inflexible", were suddenly able to make the necessary adjustments at these times.

This finding suggests the need for professionals to make every effort to include fathers at these times. While it is not possible to anticipate times of crisis, there are certain times of transition which are known about well in advance, and it would certainly seem wise for professionals to anticipate the interests of fathers in these transitions by providing extra opportunities for fathers to become involved. An example of what I am suggesting here would be a strategy whereby three to six months before a child is to change programs, the fathers could be contacted and provided opportunities to plan how the transition will be made. Even if the home-visitor is not able to meet with the parents in the evening at these times of transitions, the fathers may be able to rearrange there schedules well in advance.

By having staff members regularly contact fathers in advance of transitions, there is a strong likelihood that even fathers who are only marginally interested will become motivated to take advantage of the offer. For fathers who are already interested in the transition, the early contact by the home-visitor may draw the father in at the very beginning of the transition.

Finally, the findings of this study may prove useful to human service professionals by providing them with guidelines for planning strategies when working with families. By understanding the ways fathers become involved in activities related to their children's special needs and how they cope with stress, professionals may be in a better position to design more effective family intervention strategies. It may prove to be very useful for home-visitors to schedule yearly or twice-yearly parent conferences which include fathers not only to provide fathers with information which may be of interest to them, but also to use these times as opportunities to evaluate the fathers' patterns of involvements and thereby make more planned decisions about how best to include fathers in early intervention programs.

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APPENDIX A

CHARACTERISTICS OF THE FATHERS

#	PAT- TERN	AGE	INCOME RANGE	EDUC.	YEARS MARRIED	WIFE WORK?	NO. OF CHILDREN
03	1	31	$15-20	H.S.	7	FULL TIME	3
07	1	34	$40+	Ph.D	3	PART TIME	2
11	1	29	$15-20	B.S.	3	FULL TIME	1
12	1	29	$15-20	B.S.	9	NO	2
17	1	32	$15-20	B.A.	3	NO	1
21	1	23	$00-05	<H.S.	3	NO	1
22	1	31	$15-20	B.S.	9	NO	2
40	1	25	$15-20	H.S.	5	PART TIME	2
44	1	23	$10-15	Assoc.	2	NO	1
49	1	26	$15-20	H.S.	5	PART TIME	2
04	2	29	$ 0-05	M.A.	6	FULL TIME	1
37	2	32	$20-25	B.A.	8	FULL TIME	2
45	2	29	$15-20	B.A.	8	FULL TIME	4
02	3	25	$15-20	Assoc.	4	NO	1
06	3	31	$15-20	B.S.	5	NO	2
15	3	42	$30-35	Ph.D.	18	PART TIME	3
16	3	26	$40+	H.S.	8	NO	1
32	3	26	$15-20	H.S.	4	NO	1
34	3	33	$35-40	H.S.	9	NO	3
41	3	32	$25-30	H.S.	4	PART TIME	1
42	3	32	$15-20	B.S.	9	NO	3
48	3	40	$20-25	Ph.D.	8	NO	2
01	4	34	$15-20	Assoc.	11	NO	2
05	4	37	$25-30	B.S.	11	NO	2
09	4	46	$05-10	<H.S.	18	NO	5
10	4	34	$15-20	H.S.	9	PART TIME	3
13	4	31	$15-20	H.S.	8	FULL TIME	1
14	4	33	$20-25	B.S.	4	NO	4
18	4	29	$20-25	H.S.	7	NO	2
19	4	34	$40+	M.A.	11	NO	2
23	4	35	$05-10	Assoc.	12	PART TIME	2
25	4	35	$25-30	M.S.	13	NO	2

(continued on next page)

APPENDIX A

CHARACTERISTICS OF THE FATHERS

(Continued)

#	PAT. #	AGE	INCOME RANGE	EDUC.	YEARS MARRIED	WIFE WORK?	NO. OF CHILDREN
26	4	36	$20-25	H.S.	10	NO	2
27	4	36	$25-30	H.S.	15	NO	4
28	4	24	$10-15	H.S.	4	NO	2
29	4	39	$25-30	H.S.	8	NO	2
30	4	34	$15-20	H.S.	11	FULL TIME	2
31	4	37	$40+	H.S.	14	NO	4
35	4	27	$05-10	H.S.	6	NO	2
36	4	31	$30-35	B.S.	11	NO	3
38	4	32	$15-20	M.A.	11	NO	2
39	4	35	$25-30	H.S.	12	NO	3
43	4	27	$15-20	H.S.	5	NO	1
46	4	30	$15-20	H.S.	10	NO	2
47	4	30	$15-20	H.S.	7	NO	3
50	4	22	$10-15	H.S.	3	NO	2
08	*	33	$15-20	M.A.	11	PART TIME	2
20	*	37	$30-35	H.S.	7	PART TIME	1
24	*	33	$10-15	<H.S.	6	NO	3
33	*	34	$15-20	H.S.	9	PART TIME	1
MEANS		31.7	$18,400		8.04		2.14

NUMBER OF WIVES WHO:

DO NOT WORK = 33
WORK PART TIME = 10
WORK FULL TIME = 7

FATHERS' HIGHEST LEVELS OF EDUCATION

DID NOT FINISH HIGH SCHOOL = 3
FINISHED HIGH SCHOOL = 24
COMMUNITY COLL. (Assoc.) = 4
UNDERGRADUATE DEGREE = 11
GRADUATE DEGREE = 8

APPENDIX B

CHARACTERISTICS OF THE CHILDREN

#	PAT-TERN	AGE	SEX	FIRST BORN?	TYPE OF DISABILITY	SEVERITY OF DISABILITY
03	1	5-09m	F	YES.	GENETIC DISORDER	MODERATE
07	1	1-05m	M	YES	DEVEL. DELAY	MODERATE
11	1	0-11m	M	YES	CEREBRAL PALSY	MILD
12	1	0-07m	M	NO	DOWN'S SYNDROME	MODERATE
17	1	0-05m	M	YES	DOWN'S STNDROME	MODERATE
21	1	1-09m	M	YES	VISUAL DEFECT	MODERATE
22	1	1-07m	M	YES	CEREBRAL PALSY	MODERATE
40	1	2-11m	F	YES	VISUAL DEFECT	MODERATE
44	1	0-11m	F	YES	DOWN'S SYNDROME	MODERATE
49	1	2-06m	F	YES	CEREBRAL PALSY	SEVERE
04	2	2-09m	F	YES	DOWN'S SYNDROME	MODERATE
37	2	4-06m	M	YES	DEVEL. DELAY	MODERATE
45	2	4-10m	F	NO	DEVEL. DELAY	MILD
02	3	3-00m	M	YES	NEURO-MOTOR DIS.	SEVERE
06	3	2-09m	M	YES	DEVEL. DELAY	MILD
15	3	4-07m	F	NO	HYDROCEPHALUS	MODERATE
16	3	2-02m	F	YES	EPILEPSY	SEVERE
32	3	2-00m	M	YES	DEVEL. DELAY	MODERATE
34	3	2-09m	M	NO	GENETIC DISORDER	MODERATE
41	3	2-00m	M	YES	DOWN'S SYNDROME	MODERATE
42	3	5-03m	M	NO	DEVEL. DELAY	MILD
48	3	1-02	M	NO	CEREBRAL PALSY	SEVERE
01	4	1-03m	F	NO	DOWN'S SYNDROME	MODERATE
05	4	2-06m	M	NO	DOWN'S SYNDROME	MODERATE
09	4	1-06m	M	NO	DEVEL. DELAY	MILD
10	4	1-04m	F	YES	CEREBRAL PALSY	MODERATE
13	4	2-06m	M	YES	DEVEL. DELAY	MILD
14	4	2-00m	M	NO	CEREBRAL PALSY	MILD
18	4	1-06m	M	NO	SPINA BIFIDA	MILD
19	4	5-00m	F	NO	NEURO-MOTOR DIS.	MODERATE
23	4	2-02m	F	NO	HYDROCEPHALUS	MODERATE
25	4	4-10m	M	NO	CLEF PALATE	MILD

(continued on next page)

APPENDIX B

CHARACTERISTICS OF THE CHILDREN

(Continued)

#	PAT-TERN	AGE	SEX	FIRST BORN?	TYPE OF DISABILITY	SEVERITY OF DISABILITY
26	4	1-03m	M	NO	SPINA BIFIDA	SEVERE
27	4	5-03m	F	NO	DOWN'S SYNDROME	MODERATE
28	4	0-09m	F	NO	HYDROCEPHALUS	SEVERE
29	4	3-10m.	F	NO	CEREBRAL PALSY	SEVERE
30	4	4-11m	M	NO	DEVEL. DELAY	SEVERE
31	4	2-06m	M	NO	HEART DISORDER	SEVERE
35	4	1-06m	M	NO	DEVEL. DELAY	MODERATE
36	4	2-04m	M	NO	DEVEL. DELAY	MODERATE
38	4	3-01m	F	NO	DEVEL. DELAY	MILD
39	4	2-00m	M	NO	CEREBRAL PALSY	SEVERE
43	4	1-04m	F	YES	HYDROCEPHALUS	MILD
46	4	4-07m	M	NO	DOWN'S SYNDROME	MODERATE
47	4	3-00m	M	NO	DEVEL. DELAY	MILD
50	4	2-06m	F	YES	DEVEL. DELAY	MILD
08	*	2-03m	F	NO	CEREBRAL PALSY	SEVERE
20	*	5-10m	F	YES	CEREBRAL PALSY	MILD
24	*	1-00m	F	NO	SPINA BIFIDA	MILD
33	*	3-05m	M	YES	DEVEL. DELAY	MILD
MEAN.		2yr-08m				

NUMBER OF FIRST-BORNS = 22
NUMBER OF LATER-BORNS = 28

NUMBER OF MALES = 29
NUMBER OF FEMALES = 21

APPENDIX C

CHARACTERISTICS OF PATTERNS

TABLE C-1 Characteristics of Fathers and Children

PATTERN NUMBER	N	MEAN AGE FATHER	MEAN INCOME FATHER	MEAN # OF CHILD.	MEAN # YEARS MARRIED	% 1st BORNS	MEAN AGE CHILD.
1	10	28.3	$i5,500	1.7	4.7	90%	1-11m
2	3	30.0	$11,650	2.3	7.3	67%	3-04m
3	9	31.9	$23,300	1.9	7.7	56%	2-11m
4	24	32.8	$18,300	2.5	9.5	17%	2-08m

TABLE C-2 Highest Education of Fathers

PATTERN NUMBER	N	< H.S.	H.S.	COMMUNITY COLLEGE	UNDER-GRADUATE	GRADUATE
1	10	10%	30%	10%	40%	10%
2	3	0	0	0	67%	33%
3	9	0	44%	12%	22%	22%
4	24	8%	48%	4%	22%	16%

APPENDIX D

Participant's Consent Form

1. I agree to participate in a study being conducted by Sanford Roth as part of his research at the University of Massachusetts, Amherst. I understand that the major purpose of this study is to gain a better understanding of fathers with children involved in early intervention programs. I understand my role in this research involves participating in a tape recorded interview.

2. I understand that information generated from my participation in this study is intended to increase knowledge about fathers whom have children enrolled in early intervention programs.

3. I understand and agree with the following conditions regarding the collection and safeguarding of information collected by the study:

   a. There are no anticipated risks or discomforts by my participation.

   b. All information will be reported anonymosly. No individually (or agency) information will be reported.

   c. My participation as a consenting adult in this study is voluntary, and I may withdraw at any point.

   d. There will be no monetary compensation for my participation.

4. I understand that, at my request, the results of this study will be shared with me

5. If I have any questions about this study or any of its procedures, I may obtain more information by calling Sanford Roth at (413) 253-5693, or write to him at his home, 16 Amherst Road, Pelham, MA 01002.

____

Signature

APPENDIX E

Family Information

Your Name ______________________________

Your Age ________________________________

Your Wife's Age _______________________

The Names and Ages of Your Children

1. ____________________________
2. ____________________________
3. ____________________________
4. ____________________________
5. ____________________________
6. ____________________________

Your Occupation ______________________________________

Your Wife's Occupation ______________________________

Your Education ____

The Number of Years You Have Been Married _______

Yearly Income:	Your Income	Wife's Income
0 - 4,999	_______	_______
5,000 - 9,999	_______	_______
10,000 - 14,999	_______	_______
15,000 - 19,999	_______	_______
20,000 - 24,999	_______	_______
25,000 - 29,999	_______	_______
30,000 - 34,999	_______	_______
35,000 - 39,999	_______	_______
40,000 -	_______	_______

The age of your child when entering the program ____________

How long has (was) your child been in the program? ______

What is the reason for your child being in the early intervention program? ____

____