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THE FAMILY WITH A HANDICAPPED CHILD:
PARENTAL REACTIONS

A THESIS

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TABLE OF CONTENTS

LIST OF TABLES	v
PREFACE	vi
Chapter	
I. INTRODUCTION.	1
A. Societal Attitudes.	1
B. Chronic Stressors	2
1. Stigma	3
2. Financial Strain.	4
3. Emotional Turmoil	4
4. Burden of Care.	5
C. The Effect on the Family.	5
1. The Initial Diagnosis	6
2. Parental Reactions.	8
a. Perception of the Disability.	10
b. The Adjustment Process.	11
c. The Marital Relationship.	12
d. Subsequent Fertility.	14
3. Sibling Reaction.	15
D. Support Systems	17
1. Friends and Relatives	17
2. Religious Factor.	18
3. The Professional.	20
a. The Physician	21
b. The Educator.	24
4. Parent Support Networks/Parent Associations . . .	25
E. Hypotheses.	27
II. METHODOLOGY	29
A. The Pilot Study	29
B. The Research Instrument	32
C. Data Collection	33
D. Data Analysis	34
III. FINDINGS AND CONCLUSIONS.	36
A. Descriptive Statistics.	36
B. Inferential Statistics.	37
C. Discussion	44
E. Comments from Parents	46
F. Implications for Future Study	49

APPENDIX A	52
APPENDIX B	56
APPENDIX C	57
APPENDIX D	58
REFERENCES	61

LIST OF TABLES

1. Mean Self Rating Scores by Status of Parents	37
2. Mean Life Satisfaction Scores by Status of Parents	38
3. Mean Level of Negative Emotional Reaction by Status of Parents.	39
4. Feelings About Being a Parent by Status of Parents	40
5. Amount of Marital Disruption Attributed to the Children by Status of Parents.	40
6. Mean Number of Children by Status of Parents	41
7. Frequency of Church Attendance by Status Parents	42
8. Parental Disappointment with Teachers by Status of Parents . .	43

PREFACE

In the summer of 1976 an event occurred that affected my life to a greater extent than anything before or since. My younger child had a serious illness which left her both mentally and physically handicapped. I was not prepared for this. I had been properly socialized to achieve and excel and expected as much from my own children. Through my childhood, my parents had convinced me if I just tried hard enough I could do anything I wanted to do. Yet here I was faced with a situation which I could not change no matter how hard I tried. I tell you of my own personal involvement because, as Max Weber warns, personal values are not easily effaced from research activities no matter how scientifically objective the intentions of the researcher may be.

Before this time, I had been properly solicitous of the handicapped and their plight, yet I had never imagined the impact such a condition could have on the family. As I often had done before when faced with a dilemma, I turned to the experts in literature. From them I found no consensus. Many promised a happy land of adjustment after I had wandered through a maze of appropriate, sequential stages. Others warned of personal disintegration, trauma and other dire results. After several years of reading the works of the professionals and listening to the comments of other parents of handicapped children, I decided to use these experiences as a base for a research study focusing on handicapped children as a family problem. In conducting this research, I have sought to explore the nature of the problem; second,

to examine the effect the problem has on the family; and, finally, to investigate factors which tend to mediate the stress produced by the problem, namely, the support systems.

Before turning to a report of my research, one premise should be clarified. The handicapped are not a separate species. I do not mean to isolate them from the rest of humanity as I describe their problems. They are individuals who because of accident, illness, birth defect, or environmental influences have more limited ability than others. Their limitations may be physical, mental, emotional, or any combination of these. Because they do not fit socially ascribed normality, they are frequently isolated and denigrated. Less than two decades ago, the professional terms for them ranged from "moron" to "crippled." With the present day sensitivity to labels, terms such as "disabled" or "impaired" are more common. The names have changed; the problems, however, still appear to be the same.

CHAPTER 1

REVIEW OF THE LITERATURE

A person's relationship with a handicapped child is a relationship quite unlike any other. Husbands and wives drift apart and marriages end; healthy children grow from dependence to adulthood and independence and eventually leave their parents; parents themselves grow old and die. But a handicapped child is with you from birth-forever. He or she is a responsibility that always hovers at the edge of your life (Brown, 1976:40).

Families with handicapped children are, according to Bernard Farber (1968), in a state of crisis. The above quotation by author Helene Brown, a mother of a handicapped daughter, supports this claim. Researchers have typically used a crisis-orientation in determining the adverse effects the handicapped child has on the family. Problems appear to abound for parents in this situation. The disruptive elements include marital disintegration (Bruhn, 1980; Drotar et al, 1980; Farber et al, 1968; Fowle, 1968; Kolin, 1971; Meadow, 1980; Samit et al, 1980; Steinberg, 1980; Wikler, 1981; Willer et al, 1979), emotional turmoil (Bray, 1980; Bruhn, 1980; Darling, 1979; Schonell and Watts, 1956; Searl, 1978; Slaughter, 1960; Strom et al, 1981 Wikler, 1981), financial strain (Heisler, 1972; Howard, 1982; Steinberg, 1980), and a devalued status (Berger and Fowlkes, 1980; Goffman, 1963; Mercer, 1973; Steinberg, 1980).

Societal Attitudes

"Society does not value all of its members equally (Darling, 1979:17). Those who are handicapped are among the disenfranchised and disfavored. Historically, the handicapped have been rejected by their

communities. In ancient times, they were cast out to die. In recent history, they were warehoused in public institutions (Meyers, 1978:19). The primary objective was the same, to remove the handicapped from society. Today, America and Europe are seen as having made the greatest advances in attempting to meet the needs of the handicapped and their families (Ojofeitimi and Oyefeso, 1980:101). The turning point for the rights of the handicapped is viewed by Meyers (1978:114) as having mushroomed from the civil rights movement of the nineteen-sixties. In spite of this progress, the handicapped continue to experience social rejection because America is a success oriented society (Steinberg, 1980:182), and stereotypes and labels abound which affirm this pariah status (Parish et al, 1979). Those who do not live up "to an arbitrary set of expectations" (Darling, 1979:31), such as the cultural stereotype of a perfect or ideal child (Smith and Neisworth, 1975:180; Darling, 1979:17), are given one or more negative labels and thus stigmatized. This, however, is not the end of the process. Families share this social burden through a practice Goffman (1963:32) refers to as "courtesy stigma." Others describe this process as "guilt by association" (Darling, 1979:32) or "contamination" (Berger and Fowlkes, 1980:22). In other words, the family is stigmatized for the non-conformity of one of its members (Mercer, 1973:22).

Chronic Stressors

There are certain stresses that are unique to families with a handicapped child. As Steinberg (1980) emphasizes, no matter what the handicap, there are certain problems which are common to families in this situation. Those most frequently listed by researchers are stigma (Berger and Fowlkes, 1980; Goffman, 1963; Mercer, 1973; Steinberg, 1980),

financial strain (Heisler, 1972:38; Howard, 1982:317; Steinberg, 1980:177), emotional turmoil (Bray, 1980:162; Bruhn, 1980:155; Searl, 1978:F29, Strom, et al, 1981:289; Wikler, 1981b:282) and burden of care (Mercer, 1966:29; O'Hara et al, 1980:86; Strom et al, 1981:289; Wikler, 1981:282; Willer et al, 1979:40).

Stigma

The stigmatized status resulting from a handicapping condition produces "isolation in, [and] rejection by the community" (Steinberg, 1980:177). As Stanford Searl (1981:F28) describes this experience, he and his wife found their child's handicap "not just a medical but a social problem" and "that our child was not valued by society." Another parent explains "...how painful she found it when other people, especially children, stared at [her child]" (McMichael, 1971:88). Besides staring, other types of negative feedback occur. These include "whispered comments, teasing...rudeness, being undervalued as a person" (Steinberg, 1980:182), "judgemental [statements], murmurs of pity, and intrusive requests for personal information (Wikler, 1981:282). Langer et al (1976) speculate that the handicapped are avoided because individuals fear the impediment might happen to them. Whether blatant, or merely perceived, a fear of rejection develops and inhibits parents, and this may lead them to reduce contact with their social network (Berger and Fowlkes, 1980:22-3). If the child is "closeted" and his normalizing activities are reduced to a minimum, the entire family suffers as a result (Howard, 1982:319). This is so because, as Bengt Nirge points out (quoted in Meyers, 1978:106) "isolation and segregation foster ignorance and prejudice...."

Financial Strain

The cost of care ranks high on the list of chronic problems facing families with a handicapped child (Heisler, 1972:38; Howard, 1982:317; Steinberg, 1980:177). Medical expenses, equipment, modifications to the home, and special tutors and therapists, are among the many extras needed by these families. The financial strain imposed by these demands not only slows down social mobility of family members (Willer et al, 1979:42), but continues to be a constant source of concern and frustration to them (Meadow, 1980:13). An additional problem, highlighted by the research of Warner et al, (1975:55) is the difficulty parents experience in getting insurance to cover their handicapped child. Of those companies surveyed, seventy-five percent would not insure the mentally retarded, and among the remainder three out of five levied premiums in excess of those charged "regular" customers.

Emotional Turmoil

Drotar et al (1980:204) describe two levels of perception, the intellectual and the emotional. A parent, may understand a child's disability on an intellectual level (i.e., diagnosis, symptoms, treatment, prognosis), yet that same parent may have a low emotional level of acceptance of the child's condition (Mullen 1975:126). Bruhn (1980:158) describes a panorama of parental emotional reaction including denial, guilt, anxiety, shame, embarrassment, depression, resentment, rejection, alienation, self-blame, and bitterness. The most common of these reactions, as reported by researchers, is depression (Bray, 1980:162; Samit et al, 1980:220; Searl, 1978:F29). This ongoing feeling has been labeled by some as constant sorrow (Drotar et al, 1980) or chronic sorrow

(Olshansky, 1962; Wikler, 1981), and it is the inevitable aspect of the grief process (Samit et al, 1980:220).

Burden of Care

The dependency of the handicapped individuals has been described by many as the "burden of care" (Mercer, 1967:29; O'Hara et al, 1980:86; Strom et al, 1981:289; Wikler, 1981:282; Willer et al, 1979:40). Families report restricted activities (McMichael, 1978:F29) and mental and physical exhaustion (Samit et al, 1980:216; Steinberg, 1980:177; Wikler, 1981:282). Mercer (1967:40) further notes interpersonal conflict and family structural stress as a result of the additional caretaking responsibilities. The greater stress seems to come not from the amount of dependency, but from the lack of relief (Wikler, 1981:282). Facilities specializing in respite care are one solution to this problem. These are being established and are easing the problem for some families (Wikler, 1981:282).

The Effect on the Family

The presence of a handicapped child has a tremendous impact on a family unit. As Michael Begab describes it, "The experience can enrich lives or it can confuse them...." (as quoted in Meyers, 1978:29). Yet researchers typically use a crisis or negative orientation in discussing families with handicapped children, continually emphasizing the adverse aspects to the almost total exclusion of any positive effects (Berger and Folkes, 1980; Bray, 1980; Bruhn, 1980; Darling, 1979; Farber, 1968; Fowle, 1968; Jacobsen and Humphrey, 1979; Kolin, 1971; Schoneil and Watts, 1956; Searl, 1978; Steinberg, 1980; Wikler, 1981). This emphasis has been noted by several researchers (Darling, 1979:46; Farber, 1975:247; Jacobsen and Humphrey, 1979:600) and can probably be

attributed to the deviant status ascribed to such families. Darling (1979:68) notes that parents are in a "can't win" situation with researchers because of the many blanket assumptions generated by this deviant status.

The Initial Diagnosis

"Shattered dreams" (Heisler, 1972:ix; Slaughter, 1960:1) describes the reaction most parents experience when they realize their idealized child has been replaced by a defective one (Lucas and Lucas, 1980:21; McMichael, 1971:87; Solnit and Stark, 1962:526). The discrepancy between expectation and reality is overwhelming for many parents (Smith and Neisworth, 1975:181). Farber et al, (1968:30) report extreme initial reactions including "nervous breakdown, personal disorganization or severe depression" at the news a child is handicapped. These reactions have been described as a mourning process (Huber, 1979:267; Solnit and Stark, 1962; Willner and Crane, 1979:306). Parents must mourn the loss of the "perfect child" before they can accept the handicapped child.

The shock of diagnosis may result in the "suspension of coping mechanisms" (Willer et al, 1979:38). Many parents describe this as a dream sequence or nightmare state.

After I heard the words "retarded" and "deformed", I couldn't hear anything else. It was like watching some terrifying television program with the sound turned off. I lay in bed, silent and motionless, and hoped it would soon be over...I couldn't give birth to a baby who was not adorable and healthy... "It's only a dream," I whispered to myself. "Don't panic. You're still sleeping, still pregnant. When you place your hand on your stomach, you'll feel the baby. Please, God, let me feel the baby." (Gross, 1980:L13).

The preceding quotation illustrates the particularly severe reaction that mothers often evidence following the birth of a handicapped child.

Pregnancy and labor have already caused undue stress (Solnit and Stark, 1961:527) and the news that she has produced a "defective product" (Smith and Neisworth, 1975:181) may cause feelings of inadequacy and failure. The child may be initially perceived as abnormal or inhuman (Willer et al, 1979:39) and the mother may be consumed with guilt that she has somehow directly caused the problem (Darling, 1979:57). For parents in any situation, though, the inability to cope with this painful awareness may lead to the defense mechanism of denial (Smith and Neisworth, 1975:184; Solnit and Stark, 1962:528; Wright, 1976:162).

Disbelief, denial, or, as Kanner (1975:48) describes it, an "inability to face reality," are necessary ways to escape traumatic news which is so totally divergent from expectation that it must be absorbed gradually (Drotar et al, 1980:202). Minimizing the severity of a disability permits fantasy (Samit et al, 1980:219) and gives the parent additional time to understand the problem, yet it also creates artificial conditions, "disguises of reality" (Kanner, 1975:48). In the long run, neither the parent nor the child is helped by ignoring the situation or by living on what Heisler (1972:41) describes as a "superficial level."

Mercer (1966:29) has conceptualized the initial reaction in terms of a "congruent crisis" and an "incongruent crisis." In the "congruent crisis," an individual has experienced something similar or knows someone who has undergone the same crisis. He/she has cultural guidelines to adhere to and does not feel alone. On the other hand, in the "incongruent crisis" the situation has not been anticipated and the individual has few social guidelines or directives. The person does not

know anyone in a similar situation from whom he/she can learn acceptable responses. The parent with a handicapped child will typically have an incongruent experience.

Parental Reactions

Families can react to the presence of a handicapped child through either "estrangement" (Mercer, 1973:25-6) or adaptation (Farber, 1975:251). In situations where the child is kept at home, minimal adaptation, at the least, will be necessary (Farber, 1975:248). Revision of family roles has been described as one such means of adaptation (Farber, 1968:174; Farber, 1975:249, Farber et al, 1960:3). Sometimes the stress becomes too great for certain family members and a "crisis of role organization" (Farber et al 1960:3) can occur, requiring a renegotiation of roles and relationships in the home environment or removal of the stressor (Farber, 1975:249).

For those families with a severely or multiply handicapped child, institutionalization may be the only perceived answer (Farber et al, 1960:1). Mercer (1966:29) suggests an "additive hypothesis" according to which a family system can tolerate only a certain amount of deviant behavior and still function adequately. When the cumulative limit is reached because of "physical care problems, interpersonal tensions, and structural stress," then institutionalization may be perceived by family members as the only viable solution. According to Farber and others (1968), the decision to institutionalize is dependent on the sex of the child, the social status and religion of the family, and the marital integration of the parents. It has been noted that mothers tend to be more willing than fathers to place a child in an institution (Farber et al, 1960:35). This is especially true in lower class families

where the mother is the chief "caregiver" and may be faced with little assistance because of unsuccessful role revision with other family members (Willer et al, 1979:43). In the same respect, a single mother with chronic unresolved problems may turn to institutionalization as a way of coping with the stress (Farber et al, 1960). Family size has also been shown to affect the decision to institutionalize; the more siblings, the greater is the likelihood that institutionalization will occur (Willer et al, 1979:43).

In an attempt to cope with the emotional turmoil, parents may exhibit extreme reaction (Darling, 1979: Farber, 1975; Schonell and Watts, 1956; Slaughter, 1960). The parents' feelings of anger and envy may be manifested in a "death wish" for the handicapped child. This will inevitably lead to a guilt reaction. Zuk (1959:139) states that "guilt is a central dynamic problem impeding adjustment." Guilt feelings may lead to overcompensation in the form of total devotion to a handicapped child (Wright, 1976:163). This sacrificial attitude is evident in the behavior some describe as "super moms" (Darling, 1979:68) or the "martyr complex" (Darling, 1979:57; Huber, 1979:268; Slaughter, 1969:6-7; Wright, 1976:160) which may result in the neglect of the other family members. Although excessive care-giving and overprotection appear to have a negative impact on the situation, this behavior is reinforced by the admiration of society (Smith and Neisworth, 1975:187).

"Setting and maintaining realistic expectations...are among the most difficult aspects with which parents must cope" (Smith and Neisworth, 1975:185). As Slaughter (1960:1) states, "parenthood requires courage" because it is difficult to view the child as he is and not the way they would wish him to be (Strom et al, 1981:290). This is especially

troublesome for upper and middle class parents who are likely to have high expectations for achievement by their children (Meadow, 1980:13); and, in our success-oriented society, it may be particularly difficult for them to accept the limitations of a handicapped child (Zuk, 1959:139). Ideally, parents need to attempt to reach a balance between high expectations and overprotection (Smith and Neisworth, 1975:185). In fact, a modification or downward adjustment in expectation (Jacobsen and Humphrey, 1979:600; Strom et al, 1981:290) may be necessary initially to allow the child the opportunities to develop his actual potentialities (Slaughter, 1960:1).

By combining the work of several researchers, Power and Orto (1980:240) describe the characteristics of the family best able to cope with the stress of a handicapped child in the family. The couple would have an accurate perception of the handicap and they would approach problems in an unified and non-materialistic manner. They would have a democratic orientation with a diffusion of leadership in which the husband and wife frequently share tasks.

Perception of the Disability

The type of handicap which the child possesses has been shown to influence whether a parent will accept or reject the child. Parish et al (1979:63) found positive evaluations for physical handicaps and negative evaluations for mental retardation. In Coet's (1977:784) study, males tended to emphasize concern for "mental retardation," while females were concerned with "highly visible" conditions and birth defects.

Not only do males and females perceive handicaps differently, but the sex of the handicapped child makes a difference in their reactions. Farber et al (1960:43) have noted that there is a greater

impact for the mother if the child is female and for the father if the child is male. Moreover, as Tudor et al (1979:871) emphasize, a double standard exists for males and females in our society with regard to life goals. Expectations are generally not as high for women. According to Wilton and Barbour (1978:1144) this results in mothers making greater efforts to encourage boys than girls to achieve. Hence, when boys are retarded they are more likely to be institutionalized and at an earlier age and for milder disorders than are retarded girls (Farber et al, 1960: 46; Tudor et al, 1979:871). Willer et al (1979:43) speculate retarded girls are not institutionalized to the same degree as retarded boys because they can meet lesser role expectations, including menial chores and social graces, while boys must actively compete for jobs.

The Adjustment Process

Parental difficulties in achieving a realistic and adequate adjustment to the fact of having a handicapped child have been trenchantly described by Stanford Searl.

Parents...the theorists tell us, learn to live with their children's handicaps. They go through stages of reaction, moving through shock, guilt, and rejection to the promised land of acceptance and adjustment.

My own experience did not fit this pattern. Instead, it convinced me that most people seriously misunderstand a parent's response to the situation. The standard view does not reflect the reality of the parents' experience or lead to helpful conclusions.

Professionals could help parents more - and they would be more realistic - if they discarded their ideas about stages and progress...and they could begin to see that the negative feelings - the shock, the guilt and the bitterness - never disappear but stay on as a part of the parents' emotional life.

Most parents...never fully resolve their complexity of feelings...They don't "adjust to" or "accept" that fact, at least not in the way...books describe it (Searl, 1978:F27).

Models of parental adaptation to a handicapped child using a stage process have been patterned after the Kubler-Ross (1969) study of terminally ill patients. Adaptation geared to stages culminates with acceptance or adjustment as the final goal. As Stanford Searl notes, there are problems in utilizing this model if acceptance is described as an unvarying plateau (Huber, 1979:268). This certainly does not fit the ongoing family situation where the "problem" member of the family continues indefinitely as an interacting personality in the family situation.

Thus "it does not appear that a gradual acceptance of the severity of a disability occurs, rather" it seem "parents become more aware of their children's limitations at certain life-cycle stages" (Suelzle and Keenan, 1981:272). Each time major discrepancies from expectations occur, then parents experience grief, similar to that of the diagnostic trauma (Drotar et al, 1980:203). Periodic crises will trigger this flood of sorrowful emotions. Wikler et al (1981) emphasize that these reactions are periodic, not continuous, and must be perceived under the circumstances as normal, rather than abnormal responses. Counseling for the parents is needed in anticipation of various stages in the child's life (e.g., first day of school, puberty, twenty-first birthday). Furthermore, access to a supportive person is essential to allow "a parent to express periodic grieving without being considered pathological" (Wikler, 1981:284).

The Marital Relationship

While there is general agreement that the marital relationship is affected by the presence of a handicapped child, researchers disagree

on whether the effect is positive or negative. Although not in the majority, a few researchers report positive findings. Darling (1979:62) found that the presence of a handicapped child in the family brought couples closer together. Meadow (1980:135) has concurred, arguing the child becomes a rallying point which brings cohesiveness to the entire family. Other researchers (Wikler, 1981:283; Willer et al, 1979:41) have found better than average marital relationships among spouses with handicapped children, and they have concluded there is no direct evidence that special stresses in these families cause unusual separation or divorce rates.

Nevertheless, a tendency to emphasize negative effects is apparent. Lower marital integration or complex marital dissolution of couples with handicapped children has been a favored topic of many researchers (Bruhn, 1980:155; Drotar et al, 1980:204; Farber et al, 1960; Fowle, 1978; Kolin, 1971; Meadow, 1980:135; Samit et al, 1980:221; Steinberg, 1980:183; Wikler, 1981:283; Willer et al, 1979:41). The reasons given for this breakdown include the stress of constant child care (Schonell and Watts, 1956:214), financial strain (Heisler, 1972:38) and the inability to reallocate tasks (Kolin, 1971). The birth of a handicapped child necessitates not only the sharing of responsibilities, but more importantly, the sharing of feelings. Without this supportive communication, the relationship of the spouses may disintegrate into emotional isolation (Drotar et al, 1980:204). The probability of this breakdown is apparently increased if the handicapped child is the result of an unplanned pregnancy (Kolin, 1971).

Subsequent Fertility

Limitation of family size may be a viable mechanism for coping with the economic and emotional strain of having a handicapped child (Farber, 1968:160; Gath, 1972:214; Holt, 1975; Kanner, 1975:47; Meadow, 1980:135; Schonell and Watts, 1956:24; Tips, 1963). When a first child is born handicapped, parents may wonder if they should have any other children (Kanner, 1975:47). With a genetic link as the explanatory variable for the condition, Tips (1963:334) notes that stress increases to the "extent that reproduction of offspring essentially ceases after the diagnosis of an affected child." In a study in which one hundred and one families with handicapped children said they did not wish to have further children, ninety of the families directly attributed their decision to the presence of the handicapped child in their families (Holt, 1975:69). Similarly, Schonell and Watts (1956:211) found the largest number of disabled children in their study to be - also the youngest children in the families. This is further supported by Gath (1972:214) who reported over half the Downes Syndrome children he studied were the last born while children in a control group were evenly distributed as to birth order. Discounting these studies, Fraser and Latour (1968:885) found a decline in fertility beginning in subject families even before the birth of the handicapped child. This decline was even evident in a control group of families with children afflicted with hayfever.

For some parents with a handicapped child, however, another child may be seen as at least a partial answer to their problem (Darling, 1979:L57). Kolin (1971:1017) reports that, despite a genetic problem, "The wish to have another child...[is]...a reflection of the

intense feeling of loss and longing for the desired normal child the parents had anticipated." Also, parents may wish to expand the family support system around the handicapped child.

Sibling Reaction

Concern has been voiced that siblings may be neglected because the handicapped child demands so much attention (Darling, 1979:61; Slaughter, 1970:7-8). The greater the dependence of the handicapped child, the more adverse the effect on the normal siblings (Farber et al, 1960:3). The resultant jealousy of siblings may cause additional problems, especially if the anger is directed toward the handicapped child (Begab, 1975:33; McMichael, 1971:99; Meadow, 1980:135).

Deviant behavior has often been reported (Begab, 1975:33; Berger and Fowlkes, 1980:23; Power and Orto, 1980:236) in normal siblings, however, several researchers (Begab, 1975:33; Samit et al, 1980:220) have theorized that parents may punish the normal siblings because of pent up anger for the handicapped child. Parents have trouble expressing anger toward the handicapped child and are lax in discipline, thus the slightest infraction by a normal sibling may release a flood of emotion.

Some siblings admit to feeling shame and being stigmatized (Begab, 1975:33; Meadow, 1980:135). With others, the only evidence is shyness and withdrawal (McMichael, 1971:88). Some individuals may refuse to bring friends home because of their feelings (McMichael, 1971:88; Samit et al, 1980:219). The greater incidence of emotional problems found in several studies appears to be related to feelings of guilt about being normal (Howard, 1982:319; Samit et al, 1980:219) and the high expectations of the parents that their normal children will excel (Howard, 1982:319; Gath, 1972:216).

The age difference between siblings appears to affect the relationships involved. Farber (1968:174) reports the greatest effect when the handicapped and non-handicapped siblings are close in age. Graliker et al (1962:838) concur stating that there is little effect if siblings are ten or more years older than the handicapped child. Age itself plays a vital role. When siblings are young, they interact on an equalitarian or playmate basis. As they become older, the non-handicapped child takes the superordinate role (Farber et al, 1960:3). Adjustment in family life cycle is common "...whereby the retarded child (regardless of birth order rank) becomes the youngest child socially and never matures (Farber 1968:174). The oldest female appears to be affected to a greater extent than other siblings (Darling, 1979:62). Increased role tension and conflict with the mother may be a result of the daughter assuming part of the "caregiver role" (Farber et al, 1960:3; Fowle, 1968). Increased burden of care is a very real stressor for the normal sibling and not limited strictly to the female (Gath, 1972; Holt, 1957; Schonell and Watts, 1957). Roger Meyers (1978:36) in his book, Like Normal People, describes this responsibility as a weight he carried around in his head for many years. He knew his brother needed attention and he had to provide it.

Gath (1972) found no long term adverse reactions after comparing children with handicapped siblings and control groups of all normal children. Willer et al (1979:41) found tension and anxiety but no serious problems for normal brothers and sisters of impaired siblings. The parent attitude toward the handicapped child may be the key factor in the reactions of the normal children in a family. When the parents

accept the child, the siblings will follow with no disturbing behavior in home or school (Graliker et al, 1962). Farber (1968:174) found siblings who interact with a retarded brother or sister tend to be "oriented toward the improvement of mankind and the enhancement of social welfare." Samit et al (1980:219) describe the sibling relationship as being exemplified by loving devotion. These findings correspond to a recent report which states that siblings either become involved with the cause, advocates of the handicapped, or pull away from the problem (Meadow, 1980:137).

Support Systems

Frank J. Menolascino, M.D. (as quoted in Meyers, 1978:29-30) stresses two aspects will facilitate the coping ability of parents of handicapped children "...you've got to be able to handle stress well...[and] you've got to have good support systems--brothers, sisters, and cousins you can turn to and good professional service..." Support systems may alleviate many of the stressful elements which burden families in this situation. The following systems will be reviewed for their beneficial impact on the family unit: family and friends, religion, the professional, and the parent support group.

Friends and Relatives

Jacobsen and Humphrey (1979:58) report parents of handicapped children say they need "more supports than the average families." Another study suggests the fewest problems are found in situations in which interested friends and relatives are willing to help (Darling, 1979:71). Yet a contradiction to this was found in research by Farber et al (1968:2) in which it was concluded neighborliness and frequent

contact with friends may have contributed to marital disruption rather than providing support for these problem families. This may have happened because, "Sometimes family and friends are critical of the parents' childraising ability and see it as the root of the problem" (Samit et al, 1980:218).

The role of the grandparents as a resource and support agent for the family has been studied by Berns (1980). The initial reaction of many grandparents may match that of the parents--mourning and then rejection. These negative feelings are sometimes masked by oversolicitous and overprotective behaviour which can reduce the child's growth toward independence. According to Berns, grandparents can be an important factor in the network of resources for the family by giving emotional support, financial aid, and enlarging the child's world. Frequent interaction with the wife's mother appears to be more beneficial than interaction with the husband's mother (Farber, 1968:162; Farber et al, 1960:2). It is interesting to note that the beneficial effect from the mother-daughter relationship seems to come not from the child care assistance of the mother but from her emotional support (Farber et al, 1960:2).

Religious Factor

Religious belief may be an important variable in parental acceptance of a handicapped child (Zuk, 1959, Zuk, 1962; Zuk et al, 1961). While searching about for an answer to the ageless question, "Why me?" many people turn to religion or deep philosophical meanings (Drotar et al, 1980:204). Bray (1980:162) reports that more than sixty percent of the families in his study turned to religion for comfort. The doctrine of the particular religious group, however, may influence

the parent either positively or negatively. Some faiths view a defective child as "...a punishment for sins, an indication of unworthiness in the eyes of the deity" (Smith and Neisworth, 1975: 182). Nigerian mothers, for example, think the handicap is caused by unknown evil forces (Ojofeitimi and Oyefeso, 1980:102). Conversely, others view the child as "...a special gift of God bestowed on the parents" (Zuk, 1959:145). Catholics, some researchers have discovered, may be more accepting of their handicapped child than Protestants or Jews because their religious doctrine absolves them of all guilt (Zuk, 1959; Zuk, 1962; Zuk et al, 1961). Other reports, on the contrary, show Protestants and Catholics as equally accepting (Jordan, 1962) or Catholics as evidencing even more anxiety and guilt than Protestants (Boles, 1959).

Religion also affects the parental decision to institutionalize the child with a disability (Mercer, 1966:21). Christian belief waivers between personal duty to the disabled and recognition of the dignity of all human life to proclaiming the impaired child as an unfortunate reminder that the parents have been "cursed by the devil" (Meadow, 1980: 159). The traditional Hebrew belief that infirmity is the result of the sin of the individual or the parent, coupled with the high success orientation of Jewish people, has led many Jewish couples to opt for the out of sight, out of mind approach. Doctrine, however, has been discounted by some researchers as the important variable in this decision. Instead, the apparent acceptance and influence of strong beliefs may only indicate integration into a strong social network (Darling, 1979:49; Kolin, 1971:1015-18).

The Professional

Professionals, both physicians and educators, play an extremely important role as support systems providing services, knowledge and comfort. Therefore, professionals not only need expertise in their particular area but also counseling skills (Steinberg, 1980:180; Wolraich, 1982:324) and a general knowledge of the availability of a range of resources and services (Justice, 1971:690). Professionals make a tremendous contribution at the time of the first diagnosis of the child's condition by helping parents deal with their own feelings (Anderson and Garner, 1973:39). As Samit et al (1980:221) state, "Parents need hope; they are nourished by it." The role of the professional, then, is to maintain a delicate balance between unrealistic optimism and grief. In doing this, professionals need to reject labelling and categorization (Steinberg, 1980:178) and to discard ideas about stages and limited adjustment (Searl, 1978:F27).

The parents' readiness to accept new ideas and techniques depends on both the knowledge and the sensitivity of the professional staff (Samit et al, 1980:222). Meadow (1980:14) points out parents need a certain level of education to effectively communicate with professionals. However, it can be argued this is the problem of the professional and not the parent. Parents tend to want to be equal partners (Steinberg, 1980:177; Wikler, 1981:287) on an interdisciplinary team composed of physicians and educators in which coordination is the key element (Howard, 1982:319; Mullen, 1975:125) so that gradually the "pieces of the puzzle begin to fit together" (Mullen, 1975:126). As a result parents may take issue with professionals when the parents are not satisfied with what is happening. This, however, will require

"a lot of emotional stamina" for the parents "to talk back to professionals" (Bennett, 1981:25).

The Physician

The manner in which the parents become aware of their child's disability is viewed as greatly affecting their early reactions (Schonell and Watts, 1956:212; Zuk, 1962:406). Physicians may sometimes be evasive about the child's condition, seeking to "protect" the parents (Darling, 1979:132). Davis (1960:44) states that some doctors would rather have parents find out for themselves in a "natural way." In the delivery room, mothers may have "suspicion awareness" that something is wrong yet no one will tell them anything (Darling, 1979:54). Stress among mothers is highest when they start suspecting something is wrong with their children and no person in authority will discuss their suspicions (Anderson and Garner, 1973:39; Bruhn, 1980:159).

Feelings of inadequacy, on the part of the professional, may make the adjustment process more difficult for the parents whose anxiety can increase because the doctors will not confirm a diagnosis (Anderson and Garner, 1973:39; Darling, 1979:58). Professionals may deny the existence of a problem because they too feel anxiety (Smith and Neisworth, 1975:184). People have placed doctors in an omniscient and omnipotent role (Wolraich, 1982:325), and it is difficult for many to admit incompetence or failure. In a study of pediatricians, many admitted they did not like working with handicapped children because they could not cure the problem (Darling, 1979:24; Howard, 1982:317).

Rather than softening the blow, some professionals, however, brutalize parents with their frankness. Many parents reveal doctors have encouraged them to let the child die or to institutionalize it

immediately after birth so the family would suffer as little as possible (Anderson and Garner, 1973:39; Bennett, 1981:21; Brown, 1976:40; Darling, 1979:27; Gross, 1980:113; Meyers, 1978:58; Wolraich, 1982:324). There are many stories of parents not being adequately directed by the physician (Anderson and Garner, 1973:37). Many mothers recall feeling confused about the diagnosis because the doctor was brief in his explanations, obviously wanting them quickly out of the office. Yet, this is clearly one of those times in doctor-patient relationships which calls "for an unusual knowledge, skill, wisdom, and humanity, and more than a little time spent with the parent" (Anderson and Garner, 1973:39). The "bedside manner" of the physician, as typified in the paintings of Norman Rockwell, has been ignored during the technological advances of medicine in the last two decades, yet the importance of this approach is now being rediscovered (Wolraich, 1982:326).

Initially parents are dependent on the doctors, yet rarely do the physicians remain "significant others" for an extended period of time (Darling, 1979:23-4). The period between birth and diagnosis of a problem is one of "immense anxiety and uncertainty" which can lead to even greater problems if left undiagnosed (Steinberg, 1980:178). Since parents may lose faith in their doctors because of their inability to cure the problem, many parents go through a process called "seekership" or shopping (Darling, 1979:24; Howard, 1982:317; Slaughter, 1960:3; Smith and Neisworth, 1975:186; Solnit and Stark, 1962:530) in an attempt to find someone who can help the situation. In a study in Philadelphia, Pennsylvania, Zuk (1959:145) found parents rejecting the diagnosis, not the child. This rejection is then transferred to the one who evaluated the child, namely, the professional.

Shopping, in the traditional sense, directs criticism toward the parent for refusing to accept the truth. The family is seen as looking for a suitable doctor with an appropriate diagnosis (Huber, 1979: 268). Unwilling to accept reality, they go from professional to professional, or even worse to pseudo-medical sources such as practitioners of acupuncture or faith healers looking for a magical cure (Meadow, 1980: 134; Smith and Neisworth, 1975:186). Recently, several researchers have speculated that this phenomena needs reexamination, that possibly the parents should be absolved as perpetrators of this action and criticism directed instead at the professional. Anderson and Garner (1973:36) see professionals as possibly causing this behavior because of their attitudes and techniques. Keirn (1975:87) believes parents are defined negatively for seeking a second opinion. If the term "shoppers" is applied only to those who seek a third opinion, the number of "shoppers" becomes relatively low, three percent. The term as currently used then reflects a negative professional bias and it obfuscates the larger problem, the parent's request for help (Keirn, 1975:87).

The attitude of the physician is crucial because he is the acme of socially approved health services (Willner and Crane, 1979:59). There are, therefore, many implications for doctors in terms of pediatric management (Drotar et al, 1980:204). The physician must have knowledge about children with handicaps. He must have an accepting attitude and the skill to communicate with parents (Wolraich, 1982:324). This relationship is vital. As Bruhn (1980:159) reports, communication is sometimes the best treatment. The medical profession is just beginning to realize that patients are not isolated units and that the

family situation must also be considered because it has a direct impact on the prognosis of the patient.

The Educator

In a recent survey, researchers (Suelzle and Keenan, 1981:270) found parents, at all ages of their handicapped child's life, sought recommendations of school personnel to a greater extent than any other professionals. This presents a challenge to educators. With the trend toward deinstitutionalization, home care, and mainstreaming, schools will have even greater contact with the handicapped and their families (Wikler, 1981:287). Teachers will have the greatest contact with the child and the parents, and thus educators can be a vital link to other support personnel. This role, says Mullen (1975:126), will be one of noting symptoms, not diagnosing, and of sharing mutual concerns with the parent, leading to other professional assistance.

This function of educators is complicated by the fact teachers tend to perceive handicapped children more negatively than normal children (Green et al, 1979:829). No matter what the teachers' educational background or age or sex, pupils are evaluated in a descending "pecking order"--"gifted," "normal," "physically handicapped," "learning disabled" and "emotionally disturbed." Even when controlling for types of educators (e.g., aides and specialists) and for types of schools (public versus private institutions), a significant difference in acceptance and rejection of pupils based on their perceived normality still remains.

The family, as an institution, has passed on many of its responsibilities to other elements in society. The educational system, as one recipient of former duties of the family, has adopted the family's

developmental expectations but geared them to a grade level (Suelzle and Keenan, 1981:266) system which has not only become standardized but set in concrete. The resulting inflexibility has created frustration for many parents of handicapped children. The mother of a Downe Syndrome child expressed this feeling sharply when she said,

The point is not when one learns something, but that he learns it, if he can. Worrying about whether a child will feel out of place if he is taller or older than the rest is silly and wasteful. Octogenarians can start college, and people can learn any time they're ready. The purpose of schools is to make learning possible, not to reinforce artificial distinctions. (Bennett, 1981:25).

Parent Support Networks/Parent Associations

A feeling of isolation is a common complaint among parents of handicapped children (Darling, 1979:57; Heisler, 1972:8). Mothers even report being separated from other mothers in the hospital following the birth of a handicapped child (Darling, 1979:57). The physical isolation, however, is not as extreme as the emotional isolation. A parent of a handicapped child said, "I think it is important to know someone, (a mother) who has already been through what you've been through." She added that it is important to learn that one's reactions are normal--"...that mourning is normal and that having difficulty is normal and feeling crazy is normal" (The Exceptional Parent, 1978:F17). The mother of another handicapped child in the early 1950's described the situation in this way--"We didn't know where to go or where to turn. We felt, I felt, so lost and alone" (Meyers, 1978:30).

Group therapy or support networks of parents of handicapped children have been recommended by many researchers to alleviate the problem of isolation (Darling, 1979:24; Greenberg, 1950; Heisler, 1972:8).

Parents need emotional support in an accepting environment (Meadows: 1980:134). They need to be able to ventilate their hostilities, worries and sorrow within a therapeutic network of concerned individuals (Dempsey, 1975:128; Huber, 1979:268; Samit et al, 1980:214). Those parents who are successful in coping with a handicapped child make excellent models for the novice or the unsuccessful (Bray, 1980:162; Steinberg, 1980:177; Suelzle and Keenan, 1981:268). New participants in these therapeutic and support networks can ease the transition from recognition to acceptance of the problem through a process of "anticipatory socialization" (Suelzle and Keenan, 1981:268) in which they are prepared for potential crises (Wikler, 1981b:287) by being "in contact...with persons [already] functioning in the role" (Suelzle and Keenan, 1981:268).

A parent association may be a sounding board for ideas (Darling, 1979:24). Families describe being in an "information vacuum" (Suelzle and Keenan, 1981:269) and becoming immobilized because of a "fear of the unknown" (Berns, 1980:238). Further frustrated by the strange medical terms (Bray, 1980:162), the parent cannot find the answers in the usual manner by calling the next door neighbor or opening a copy of Dr. Spock (Berns, 1980:238). Thus, the group composed of parents sharing a similar problem allows for exchange of information about childcare, schools, physicians, and support services available.

Besides the emotional support and information sharing, parent associations can become power coalitions for needed social change. The following is a quotation from an interview with Laura Sparks Bloom, a leading advocate, for improved human services, who describes her reasons

for wanting to start a parent group in the nineteen-forties.

Whenever I went to the store or walked in the city, I saw children who were retarded. Yet, the school system and the government said there weren't enough retarded children around to make it worthwhile to start programs. So I thought, if we could get together we could change their minds (as quoted by Meyers, 1978:76).

As parents become effective "agents of change" (Samit *et al*, 1980:216), they may find themselves in positions of leadership (Searl, 1978:F28). Caution though in assuming such a role must be exercised, for as Wikler (1981:282) warns, parents must be sure of their own attitudes before they take up the banner of advocacy. One mode of action may be "parental entrepreneurship" in which parents become crusaders for the rights of the handicapped (Darling, 1979:24). Berkowitz (1980) supports this idea in his article dealing with the advocates of mental retardation legislation.

Steinberg (1980:177), reporting the results of a conference attended by mothers of handicapped children from all over Australia, states that no matter what the handicapping condition, the problems are the same for the mothers. She emphasizes parents should band together as a united front rather than segregating into isolated groups. This type of coalition, she argues, can help to change community attitudes and improve services for everyone.

Hypotheses

The review of the literature reveals certain factors that highlight the areas in need of research. The negative attitude towards the handicapped that is prevalent in society may affect the parents' feelings about themselves and their handicapped children. The presence of the handicapped child may affect the family members in their other

relationship within the family. This influence may be especially noticeable in its affect on the marital relationship and the decision to have additional children. As the literature emphasizes, support systems may be the critical factor in the family's ability to cope with the stress of having a handicapped child. Of the areas discussed, religion and education would be the most comparable experiences for control group testing. The foregoing assumptions lead to the development of the following hypotheses to research:

1. The parents of handicapped children have a lower self rating than do other parents.
2. The parents of handicapped children have a lower level of life satisfaction than do other parents.
3. The parents of handicapped children have a more negative emotional reaction to their children than do other parents.
4. The parents of handicapped children less frequently report that they enjoy parenthood than do other parents.
5. The parents of handicapped children report more marital disruption resulting from the children than do other parents.
6. The parents of handicapped children have fewer children than do other parents.
7. The parents of handicapped children more often report frequent church attendance than do other parents.
8. The parents of handicapped children more frequently report disappointment with their children's teachers than do other parents.

CHAPTER II

METHODOLOGY

The Pilot Study

A pilot study was conducted in 1980 (Springs et al, 1981) with reference only to families with handicapped children. Two assumptions were stated:

1. The presence of a handicapped child has a negative impact on the family, in general, and the attitude of the parents, in particular.
2. Fertility is expected to diminish or cease following the birth or presence of a handicapped child in the family.

Based on the second assumption, a distinction was made between those parents who had additional children after the birth or presence of a handicapped child and those who did not. Following the reasoning of the first assumption, it was predicted that parents with additional children after having a handicapped child would have a more positive attitude than those who opted not to have additional children in such circumstances.

A questionnaire (see Appendix A) developed by Loyd Wright of Southwest Texas State University was administered originally to thirty-three families in Central Texas with a handicapped child. A non-random sample was conducted to gather the data. Included in the questionnaire were attitudinal scales also provided by Dr. Wright, who had drawn them from previous research on drug abuse problems among college undergraduates (Wright and Moore, 1982). The scales included a Self Rating Scale (see Appendix B) and a Life Satisfaction Scale (see Appendix C).

The Self Rating Scale contained twenty-four items in which parents were asked to respond to a series of adjective pairs, such as "rigid-flexible," describing their attitudes. The respondents, using a five point scale, checked a point on a line between each pair of adjectives which best described their attitude. Each set of adjectives were regarded as containing polar opposites. Hence, responses were calculated with the most positive response carrying a maximum weight of five and the most negative response weighted zero. The Self Rating Scale made no reference to the presence of a handicapped child in the family. The Life Satisfaction Scale contained eight statements which either positively or negatively related to life satisfaction, and, once again, with no mention of a handicapped child. Answers were coded using a Likert format.

Included in the questionnaire were items to secure demographic data on each family and also questions pertaining to the handicapped child in the family. Within the body of the questionnaire was an Emotion Scale developed to measure the frequency of negative reaction (e. g., shame, depression) felt by the parent pertaining to the handicapped child. Parents responded to a list of seven negative emotions by checking categories ranging from "frequently" to "never" experienced. The list of emotions was scored as a Likert scale with the response of "frequently" carrying a maximum point value; therefore, the more negative the emotional reaction to the handicapped child, the higher the scale score. Finally, the attitude toward being the parent of a handicapped child was measured with a single question: "How do you feel about being a parent of a handicapped child?" An ordinal check list accompanied the question with categories ranging from "I enjoy it" to "I hate it."

Although all of the initial hypotheses were rejected in the preliminary study, interesting findings did point to future research in several areas. The review of the literature had led to an expectation that mothers would be more emotional than fathers about a daughter being handicapped and, in a similar fashion, the fathers about a son. The pilot study did disclose a tendency present for each parent to manifest more negative emotion toward a handicapped child of his or her own sex. The difference was found to be significant for mothers, but not for fathers. Additional analyses revealed the mother's attitude to be significantly affected by both the sex of the child and the type of disorder, namely whether it was genetic or non-genetic. Mothers were more negative toward children with genetic than non-genetic disorders. Moreover, when evaluating themselves, mothers, who had handicapped children with genetic disorders, produced higher self rating scores if they had additional children. On the other hand, mothers who had handicapped children with non-genetic disorders scored higher on self rating if they had no additional children. Again highlighting the impact the genetic link may have on the parents' attitude, it was found that mothers had a lower self rating if they had a female rather than a male child with a genetic disorder. These findings emphasize that individuals may identify more readily with a child of their own sex and that this significantly affects how parents respond to a handicapped child. Also, these findings accent the fact that parents may manifest a greater guilt reaction if there is a genetic link to explain the child's disability.

A flaw in the preliminary study was the absence of a control group. The effect the handicapped child has on the family unit might be better

understood if there was a basis of comparison. With this in mind, plans were made to expand the original survey to include families in which no handicapped child was present.

The Research Instrument

In order to make a comparative analysis, a modified instrument was necessary as well as a control group. The original instrument was lengthy and contained questions which were inappropriate for the control group. Biographical questions were left in their original form, as long as they did not refer to the presence of a handicapped child. When this type of reference was present in the original form, the questions were either deleted or modified. An example of a deleted passage, would be one referring to the onset or severity of the handicap. In some cases, the wording was changed to make the question acceptable to a general audience. Thus, the passage, "Describe the effect a handicapped child has had on your marriage," was altered to read, "Describe the effect a child has had on your marriage" (see Appendix D).

The attitudinal scales were the same as those used in the pilot study and were described in the previous sub-section. The variables derived from these were once again, self rating scores, life satisfaction scores, and an emotion score. For the control group, the scales were used verbatim with the exception of the preface for the emotion scale. This preface originally read, "Check the frequency with which you have experienced the following emotions as a result of being a parent of a handicapped child." The sentence was revised so as to end with the word "parent" and delete the phrase "of a handicapped child."

Since all references to a handicapping condition had been deleted from the questionnaire for the control group, a question was added to the questionnaire asking whether any of their children had a handicap. If the answer was yes, they were to list the child's age, sex, and handicapping condition. This information was necessary to assure the sample population drawn as a control group did not inadvertently include an inappropriate family unit.

Data Collection

The control questionnaire needed to reach the general population with one limitation. The respondents needed to have children living at home. Hence, the public school system was utilized as the source of contact for the distribution of the questionnaire. The research was limited to a small town in Central Texas which contained only one elementary school. The population of the school district was heterogeneous in terms of ethnicity and socioeconomic status.

Elementary school students received the questionnaires and took them home to their parents or guardians. A cover letter was attached assuring the respondents of anonymity and confidentiality. To refrain from affecting the results of the research, no mention was made of the nature of the study. Instead an explanation was given stating that the research concerned families. To assure only one questionnaire would be sent to each family, advance work was done with school administrative staff to limit distribution of the questionnaires in families in which there was more than one child in the school.

Only one parent in each family was asked to fill out the questionnaire. It was to be sealed in an envelope, which had been provided, and

returned to the elementary school. The instruments were collected from the elementary staff by the researcher with a return rate of approximately eighty percent. The responses were then coded and added to the data file from the pilot study. Those families without handicapped children became the control group. The general survey totalled forty-two respondents who did not have a handicapped child in the family and increased by two the number in the experimental group as well.

During the same period, families with handicapped children were contacted through special education classes in the public school system. All the families who were contacted agreed to fill out the questionnaire and scales. With the addition of the new data, the number of respondents in the experimental group totalled forty-nine.

Data Analysis

The independent variable in all eight hypotheses was the distinction between the parents of handicapped children and the parents of non-handicapped children. In all, there were eight different dependent variables. Those dealing with parent attitude were self rating, life satisfaction, and emotional reaction. Others dealt with family situations such as marital disruption, number of children, and enjoyment of parenting. Finally, the variables relating to support systems were frequency of church attendance and attitude toward teachers.

In four of the hypotheses, the dependent variables from the questionnaire were either interval or ratio. They included the three attitudinal scales, the question dealing with the number of children. These hypotheses were tested by a comparison of means for the two types of parents with a t-test performed on the significance of the difference between the means. Since the dependent variables in the other four

hypotheses were either nominal or ordinal, a cross tabulation was performed and a chi square computed to test each of these hypotheses.

CHAPTER III

FINDINGS AND CONCLUSIONS

Descriptive Statistics

A total of ninety-one persons responded to the questionnaire. Ranging in age from twenty-two to sixty-seven, the median age for the parents was thirty-four. An overwhelming majority of those responding, equalling almost eighty percent of those surveyed, were female. Although the range of educational attainment was great, less than ten percent claimed only primary level education. In the high school level and college level categories, a fairly even distribution was present with more than forty percent in each category. A majority of the respondents claimed to be middle class. When the classification working class is also considered, the combined total comes to almost ninety percent. Concerning economic conditions, most stated they were satisfied economically. In terms of religious membership, nearly three-quarters of those surveyed claimed to be Protestant, another one-quarter stated they were Catholic, and a few responded as having no preference. Finally, the families represented had between one and ten children with over ninety percent having four children or less.

Over one-half of the respondents had a handicapped child in the family. In terms of that child, sixty percent were male. When birth order was considered, over sixty percent of the handicapped children were either the youngest or the only child in the family. Of the

many conditions named, when grouped into broad categories, there were more mentally handicapped than physically handicapped children. A small percentage of the children needed to be grouped into the category "multiply handicapped."

Inferential Statistics

Hypothesis One predicts that parents of handicapped children will have a lower self rating than other parents. As the first table illustrates, there is no statistically significant difference between the means of the self rating scores of these two groups of parents; therefore, this hypothesis must be rejected. However, a comparison of the self rating scores for each category shows a slightly more positive rating for the parents of non-handicapped children, thus the tendency was in the right direction even though the findings were not significant.

TABLE 1
MEAN SELF RATING SCORES BY STATUS OF PARENTS

Status of Parents	Self Rating Scores		
	N	Mean	Difference Between Means*
Parents of Handicapped	48	3.74	0.10
Other Parents	40	3.84	
Total	88	3.78	

* $P > .05$ (t-test)

The Second Hypothesis states that parents of handicapped children will have a lower level of life satisfaction than other parents. Again, the difference in mean levels is not statistically significant; therefore, this hypothesis too is rejected (see Table 2). Also, the tendency of the results is in the opposite direction of that predicted in the hypothesis.

TABLE 2
MEAN LIFE SATISFACTION SCORES BY STATUS OF PARENTS

Status of Parents	Life Satisfaction Scores		
	N	Mean	Difference Between Means*
Parents of Handicapped	44	3.64	0.05
Other Parents	38	3.59	
Total	82	3.61	

*P > .05 (t-test)

The prediction in Hypothesis Three anticipates a more negative emotional reaction from the parents of handicapped children than from other parents. The data in the third table does match this prediction. In this case, the higher the score, the more negative the reaction. The difference in mean scores for the two sets of parents is statistically significant and is in the expected direction. This hypothesis is not rejected as Table Three illustrates.

TABLE 3
MEAN LEVEL OF NEGATIVE EMOTIONAL REACTION
BY STATUS OF PARENTS

Status of Parents	Level of Negative Emotional Reaction		
	N	Mean	Difference Between Means*
Parents of Handicapped	46	1.77	
Other Parents	35	1.49	0.28
Total	81	1.65	

* $P < .05$ (t-test)

Hypothesis Four states that the parents of the handicapped will less frequently report they enjoy their parental experience than will other parents. As Table Four indicates, less than a third of the parents of the handicapped say they enjoy parenthood, while almost all of the other parents say they enjoy being parents. The pattern is both distinctive and statistically significant; therefore, the fourth hypothesis is not rejected.

It was anticipated in the Fifth Hypothesis that the parents of the handicapped would report more marital disruption than other parents. An examination of Table Five reveals that half of all parents reported the presence of the children in the family strengthened the marriage, while one-fifth reported the children caused problems in the marriage.

TABLE 4

FEELINGS ABOUT BEING A PARENT BY STATUS OF PARENTS*

Parental Feelings	Status of Parents					
	Parents of Handicapped		Other Parents		Total	
	N	%	N	%	N	%
Enjoy it	12	29.3	38	92.7	50	61.0
Do Not Enjoy It	29	70.7	3	7.3	32	39.0
Total	41	100.0	41	100.0	82	100.0

*P < .05 (Chi Square)

TABLE 5

AMOUNT OF MARITAL DISRUPTION ATTRIBUTED TO THE CHILDREN
BY STATUS OF PARENTS*

Amount of Marital Disruption	Status of Parents					
	Parents of Handicapped		Other Parents		Total	
	N	%	N	%	N	%
Caused Problems	15	33.3	2	5.3	17	20.5
Little Effect	13	28.9	12	31.6	25	30.1
Strengthened	17	37.8	24	63.2	41	49.4
Total	45	100.0	38	100.0	83	100.0

*P < .05 (Chi Square)

When the two groups of parents are examined separately, however a major difference emerges. Fully one-third of the parents of the handicapped reported problems while only a small fraction (5.3%) of other parents admitted to problems. The pattern is statistically significant; therefore, Hypothesis Five cannot be rejected.

The question of family size limitation was broached in Hypothesis Six. This hypothesis predicts that parents of handicapped children will have fewer children than other parents. Although among the families studied there is a marginal difference in the right direction, it is not statistically significant; thus, the hypothesis must be rejected.

TABLE 6
MEAN NUMBER OF CHILDREN BY STATUS OF PARENTS

Status of Parents	Number of Children		Difference Between Means*
	N	Mean	
Parents of Handicapped	48	2.6	
Other Parents	42	2.7	0.1
Total	90	2.6	

* $P > .05$ (t-test)

In reference to the presence of a support system, Hypothesis Seven predicts more frequent church attendance for parents of the

handicapped. On the questionnaire, there was an ordinal checklist of church attendance ranging from "never" to "at every opportunity." During the statistical evaluation, because of the small cells, these five categories were collapsed to two categories, "less" and "more." As Table Seven indicates, the frequency of church attendance of parents with disabled children compared to other parents is in the expected direction; however, there is no statistically significant difference. Hypothesis Seven must then be rejected.

TABLE 7
FREQUENCY OF CHURCH ATTENDANCE BY STATUS OF PARENTS*

Church Attendance	Status of Parents					
	Parents of Handicapped		Other Parents		Total	
	N	%	N	%	N	%
Less	18	42.9	19	45.2	37	44.0
More	24	57.1	23	54.8	47	56.0
Total	42	100.0	42	100.0	84	100.0

* $P > .05$ (Chi Square)

The professional as a support system was studied in Hypothesis Eight. It was predicted that parents of the handicapped will more frequently report disappointment with their children's teachers than other parents. As Table Eight illustrates, the findings were not statistically significant and the tendency was in the wrong direction; thus, the final hypothesis must be rejected.

TABLE 8

PARENTAL DISAPPOINTMENT WITH TEACHERS BY STATUS OF PARENTS*

Parental Disappointment With Teachers	Status of Parents					
	Parents of Handicapped		Other Parents		Total	
	N	%	N	%	N	%
Not Disappointed	13	26.5	6	14.3	19	20.9
Disappointed	36	73.4	36	85.7	71	79.1
Total	49	100.0	42	100.0	90	100.0

* $P > .05$ (Chi Square)Discussion

When comparing the self rating scores and the life satisfaction scores between the two groups, no statistically significant difference was found for Hypotheses One and Two. The reason for this may have been highlighted in the preliminary research when it was noted that sex of the child and genetic implications may greatly affect the scores. Therefore, attitudinal differences between the two sets of parents may be affected by variables not considered in the present research. Another explanation may be that the parents learn to be more optimistic after the initial crisis period is over, and thus they were more accepting of the situation by the time the study was conducted.

The prediction of a more negative emotional reaction (Hypothesis

Three) to parenthood by those with a disabled child was, however, supported by the data. The explanation for this may rest with the nature of the measures employed. The Self Rating Scale and the Life Satisfaction Scale make no reference to children or the parental experience at all. The parents of non-handicapped children were asked to respond in terms of their reaction to being a parent. The parents of a handicapped child, on the other hand, were asked to respond to their reaction to the handicapped child specifically.

A similar explanation may apply to the difference reported regarding the "enjoyment" of parenthood (Hypothesis Four). The parents of the handicapped were asked how they felt about being parents of a child with a disability. For other parents, the question was non-specific. The direct references to the handicapped child may have elicited more negative responses than references to children in general.

The significant differences reported in testing Hypothesis Five may well reflect the impact of the handicapped child on the marital relationship. It is certainly understandable that the emotional and economic strain created by the presence of an impaired child could undermine a relationship. The items which were used to check the respondents' views of the effect children have had on their marriages clearly indicated the presence of a handicapped child is perceived as having a negative impact on the marital relationship. In this connection, the role of the father in the marital breakdown is deserving of further study. As the comments indicated, there may be a communication problem as the father becomes less involved with the family. Variables affecting his behavior should be researched to a greater extent. Furthermore, with a larger sample, the incidence of divorce among the parents of

handicapped children might be compared to the divorce rate for other parents.

The anticipated difference in family size for the two family groups in the study did not appear as predicted in Hypothesis Six. Since this assumption was not supported by the data, perhaps even though there may be economic and emotional strain, some parents of a disabled child may have another child as a form of compensation. Probably, many variables affect this decision. The preliminary research indicated higher self rating scores when there were additional children if the disorder was non-genetic. It may also be that parents perceive the presence of a younger child in the family as having a positive effect on the handicapped child. Demographic fashions in child bearing, as well as social and psychological explanations, may also be influential. Most of the parents studied in either group had only two or three children. The contemporary cultural norm in family size encourages small families, a fact which provides only limited opportunity for the handicapped child to influence subsequent fertility. In this study, over sixty percent of the handicapped children were either "last born" or "only children." Whether this position was a trick of nature or an active decision on the part of the parents is deserving of further study.

Church attendance was probably a poor choice to represent involvement in a support system (Hypothesis Seven). The findings were not statistically significant. As the comments of the respondents verified, they are very much involved with the religious belief system and rely on it for emotional support, but regular church attendance may be impossible for many of them with their ongoing childcare responsibilities.

Hypothesis Eight predicted parents of the handicapped will report disappointment with their children's teachers to a greater extent than other parents. Teachers, rather than medical professionals, were chosen as significant support personnel for this study because it was felt there is a more comparable relationship for the two groups of families to these individuals. The predicted difference in parental relations to teachers was contradicted in comments from the respondents, who described teachers as being helpful and supportive of both handicapped and normal children.

Comments from Parents

The original questionnaire was partially open-ended, allowing for comments and suggestions from respondents. The information garnered in this way will be shared in this section, not in an empirical manner, but as generally consistent with the literature and supportive of the research. Focus will be on the comments of the parents of the handicapped, who had a number of common themes they wished to stress.

The question voiced most often was "Why me?" and, secondly, "Why my child?" For some there was disbelief this could be happening to them. Parents not wanting to admit there was a problem had tremendous support for this view from family, friends, and professionals who were at the ready with the classic, "He will grow out of it." For others, there was anger and a resentment of normal children.

The respondents reported males had a greater difficulty than females in accepting the diagnosis of a handicapped child. They were often described as being embarrassed about their child, as being unsympathetic, and as isolating themselves from their families by becoming workaholics. One father reportedly refused even to see his

multiply handicapped child until eight months after its birth when it was near death. One reason for this negative reaction of many fathers may be society's success and achievement orientation which has been traditionally socialized into most males. Hence, fathers of handicapped children may see such children as public evidence of failure. The other critical factor may be that eighty percent of the respondents were female and their comments may be a reflection of displaced anger at those males who have not shared in the burden of the care.

Second, only to fathers, as objects of critical comments, were the medical professionals. Many parents blamed doctors for problems which developed during pregnancy or at birth. Doctors reportedly, at times, ignored symptoms, thereby forcing the parents to convince the physicians something was wrong. Some admitted to parents they would rather not treat a handicapped child because there was no cure. Others brutalized parents with their frankness by urging institutionalization. These negative feelings toward the physician may in some cases be justified. Another partial explanation, however, may be redirected hostility of the parents towards the one who has made the diagnosis rather than aiming the anger at the child or the diagnosis itself.

A large number of parents referred to their religious beliefs as they sought an explanation of the problem or a way to cope with the stress. A small number viewed their child's condition as God's punishment for their past sins. Most, however, viewed it in a positive manner as God's will or a blessing. The typical comments ranged from acceptance, "I love my child and I am not disappointed having her as God sent her, to joy, "We feel very lucky that God gave us this precious angel to take care of. He is the joy of our lives. He couldn't be loved more by us

or our families. We have truly been blessed." Religious belief systems appear to be an important emotional support for many of the respondents.

Advocacy or parental entrepreneurship was a viable outlet for many of the parents and siblings. A number reported becoming special education teachers or assuming other positions in the educational system, either as a professional or on a voluntary basis. Some explained they had started parent groups or associations to aid and support the handicapped and to help themselves. The idea of activity or the need to do something seemed to be as important to some people as the cause. As one mother commented, the crisis with her own child had made her more sensitive to the problems of others and she wanted to help in any way she could.

A common concern voiced, especially by those with children nearing their teens, was the problem of independence and acceptability. A mother of a mentally retarded daughter was troubled over the problem of birth control. A father stated he was more embarrassed as his child got older and the discrepancies became more apparent. However, the biggest worry was the future, "What will happen when I'm gone?" With this in mind, many parents stated they had made special provisions for care or were stressing independence training.

Many respondents wished to share their experiences. They often stressed the importance of sharing feelings with a spouse, a friend or in a parent group, and to recognize it is normal to cry and feel hurt, but not to isolate yourself or your child. Repeatedly, the parents emphasized, "Don't hide your child!" Though honestly admitting the difficulties, many parents evidenced a remarkably positive attitude, as characterized in this statement by the mother of a multiply

handicapped, five year old boy: "Although there are extra pressures and anxieties with 'John', there is also greater love and understanding of life because of him."

The most common advice was to "Take one day at a time." This comment repeatedly surfaced on the questionnaires. By way of explanation, some remarked they had learned to be thankful for the good things in their lives and they lived each day to its fullest.

Implications for Future Study

In terms of future research, a number of variables need more attention. The significance of the degree or severity of the handicap and the genetic/non-genetic link on parental attitudes need to be closely studied. The decision to limit or increase family size when a handicapped child is present should be examined in more detail. Physicians' attitudes, with emphasis on the pediatrician, need to be studied in depth with implications for practical intervention of the findings into the medical school curriculum. The role of the father, as well as other family members, should be further researched, not only for scholarly information and insights, but for practical suggestions for those doing family counseling.

Childcare is still a major problem for families of the handicapped; from day care to respite care, the needs are great. With the debate still raging over the benefits of home care over that of professional care, many questions related to child care are still left untouched. According to the literature, the saving grace for many parents has been the increase in the number of support groups or parent associations to provide emotional backing, information, and a power coalition as well as a network of resources. In future studies, parent support

groups such as Pilot Parents should be included. Moreover, if the population in future research is well distributed, urban versus rural differences in support will likely be noted.

Finally, there is substantial support for using the crisis orientation which Bernard Farber and many others have echoed in studying parents and their handicapped children. The emotional and economic strain is obviously great for these parents. The key to successful adjustment may very well be the presence or absence of a support system --family and friends, a religious group, professionals, or a parent association. Comparative studies could yield valuable information along these lines. As this study indicates, the questions still remain: what we have yet to find are the answers.

APPENDICES

APPENDIX A
QUESTIONNAIRE

1. Sex (check one): Male____ Female ____
2. Your Age ____ Spouse's Age ____
3. Marital Status (check one):
____Married ____Divorced ____Widowed
____Remarried ____Separated ____Single
4. Formal Education (circle highest level reached);

<u>Primary School Grade</u>	<u>High School</u>	<u>College</u>
6 7 8	9 10 11 12	1 2 3 4 5
5. Employment (check all categories that are applicable):
 - a. Are you presently employed? Yes____; No____; Full time____; Part time____
 - b. Are you any of the following:
____Retired?
____Unemployed?
____A full-time student?
____A part-time student?
____A homemaker?
 - c. What is your occupation? _____
What is your job title and that of your spouse (i.e. Supervisor, Manager, Foreman, Employee, Homemaker)?
Own job title _____
Spouse's job title _____
6. Economic (We are interested in how people are getting along financially these days) So far as you and your family are concerned, would you say that you are (check one):
____Pretty well satisfied with your present financial situation?
____More or less satisfied?
____Not satisfied at all?
7. If you were asked to use one of four names for your social class, which would you say you belong in (check one):
____The lower class?
____The working class?
____The middle class?
____The upper class?

8. Do you have a religious preference? _____
If yes, what is it? _____
If you attend a church or synagogue, about how often do you attend? _____
9. How many people live with you? _____
Please provide the following information on people who live with you:
The ages of your male children _____
The ages of your female children _____
If there are others who live with you, what is their relationship to you? _____
10. Your handicapped child's sex _____; age _____; and handicapping condition _____
11. In your opinion, is your child's handicap very severe _____; severe _____; moderate _____; or mild _____? Please check one.
12. Do you know what caused your child's condition? _____
If yes, please explain briefly. _____

13. How old was your handicapped child when you first became aware that he/she had a problem? _____
14. How did you become aware of the problem? _____

15. What was your initial reaction to this awareness? _____

16. Did you or your spouse ever deny that your handicapped child had a problem? _____
If yes, please explain. _____

17. Did (do) you ever feel responsible for your child's handicap? _____
If yes, please explain _____

18. Did (do) you ever blame others for your child's condition? _____
If yes, please explain. _____

19. Check the frequency with which you have experienced the following emotions as a result of your child being handicapped.

	Never	Occasionally	Frequently
depression	_____	_____	_____
self pity	_____	_____	_____
resentment	_____	_____	_____
shame	_____	_____	_____
guilt	_____	_____	_____
anger	_____	_____	_____
anxiety	_____	_____	_____

20. Check the following sentence which best describes how you feel about being a parent of a handicapped child:

☐ I enjoy it.
☐ I don't like or dislike it.
☐ I dislike it.
☐ I hate it.

21. Check the following sentences which best describes how you feel.

☐ I have recovered from the shock of having a handicapped child and accept my child as he is.
☐ I love my child, but don't think I will every fully recover from the disappointment which accompanies having a handicapped child.

22. Have you received help from your family doctor in obtaining services for your handicapped youngster? Yes ☐ No ☐

23. Check the following sentences which best describe your experience with public school teachers who have taught your handicapped child.

☐ They have helped me a lot.
☐ They have helped my child a lot.
☐ I have been disappointed with my child's teachers.

24. Check the following sentences which best describe your experience:

☐ My relatives have been very helpful in caring for my handicapped child.
☐ My friends have been very helpful.
☐ My relatives have been neither understanding nor helpful.
☐ My friends have been neither understanding nor helpful.

25. Having a handicapped child usually creates additional expenses. Please estimate how much you spent during the last year (or as indicated) for the following:

	<u>Amount Spent</u>
a. special services (tutoring, training, therapy, counseling, etc.)	_____
b. special equipment and materials	_____
c. repairing damage caused by handicapped child	_____
d. medical expenses	_____
e. traveling expenses to obtain special services at .16/mile	_____
f. alterations to house or property to accommodate handicapped child, such as, ramps, fences, etc. (within child's lifetime).	_____

26. Check the following sentence which describe the effects of having a handicapped child on your marriage.

_____ It strengthened our marriage

_____ It had little effect

_____ It caused a lot of problems

_____ It destroyed our marriage

Other comments: _____

APPENDIX B

Self-Rating Scale

Listed below are a number of adjectives which people sometimes use to describe themselves or other people. We would very much appreciate it if you would indicate which of the two adjectives on each line you think describes you best. For example, if one of the pairs were:

ANGRY ____: ____: ____: ____: CALM

and you think of yourself as a very angry person, you would put a mark close to ANGRY like this:

ANGRY X : ____: ____: ____: CALM

If you think of yourself as very calm, put your mark next to CALM, like this:

ANGRY ____: ____: ____: X : CALM

If you think of yourself as a calm person, but not quite as calm as other people, then put a mark a little further from CALM, like this:

ANGRY ____: ____: X : ____: CALM

Please look at each pair of adjectives listed below and put a mark between them which will/would best describe how you feel at this time.

CONFIDENT	_____	:	_____	:	_____	:	_____	:	_____	:	_____	UNSURE
STRONG	_____	:	_____	:	_____	:	_____	:	_____	:	_____	WEAK
SECURE	_____	:	_____	:	_____	:	_____	:	_____	:	_____	INSECURE
SHAKY	_____	:	_____	:	_____	:	_____	:	_____	:	_____	STEADY
SUCCESSFUL	_____	:	_____	:	_____	:	_____	:	_____	:	_____	FAILURE
TIRED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	REFRESHED
INFERIOR	_____	:	_____	:	_____	:	_____	:	_____	:	_____	SUPERIOR
TROUBLED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	SERENE
NERVOUS	_____	:	_____	:	_____	:	_____	:	_____	:	_____	RELAXED
STABLE	_____	:	_____	:	_____	:	_____	:	_____	:	_____	UNSTABLE
HAPPY	_____	:	_____	:	_____	:	_____	:	_____	:	_____	SAD
DISSATISFIED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	SATISFIED
CALM	_____	:	_____	:	_____	:	_____	:	_____	:	_____	ANGRY
RIGID	_____	:	_____	:	_____	:	_____	:	_____	:	_____	FLEXIBLE
ACCEPTING	_____	:	_____	:	_____	:	_____	:	_____	:	_____	REJECTING
GUILT RIDDEN	_____	:	_____	:	_____	:	_____	:	_____	:	_____	PEACE OF MIND
ASHAMED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	PROUD
DEPRESSED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	ENERGETIC
INTERESTED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	BORED
RESENTFUL	_____	:	_____	:	_____	:	_____	:	_____	:	_____	FORGIVING
DISAPPOINTED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	PLEASED
JOYFUL	_____	:	_____	:	_____	:	_____	:	_____	:	_____	MISERABLE
WORRIED	_____	:	_____	:	_____	:	_____	:	_____	:	_____	CONFIDENT
SMART	_____	:	_____	:	_____	:	_____	:	_____	:	_____	DUMB

Person filling out this form: Mother_____, Father_____, Stepmother_____,
Stepfather_____

APPENDIX C

Life Satisfaction Scale

Here are some answers about life in general that people feel differently about. When you answer these questions, please base your answers on your general feelings about the past year. Also please answer the questions without taking into consideration whether you expect the future to be better or worse than the past and present. If you agree with a statement, please put a check mark in the space under either "Agree Strongly" or "Agree Somewhat," whichever describes your feelings best. If you do not agree, put a check mark under either "Disagree Strongly" or "Disagree Somewhat". Put a check mark under "Undecided" only if you can't decide whether you agree or disagree with the statement. PLEASE BE SURE TO ANSWER EVERY QUESTION ON THE LIST.

	AGREE STRONGLY	AGREE SOMEWHAT	UNDE- CIED	DISAGREE SOMEWHAT	DISAGREE STRONGLY
As I grow older things seem better than I thought they would be.					
I seem to get more bad breaks from life than most people I know.					
This is the dreariest time of my life.					
I don't have time to do the things I really enjoy.					
My life could be much happier than it is.					
Compared to other people, I suffer more frustration and disappointment.					
I would change a lot of things about my life if I could.					
In general, I am satisfied with my life.					

Person filling out this form: Mother____, Father____, Stepmother____,
Stepfather_____

58
APPENDIX D
QUESTIONNAIRE

Please do not put your name on this!

1. Sex (check one): Male____ Female____
2. Your Age____ Spouse's Age____
3. Marital Status (check one):
Married____ Divorced____ Widowed____
Remarried____ Separated____ Single____
4. Formal Education (check highest level reached):
____Elementary ____College Attended
____Junior High ____Bachelors
____High School ____Masters, Doctorate
5. Your occupation (job title--homemaker, lawyer, etc.; a description of the work or the type of business)

6. Spouse's occupation _____

7. Economic situation (As far as you and your family are concerned, would you say that you are--check one)
____Well satisfied with your present financial situation
____More or less satisfied
____Not satisfied at all
8. If you are asked to use one of four names for your social class, which would you say you belong in (check one):
____The lower class
____The working class
____The middle class
____The upper class
9. Religious preference: ____Protestant What particular denomination?
 ____Catholic _____
 ____Jewish
 ____No preference

How frequently do you attend church?

☐ Never
 ☐ Frequently
☐ Rarely
 ☐ At every opportunity
☐ Occasionally

0. Would you please list the ages of your children?

Male children _____

Female children _____

1. Do any of your children have a handicap? If the answer is yes, please list the child's age, sex, and handicapping condition _____

Is this child presently living with you? _____

If not, where does he/she reside? _____

2. Check the frequency with which you have experienced the following emotions as a result of being a parent.

	Never	Occasionally	Frequently
depression	_____	_____	_____
self pity	_____	_____	_____
resentment	_____	_____	_____
shame	_____	_____	_____
guilt	_____	_____	_____
anger	_____	_____	_____
anxiety	_____	_____	_____

3. Check the following statement which best describes how you feel about being a parent.

☐ I enjoy it.
☐ I neither like nor dislike it.
☐ I dislike it.
☐ I hate it.

14. Check the following sentences which best describe your experience with public school teachers who have taught your children.

☐ They have helped me a lot.
☐ They have helped my children a lot.
☐ I have been disappointed with my children's teachers.

15. Check the following sentence which best describes the effect your children have had on your marriage.

_____ It strengthened our marriage.

_____ It had little effect.

_____ It caused problems.

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