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THE PROBLEMS, CONCERNS, AND SERVICE NEEDS OF
FAMILIES WITH HANDICAPPED INFANTS AND PRESCHOOL CHILDREN

by

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Table of Contents

Chapter 1, Introduction.....	1
Chapter 2, Review of the Literature.....	4
Grieving.....	4
Family Functioning.....	10
Informal Support Networks.....	20
Formal Support Networks.....	23
Summary.....	46
Chapter 3, Procedure.....	48
Chapter 4, Mothers' Responses to Interview.....	52
Referral to the Special Program.....	52
Perception of the Child's Handicap.....	54
Early Responses to Child's Handicap.....	60
Sources of Help.....	64
Sources of Difficulty.....	69
Community Services Utilized.....	75
Perceived Need to Improve Existing Services.....	77
Parent Suggestions for Additional Services.....	81
Perceived Need for Family Life Education.....	83
Parent Child Interaction.....	85
Summary.....	91
Chapter 5, Implications for Family Life Education.....	94
Chapter 6, Summary.....	102
References.....	106
Appendices.....	111

CHAPTER I
INTRODUCTION

Advances in medical technology have allowed the survival of many high risk infants. These infants begin life at a disadvantage due to health conditions present at birth. The effects of heredity, prenatal factors, prematurity, low birth weight, physical illness, and events during birth and delivery as well as many congenital anomalies may not be observable until later in the child's life. The interaction of the infant with a variety of medical and social factors relate to later developmental difficulties in behavior and achievement. While many of these children recover completely, others will require some level of intervention during early childhood, the school years or throughout their lifetime. It is the family that will provide the long term help needed.

Researchers have recognized the stresses present in families of handicapped children (Breslau, Staruch, & Mortimer, 1982; Cummings, 1976; Faber, 1972). After the disability has been diagnosed, the family must begin coping with long term uncertainty regarding the child's present and future functioning and occasionally even the child's viability. Successful family functioning and coping is further complicated as each member grieves the loss of the "perfect" child (Bristor, 1984; Featherstone, 1980).

Parents of handicapped children experience higher levels of psychological stress, anxiety and depression, than parents of "normal" children (Breslau, Staruch & Mortimer, 1982; Cummings, 1976). Other sources of stress relate directly to parenting issues (Kazak & Marvin, 1984). Inadequate family income also causes stress and may contribute to the decision for institutional placement of the child (Sherman & Coccozza, 1984). An examination of the small body of research on siblings of handicapped children suggests that they may be at risk for emotional problems and increased demands for assistance as a result of their brother's or sister's handicap (Breslau, Weitzman & Messenger, 1981; Cleveland & Miller, 1977).

When parents are told that something is wrong with their child the immediate reactions to such news are as individual as the parents themselves. Many experience feelings of anger, shock, disbelief, fear, isolation, shame or guilt (Bristor, 1984). Others may feel relief that the problem has finally been diagnosed (Featherstone, 1980). There is one response that all parents profoundly share, the need for help and guidance.

The family's ability to cope with stress is mediated by each member's personal coping ability and the availability of social and community support systems (McCubbin, 1979). Extended family members can be potent sources of emotional support and direct assistance with child care (Kazak & Marvin, 1984; Pieper, 1979).

Federal, state and local programs, private agencies, and professionals provide a range of community services for handicapped children and their families. Variations exist between states and

localities as to the availability, cost, and quality of services for handicapped children from birth to age five. Currently, forty-two states mandate special education services to some portion of the preschool handicapped population but only seven of these mandate services for all handicapped children from birth to age five (U.S. Office of Special Education and Rehabilitative Services, 1985). Eligibility for many services depends on a number of factors including the geographic location of the family, income, nature of the disability, and transportation.

The optimal growth and development of the handicapped child requires that parents understand, love, and care for their child. Greater concern and attention must be focused on the families of handicapped infants and preschool children and the problems and needs encountered in caring for the child. The purpose of this report is to attempt to fill this void by examining the problems and needs of families with handicapped children from birth to age five; to describe the services desired by parents of handicapped children; and to suggest implications and direction for family life education. These objectives will be accomplished by: 1) reviewing the available knowledge of family responses to the presence of a handicapped child and the nature of family support networks available; and 2) examining first hand information obtained through interviews with parents of handicapped infants and preschool children.

CHAPTER 2

REVIEW OF THE LITERATURE

The birth of any child represents a point of transition for families requiring the establishment of new family routines and redefining of relationships. The birth of a handicapped child alters family patterns and roles in particularly stressful ways. Parents have to make certain painful emotional adjustments. Successful parental coping is essential for family functioning and the growth and development of the child. In this chapter we will examine the impact of the birth of a handicapped child upon the psychological well-being and functioning of the family, identify areas of potential need, and the sources of support which may be available. Support networks for parents of handicapped children include family members, relatives, neighbors, friends, and representatives of social services, health care, educational and religious organizations. A variety of useful services exist for each family member. However families may differ widely in the nature and sources of support available to them.

Grieving

The diagnosis of a handicap may be made immediately at birth (e.g. Down's syndrome) or it may come sometime later in infancy or early childhood (e.g. mental retardation, cerebral palsy). Long before the child is diagnosed, parents begin to worry that something is wrong, notice differences in the child's development, and attempt to explain

away these fears by recognizing that children develop at different rates. At some point, however, their suspicions are confirmed. This comes as a terrible blow. Parents grieve the loss of their ideal child experiencing many emotions: shock, anger, denial and deep despair. Cohen (1962) proposed that before parents can reach the point of truly accepting the child's handicap they have to work through a series of adjustment stages. These are: experiencing a period of grief, acknowledging and learning to handle their anger, dealing with the anxieties aroused by the impact of the child's disability on their usual adaptive patterns, and making adjustments in their way of life that will affect not only the handicapped child but the total family unit.

Featherstone (1980) rejects the popular stage theories of grieving. While agreeing many families follow similar patterns of grief and despair, the actual process is more complicated and does not necessarily follow a linear pattern toward acceptance. According to Featherstone, parents may recognize, accept, and adjust to their child's disability but most also have periods of recurring pain and sadness.

Bristor (1984) discusses a holistic model of grieving the birth of a handicapped child, using the theoretical framework of John Schneider. According to Schneider (cited in Bristor, 1984), the nature of the loss has four important aspects that affect an individual's reaction to loss. The first is the degree of attachment established by the parents (the mother in particular) during pregnancy and through delivery. The second aspect is the change the loss causes in day to day routine. The realization of how much the families' lives will change by the loss usually cannot be fully comprehended in the initial stages of grief.

This is especially true at the birth of a handicapped infant because the degree of the incapacitation is often difficult to assess at birth. The child's individual potential for growth and development remains unknown. A third aspect that influences an individual's reaction to loss is the individual's ability to cope. Coping is defined as problem solving efforts made by an individual acting as his or her own resource and/or seeking support, assistance, or validation from the social environment (Schilling, Gilchrist & Schinke, 1984). The fourth aspect influencing reaction to grief and loss is the individual's support system. Support helps the individual get on with the necessary grieving when external pressures for acceptance of the child may push the parents to stop their grieving prematurely. Unresolved grief may become a major stressor in life, consuming energy needed to care for the child.

Schneider's holistic model of grieving includes six phases in which grief is not time bound to a sequential pattern nor does the individual necessarily experience all phases. This allows for a great deal of variability in individual responses yet recognizes how parents cope with loss. Bristor (1984) reviews the six phases of grief of the mother and family at the birth of a handicapped child. A summary follows.

"Initial awareness" is the first phase where a loss becomes a reality. The family, especially the new mother, is stunned by the news of the child's handicap. Shock, loss of balance and increased vulnerability with lowered resistance to infection are frequent manifestations. An effort to fully understand what is happening may be overwhelming at this time. Guilt feelings are difficult to cope with.

The mother is particularly vulnerable. She is overburdened with emotions at a time when her body is physically tired from the delivery and may affect her physical well being.

"Strategies to overcome the loss" include two very different strategies of coping. The ambiguity of the child's developmental potential contributes to strategies for coping which vacillate between feelings of "holding on" to the image of the perfect child and a normal family routine to "letting go" of that image and dealing with the inevitable changes that must ensue. In this phase conflicting emotions are common especially in situations of not knowing the extent to which life will be changed (Bristor, 1984). Individuals who speak of fantasy cures, relatives who stress the child's assets while ignoring limitations, or professionals who emphasize diagnostic imprecision and limitations of knowledge, significantly contribute toward postponing the parents' confrontation with reality by increasing their uncertainty (Gayton, 1975). Murphy, Pueschel, and Schneider (1973) found that specific facts are frequently lacking on what the diagnosis entails or how the child may develop, and there is little opportunity for parents to check their fantasy of the child's future functioning against a more objective reality. Parents wanted facts about what such babies are like, what they can do, whether they will be able to function like other children in activities such as walking, communicating and caring for themselves.

"Awareness of the loss" is the extensive and intensive exploration of the extent of the loss and its present implications. Parents may experience feelings of resentment toward the child for having so

drastically changed their lives. Some may wish that the child would die or never have been born (Camino & Reeve, 1980; Featherstone, 1980). Parental attention may turn to seeking the cause of their child's deficiency and the person responsible. Anger and frustration may be directed at family members, friends, professionals, and inward at the self. Parents need help to recognize and accept these feelings as part of the natural grief process. This phase is a very introspective time and loneliness is a prominent feeling; many beliefs are questioned and reevaluated which requires time to be alone.

"Gaining perspective" is the fourth phase of grieving in which individuals terminate their grief process in one of three ways. A mother may return to strategies which limit awareness because she believes that she is incapable of tolerating any further suffering. Or, the parent goes through a process of healing and acceptance of the child's handicap and present limitations. A third way individuals terminate their grief is by engaging in an active step of self forgiveness, restitution, or resolution of the loss (Schneider, 1984). The parent then is able to direct more energy to cope with the present problems and grow more attached to the child.

"Resolution and reformulation" is the phase in which continued healing occurs and the mother and family begin to show an interest in outside activities. Acceptance allows the mother to cope better with the demands of her family and provide care for the handicapped child. The family begins to recognize some joys in caring for the child.

However, a variety of events may trigger anger and a previous phase of grief. Featherstone (1980) describes her feelings of fear and intense anxiety as she drove to an appointment to select a school for her severely retarded son. She suddenly saw the child she had come to accept, love, and enjoy as he must appear to an outsider, bringing back painful feelings of sorrow and despair. Resolution is often a lifetime process as new situations and normative life changes occur. Wikler, Wasow, and Hatfield (1981) provide empirical support for the theory that grieving over a child's handicap is characterized by "chronic sorrow." The parents surveyed experienced occasions on which the intense grieving feelings were reevoked and experienced throughout their child's development.

The sixth phase is "transcending the loss." In this phase parents begin to see more options for themselves and for the child; individual growth is no longer bound by the loss.

Through the grieving process, parents must deal with a large component of guilt which can take many forms, such as extreme dedication to the care of the infant to the exclusion of others. Guilt feelings must be acknowledged and worked through. Even though the parents may be able to verbalize a realistic understanding of their part in "causing" the handicap and acknowledge the destructiveness of their guilt feelings, it may be extremely difficult to set aside feelings that they were somehow totally responsible (Featherstone, 1980).

The holistic model provides a useful framework for understanding the nature of the grieving process. It recognizes means of coping, how

parents try to handle the loss, while allowing for a great degree of variability in individual responses. Grief is not time-bound to a sequential pattern nor does it necessarily reach an end point where all the bad feelings have completely disappeared.

Family Functioning and Stress

Families differ in the amount of resources available to them to deal with a stressor event. While families at all socioeconomic levels may have handicapped children, those characterized by low income and less education may be even more vulnerable to the stress of rearing a handicapped child due to the lack of financial resources (Eheart & Ciccone, 1982). Numerous studies have suggested the severe disability in children has adverse effects on their families (Cummings, 1976; Faber, 1972; Kazak & Marvin, 1984; Schilling, Gilchrist, & Schinke, 1984). The daily care of the child often depletes parents' energy and time causing withdrawal from social and cultural activities. Frequent visits to physicians and hospitalizations may disrupt family life and parents' employment.

Mothers

Mothers are strongly affected by their handicapped children since mothers usually have the greatest responsibility for caring for the handicapped child. In a study (Eheart & Ciccone, 1982) assessing the needs that were created or intensified for a small sample of low income mothers in the first years after learning they were parents of a developmentally delayed child, the overwhelming need of the mothers was to learn how to cope with the many unknowns about their children's

futures. From a list of eighteen needs, nearly seventy percent of the mothers indicated an important need was to understand more about the child's development: will he/she be able to walk or talk? Other frequently chosen needs were for parent groups or someone with whom to share information and concerns (42%), and programs for the children (43%). Over half of the sample reported financial problems due to the mother's inability to return to work or to necessary costs of medical care and/or costs of equipment. (These were mothers of severely delayed children). Most of the mothers recognized a need for time alone but only half were able to have such time regularly. It is important to note that this was true despite the fact that all the children were attending an early childhood intervention program. Only half of the married mothers said they were able to discuss the child with their husbands. Some of the mothers indicated they had no family or friends with whom they could share their concerns.

Much of the stress and coping literature centers upon the emotional and physical distress of mothers with handicapped children. A recent study (Breslau, Staruch, & Mortimer, 1982) examined the impact of child disability on psychological distress in mothers with chronically ill, physically handicapped and mentally retarded children compared to a group of randomly selected control mothers with normal children. Mothers of the handicapped children scored significantly higher on each of the two indexes of psychological distress used. These findings persisted even when the investigators controlled for the mother's education, family income and race. The type of disability was unrelated

to the mothers' level of psychological distress. The disabled child's dependence upon others in daily living activities had a significant effect on both measures of distress, the more dependent the child, the greater the mother's distress.

These findings, that the level of the child's dependence rather than the type of disability created more stress for mothers, along with previous findings that mothers' most important needs were to understand more about their children's development may be interrelated. A mother's confusion concerning her expectations of appropriate child behaviors for a given disability may result in parenting behavior which promotes excessive dependency in the child, thus creating a vicious cycle.

Strom, Rees, Slaughter, and Wurster (1981) assessed the child-rearing expectations of 101 parents of developmentally disabled children using the Parent As A Teacher Inventory. Parents were asked how they felt about interactions with their children as well as their parental values and expectations about how these children ought to behave. Findings were that parental attitudes generally fell within the range of responses of parents with healthy children on dimensions such as play, frustration and creativity. These parents were aware of the need to modify normal developmental expectations but were confused about the norms for children with disabilities. The issue of how much control to exercise over their children's behavior was more confusing to them than it was for parents of healthy children.

It appears that mothers of handicapped children are under a great deal of stress due to the heavy care demands, lack of personal time

alone to release tension and rest. The high level of stress experienced also appears related to confusion about their parenting role. They are aware of the need to modify their expectations of their children but have some confusion as to what they can realistically expect. This confusion may spill over into the area of discipline with the possible effects of maintaining or even promoting dependent behaviors in the child.

Fathers

The impact of a child's disability on the father has not been as well studied but, in general, research findings indicate that fathers experience high levels of stress. Cummings (1976) found that fathers of mentally retarded and chronically ill children showed significantly higher levels of depression and impaired self esteem when compared to a control group of fathers with normal children. These fathers tended to view their retarded child more negatively than their other children. Stress was not related to the sex of the child but was related to the age of the child. Fathers of older children (9-13 years) showed slightly lower psychological stress than fathers of younger children. This may be due to having had longer periods of gratification interacting with their healthy children as well as to reassurances regarding their handicapped child's health and longevity. Fathers' parental roles infrequently included rehabilitative tasks such as taking the child to the doctor or special schools. The investigator noted that fathers have fewer opportunities to do something constructive for their children which provides concrete evidence of their love and concern

and counterbalances their sense of loss, frustration and anger. Fathers also have fewer opportunities than mothers to participate in support groups resulting in less social sharing of the burdens of parenting a handicapped child.

A handicapped child may also have a negative impact on the father's career mobility. Farber (1972) found that the timing of the birth of a retarded child was associated with the movement of the parents upward or downward in the social structure. The earlier in the marriage the child was born, the greater were the chances of the birth having a depressing effect on the parents' social mobility.

Siblings

The effects of the handicapped child upon siblings have not been adequately studied. Cleveland and Miller (1977) investigated the influence of a severely retarded sibling on the life commitments and attitudes of older siblings. A questionnaire eliciting childhood and adolescence recollections in addition to information about the effect their retarded brother or sister had on their own marriage, family and career was given to ninety men and women. There were two main findings. The first was that most families in this sample had adequate personal resources to cope with the problems of having a retarded child and were able to provide an environment for the proper development of their normal children.

The second area of significance was the importance of the siblings' sex in their reaction to having a retarded brother or sister. The male siblings' responses revealed distancing and a lack of information about

the retarded child that continued into adulthood. Cleveland and Miller (1977) suggest a potential concern for the male sibling is that the lack of information may lead to anxiety about having a retarded child of his own. The female sibling's responses showed a closer relationship to the retarded sibling not only in childhood but also in her adult years. The role demands of the female sibling were heaviest when she was the oldest female sibling in the family. She reported more often having frequent responsibility for the care of the retarded child. The data also show that the oldest female sibling was more likely to seek professional counseling for personal problems and was more likely to choose a "helping" career than the other siblings. Non-handicapped children who were single sibs of the handicapped children were more likely to be oriented towards educational achievement than the other siblings in the study. The investigators speculated that this could be a function of their parents' need for vicarious fulfillment. The only female sibling (also the oldest) more frequently reported feeling that she did not receive enough attention from her parents as a child and as an adult reported that this influenced career and family decisions.

Breslau, Weitzman, and Messinger (1981) compared children with handicapped siblings to a randomly selected group of controls with no handicapped siblings in an investigation of the psychological effects of handicapped children upon siblings in the family. Mothers with and without handicapped children completed the Psychiatric Screening Inventory for a randomly selected sibling. The two sibling groups were not significantly different on the total inventory; however, siblings of handicapped children scored significantly higher on mentation problems

(loses train of thought, thinks slowly, trouble remembering things, average grades failing), fighting, and delinquency subscales. Birth order was found to have a significant interactive effect with sex on psychiatric impairment. Younger male siblings and older female siblings of the disabled children were psychologically worse off.

The finding of adverse effects on the older female siblings support the data of Cleveland and Miller (1977) suggesting that parents may make inappropriate demands of older daughters to share domestic and child care responsibility. Perhaps the higher levels of fighting, delinquency and mentation problems are a reflection of the heavy burden of care and extra time spent with the handicapped child at the other children's expense. Or it may be due to jealousy, guilt feelings or as a way of differentiating him/herself from the rest of the family and the stigma of being "different," rather than parent inattention. A limitation of the study is that the siblings themselves were not the subjects.

Few studies have been reported which identify the specific problems and concerns of siblings of handicapped children. Banta (1980) reviewed the literature on the siblings of deaf-blind children and identified the following repeated concerns: 1) the kind and amount of attention the disabled child required of parents and siblings which interfered with the normal child-parent relationship, with family activity and social life outside the home; 2) the disappointment of not having a normal sibling and the problem of relating to the disabled sibling in the company of peers or in public; 3) the heavy requirement of normal

siblings to care for the disabled sibling; 4) the pressure on the normal child to "make up" for the deficits in the disabled child; and 5) concerns of adolescents about future genetic risks for themselves.

It may be that normal siblings suffer even greater effects than parents due to the extra stress a disabled sibling can place on them during critical developmental years. As the child does not yet have mature coping mechanisms, the child may express feelings in behaviors which are not understood by parents. A well adjusted normal child can be expected to have some negative feelings about his or her normal siblings; a disabled sibling brings additional problems to the situation (Banta, 1980). More research is needed in this area.

Marital Relationships

It has been assumed that the presence of a disabled child has had a deleterious effect on the marriage. Empirical findings are contradictory. Friedrich and Friedrich (1981) surveyed middle class families with a handicapped child (mentally retarded) compared to control parents. These parents reported less satisfactory marriages, less social support and less psychological well being than did the group of parents with nonhandicapped children. This group not only appears to report more stress but also fewer psychosocial assets to help ameliorate the continual burdens of caring for a handicapped child. Other investigators have found parents of handicapped children (spina bifida) to have slightly higher levels of marital satisfaction than controls (Kazak & Marvin, 1984). The contradiction challenges the general assumption and suggests the importance of further study. In a review of

the literature, Longo and Bond (1984) summarized the research regarding the quality of the marriage. They were struck by the number of investigators who found that the quality of the marriage in the families they studied remained stable regardless of the specific disability of the child or the method of evaluation.

The relationship of marital satisfaction and coping is more clear. Friedrich (1979) surveyed ninety-eight mothers of children having a wide variety of handicaps. Marital satisfaction was found to be the most accurate predictor of successful coping and accounted for seventy-nine percent of the variability in the findings providing evidence of the importance of intimate supports.

A recent study (Kazak & Marvin, 1984) provides additional support to those already reviewed with regard to three types of stress, individual, parenting and marital. The results confirmed earlier findings that parents of handicapped children experience more personal stress but further clarify that it is the mothers who are particularly subject to this stress. Mothers of spina bifida children spent a significantly greater amount of time caring for their children, and reported having a significantly smaller percentage of time spent by themselves and with their spouses.

The results indicate that rather than affecting the marital relationship, the stress in families with handicapped children related directly to parenting issues. The mothers of spina bifida children perceived their children as being less adaptable, more demanding, and less adequately fulfilling of the mothers' expectations. They tended

to experience more depression around parenting issues and felt less competent as mothers. Spina bifida fathers reported significantly higher levels of disagreement with their spouses over issues of child discipline than did comparison fathers.

It was reported that parents with handicapped children tend to have highly specialized roles in which the father is relatively excluded from child care. The daily demands of parenting a disabled child and the heavy financial burden involved produces a situation in which role of specialization becomes the most efficient means of accomplishing necessary tasks. The cost of role specialization is that the mother functions as a parent in isolation; the cost to the father is not clear but could be employment related. The costs might lead to a higher incidence of marital conflict and divorce if not for the fact they may be outweighed by the benefits (Kazak & Marvin, 1984).

In summary, the literature on family stress and family functioning provides evidence that the parents are stressed by the presence of a handicapped child in the home in terms of the burdens of the care and less time for themselves. Stress is also related to parenting issues: how much control to exercise over the child's behavior and establishing appropriate expectations for the child. The contribution of grieving to higher levels of stress may be difficult to evaluate but must not be overlooked. The effects of a handicapped child upon siblings are not fully known. Present findings suggest that families are able to provide an adequate home environment for normal development of

siblings, but older female siblings may be negatively affected by inappropriate demands for child care and domestic assistance. There may be a greater incidence of aggressive behavior in siblings but the exact causes of this are not understood. Expressed concerns of siblings have also been identified. Empirical findings regarding the marital relationship are contradictory and require additional research.

The role structures of parents with severely handicapped children appear to be highly specialized which enables parents to perform needed tasks in efficient ways. An additional advantage is that there is less conflict between partners when roles are clearly defined. A problem with this is that the father has few opportunities to do something constructive for his handicapped child which may help him to counterbalance his feelings of loss, frustration and grief. It also results in the mother functioning as a parent in isolation. It is clear that these families need support to help them cope with feelings of grief, guilt and frustration as well as assistance with child management activities.

Informal Support Networks

Personal coping abilities are important factors in how individuals respond to loss (Bristor, 1984). One effective coping strategy is endowing the illness/handicap with a meaning compatible with a previously existing philosophy of life. Many families develop positive attitudes by emphasizing life styles and philosophies that are compatible with their circumscribed life. Some emphasize the child's

positive qualities over that of his/her limitations. Another coping strategy reported is sharing the burden with others. Families function better if they have both internal and external supports (Schilling, Gilchrist & Schinke, 1984).

Support networks for parents of handicapped children include family household members, extended family, neighbors, friends and representatives of social services, health care and educational systems. While personal coping helps parents as they confront the reality that they are responsible for the well-being of their handicapped child, social supports compliment personal coping. Social supports are especially important should the individual's internal coping mechanisms fail or weaken (Schilling et al., 1984).

Kazak and Marvin (1984) looked at the characteristics of the social network structure of families with spina bifida children as compared to controls. With regard to social networks, results indicated that families with spina bifida children had smaller overall social networks than did the comparison families. There were no differences in terms of their family network size, the major difference was in terms of friendship networks. Families with spina bifida children tended to interact more with relatives than did comparison families. This may be a more comfortable arrangement for the family as there may be more reluctance to call upon friends or neighbors for aid as this subjects the family to a debt which it may feel unable to repay. Relatives are expected to ignore this inequity due to bonds of affection and desire to provide support.

A recent study suggests the importance of informal support networks to adaptive family functioning. German and Maistro (1982) interviewed 112 mothers of mentally retarded children to assess the relationship of the replacement of the child (home vs. respite care vs. residential) to the mothers' perception of the extent of their support systems and the stresses acting on the family. The mothers in the families who chose to retain their children at home perceive that they receive more support from their own parents and extended family members in addition to having greater availability of sitters than did mothers with children in respite care or residential facilities. These mothers were more likely to be married, less likely to perceive the child as causing behavior problems, and perceived fewer stresses acting on the family. A major source of emotional support that enabled a family to maintain its mentally retarded child in the home was the presence of both parents in the home.

The data regarding emotional support from extended family members (grandparents, aunts, uncles, cousins) suggest that extended family members are a source of emotional support that enables families to withstand the stresses of maintaining a mentally retarded child in the home. Parents indicated that they felt it inappropriate to ask for assistance with child care from their own siblings. Grandparents were called upon to help with childcare because they had more time available than siblings (German & Maistro, 1982).

Pieper (1976), a parent of a severely mentally retarded child, identifies grandparents as a potent source of emotional support and

assistance. In a personal account of her family's experiences, Pieper emphasizes that grandparents also experience grief which can lead to family conflict and hurt feelings. Pieper identifies a need for families to communicate and try to understand the other person's perspective, and discusses two ways in which grandparents provide assistance. First, grandparents can help with child care. They may be expected to understand the couple's need for a night out, or time alone because they have experienced these same needs. Second, grandparents can help the parents think more objectively about their problems by sharing their opinions and knowledge of community resources.

In summary, empirical findings suggest that informal support networks of families with handicapped children consist primarily of assistance and support from family and extended family members and to a lesser extent from friends. Grandparents appear to be particularly helpful sources of support.

Formal Support Networks

Parents of handicapped children come into contact with a large number and variety of professionals in the course of seeking and obtaining assistance for their children. These may include physicians, therapists, nurses, teachers, social workers, counselors, psychologists, and lawyers. A wide range of services may be available in the community through state, local and federal programs as well as services sponsored by private agencies and organizations. The availability, cost, and quality of services may vary depending on the family's geographic location, the child's particular handicap, availability of

transportation, characteristics of the sponsoring agency, and the individual(s) providing the service. Parents may have difficulty finding the service they need. In addition parents who see large numbers of professionals because of the complexity or severity of the child's condition receive a variety of different viewpoints. Parents' search for services can be a confusing process (Camino & Reeve, 1984).

Relationships With Professionals

Professionals help parents of handicapped infants and young children by providing information, diagnosis, counseling, recommendation of specific intervention(s) and/or emotional support and referral to other professionals and/or services. Parents occasionally encounter difficulties in their contacts with professionals. Camino and Reeve (1980) derived the following (abbreviated) list of concerns from literature examining parental concerns:

1. Inappropriate use of screening procedures/criteria for special class placement.
2. Failure to involve the parent in the diagnostic process and in the planning of services to be rendered despite the parents responsibility for deciding what services the child will receive.
3. Lack of accountability for the quality of the service.
4. Failure to monitor and inform parents of the child's progress.
5. Failure to clearly specify educational or therapeutic objectives or implications for future management and prognosis.
6. Failure to inform parents regarding the duration of treatment or cost of services provided.

7. Prevention of the parents reading the contents of their child's reports or records.
8. Judgmental attitudes on the part of professionals towards parents who do or do not choose to institutionalize their child.
9. Ignorance on the part of professionals of ancillary support services.
10. Unwillingness by professionals to listen or apparent lack of concern about the parents' situation and feelings.
11. Failure of legislators to fulfill their promises to provide community services that will meet the needs of exceptional children from birth.
12. Failure to inform parents that the diagnosis may change as the child continues to grow and develop.

Although parents occasionally experience difficulties in their contacts with professionals, the degree to which families can avail themselves of professional assistance beyond that of family support significantly influences their ability to cope (McCubbin, 1979). Recent studies investigating the nature of parent-professional relationships focus on the nature of the communication and information provided; the professional's level of knowledge, sensitivity and awareness of community services available.

Physicians.

It is most often the physician who informs parents of their child's handicap. Sometimes this information is given at the time of the child's birth as with congenital handicaps, or the diagnosis may come

sometime when the child is older, for example, developmental delays or cerebral palsy. Successful communication may be difficult because of the distressing nature of the information.

McDonald, Carson, Douglas, and Slay (1982) surveyed physicians' actual methods of providing diagnostic information to parents of newborn handicapped children. Physicians across the state of Texas (69 respondents) were interviewed about their methods of presenting diagnostic information to parents of handicapped children. A total of 91 percent indicated they were the initial informants to parents regarding the existence of a handicap in their newborn child. A total of 88 percent stated the information was presented immediately after birth to both parents and specific diagnostic labels were given if known. In addition 97 percent of the physicians said they provided additional information such as possible causation, prognosis and resources for the family. Most (87%) referred families to available community resources for additional psychological, economic, or educational support. Results indicate that 44 percent of the sample modified the information they gave according to the parents individual characteristics (eg., education, race, social class, severity of the child's handicap and/or parents' emotional stability). Some physicians emphasized the necessity for communicating in terms which parents can understand and at a pace which they can absorb. However, 34 percent of the physicians stated parent characteristics did not affect their provision of information.

The findings from this study suggest physicians are aware of the

concerns voiced by parents and are making a concerted effort to deal openly and honestly with them. Because of the traumatic nature of such diagnostic information it may be difficult to meet parents' emotional and information needs at the diagnostic conference. No matter how sensitive or supportive physicians may be, parents may perceive a lack of support for themselves and their handicapped infant. On the other hand it may be that the physicians' behavior is not truly represented by their verbal reports or that the sample is not representative of the general population of physicians (69 respondents out of 300 contacted). It is also significant that many physicians stated that they did not modify the information they gave to parents according to their individual characteristics.

A survey of the feelings of thirty-seven couples with a school age Down's syndrome child (36 children living at home) suggests a different view of the physician-parent communication (Springer & Steel, 1980). The majority of the parents felt that the early advice they had been given by physicians on the developmental potential of their children had been unduly pessimistic. A majority of parents reported that they first learned of educational programs and other community services from the Association for Retarded Citizens or other parent associations; only fourteen percent obtained this information from physicians. The investigators conclude that physicians' early counseling of parents should educate them to the wide range and variability of developmental potential in Down's syndrome children and provide better referral to special services and programs available.

The degree of the physicians' knowledge and familiarity about developmentally disabling conditions will affect the content of what the parents are told. It may also affect the physician's ability to give the needed time and attention to affective parental concerns and reactions. In a review of the literature, Wolraich (1982) noted repeated empirical findings in which a majority of the physicians surveyed believed that their training in developmental problems was inadequate. Wolraich suggested that physicians could improve their services to parents of handicapped children by increasing their knowledge of local and regional services; examining their own attitudes, assumptions and level of knowledge about a particular handicapping condition; and by obtaining special training to provide information in emotion laden situations.

Teachers.

The special education teacher can be an important source of support and information for parents. Teachers' specialized knowledge of child development and behavior management techniques can help parents improve their understanding of the child's behavior and special needs.

A source of concern is the professional training and preparation of preschool special education teachers. Early childhood programs are extremely diverse in terms of services and curricula offered, resources available, numbers of staff members, and training backgrounds. Unlike elementary school teachers, preschool teachers have not all passed through a common university-level pre-service training program; not all are certified or even college educated (American Association of School

Administrators, et al., 1984). Therefore many preschool special education teachers may have inadequate preparation to work with parents effectively. This could contribute to misunderstandings, conflict and feelings of frustration between parents and teachers as well as affect the child's progress toward learning objectives.

Social workers.

Wikler, Wasow, and Hatfield (1981) investigated parent versus professional depiction of the adjustment of parents of mentally retarded children. In response to a questionnaire mailing, parents of mentally retarded children and social workers essentially agreed that such parents experience periodic crises during the child's development rather than time bound adjustment. Findings indicated that the social workers significantly underestimated the intensity of the parents' difficulties in the later developmental periods and tended to over-estimate how upsetting the parents' early experiences were. These findings suggest the importance of continuing education and workshops to help professionals develop greater sensitivity and awareness of exceptional family needs over the life cycle.

Clergy.

The clergy constitute a valuable source of emotional support and counseling available to families and their handicapped children. Heifetz and Franklin (1981) investigated the variety of services provided by the clergy on behalf of mentally retarded persons and their families. The findings reveal that the clergy provide a wide range of services as a whole and show clear preferences for some areas of service

over others including: providing emotional support and encouragement to family members, encouraging the family to get information about available services and to join in church activities, discussing theological issues of retardation with families, child rearing issues and personal problems. The clergyman surveyed identified a need to acquire teaching/communication techniques to aid in the religious instruction and counseling of mentally retarded children and adults. This finding suggests a need to collaborate with other professionals.

In summary, several ways to improve professional services to families with handicapped children were identified. Especially important is the need for professionals to become more knowledgeable of available community resources and provide advice to parents on how to go about getting what they need.

Support From Other Parents

Another important source of support is other parents of handicapped children. Parent visitor programs and support groups are valuable sources of information and emotional support.

Parent visitors.

Davidson and Dosser (1982) describe the "Parents Helper Program" designed to provide families who experience the birth of a developmentally disabled infant with support and information to maximize family adjustment. Parents with handicapped children who have made successful adjustments serve as parent-peer helpers for families with newborn developmentally disabled infants. Parent helpers listen to parent concerns, share their own experiences and provide information about community and parent groups which meet regularly. Since they have been

through the crisis they serve as role models and provide comfort, conveying the message "I, too, have felt like you and thought it unbearable and I have learned to cope and adapt." The parents served by the parent helpers have overwhelmingly expressed thanks and appreciation for this support.

Parent support groups.

Featherstone (1980) identified parent support groups as a valuable resource in terms of exchanging information regarding the availability of services, educational programs, schools, government programs, and financial assistance. The most important function however was in terms of providing emotional support and an outlet for expressing both positive and negative thoughts and feelings in an understanding atmosphere.

Tavormina, Hampson and Luscomb (1976) looked at three kinds of group counseling experiences focusing on the mothers' evaluations of the worth of their group as derived from a questionnaire and an interview. Forty-five mothers with a retarded child living at home were divided into one of the three eight-week group treatment conditions, one group received behavioral counseling, the other received reflective feeling focused counseling and the third group received a combination of the two.

All mothers reported satisfaction with their group experience, however, differences in the magnitude of satisfaction occurred across groups. Mothers voiced more satisfaction with the more behaviorally oriented groups (including the behavioral and combination methods). The specific application of behavior management techniques to target problems probably helped the mothers deal with troublesome issues (eg.

toilet training, discipline) whereas the reflective group members learned to understand their problems but still had no specific solutions to apply. The reflective groups facilitated personal change in the mothers (patience, tolerance, awareness). The mothers in the reflective groups also felt that the experience had helped to improve their relationships with the handicapped child and other family members. Combination group mothers were the most satisfied with the group format offering fewer suggestions for change than members of other groups.

The mothers had a number of suggestions for improving the groups including more personal involvement, closeness and sharing of experiences and a greater focus on the spectrum of problems they faced in raising their retarded children, including behavior problems, others' reactions, expectations, schooling, the meaning of IQ, effects on other family members, especially siblings and spouses. These mothers felt the need to be prepared and wanted guidelines for coping with new situations.

The mothers felt that their husbands needed a group counseling experience but were not sure how allowing husbands to take part in their own groups would affect their own participation. Many felt that husbands should have their own groups so as not to infringe on the mothers' experience. The mothers felt their group experience had helped them become more aware that others had similar problems which helped them put their own into perspective and realize they were not alone.

Sibling Support Groups

Sibling support groups focusing on individual feelings, attitudes

and need for information can help each child develop a wider perspective to view his or her handicapped sibling and reduce the feeling of being alone with a problem. Opportunities arise for support, catharsis, insight concerning relationships with family members and others, and techniques for managing specific situations (Murphy, 1980).

Chinitz (1981) described her experiences as leader of a sibling group for brothers and sisters of handicapped children attending a special program for pre-school and young school-aged children. The siblings ranged from 7 to 14 years of age. While the older children were more verbal and the younger ones tended to take a more passive role in the discussions, there was no real difficulty caused by the disparity of ages of group members. The meetings were generally unstructured but the leader used techniques to encourage the children to begin talking about their feelings/experiences and to facilitate group discussion such as reading selections from books and articles written by or about siblings of handicapped children. The children were able to use the group to share ways of coping with the demands imposed on parents' time by their handicapped sibling, offered each other suggestions for solving problems they had been unable to resolve on their own and gradually began to speak of positive and negative feelings toward their handicapped sibling. The sibling group also helped children clarify their understanding of the nature of the handicapping condition. When asked to describe the handicap, some children were at a loss while others focused on concrete, observable aspects. The children seemed especially confused about the medical intervention received by their handicapped sibling.

Chinitz noted some important limitations of a sibling group. First, sibling groups cannot provide adequately for a seriously troubled child, or substitute for professional psychological help. Second, although siblings receive clarification and support through this type of intervention, it may be important to share some of the child's experiences with the parents in order to improve patterns of family interaction.

Finally, the gains obtained through participation in a sibling group cannot be expected to be maintained indefinitely. Children move through different developmental stages and are learning new ways of processing information and experience new situations and feelings as they grow older. Chinitz concludes that sibling groups appear to be a useful means for children to learn more about family members and specific handicaps, to discover their own feelings are not unique and to foster a view of themselves as informed and valued individuals. It is also hoped that the experience will work to improve family functioning and facilitate each child's future growth and development.

Child Care

The heavy demands of caring for a handicapped child can be lessened by providing the mother with regular opportunities to have some time to herself. Time away from the child allows the mother to rest and pursue personal activities which help to release tension, and to spend time with her spouse and other children which may result in more satisfying family relations. This may be done in a number of ways if family members or relatives are available they may assume the child care

responsibilities for a short period of time giving the mother a break. For families who have no relatives nearby or are incapable of performing this task, other options must be made available. Furthermore, should the mother desire employment outside the home for personal satisfaction or due to economic need, child care services are a necessity.

Day care.

Research on the availability of day care and quality of services provided for handicapped children is scant. Geist and Baer (1980) surveyed ninety-seven mothers of mentally retarded children on their lifestyle and how they spent their time. Forty-five percent of the mothers were working. Seven percent of their retarded children stayed home alone while the mothers worked. Of those who had made arrangements for child care, only half were satisfied with the arrangement, however only five percent of the mothers felt that their outside activities had a negative effect on their children.

Respite care.

The national deinstitutionalization movement of the 1970's to provide the "least restrictive" setting for the mentally handicapped has led to the development of respite care services in recognition of the need to provide some relief for home care givers. Respite care is short term, temporary, paid care for disabled or chronically ill people living at home, provided in or out of the home for a few hours or up to two weeks in duration (Cohen, 1982).

The impact of respite care upon perceptions of family well being was examined by Joyce, Singer and Isralowitz (1983). In all,

twenty-four families utilizing a respite care agency were questioned about the impact of services on their family relations, social activities, emotional and physical strains, and plans for institutional care. The children had a wide range of handicaps (ages ranged from 1 to 29 years). Over half the mothers responding said that the family gets along better since receiving services, sixty-eight percent agreed that the care had helped relieve family stress, and thirty percent indicated that they would be unable to care for their child at home without respite care. Parents caring for younger children viewed the services as more helpful than parents caring for older children or adults.

Cohen (1982) conducted a larger study over a two-year-period. Data were collected from 357 families living in states along the east coast. Findings of the study were that families using services were more likely to have a disabled child whose care was extremely burdensome, lack a network of persons outside the home to call on for help during times of greater stress and/or have a second disabled individual in the home. Parents reported greater satisfaction with life, ability to cope with the child and more positive attitudes toward the child since using respite care services. There were low but significant correlations between degree of respite utilization and improvement in family functioning.

In summary, the need for child care services for handicapped children must not be overlooked. The cost, availability, and quality of services provided are important issues demanding additional research and review by policy makers.

Associations and Community Groups

An important source of information and assistance for parents and families of the handicapped is their particular association or organization such as the United Cerebral Palsy Association or the Association for Retarded Citizens (see Appendix B). Available in many communities, these organizations of parents and concerned citizens maintain information on where to find educational programs and other essential services such as respite care, socialization, recreation programs and employment counseling. These organizations also provide information on all aspects of the handicapping condition, diagnosis and treatment and sponsor public and professional education programs. The groups also act as a source of information on law and legislation in the field of the handicapped (Dean, 1975).

Closer Look, or the National Information Center for the Handicapped (NICH) provides information to parents of handicapped children, professionals who work with handicapped children, students looking for career information, parents groups seeking advice on how to make their organization work, and the adult disabled (Dean, 1975). Although it cannot match a child with a program, it can get a child and family closer to needed services by providing information and referrals to state and local resources. Specific services helpful to parents include: literature searches, referral to particular associations or organizations and/or to state or local coalitions for the handicapped. The organization will also help parent groups who wish to form a coalition through assistance in conference planning and obtaining

speakers experienced in forming coalitions. The center also has a program to teach parents how to be their own advocates by providing them with information about their rights and advice on how they can work as partners with their school system.

Education

Human learning and development occur at their fastest rates in the years prior to any child's entrance into school. For the handicapped child, these early years are even more crucial. A child with a problem in only one developmental area may begin, as a result, to have problems in other developmental areas. Empirical findings indicate that early intervention can ameliorate many handicaps and may prevent the child from becoming further delayed in other aspects of development (American Association of School Administrators, 1984; Suran & Rizzo, 1979). Current legislation, early identification, parent involvement in education and program effectiveness are the aspects of special education services to be addressed.

Early identification.

Lessen and Rose (1980) conducted a survey of state consultants responsible for preschool handicapped education to determine the degree of accord which exists with respect to defining the population. Forty-four states responded. Seven of the responding states had a specific definition for the preschool handicapped. Of these, two states offer a definition which includes age, use of special education services, as well as objectives for preschool handicapped education. Other criteria used included deviation from the child's chronological

age group and categorical criteria. Two states specified preschool education for those children requiring preventive services in order to preclude problems which may occur during the school years. The remaining respondents had adopted no specific definitions.

The investigators determined that only five of the responding states adopted definitions that are unique for this population and do not rely on traditional categories. These findings point to the apparent difficulties in identifying the preschool handicapped population. Difficulties include variability in normal development and environmental experiences, and questionable identification and diagnostic instruments. To reduce the probability of misdiagnosis, especially leaving children out who are in need, requires a vigorous definition of the preschool handicapped population as well as statewide screening programs to detect children in need of special education services at the earliest age possible.

Legislation.

The 1975 Education for All Handicapped Children Act, Public Law 94-142, provided the impetus for state Departments of Education to provide "free appropriate public education in the least restrictive environment" to all handicapped children. This federal law provides grants to states for planning, development or implementing state plans for serving children from birth through five years of age. The law requires states to locate, identify, and evaluate handicapped children from birth to age twenty-one and mandates that whatever is provided for nonhandicapped children must be provided for handicapped children as

well. In states where nonhandicapped preschool children (birth to age 5) are not provided for there is no federal mandate to provide for those who are handicapped (American Association of School Administrators et al., 1984).

The education of the Handicapped Act Amendments of 1983, P.L. 98-199, includes the Early Childhood State Grant Program which authorizes a grant to each state to assist in planning, developing and implementing a comprehensive delivery system for the provision of special educational and related services to handicapped children from birth through five years of age. In 1984, twenty-three planning, two development and one implementation (Nebraska) grants were awarded. Projected activities vary widely among the states. These include interagency collaboration, training for families and professionals, identification of administrative and program resources, structures, and strategies. Some of the projects emphasize service to specific disability groups or age ranges (U.S. Office of Special Education and Rehabilitation Services, 1985). The development of systematic procedures within states and local governments will help improve preschool services for handicapped children. Currently, forty-two states mandate services to some portion of the preschool handicapped population from birth through age five. Nineteen mandate services for all three- through five-year-old handicapped children, another twenty-three mandate services for some portion of the three- through five-year-old population (e.g., for only certain types of handicapping conditions). Only seven states mandate services from birth to age five

(U.S. Office of Special Education and Rehabilitation Services, 1985).

An examination of this year's Child Count data indicates that states with preschool mandates reported serving a larger percentage of three- to five-year-old handicapped children than states without mandated services (U.S. Office of Special Education and Rehabilitation Services, 1985). Clearly many handicapped children in need of services are not being served. Most critical is the need to expand services from birth to age two.

Private agencies sponsor special education services in many communities. Programs may vary in terms of availability (e.g., restrictions on numbers of children, age range or handicapping condition), costs and quality of services. In Kansas it is estimated that only one out of four children are enrolled in an approved program. The reasons for this gap of unserved children includes failure to accurately identify their handicapping conditions at an early age, families cannot afford the exorbitant costs which must be charged by some agencies, and still others are unserved because of geographic locations (Kansas Alliance for Special Education, 1984).

If and when free public education becomes available to all handicapped children from birth to age five, the following changes might be anticipated: 1) many more children who need services will be identified early; 2) early intervention should result in greater cost-effectiveness because special education is provided earlier when the handicap is more amenable to change; and 3) the need for later special education may be eliminated in many cases and result in fewer

children who require institutionalization (American Association of School Administrators, et al., 1984).

Effectiveness of early intervention programs.

In a review of the literature, Simonson, Cooper, and Scheiner (1982) examined twenty-seven studies describing early intervention for biologically impaired infants and young children including asphyxiated and low birth weight infants, those with genetic, metabolic, neurologic or anatomic defects, and specific conditions such as cerebral palsy, mental retardation, communication disorders, or combinations of these handicapping conditions. The programs evaluated in these studies emphasized multidisciplinary therapies and specified roles for parents in comprehensive programs.

Variability of criteria for success and methodologic difficulties made the determination of effectiveness problematic. Difficulties associated with assessment of infants and young children in general become exaggerated when biologically impaired infants and young children are considered. Statistical procedures were used in 59 percent of the studies. Statistical support for the effectiveness of early intervention was reported in 81 percent of the studies that incorporated statistical procedures. Effectiveness on the basis of subjective, clinical, conclusions was reported in 93 percent of the studies. The authors estimate that the effectiveness may be closer to the 93 percent figure for a number of reasons: 1) handicapped children made progress but statistical significance was not obtained given limited sample sizes; 2) children made progress but it occurred in domains not

measured by the dependent variables; or 3) progress was in terms of family or sibling adjustment. The authors concluded that the research provides qualified support for the effectiveness of early intervention.

A recent study (Lieberman, Barnes, Shih Ho, Cuellar, & Little, 1979) assessed the economic impact of a Texas program providing training and education for mentally retarded children from birth to twenty-one years for whom no other appropriate program exists. Day care, summer programs and social services are also provided. The investigators found that a significant increase in incomes was realized for the ninety-seven families in the study after one year of service. Increases from one percent to 151 percent were demonstrated in 57 percent of the families. The median increase was 31 percent. The most dramatic increases were found in families with two working parents, with a median increase of 80 percent. Of a total of eleven families who were on welfare when the study began, seven became self sufficient after one year. In addition to higher family incomes, the program provided services at a substantially lower cost than state schools. Although no data are provided, other program benefits were expected in terms of positive effects on family functioning and stress reduction by providing relief from child care activities.

Parent involvement.

The Education for All Handicapped Children Act of 1975 (P.L. 94-142) requires that the parents of handicapped children be included as an integral part of the child's education program. This change, in

large measure, resulted from mounting parental pressure to have a voice in the placement and programming decisions that affect their children. Parental involvement (e.g., parent-teacher discussion groups, parents as aides, or parents directly instructing their child) may result in better scholastic achievement for exceptional children and help the parent feel more confident as an advocate for the child's educational needs. Parent involvement in the educational process can also help in establishing a set of realistic expectations of the child's abilities and needs for discipline (Warfield, 1976).

A recent study describes and evaluates a training program provided to parents enrolled in a center based early intervention program (Sandler & Coren, 1981). Following an intensive eight-week initial training program, the parents took part in an ongoing program to maintain existing teaching skills, develop new skills and stimulate regular instruction of children at home on the same educational program being carried out in school. Specific activities included team meetings consisting of teacher, therapists and parent every six weeks for each child. A modeling session was held where the parent observed child-teacher interaction after which the parent was videotaped teaching the child and given feedback by the parent trainer. The child's progress was recorded on a sheet which went back and forth daily between home and school. Finally, parents and teachers met individually once a week to further coordinate home and school programming efforts.

The parents generally expressed a high level of satisfaction with the program. Forty-five percent of the parents felt somewhat better and

fifty-five percent of parents felt definitely better able to advocate for their child's educational needs. It is interesting to note that the parents participating in the program were generally well educated and middle to upper-middle class in socioeconomic status. The program may not be appropriate for parents from other social economic backgrounds. No data were available on child learning effects.

Bricker and Casuso (1979) emphasize a philosophy that parent involvement programs should be based primarily on a family's needs and secondarily on information and skills professionals believe parents should have. The program they describe includes social service assistance and counseling as well as education and skill training which consist of sequences that begin with simple responses and move to more complex. The parent education program provided allows for flexibility in the amount and levels of parent involvement.

In their review of the literature, Turnbull and Turnbull (1982), conclude that parents may vary greatly in the degree to which they desire or are able to be involved in the child's special education program. The authors recommend that parent involvement activities be planned with consideration of individual parent viewpoints rather than that wholly of professionals or other policy makers.

Financial Assistance

The provision of financial assistance, professional services, and community programs enable families with handicapped children to be cared for in their own homes rather than in institution. For children with less severe handicapping conditions (e.g., speech

disability, hearing impaired) financial assistance may enable the family to purchase needed services (e.g., special education, speech therapy) early in the child's developmental years rather than waiting until the child is older when these services are provided free by the public school system. A description of several financial assistance programs is provided in Appendix B including: Shriners Hospitals, Services for Crippled Children, and Social and Rehabilitation Services.

Summary

The literature on family stress and functioning provides evidence that parents are stressed by the presence of a handicapped child in terms of the burdens of care and less time for themselves. Stress is also related to parenting issues. The role structures of parents with severely handicapped children appear to be highly specialized. Families also experience grief and these feelings may intensify during normal changes in the family life cycle. It also appears that siblings may experience adverse effects. Informal and formal support networks bolster adaptive family functioning. Families derive informal support and assistance primarily from family and extended family members (particularly spouses and grandparents) and to a lesser extent from friends. Formal support networks include a large number and variety of professionals. Findings from the literature suggest a number of difficulties experienced in the parent-professional relationship including attitudes, sensitivity and the professional's lack of knowledge/referral to other community services.

A wide range of services exist for preschool handicapped children and their families including support groups, respite care, national organizations, and special education. Yet the availability, cost, and quality of services vary between different states and localities. Federal legislation has helped States to plan, develop, and implement special education services for children from birth to age five. However, many children are not being served especially those from birth to two years of age.

Much remains to be done in terms of improving services and support to adequately meet the needs of parents and families of handicapped children. In the following chapters data from parent interviews provide first hand information about parents' perceived needs for support and services for themselves and family members.

CHAPTER 3

PROCEDURE

Twenty mothers, with handicapped children (birth to 5 years) enrolled in a special education program, were interviewed in order to gather information about their problems, concerns, and desire for services. Mothers were asked open ended questions regarding their children's handicaps, what kinds of services they found helpful, what problems they had experienced, and what additional services they wanted. A copy of the interview questions is in Appendix A.

Description of the Special Infant/Preschool Program

The program in which the children were enrolled is a private, nonprofit organization providing a range of services to handicapped individuals and their families. The infant program includes children from birth to two years of age and their parents. A teacher and an occupational therapist met weekly with one or both parents and the child at one of three program centers located in adjacent counties. The teacher and therapist worked with the parent(s) and child, discussed progress toward set goals, and suggested activities to do at home.

The preschool program is administered in a group setting and includes children from 2 to 5 years of age. Occupational therapy and speech therapy are provided according to each child's individual needs. Psychological consultation is also provided.

Teachers meet at 6-month intervals with parents to review each child's individualized education program (IEP), his or her progress toward goals, and home care practices which will support/supplement what the child is learning in the program.

The program also sponsors parent support groups which meet monthly at each of the three centers. Meetings consist of a brief education program presented by a guest speaker followed by group discussion. An agency social worker is available to consult with parents and staff and provide information about services and financial assistance.

The program is funded by private donations, government grants, contributions from charitable organizations, a county mil levy, and family fees. Each family pays a sliding scale tuition fee according to their income. No family is denied services because of inability to pay.

Sample Description

The parents of all forty-four children enrolled in the special education program were asked to participate in the interviews by signing consent forms which allowed their names and phone numbers to be released to the interviewer. A total of twenty mothers volunteered and were interviewed. Eighteen mothers had also been contacted by the interviewer through the parent support group sponsored by program staff at each of the three centers. Two mothers who were not involved in the parent group but had a child in the infant program, were recruited by program staff.

Precise demographic data were not solicited. However each of the twenty mothers had a child who had attended the program for six months

or longer; seventeen in the preschool and three in the infant program. At least three mothers had a child who had been involved in the program from infancy and was now in the preschool program. One child in the preschool program had been involved in an infant stimulation program in another state.

The children in the sample varied considerably in the severity of their handicaps or disabilities which included congenital defects, developmental delays, cerebral palsy, and mild to severe speech disabilities. Four children lived in rural areas at a distance of 20 miles or more from the special program center which they attended.

Of the twenty mothers, seventeen were presently married and living with their spouse, three were single parents. All but one mother had at least one other child living at home in addition to the handicapped child. A total of four were from minority backgrounds: three black and one hispanic.

A few of the parents, mothers and/or fathers, had some professional training. Several fathers were enlisted in the military services; the rest were semi-skilled wage earners.

Interview Format

The interview instrument (see Appendix A) consisted of eleven open ended questions to which parents gave their free responses. The questions have face validity in that parents were asked to give specific information sought by the interviewer. Follow-up questions were asked to clarify answers, encourage more detailed explanations, and provide a rough reliability check.

Interview Technique

Interviews were conducted in the homes of all but six mothers. Four were conducted at the centers and two at the interviewer's home. Each mother had met the interviewer at least once prior to the interview session with two exceptions. In addition, the interviewer had observed and interacted with each child for one or more sessions at the child's program center. These measures were taken in order to give the interview sessions a more familiar/comfortable atmosphere in which mothers would be more willing to share their feelings, attitudes, and concerns.

The purpose of the interview was explained, both at the time mothers were asked to volunteer, and at the time of the interview session. Mothers were told that the interviewer was interested in the problems and concerns of families with young handicapped children and the kinds of services which had been or would be helpful.

Each interview began with some general comments about the child or school and a short explanation of the purpose. The interview questions served as a guide for soliciting information. Parents were encouraged to talk about anything they wished. The mothers often discussed items included in later questions and offered comments about their experiences/feelings in addition to the information sought through the interview format. The interviewer took notes during the interview and wrote a total report including all information received as soon as possible after the interview session (within one hour). The interview sessions varied in length from approximately forty-five to ninety minutes.

CHAPTER 4
MOTHERS' RESPONSES TO INTERVIEW

A total of twenty mothers were interviewed to gain information about their individual experiences, problems, concerns, and perceived need for community services for their handicapped child and family. Each parent had an infant or preschool child with mild to severe handicaps enrolled in the special education program. The responses to each question were organized into categories judged meaningful by the interviewer. Each question will be examined.

Referral to the Special Infant/Preschool Program

Mothers were asked: "How did you find out about the special infant/preschool program?" Responses were coded in the following categories.

<u>Program Referral</u>	<u>N=20</u>	<u>Percent</u>
Referred by professionals	12	60%
Referred by friends	3	15%
Self referred	4	20%
Contacted by program personnel	1	5%

Referred by Professionals

Professionals from a variety of different fields referred twelve parents to the special infant/preschool program. Of these, four mothers reported that the county health nurse referred their children to the

program for further evaluation after routine health screening. Six mothers were referred by the child's physician or the staff at their medical center. An adopted child continued in the program on the recommendation of program staff. A preschool teacher referred another child and his parents to the program for special help with a speech problem.

Referred by Friends

Two mothers found out about the program from a friend or acquaintance who had a child in the program. The third mother reported she was familiar with the program because she knew one of the staff and had heard the program mentioned at a church function before her child was born.

Self Referred

Four mothers were self referred to the special infant/preschool program: One had other children included in the program; the other three set out to find special help for their children. One asked a friend from out of state, knowledgeable in special education, to help her find a program for her child; two reported they tried calling "every place" to find out if there was any kind of program available to help their children.

Contacted by Program Personnel

One mother of a child with a genetic disorder was contacted in the hospital by the program's social worker. This mother stated that she did not appreciate the visit at the time, because she "did not want to believe there was anything wrong" with her child. She said that she was grateful later that she had a way of getting information but still found

it disturbing that the agency had obtained personal information without her knowledge or consent.

Discussion

Many parents looked to professionals for information and referral to community services. Professionals need to keep aware of community resources in order to help clients meet all of their needs. While parents expressed appreciation for knowledge of services, there was some concern about confidentiality. Professionals must be careful to respect client confidentiality and obtain parents informed consent before sharing any information about them or their families with other service providers.

Perception of Child's Handicap

Information was solicited concerning the mother's perception of her child's handicap in questions 2 and 3. Mothers were asked: "Why does your child attend the special program?" and "Tell me about your child's handicap or difficulty." Each child was placed in a category according to the mother's explanation of the child's handicap or difficulty. Responses were varied but were coded in the following categories.

<u>Handicapping Conditions</u>	<u>N=20</u>	<u>Percent</u>
Congenital Defects: Down's syndrome <u>3</u>		
microcephaly <u>1</u> , other chromosome disorder <u>1</u>	5	25%
Cerebral Palsy	2	10%
Developmental Delay	5	25%
Speech Disability	7	35%
Social Development	1	5%

Congenital Defects

Five mothers characterized their child as having some kind of congenital defect. Congenital defects are abnormalities present at birth resulting from either heredity or the events of prenatal development. A hereditary defect is one that is inherited in the genes or the chromosomes from the parents and can be passed on to future children. The second kind of defect results from an event occurring after conception (examples: exposure to irradiation, drugs, or German measles during pregnancy). The defect is present at birth but cannot be passed to the next generation because it is not carried on the genes or chromosomes (Annis, 1978).

Three mothers have a child with Down's syndrome. Down's syndrome is a condition characterized by mental retardation and physical abnormalities resulting from the presence of three No. 21 chromosomes (Annis, 1978). Two of the mothers felt that their children were doing well and seemed to have only "mild delays." The third mother noted several delays in her three-year-old child who was not yet potty trained and just beginning to speak in one word sentences.

The fourth mother reported that her child has "abnormal chromosomes." According to this mother, her child is behind in physical growth and motor development and engages in several kinds of autistic behaviors. After explaining these problems in detail, the mother commented that she really did not believe anything was wrong with her child and that he would eventually "catch up."

The fifth mother reported that her child was "microcephalic" which

means the "head is smaller than normal." A head circumference smaller than chest circumference in the newborn infant is diagnosed as microcephalic, a condition secondary to microencephalis, or small brain. It may be caused by maternal infections such as toxoplasmosis, irradiation, or any one of a number of factors genetically or environmentally induced (Scipen, Barnard, Chard, Howe & Phillips, 1975). The mother explained that her child's condition was not as severe as other children with this problem and noted that her child was making progress although it was "very slow."

Cerebral Palsy

Cerebral palsy is a term used to describe disorders created by damage to the motor centers of the brain. This damage may occur before, during or shortly after birth and may result from severe anoxia in the perinatal period, trauma at birth or infections or kernicterus during the postnatal period. These children range from those with very mild affects requiring no treatment, to those with severe handicaps and profound mental retardation (Scipen et al., 1975).

Two mothers stated that their children had "mild to moderate" cerebral palsy. Both children are affected in their lower extremities. One mother was hopeful that her child would be able to learn to walk with crutches soon. She explained that her child also had some visual involvement but that this has improved. The second mother reported that her child has a speech delay but feels that he is able to understand much more than he is able to speak. She stated that she does not believe her child is mentally retarded although it remains a possibility.

Developmental Delay

Developmental delay refers to any significant delay in one or all five areas of development and cognitive, social-emotional, communication, self help, and sensory motor. On the other hand, mental retardation is a diagnostic label. The American Association on Mental Deficiency defines mental retardation as significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period (cited in Suran and Rizzo, 1979). The director of the special program feels that "developmental delay" is a more appropriate term for children at the infant-preschool level. Suran and Rizzo (1979) explain this further; although the child is developing slow according to the norms, the child is still developing and there may be a number of causes known or unknown which may be reduced or eliminated by the time the child enters school (for example: epilepsy, physical illnesses, malnutrition, or problems related to ineffective caretaking practices). This category includes some children who eventually will "catch up" to children of the same chronological age and others who will later be diagnosed as learning disabled or mentally retarded.

Five children are included in this category. One mother described her 2½-year-old child as having "slow development in everything." The mother felt that the overall delay was due to prematurity and the many illnesses her child had during infancy but felt he was "really catching up now." Another mother explained that her child had "slow development" with motor and speech delays and needed to be with other children. She

had noticed the delays from early infancy. The third mother reported that her 4-year-old had "generalized delay" explaining that this meant that for some unknown reason, her child is delayed in all aspects of development with an IQ in the 50's. A mother of a 15-month-old infant born 2½ months premature reported that her child was "behind in development." She stated that the child is just now beginning to make large gains in physical growth and is showing some progress in motor development.

The fifth child included in this category had suffered spinal meningitis as an infant and was not yet able to walk at 2½ years of age. The mother reported that the child made rapid gains since beginning in the special program and changing the home environment. The mother explained that her child continues in the program because of a "speech delay". She stated very firmly that her child is continuing to "catch-up and is not mentally retarded."

Speech Disabilities

Speech disabilities may be manifested in a number of distinct forms, including delayed onset of speech, speech usage below age expectations, oddities of articulation, peculiar usage of language, stuttering, unusual intonation or voice quality, paucity of speech, inability to recall or use appropriate words, poor self expression, or total absence of speech. All speech disabilities have in common an impairment of effective verbal communication to the degree that the intelligibility of spoken language is reduced (Suran & Rizzo, 1979).

Seven mothers identified their child's difficulty as a "speech

problem or delay." Most of the children were reported as having problems producing understandable words and/or "behind" in their speech production. One mother noted that although her child could repeat a ten-word sentence correctly, the child still "talked gibberish" when engaged in independent play. Each of these mothers had additional concerns for her child such as being shy and needing to interact with other children or learning to be comfortable in groups. One mother stated that her child also had some visual problems; another reported that tests had shown that her child also had a slight motor delay; and a third mother stated that her child also had a "behavior problem."

Social Development

Social development is defined as the general socialization process by which the child acquires skills, values, beliefs, behavior patterns and other characteristics necessary for an individual to interact cooperatively with other individuals in a particular society (Suran & Rizzo, 1979). One mother explained that her child attended the program in order to "be around other kids" and have some "playmates," reporting that her child is above average in development for her age.

Discussion

The children suffered from a variety of handicaps which ranged from mild to severe in nature. Each child was categorized according to the mother's perception of his or her handicap. No attempt was made to verify the information given. There was a tendency to look toward the goal of "catch-up" in many cases which may or may not be possible.

Parents need to have hope but must be able to face reality in order to provide the appropriate kinds of help, both at home and through contact with professionals.

Early Responses to Child's Handicap

Mothers were asked to "tell (me) about the time you became aware of your child's handicap or difficulty" in question 4. Each of the mothers reported the age of their children when they first noticed the difficulty(s) and discussed their own response and/or those of other family members. All sought help for the child at some point through medical or educational professionals. One child was reported as normal and therefore not included.

Responses of Parents/Family Members to Child's Handicap

	<u>N=20</u>	<u>Percent</u>
At first one or both parents did not want to believe that anything was "wrong" with the child.	5	26%
Parents continued to "worry" despite advise not to worry because the child would "catch up" or "outgrow" the problem.	6	32%
Parents/family members feared for the child's survival at birth and/or through infancy.	6	32%
One or more family members felt anger and/or blamed the physician.	2	10%

Five mothers reported that they or their spouses did not want to believe that anything was "wrong" with the child at first. Two mothers explained that it was difficult for them to acknowledge that the child had a speech problem. Each mother sought help for the child

after being urged to do so by her husband and/or friends. In two instances the mother described feelings of shock and disbelief at the news that her newborn child had Down's syndrome. The fifth mother reported that her husband "never did believe" that their child had a speech problem and did not want the child in any kind of program.

Six mothers explained that they continued to "worry" and were concerned for their children despite the advice that the child would probably "catch up." One mother stated that she noticed that her child was having trouble pronouncing words. "Everyone said he'd grow out of it but I was worried. He was still having trouble (at age 3) and we couldn't understand what he said at all." After expressing concern to their pediatrician, five mothers reported having been told "not to worry, give the child time to grow out of it." Three of these mothers described intense feelings of concern, frustration, and anger after being told "not to worry" by several different doctors. One family finally took their child to a major medical center for evaluation by specialists at their own expense. (All three were utilizing the military health care system.) Another explained that her pediatrician had told her that her child probably needed some extra time to "catch-up" because of prematurity and many illnesses. When the child continued to have delays at one year of age the doctor referred them to the special program.

Six parents feared for the child's survival at birth and/or through infancy. Five mothers explained that their children were born prematurely and suffered from serious physical complications and

illnesses during their first year of life. The sixth mother explained that her child, born with a chromosome disorder, also had a congenital heart defect which could not be repaired until the child was at least a year old. The mother described her child's serious physical health/growth problems in detail. This seemed to be an especially stressful time period for each of these families.

Two mothers felt that the doctor might be at fault in some way. One mother explained the circumstances of her child's birth. A number of things went wrong which she felt could have been prevented by the physician. When asked about her feelings of anger, this mother explained that she no longer "accepted a doctor's word as gospel" and now "asks a lot of questions first." She also expressed concern for her oldest child who seemed to carry the greatest amount of anger. The second mother explained that she was dissatisfied with the medical care her child received after a severe fall. She wondered if her child had suffered some brain damage which "caused" his speech problem and whether the doctor could have done more to have prevented this.

Although definite physical anomalies were present at birth, two mothers reported that they were not aware that anything might be wrong with their children until the latter half of the first year when they recognized motor delays. Three children with genetic disorders were diagnosed shortly after birth. The mothers of the children with developmental delay began noticing things such as poor muscle tone or "floppiness" and lack of skill development such as failing to roll over, sit up, crawl, walk, coo, or smile at the expected times.

Age of Child When Parents First Aware of Child's Handicap

	<u>N=20</u>	<u>Percent</u>
Birth to 1 month congenital defect <u>3</u> , developmental delay <u>1</u>	4	21%
One to six months developmental delay <u>2</u> , cerebral palsy <u>1</u>	3	16%
Six to twelve months congenital defect <u>2</u> , developmental delay <u>2</u> , cerebral palsy <u>1</u>	5	26%
One to two years speech disability <u>2</u>	2	11%
Two to three years speech disability <u>5</u>	5	26%

One of the children with cerebral palsy was diagnosed at about 6 months of age. The other child was not diagnosed until almost a year of age although the mother stated she had noticed that her child's legs seemed "tight" in early infancy and later he seemed to have problems with his feet when crawling.

Five of the children with speech problems or delays were about 2 to 3 years of age when their parents said they first became aware of the problem. Two children were about 18 months of age when their parents became concerned. One mother explained that she noticed that her child had trouble pronouncing words; the other mother was worried because her child had not learned to say "even one word."

Discussion

The period of time surrounding the discovery of the child's handicap seemed to be especially stressful for each of the families. Parents and family members experienced shock and disbelief, at the news of the child's handicap. Some expressed feelings of anger and blamed professionals. Many gave lengthy accounts of early experiences with the child, of efforts to find help and of their contacts with professionals. One mother began to cry for several minutes after describing this early time period. Some of the children had been seriously ill at birth and/or through their first year. Parents described the child's medical problems and treatments and their own feelings in detail. Other parents described intense feelings of concern for their children despite assurances from family members and/or professionals. Some of these parents seemed to want a specific diagnosis of the child's difficulty in order to get help for their child and/or qualify for special programs. Two mothers, each of whom had a child with physical anomalies present at birth, said that they were unaware that "anything" was wrong until several months later. It may be that these mothers did not understand the full significance of the anomalies in terms of the child's future development.

Sources of Help

In question 5 each mother was asked: "What kinds of things were helpful that family members, friends and professionals said or did at this time?" Most identified and discussed two or more sources of assistance listed below.

<u>Sources of Help</u>	<u>No. Mothers Reporting Use</u>
Professional support/information	14
Help and support from father single parent family <u>3</u> , two parent family <u>17</u>	11
Help and support from family members	15
Help and support from friends	5
Information	6
Outside interests	5
Inner resources	3

Professional Support/Information

Professional support and information was frequently mentioned as a source of assistance and emotional support. Most mothers remarked that the teachers and program staff were helpful in answering questions, referring them to community resources, and providing emotional support. Many mothers particularly appreciated that the teachers explained what they could do at home to help their children achieve set goals. One mother explained: "It makes me feel a part of it and like I'm doing something too." Several mothers mentioned that county health nurses helped by providing information and referrals to other programs and services available. A few mothers mentioned that hospital and clinic staff were helpful by providing information about community services. Two mothers felt that doctors who are "honest and admit that they can't be certain of the exact level of functioning my child will achieve are much more helpful" than those who attempt to give specific parameters.

A mother of a Down's syndrome child concluded, "parents need to hope or they may give up and just let the child lay there if that's all they think he can do." Two mothers stated that the occupational therapist "really seemed to understand" their problems and concerns. One mother was especially grateful, explaining that the therapist had provided valuable information and assistance obtaining medical direction in setting new therapy goals.

Help and Support from Father

Most mothers reported that their husbands spent time with their handicapped children and other children in play, assistance and/or care taking activities. One father made special toys and furniture for his child and was actively involved in "working" with the child in the infant program. Two mothers said their husbands occasionally helped with housework. Two reported that their husbands were willing to "babysit" in order to give them some time to themselves. Three mothers were single parents; of these, only one father was in contact with his children.

Help and Support from Family Members

Another frequently mentioned source of help was from family members. Grandparents provided most of this help which consisted of child care assistance, encouragement and acceptance of the handicapped child, and as a primary source of emotional support to the parents. One mother reported that her older children were great helpers in sharing household tasks and took turns teaching and playing with their handicapped sibling. Aunts and uncles were also helpful. One mother

reported that her sister was very supportive and helped by explaining the news of her child's handicap to other relatives and gave her good advice about "breaking the news" to the older children.

Help and Support from Friends

Friends were mentioned as sources of support and understanding. A mother of a Down's syndrome child stated that she appreciated the visits and emotional support that friends provided just after the child's birth. Another mother said that it was her friends at church who encouraged her to find some help for her child's speech problem. A few mothers mentioned that friends from their church groups offered prayers and gave emotional support. The parent support group sponsored by the special program staff was frequently mentioned as providing valuable opportunities to talk with other parents who "understand what it's like to have a handicapped child," and share information.

Information

Parents obtained information from a number of sources. One mother reported that hospital staff arranged for another mother who had a Down's syndrome child to visit after her child was born. This mother was very appreciative of the visit and information she received. Two mothers mentioned titles of books they had read about other families with "special" children and books which gave specific information about the handicapping condition. "We learned all we could about it; we know the medical jargon as well as any doctor."

Outside Interests

Only a few mothers mentioned outside interests which they found

helpful in maintaining their morale. One mother worked full time and reported that being able to get away for awhile every day "saved her sanity." Another mother joined a woman's group which was a "source of inspiration" and personal enjoyment for her. Poetry, books, magazine and newspaper clippings, and public speakers on motivation were sources of personal inspiration for another mother and her husband. Two mothers attended an educational program regularly and stated that although this placed greater demands on their time, they enjoyed "getting away."

Inner Resources

Several mothers mentioned that church and religious beliefs were an important part of their ability to cope. Some talked at great length about how their faith helped them to "continue on." Another inner resource that many of the mothers possessed was a sense of humor. Many were able to find humor in difficult situations and seemed to enjoy the uniqueness of their children.

Discussion

Parents wanted information about their children. They wanted information about the handicaps and community resources available. Mothers valued the information that teachers and therapists provided concerning the child's progress as well as suggestions for helping the child at home. While some wanted information about the child's specific disability, others felt that professionals should emphasize that they could not be certain about the child's future potential. These parents felt that this enabled them to hope (for the most positive outcome) and helped them work with child at home towards set goals.

Parents seemed especially appreciative of people who seemed to understand their problems and needs. "People who care" were identified as family members, friends and professionals. Of the seventeen two-parent families in the group, eleven fathers provided some kind of assistance with child care and/or housework, allowing the mother some time away.

Sources of Difficulty

In question six, mothers were asked: "What things were not helpful about family, friend's, professionals or others." Mothers frequently included information concerning the difficulties they encountered as they discussed the helpful behaviors and services provided by others. A number of difficulties were identified.

<u>Difficulties Identified</u>	<u>No. Mothers Reporting</u>
Attitudes of friends and neighbors	10
Difficulty with health care/education systems	8
Time crunch	7
Lack of sensitivity in professionals	6
Other stress/crisis situation	7
Attitudes of family members	3
Lack of support from husband	2
Unable to think of any difficulty	3

Attitudes of Friends and Neighbors

Parents found the attitudes of friends and neighbors upsetting at times. The most frequently mentioned problem was that of other children

teasing the handicapped child and/or the child's older sibling(s). Two mothers stated that they "had a talk" with the neighbor children and that this had helped somewhat. One mother was also frustrated with the parents: "They don't care, they just ignore the whole situation, so it's up to me to handle it as best I can." One mother stated that her child did not seem to notice the strange looks, snickering and pointing, but that it made her angry at times. Another mother expressed feelings of hurt and loss when a close friend told her that she had "really changed" since the birth of her handicapped child. "My friend just doesn't understand; of course I've changed! I'm much busier now. I don't have time to goof around but I'm still the same person inside." A second mother expressed her frustration with "friends who offered to babysit but always had excuses" when asked to do so. This mother also admitted feeling apprehensive about her friends' ability to provide appropriate care for her handicapped child.

Difficulty With Health Care and Education Systems

The next most frequently mentioned problem concerned difficulties with health care and educational systems. Three mothers complained that they did not know where to go to find help for their children. A few found out about the special infant/preschool program "by a chance comment" made by an acquaintance. Two mothers explained that they had their children in a program in the past but had difficulty finding out if there was a program available here. A few parents complained that they had trouble getting into the special program right away due to a waiting list.

Three mothers gave detailed accounts of their difficulties with the military health care system. The common concern seemed to center around convincing a physician that their children had problems which were not getting better. One mother felt that her child's problem should have been diagnosed months earlier commenting, "I know pediatricians can't know everything but shouldn't they be able to recognize the more common handicaps?" Another mother complained that she "never saw the same doctor twice." The third mother explained that she took her child elsewhere for evaluation by specialists because they were "getting nowhere." Another comment made was "there is no follow up to evaluate how my child is progressing. I have to tell them what I want for my child. The problem is that I don't always know what my child needs or what kinds of things might help." A fourth mother complained that health care professionals did not listen to her suggestions about what worked best for her child during medical procedures which resulted in "more work and trauma for everyone."

Time Crunch

Several mothers admitted that they had little free time to themselves due to tight work schedules, transporting their children to and from the special program every day, completing essential household tasks, and performing routine child care activities. One mother reported that she occasionally fell asleep at night still in her clothes. Two mothers reported that they had not been out alone with their husbands since their children were born. One mother was attending night school as well as managing household chores and caring for three

young children during the day. Three mothers commented that they had few chances to meet new people or get together with friends. One mother felt especially overburdened with child care and household tasks. She stated that she was sometimes so exhausted that she did not work with her severely handicapped child as much as she felt she should. Another parent reported that in addition to tasks related to her handicapped child, she is also responsible for her elderly mother who lives with her.

Lack of Sensitivity in Professionals

Three mothers complained that their pediatricians seemed to over-emphasize the disability and failed to explain the positive outcomes possible. One mother complained: "He told me all the bad things that could happen; I didn't realize that my child could learn to do some things until I found some books to read." A fourth mother was critical of a preschool teacher at a daycare center her child had attended. Another mother also complained about a teacher whom she felt was too critical of her child and rejecting of children in general. The sixth mother expressed her outrage with a professional who had made an inappropriate comment about her child's physical appearance.

Other Stress/Crisis Situation

Several mothers reported that their families experienced an additional crisis situation within a few weeks or months of the time they discovered their children's handicaps. One mother felt that the diagnosis of her child's handicap was "too overwhelming" for the child's father, who left the family a few days later. Three children with

speech problems also had a sibling born prematurely, shortly before or after they were enrolled in the special preschool program. Their mothers explained that this was a very difficult time period for their families. Two mothers went through divorces, giving few details, but it is likely that the family situations were stressful. One mother reported that her father died just a few weeks before her child was diagnosed with cerebral palsy. Two mothers reported that their husbands were away on military duty at the time of the child's birth and through most of the child's first year. This was especially stressful because each of these children suffered serious illnesses during their first year.

Attitudes of Family Members

While most of the mothers said that family members were supportive and provided much needed assistance, a few seemed somewhat disturbed by family attitudes. Two mothers explained that either their own parents or husband's parents have not been able to acknowledge that anything was wrong with the child. These grandparents felt that the child was a little slow, but would catch-up soon. "It's frustrating," said one mother. Another mother felt that her relatives really did not understand what it was like to care for a handicapped child. (This family lived several hundred miles away from their relatives.) One parent reported that she received very little support from either set of grandparents despite the close proximity. She felt uncomfortable leaving her children with one set of grandparents, and the other

grandparents were willing to babysit only in times of special need because they felt the couple should handle their own problems.

Lack of Support from Husband

Two mothers stated that they were uncomfortable leaving their children alone with their husbands because they did not provide adequate supervision. In addition, the mothers reported that their husbands spent little time with them as a family preferring to pursue their own interests in their spare time.

Unable to Think of Any Problems

Three mothers said that they did not experience any difficulty obtaining the help and support they needed for their families and themselves. Two of the mothers had children with speech disabilities and were referred to the special program at the time these were detected. The third mother reported that her child was normal.

Discussion

Parents reported a variety of problems in adjusting to the children's handicaps and finding help. Parents were sensitive to the attitudes of family and friends. It was particularly upsetting to them when their children were teased by other children in the neighborhood. Understanding and emotional support from family members and friends seemed equally important as other kinds of assistance. A common problem was the time crunch. Many mothers felt overburdened with child care and household tasks leading to exhaustion and guilt feelings. Most of these mothers had children with the more severe handicaps and/or received little assistance from husbands or others. Several mothers complained

about the insensitivity of professionals who seemed to over-emphasize the disability, failed to provide information about the most positive outcome possible, failed to listen to parents, and those who seemed uncaring or critical. In a few instances, parents seemed to feel that a professional was deficient in knowledge or skill which they felt prevented the child from receiving help earlier. Several families experienced other stressful events (divorce, father absence and the child's serious illnesses, birth of a premature sibling, death of a close relative) within a few weeks or months of the time the parents discovered the child's handicap. These families seemed to derive a great deal of emotional support and assistance from extended family members as well as from professionals.

Community Services Utilized

The seventh question asked each mother was: "As your child has grown older what kinds of services have you used?" Responses were grouped into four categories.

<u>Community Services</u>	<u>No. Mothers Reporting Use</u>
Financial assistance (SRS, Champus, school district)	9
Emotional support and information services in addition to the parent group sponsored by the special program (counseling, community groups)	5
Special services (Exceptional Child Program, Services for Crippled Children, Specialty Clinic, Shriners Hospital for Crippled Children, County Health Department, Respite Care)	11
Special education (programs/therapy in addition to present special education program)	7

Financial Assistance

Five families were receiving financial assistance from SRS available through the county social services department. One family received some financial help from the local school district which provided a fund for special education for handicapped children under five. Three other families received funding for the special program through Champus, an organization which funds health care and therapy unavailable through the military health care system.

Support and Information Services

All but three of the respondents regularly attended the parent support group sponsored by the special program staff. One family was involved in family therapy at a mental health clinic. The mother explained that it was helping the family to work through their feelings regarding the youngest child's handicap and their relationships with each other. Other supportive services used included: Parents Anonymous group, a sibling support group, and a community group which sponsors a guest speaker each month to talk about issues concerning the handicapped.

Special Services

Three mothers reported that their families were enrolled in the "Exceptional Child Program" in which the military agrees to make duty assignments available to these families in areas which possess services appropriate to the family's need. Two families received assistance from the state "Crippled Childrens Services" which supplies walkers, crutches, or therapeutic appliances as well as any prothesis needed.

Two children had attended a special occupational therapy program available through military medical services. Another mother explained that her child is being followed by a special team of health professionals at a major medical center. Shriners Hospital provided free medical care and services for another child. The county health department was utilized for health screening, information and referral services by at least four families. Two mothers stated that they planned to use respite care services in the future.

Special Education

All mothers had a child attending the special infant or preschool program available in their communities. Several children had previously been involved in other programs including private speech therapy, an infant stimulation program, and a military sponsored special preschool program.

Discussion

Families utilized a variety of community resources but many available services were not mentioned (see Appendix B). Mothers reported difficulties finding help for their children and seemed especially appreciative of any information about community programs and organizations. The parent support group was highly valued for the emotional support it provided and as a means of sharing information about available community services.

Perceived Need to Improve Existing Services

In question eight, each mother was asked: "Could these (services) be done better or improved?" More than half of the mothers felt

services could be improved in some respect. Their responses are categorized below.

<u>Improvement Needed</u>	<u>No. Mothers Reporting</u>
Services inadequate (Exceptional Child Program, Sibling support group, special education program	8
Failure to qualify for service needed (financial assistance)	7
Bureaucracy	3
Satisfied with services used/no improvements necessary	9

Services Inadequate

Parents reported that the military "Exceptional Child Program did not work very well." The three families enrolled in the program reported several difficulties including problems obtaining appropriate housing, medical care, and special education program for their children. The sibling support group dissolved after only a few sessions. The parents of the children felt that the group had too wide an age span for the small size of the group. "My older children resented being treated like little kids," said one mother. Another mother explained that her child, much younger in age, did not understand the things that the other kids talked about. The mothers felt that a larger group of siblings from several different families would insure that there were more than one child in each age group. Four mothers who had children attending the special preschool program at the same center felt that improvements

could be made, particularly more staff in order to give the children more individualized attention. Three mothers also felt that a larger building was needed. One mother added that the program should relocate to a "better neighborhood." Another parent verbalized a concern that her mildly handicapped child seemed to imitate the behavior of the more severely handicapped children at times and felt the children should be separated according to their disability. A few parents stated that they felt that special education programs should be a guaranteed right for children with handicaps or disabilities nationwide, starting from birth.

Failure to Qualify for Services Needed

Seven mothers reported that their families had applied for financial aid but did not qualify. Five had applied for SRS assistance, two for Champus. Each mother remarked that they were thankful that the special program accepted what the family was able to pay. One mother stated: "I think it really shouldn't matter how much money a family has; without financial help, some people just wouldn't put their child in a program."

Bureaucracy

One mother commented that SRS could speed up the processing to narrow the gap between acceptance in the program and paying out the money. She explained that it was almost a year since her family was accepted but they had yet to receive a check. Two mothers felt that the military health care system needed some kind of follow-up system for handicapped children in order to connect families with needed services and to coordinate therapy with medical advice. Another mother gave a

detailed account of the many difficulties they encountered in effort to get their child evaluated and a diagnosis established. She also described their "lengthy and humiliating struggle to obtain financial help," and how they worked their way through the system. Only three parents mentioned such problems. It may be that others simply accept the conditions as part of the system.

Satisfied with Services Used

Nine mothers said that they were satisfied with the services they had used or were unable to think of any way to improve them. Three mothers commented they wished that they had learned of them sooner. Many made favorable comments about the special program. In general, parents stated that they noticed improvement since their child started the program. Four mothers stated that they felt the teachers really seemed to care about the children and were appreciative of their suggestions for helping the child at home.

Discussion

Nearly half of the mothers said that they were satisfied with the services they utilized and seemed to feel these met their needs adequately. Other mothers made some useful suggestions to improve services. Some parents felt that improvements could be made in the preschool program. A particular concern was for smaller teacher-child ratios to allow more time for individual instruction. Most seemed aware of the financial constraints involved with the proposed improvements. Several mothers felt frustrated that they did not qualify for financial assistance to help pay fees. Some of these mothers expressed opinions

that special education should be a right for handicapped children from 0 to 5 years of age. They felt that such legislation would enable more children to be served, eliminated the search for an appropriate education program, and ease financial pressures on families.

Parent Suggestions for Additional Services

In the ninth question, each mother was asked: "What other services could have helped?" Parents provided a variety of suggestions organized in the categories below.

<u>Additional Services Needed</u>	<u>No. Mothers Reporting</u>
Counseling-information services	9
Transportation services (bus to school)	7
Financial assistance	7
Respite care	2
Mothers helper service	1
No need for other services	5

Counseling, Information Services

Four mothers wanted a service that would help parents find out about programs and services available to help her child. As one mother put it: "Something, anything, to make the process less traumatic and exhausting."

Five mothers wanted a counseling service available to provide information about handicaps and give emotional support. One of the mothers felt parents should be referred to this service at the time the child is diagnosed to help parents get information and help them cope.

The mothers felt a need for a service which would offer one to one counseling and/or group counseling where parents could share information and obtain emotional support. Many felt that the program sponsored parent group could meet these needs.

Transportation Service

Seven mothers suggested that a bus service to take their children to the program center would be a helpful time saver. Two of these mothers drove more than 25 miles each way every day.

Financial Assistance

Seven mothers wanted financial assistance to help pay the monthly fees for special programs but did not qualify. Three of these mothers mentioned that they felt they should be able to get some financial help and noted differences between various states in what services are provided.

Respite Care

Two mothers planned to utilize respite care services. However, one mother had some concerns regarding the availability and qualifications of care providers in her community.

Mothers Helper Service

"A service to help with housework, childcare and to tutor my handicapped child occasionally would be wonderful," said one mother. "It would give me some free time to rest."

No Need for Other Services

Five mothers said that they did not need additional services and felt satisfied with the programs they were utilizing.

Discussion

Parents identified a number of services that would help them. These were mainly related to themselves and indirectly for the child. They wanted support and information services to speed up and simplify the process of finding needed services. They also wanted services which would provide them some time to themselves: a bus to take children to the program center was one means of making their daily schedules lighter. Others wanted direct assistance with childcare and household management. Several mothers wanted supportive services such as individual and group counseling to help them anticipate problems, share information, and obtain emotional support. Many of the services mentioned were already available in the community (see Appendix B).

Perceived Need for Family Life Education

Mothers were asked: "How do you think someone like me, a family life educator could assist families such as yours?" Several parents asked for an explanation of "family life educator." These respondents were told briefly that a family life educator was a person with knowledge of family experiences as they grow and manage change through the family life cycle. Mothers' responses were organized into four categories.

<u>Perceived Roles for Family Life Educator</u>	<u>No. Mothers Reporting</u>
Provide information and referral	7
Plan and organize programs (for parent support group)	11
Make home visits (provide information & support)	9
Develop community programs to increase public awareness and understanding of families with handicapped children	2

Provide Information and Referral

Seven mothers suggested that a family life educator provide an information and referral service for families of handicapped children. These mothers thought such a service was much needed to both speed up and simplify the process of finding appropriate help.

Plan and Organize Programs for Parents

Eleven mothers mentioned that a family life educator could help organize and plan programs for the parent support group sponsored by the special education program centers. One of the mothers thought that the family life educator should lead the group discussion. Another suggested that the family life educator think of ways to get fathers more involved in the group.

Make Home Visits; Provide Information and Support

Nine mothers suggested that a family life educator could make home visits. Each of these mothers remarked that she found it helpful to talk to someone individually about their concerns as well as in a group setting.

Develop Community Programs to Increase Public Awareness and Understanding

Two mothers remarked that it would be especially helpful if a family life educator could develop community programs to help other families and "normal" children to understand what it is like to have a handicapped child in the family. A mother explained, "other children tease and run away from the little girl with Down's syndrome next door. They're afraid they may catch it. They don't understand."

Discussion

Most mothers paused to think for a few minutes before answering. Many ideas were generated. Mothers felt that a family life educator would be useful in facilitating the parent support groups by planning program presentations or leading the group discussion. Most seemed to enjoy the home visits and several mothers mentioned that this was helpful. The mothers viewed a family life educator as someone who could provide them with information and support. A few felt that such a person could help promote community awareness of their problems and concerns which should be extended to groups of children, adults and professionals.

Parent-Child Interaction

The last question each mother was asked is "What are some things you do with your children that really seem to work well?" This was a difficult question to answer. Therefore, follow-up requests were made concerning examples of 1) fun things parent and child do together; 2)

learning activities; and 3) discipline techniques used. Each of these three categories are organized and discussed separately.

<u>Fun Things: Parent/Child</u>	<u>No. Mothers Reporting</u>
Outdoor activities (play in yard, go to park, walks, picnics, go for rides, look for rocks)	18
Physical activities (softball, games, swimming, camping, bike riding, rough housing)	13
Play/watch animals (zoo, pets, feed ducks, visit farm)	5
Organized community events (spectator sports, fireworks, etc.)	3
Indoor activities (go out for lunch, color, play on floor with toys, family gatherings)	6
"We do lots of things together as a family"	3
The older kids don't always want to participate in family outings	1
Children do not have playmates nearby	4

The mothers mentioned a variety of fun activities that they participated in with their children. Many of these activities were associated with the outdoors including going outside for talks, picnics, play in the park, or having something to do with animals (examples: playing with pets, feeding ducks, visiting a farm or the zoo). Physical activities such as camping, swimming, games, and rough-housing were also

mentioned. Two mothers mentioned participation in organized community events such as sports events, fireworks in the park, and Easter egg hunts.

Most parents mentioned two or three favorite joint activities they participated in with their children. Several were "family" activities including the father (picnics, camping). One mother seemed to find this a very difficult question, and could not readily think of a joint fun activity she did with her children. She commented that maybe she should do more things with them. A few mothers mentioned problems. One parent was concerned because the older children (in their early teens) did not always want to participate in family outings. Four mothers mentioned that their children did not have playmates nearby. Two of these mothers stated they became tired and bored in joint activities long before their children and felt that finding playmates would be a good solution.

<u>Learning Activities: Parent/Child</u>	<u>No. Mothers Reporting</u>
1. Plays with creative toys (leggos, playdo, blocks, specially made toys)	4
2. Music (toy piano)	1
3. Reads stories (naming objects, letters numbers)	8
4. Self help skills (child performs household task)	4
5. Educational television (Sesame Street)	4

Parents did not always distinguish between fun and learning activities; therefore the two categories are organized somewhat arbitrarily. "Learning activities" includes activities more closely associated with creativity, cognition and fine motor development. Parents mentioned a variety of different learning/play activities that their children enjoyed. Many of these involved the parent in some way; for example, reading stories, naming things, practicing ABC's and numbers, taking children to the library and helping parents with household tasks. Other activities included watching "Sesame Street", playing with playdo, building blocks, or other specially designed toys.

One mother stated that she tried to let her children do things for themselves when she sees they are able. A few mothers expressed feelings of frustration that no matter how hard they worked with their handicapped child at home, he or she still could not do it right.

Discipline.

Discussion of discipline also presented difficulties for the mothers. Many of the mothers considered only punitive measures. Their responses were categorized as follows on page 89.

Four mothers stated that discipline was no real problem for them. One of these mothers regularly attended "Parents Anonymous" with her husband and felt that this has helped them to handle their discipline problems more effectively. The second mother said discipline was no problem because her only child (infant) was too young to get into trouble. Of the other two mothers, one felt that spanking worked the

<u>Discipline Approaches</u>	<u>No. Mothers Reporting</u>
1. Handicapped children need discipline but it's hard to do sometimes	4
2. Spanking does not work anymore	2
3. Time out technique does not work	5
4. Oldest child is jealous/hits the younger child	2
5. Child follows mothers, hangs on to her	2
6. Normal child hits/pushes/steals from handicapped child	1
7. Discipline is not a problem	4

best, the other mother explained that she tried to consider the child's feelings and motives and talked with her child about the problem. Most mothers admitted that discipline was a problem at times. Several mentioned they had trouble with the time out techniques (sits on chair, stands in corner, stays in room). One mother complained that her child "begs to get off the chair and promises to follow the rules but does the same thing again a half hour later." Several parents reported that they spanked their children; most of the parents usually tried other techniques first such as explaining what the parent doesn't like and why. One mother noted that spanking was not working as well since her children have grown older. She stated that she needed to try another technique and decided to try "talking" with her children about their

misbehavior rather than yelling or spanking. Several parents acknowledged that handicapped children need discipline but that it was hard sometimes. Another difficulty concerned sibling interactions. One mother reported that she has trouble with her normal child who hits, pushes, and takes toys away from the handicapped sibling. Two other parents had similar problems in which the oldest child hits the youngest child. Each mother stated that she realizes the older child is jealous and has "tried everything, but nothing seems to work."

Discussion

Parents reported a variety of fun and learning activities in which their children participated. The fun activities mentioned frequently involved physical play (65%) or outdoor activities (90%) in which the handicapped child may participate more easily. Those mothers who reported participating in activities as a family unit seemed to especially value these experiences. A few mothers related difficulties associated with the lack of playmates for their children. These mothers felt the need to provide their children with more activities yet found these activities boring long before their children tired of them. The learning activities mentioned included things the child could do alone and/or with a parent. While many parents seemed eager to teach the child at home (example: write numbers and letters, name things), a few felt frustrated with the child's seeming lack of progress. Some parents seemed unaware of the importance of encouraging the child's effort as well as the correct responses.

Most mothers admitted that discipline was a problem at times.

Several related difficulties managing jealous siblings and difficulties with a particular technique. Some acknowledged that it was occasionally difficult to discipline the handicapped child. These mothers wanted alternative suggestions for managing child behavior and were appreciative of the suggestions the interviewer provided.

Summary

The interview mothers provided useful information regarding their problems, concerns, and need for services. The time period when parents first became aware of the child's handicap was particularly stressful for most families. Parent responses included shock and disbelief, denial, fear, anger, and grief. Some continue to feel anger towards professionals. Family members, relatives, friends, and professionals provided emotional support and assistance. Religious beliefs, a sense of humor, other parents of handicapped children, and outside interests also helped parents to cope.

After the parents recognized the child's difficulty, they sought help. Several mothers reported that they had trouble finding the service they needed. Other parents had difficulties persuading medical professionals that "something was wrong" with the child. Many complained of difficulties experienced with the health care and educational systems. Other sources of difficulty were the attitudes of family members, friends, and neighbors. Many mothers reported having little time to spend alone or with their spouses and other children. While most fathers helped with childcare and household tasks, some mothers felt that their husbands did not provide this help.

Parents reported some difficulties in their contacts with professionals. Some wanted specific information about the children's future functioning while others preferred general information about the range of possibilities. (There was a tendency to look toward the goal of catch-up). Parents seemed to value professionals who were honest with them, listened to their concerns, and who were knowledgeable about the handicapping conditions and community services available.

The special education program seemed to be highly valued by almost all of the mothers including those who felt improvements were needed. Mothers also valued parent groups to exchange information and share problems and experiences with parents "who know what it's like to care for a handicapped child."

Parents utilized a variety of community services yet a number of programs were available that were not mentioned (see Appendix B). Mothers suggested additional services that would be helpful. Several mentioned that a transportation service to and from the program center would save them time as well as enable the child to attend more regularly. Some mothers also suggested that a community referral service would be very helpful. Others wanted help with childcare. Nearly all mothers discussed the need for financial assistance. Many families did not qualify for aid but felt they should qualify. A community education program to increase public awareness and sensitivity to the problems of families of handicapped children was also suggested by some of the mothers.

Parents reported a variety of enjoyable learning activities in which their children participated. Many of the mothers admitted occasional problems with child management. Some acknowledged that at times they found it difficult to discipline the handicapped child. These mothers wanted ideas and information about alternative techniques to try. Parents were also concerned about sibling interactions and teasing by peers.

CHAPTER 5
IMPLICATIONS FOR FAMILY LIFE EDUCATION

The literature on families of handicapped children and information from the parent interviews suggest several implications for family life education. Although families of handicapped infants and preschool children have similar needs for family life education as families with normal children, this information must be tailored to their particular problems, needs, and concerns. Whether the handicap is present at birth or discovered later, the child's disability alters the expected patterns of family relationships and interactions in stressful ways. Family life education programs for families of handicapped, the professionals who serve them, and members of the community can help meet family needs for information, support, and appropriate services.

An important concern identified in the literature and parent interviews was the need for information. Parents wanted information about handicapping conditions. They also wanted referrals to community services for themselves and their handicapped and nonhandicapped children.

Parents wanted information about their children's handicaps yet the literature on grief and loss suggests that parents may differ in their capacity to accept such information depending upon their emotions and individual coping abilities. Timing of such information may be crucial.

One of the mothers interviewed experienced this difficulty. The mother "resented" those who tried to supply her with information shortly after the diagnosis of her child's handicap. She explained that she "wasn't ready" to believe that her child had a defect; however, she was thankful for this information later. Parent educators must be sensitive to timing the information they provide in order for it to be meaningful for individual parents or groups of parents. An understanding of the emotions (grief and loss) and the problems the family must confront will help parent educators plan appropriate and effective ways of conveying information to help families manage changes in patterns of interactions/ activities and provide the care needed by the handicapped child.

Parents need help in dealing with the ambiguities of the handicap. Parents wanted information regarding the handicap yet differed in what they wanted to know. Some preferred to think of potential as unknown and resented professionals who gave specific predictions. Yet others wanted a specific diagnosis and developmental parameters. Many experienced high levels of stress and frustration when professionals were unable to provide this information. In either of these instances, there is an inherent danger in that parents may form unrealistic expectations and hopes for children. Parent educators, therefore, need to offer hope by acknowledging the wide variation in developmental potential and at the same time give information in which realistic developmental expectations can be formed in order to meet children's present needs.

Parents wanted information about services available in the community for themselves and their handicapped and nonhandicapped children. Services parents wanted and valued were: parent groups, special education programs for children, and assistance with child care. These families seemed to have difficulties in accessing the services they needed and had a narrow range of known alternatives. Parents also encountered difficulties with paperwork, waiting lists, and red tape. It was important that services be affordable and that the parents had reliable transportation available. Parent educators can help families access community services through parent workshops designed to enhance communication and problem solving skills needed in order to communicate their needs effectively and locate desired services. Parent educators can also provide direct referral and information regarding available federal, state, and local programs. Information regarding application procedures and eligibility requirements for specific programs would reduce paperwork and shorten waiting periods by allowing parents to gather the appropriate documents and data needed in advance.

Families differed in the nature and adequacy of their support networks depending on family characteristics, resources, and services available in the community. The empirical literature and parent interviews suggest the importance of both family and community support networks and some of the difficulties parents may encounter.

Spouses, siblings, grandparents, aunts, and uncles provided emotional support and assistance with child care. Yet some of the mothers seemed distressed by the attitudes of grandparents, relatives,

or friends, many of whom failed to recognize the child's handicap and therefore were unable to appreciate the families' needs. Family life education programs must point out that extended family members also experience feelings of loss and grief and should emphasize communication skills to share and express feelings. Programs can help relatives, friends, and concerned community members develop better understanding and awareness of the family's experiences, problems, and need for emotional support and direct assistance.

It is important that family life education programs include marriage enrichment. Several mothers reported that they had not been out alone with their husbands since the children were born. Many of the mothers identified a need for time away from their handicapped children, to rest, for time alone, personal interests, or to spend time with their husbands or other children. While most fathers provided some assistance with childcare, some did not. Marriage enrichment programs should emphasize the importance of planning regular times to be together alone; of communication of feelings, needs, and concerns; and of the need to renegotiate and effectively share the burden of child care.

Parent visitor programs and parent support groups were highly valued by parents surveyed in the literature and through the interviews. Most of the mothers interviewed seemed to enjoy the sessions; some requested the interviewer to visit again; and several commented that they found it helpful to be able to talk to someone, one to one, in their homes. These mothers seemed to be lonely. They also seemed gratified that someone took interest in their personal concerns. Parent

visitors may be a particularly valuable source of emotional support and information about alternatives.

There are many ways in which family members can obtain emotional support. One to one contacts with professionals or trained volunteers (paraprofessionals) allow greater intimacy and expression of both negative and positive feelings. Or small groups of parents with fixed membership would allow greater sharing of personal concerns. It is important that fathers be given opportunities to participate in parent groups or visitor programs as well. Family life educators can help develop these support services, provide training for parent visitors, and assist parent groups or associations in planning programs, obtaining information, and locating resources.

Parents were concerned and wanted help for their nonhandicapped children. Sibling groups can assist children to verbalize their feelings and concerns and help them develop effective ways of coping. Nonhandicapped siblings gain greater perspective and insight into their individual experiences. Programs which bring groups of families with and without handicapped children together for recreation and group discussions may also help improve peer relations between handicapped children, their siblings, and other children.

In addition to emotional support, mothers indicated a need for special knowledge and skills in dealing with parent-child interactions. Some mothers seemed frustrated with their children's lack of progress despite efforts to teach them at home. A mother observed during the interview session seemed unaware that she had discouraged her child's effort to learn a new skill. The mother failed to see that her child

had actually made a correct response. To her it was "wrong" because of a technicality. Discipline was another area of difficulty for parents. Most tended to view discipline as "punishment". Mothers wanted information about alternative techniques. Parent education programs are needed which focus on child management techniques; motivation and learning; and child development.

Most mothers seemed to focus on the problems of the present. They did not appear to be aware of continuing and future problems of caring for their handicapped children. Robert Perske (1972) identified several issues of concern to parents and family members over the life cycle. These include: the child's entry into the public school system, sexual development, sexual and affectional expression, marriage and parenting roles for handicapped individuals, the decision whether to institutionalize, and guardianship. Families need advance knowledge of potential problems and decisions that may be required during transition periods in the family life cycle to help them prepare for changes. Family planning information may also be useful in making decisions about the number and spacing of children and/or referring parents to other resources such as genetic counselors or health care providers.

Community awareness and understanding was another concern identified by parents. They felt that their handicapped children were misunderstood by peers and that other parents could be more sensitive to the need to educate their children about children with handicaps. Parents also felt that relatives, friends, and community members failed to understand what it is like to be a parent of a

handicapped child. Family life education programs are needed to increase public awareness and understanding of the problems, concerns, and service needs of families with handicapped children. In addition, public support can influence legislative action (at federal, state, and local levels) and policy changes to meet needs for community services especially for public education programs for all handicapped children from birth, as well as appropriate child care services. Public awareness can also generate volunteers to provide direct services or donations to support and expand ongoing programs.

Professionals and paraprofessionals who work with families with handicapped children need to become more sensitive to the problems, feelings, and concerns such families may experience. Professional training and in-service programs are needed to help professionals prepare information and services for families. How the professional communicates information along with appropriate timing are of crucial importance in order to promote effective utilization and acceptance of this information.

Several implications for family life education have been identified. Families of handicapped children can benefit from enrichment programs to enhance family functioning and interaction. Programs are also needed to provide information to help them prepare for changes in the family life cycle; increase their knowledge of child development, available resources, and community services; enhance communication skills; and help them understand their legal rights. Family life education programs for professionals can help

improve communication, understanding, and sensitivity to the needs of parents and siblings as well as those of the handicapped child. Public programs to increase awareness of family problems, concerns, and needs for services can lead to the appropriate legal actions, policy changes, and initiation of volunteer services. Family life education programs can help parents obtain the special skills, information, emotional support, and community services they need in order to care for their handicapped children.

CHAPTER 6

SUMMARY

The optimal growth and development of the handicapped child requires that parents understand, love, and care for their child. It is the parents who will provide the appropriate help needed by the child. This report has examined many problems, concerns, and needs of families with handicapped children from birth to age five and has described the services desired by parents through a review of the literature and parent interviews. Implications and direction for family life education have also been presented.

The presence of a handicapped child alters family patterns and roles in particularly stressful ways. The mother may have almost the entire responsibility for the heavy burden of the child's care. Parents have little time for themselves. They may experience confusion over how much control to exercise over the handicapped child's behavior. Sibling concerns were identified. The small body of available research suggested that siblings, particularly the oldest daughter, may experience adverse effects. Parents were also concerned for their non-handicapped children and wanted to help them cope with their feelings and specific problem situations (e.g., peer responses). Family members must also cope with feelings of grief and loss which may be re-evoked at transition periods in the family life cycle. Each family

member experiences feelings of grief and loss at the news of the child's handicap. In order to provide appropriate help for the child, parents must be able to accept the reality of the child's handicap and present limitations.

Support networks for parents of handicapped children include family members, relatives, neighbors, friends, other parents of handicapped children and professionals from health care, education, and social service agencies. Spouses and grandparents were particularly helpful sources of emotional support and assistance with child care.

Professionals provided information, advice, and emotional support as well as direct intervention (e.g., medical, special education). Parents occasionally experienced difficulties in their contacts with professionals. Some complaints were that professionals were insensitive to the parent's feelings or concerns, lacked knowledge of specific handicapping conditions or other services available. Another complaint was that the information given about the child's developmental potential was either too specific, too general, and/or overly pessimistic.

Several ways to improve professional services to families with young handicapped children were identified. These include special programs for professionals to improve communication skills and increase their knowledge of specific handicapping conditions and awareness of family responses and special concerns.

A wide range of services were identified. These services are administered through public and private agencies/organizations at the federal, state and local levels. Of particular concern is that the

availability, cost and quality of services may vary depending on the family's geographic location, the child's particular handicap, availability of transportation, and/or characteristics of the sponsoring agency and personnel. An important need for most parents was a special education program for their handicapped children. Yet only a few states currently provide special education services to all handicapped children from birth. Clearly many children in need of programs are not being served. Parents wanted additional services for themselves and their children. These included: a bus service to the child's school, financial assistance, an information and referral service, assistance with child care, sibling groups, and family life education programs to increase public awareness and understanding of their needs. Parent support groups were highly valued for emotional support and opportunities to share information and resources.

Several implications for family life education were presented. Family life education programs need to address family needs for information about the spectrum of problems they might encounter through the family life cycle; provide information about their legal rights and community resources available; and provide information and alternatives with regard to child management issues (e.g., discipline, behavior expectations, child care services). Programs to improve communication skills and provide information about individual responses to grief and loss can increase awareness and understanding of individual feelings and emotional needs among family members. Such programs can benefit professionals as well. Family life education programs for professionals

can help improve communication, understanding, and sensitivity to the needs of parents and siblings as well as those of handicapped children.

Family life educators can develop and coordinate supportive services such as the parent visitor program, assist parent groups plan programs, or help locate resources. Finally, programs to increase public awareness of family problems, concerns, and need for services can lead to appropriate legislation, policy changes, and volunteer services to be initiated. Much more can be done to assist families of handicapped infants and preschool children.

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APPENDICES

Appendix A

Interview Instrument

1. How did you find out about the special infant/preschool program?
2. Why does your child attend the special program?
3. Tell me about your child's handicap or difficulty.
4. Tell me about the time you became aware of your child's handicap or difficulty.
5. What kinds of things were helpful that family members, friends, and professionals said or did at this time?
6. What things were not helpful about family, friends, professionals or others?

7. As your child has grown older, what kinds of services have you used?

8. Could these be done better or improved?

9. What other services could have helped?

10. How do you think someone like me, a Family Life Educator could assist families such as yours?

11. What are some things you do with your children that really seem to work well?
Full things you do together:

Learning activities:

Discipline:

Appendix B

Description of Available Community Services

Source: Manhattan Social Services Directory (1985).
Department of Family and Child Development,
Stephen Bollman, Director, Manhattan, KS.,
Kansas State University.

Association for Retarded Citizens, Inc.

Services provided include a series of programs and advocacy for mentally retarded citizens. Cooperates with other agencies serving the needs of the mentally retarded. Anyone is eligible to attend. There are no fees for service. Membership fee is \$15.00/year. Volunteer staffing.

Cerebral Palsy Association

This service gives aid to people of all ages who are afflicted with cerebral palsy through therapy, financial assistance, vocational rehabilitation and instruction on child care of cerebral palsy children. Speech and physical therapy available through the Developmental Center. There are no fees and everyone is eligible for services.

The Kansas Society for Crippled Children

Federally funded organization which provides direct care and treatment to crippled children who do not meet the legal requirements for services under other agencies or for whom there is no other source of aid. Included is care to children with hearing and seeing defects. Services are facilitated through this organization and carried out by doctors and hospitals. Children of low income families are eligible for services and there are no fees.

Fort Riley Army Community Service

The primary goal is to help military families help themselves by getting questions answered and problems solved. This is seen as the appropriate direction for returning the service member to his or her productive self within the family and the military. In achieving these aims, services extend to the elderly, and the handicapped, as well as to the family through help concerning housing, legal aid, consumer protection, employment, income maintenance, and emergency services. These services are made available through appointments in the office, home visits, and community education for military wives and key leaders (supervisors).

The service is provided for active duty or retired military and family, Department of Army civilians and family.

There are no fees. Services are provided by professionals and volunteers.

Headstart of Manhattan

This program provides a pre-school program for children of low-income families with emphasis on comprehensive services and parent involvement. Areas of service include classroom education, parent workshops and home visits with attention to dental, nutritional and mental health of the children.

Children 4-5 years old are eligible. There are no fees.

Professional and paraprofessional staff.

Health and Homemaker Services, Riley County

Riley County Health & Homemaker Services, Inc., commonly referred to as Home Health Services, is a private, not-for-profit Home Health Agency providing a wide range of in-home services for Riley County citizens.

Referrals may come from self or family, physicians, hospitals, or other agencies. In home skilled services include:

- 1) Skilled Nursing
- 2) Home Health Aides
- 3) Physical Therapy
- 4) Occupational Therapy
- 5) Speech Therapy
- 6) Medical Social Services

Comprehensive health care is provided to patients in their own home. Services are tailored to the special needs of the individual. All care is provided under the direction of the patient's physician. In-Home Support Services:

- 1) Homemaker Service
- 2) Case Management (ACE)
- 3) Companion Sitter Service
- 4) Custodial Personal Care Service

Riley County Residents are eligible for services.

Medicare, Medicaid, and other insurance may pay all or part of the cost of skilled home care. Services are supported by client donation. Program costs are fee for service and funded by Federal Grants, County Mill Levy, City Revenue Sharing, United Way, and Memorials.

Staffing is by professional, paraprofessional, and volunteers.

Kansas Advocacy and Protective Services for the Developmentally Disabled (KAPS)

KAPS is a private, non-profit corporation created to fulfill the requirements of section 113 of P.L. 94-103 as amended by P.L. 94-602, the Developmental Disabilities Assistance and Bill of Rights Act. The Developmental Disabilities Act calls for each state to provide that a system exists with authority to pursue legal, administrative, and other appropriate remedies to assure for the protection and advocacy of developmentally disabled children and adults. KAPS receives and processes complaints of alleged rights violations from individuals and groups, offers information and referral assistance, and provides comments on proposed bills and rules and regulations which would affect developmentally disabled people. Services are offered on a statewide basis.

KAPS also heads up a program designed to recruit train, and support persons willing and qualified to serve as guardians and/or conservators for court adjudicated incapacitated persons throughout the state. The Kansas Guardianship Program Coordinator is Jim Lackey.

Any developmentally disabled adult or child is eligible for services free of charge. SRS approved adults for guardianship. Professional and paraprofessional staffing.

Kansas Children's Service League, Manhattan/Junction City

KCSL is a state-wide, private, non-profit United Way agency founded in 1893. KCSL provides three types of foster care:

1. TEMPORARY FOSTER CARE
Short-term placement for children whose parents must be out of the home due to illness or a crisis in the family.
2. EMERGENCY FOSTER CARE
Short-term placement for children who are removed from their homes because of abuse, neglect or behavioral problems.
3. RESPITE FOSTER CARE
Planned, short-term family living for handicapped children whose parents need a break from the difficulties of parenting a handicapped child. Parents meet the family in the family's home before the actual stay of the child.

Children ages 0-17 are eligible for the foster care programs and people with a need or an interest in the program.

Sliding scale fees are charged based on the ability to pay.
Professional staffing.

Knights of Columbus

As a non-profit, fraternal organization of the Catholic Church, this group conducts two services benefiting the Manhattan community. An emergency disaster aid program exists for possible use in the event of a severe hardship to a local family or individual, subject to approval by the state council. An annual Tootsie Roll Drive raises money to finance the state's Special Olympics and Free Throw contests. Some funds also come back to the local Federation for Handicapped Citizens.

Catholic men in good standing with the church are eligible for membership.

Yearly membership fees.

Manhattan Parks & Recreation Department

The Parks and Recreation Department provides a variety of recreational opportunities for people of all ages and interests. The Arts in the Park series, sports for all ages, and coordination of coaches and teams become an integral part of the department. In addition, educational programming of the visual arts, intramural programming, and science and zoo classes are offered. Services are available for those 3 years and older and Manhattan residents.

Fees have been established for each program.

Professional, trainee, and volunteer staffing.

Medi-mate Memorial Hospital

Medi-Mate is designed to meet the needs of the elderly, handicapped, and functionally impaired. Medi-Mate is a hospital oriented, 24-hour emergency response system that enables the home user to automatically call for help in times of emergency. This program helps those persons who live independently have the reassurance that they are in contact with the hospital 24 hours a day.

Everyone is eligible for services.

Charges are \$15.00 per month or \$165.00 per year. No installation charge.

Professional and volunteer staffing.

Memorial Hospital Family and Social Services Department

This program helps hospitalized patients and/or their families in need of social work services through support or direct referral to community agencies. Home visits can be made following discharge of the patient or by referring patient or family to community resources. Parents Encouraging Parents Support Group for parents who have premature infants and infants born with special problems is run through this department. The Medi-Mate Program is coordinated through this office. Medi-Mate is a personal emergency response system designed for those who are handicapped or elderly. Medi-Mate helps these persons live independently while having the reassurance that they are in contact with the hospital 24 hours a day. Everyone is eligible, no fees.

Parents Anonymous

Parents Anonymous is a self-help program designed to help parents. Parents are given the support and assistance they need to prevent their frustrations from taking the form of child abuse and neglect. The program promotes positive relationships between parents and children. Anyone may participate.

No fees, free child care is offered during the meeting.

Professional staffing.

Riley County-Manhattan Health Department

The Health Department serves residents of Riley County through the following programs:

Personal Health Services

- Family Planning
- Pregnancy Testing and Counseling
- Maternal and Infant Project: Teen mother program for women age 17 and younger. Designed to help young women cope with pregnancy. Provides pregnancy counseling and education and support through peers.
- WIC: Is a supplemental food program for pregnant and nursing mothers, infants and children up to age four.
- Venereal disease: Testing, treatment, and counseling.
- Vaccinations and Overseas Travel Information
- Pregnancy and Parenting Educational Classes.
- Well Child Physicals: Assessment of development, hearing, vision, hemoglobin, sickle cell, immunizations and urinalysis on children under age 18.
- Kansas Crippled Children Program: For handicapped children whose condition can be corrected.
- Hypertension Screening.

- Home Health Nurse Visits: Provides skilled care, health education, and counseling for sick or injured persons who are unable to care for themselves.

- Health Education: Is available to groups or individuals upon request.

- Newborn Visits: Provides information on parenting, health services, and support for new mothers. Nursing care available when needed.

- Lively: Health assessments for the older adult also includes health promotion programs.

- Communicable Disease: investigation, and follow-up of people exposed.

Anyone is eligible for services. Fees are based on income. Professional staffing.

Riley County Extension Service

Provides written materials including information on gardening, cooking, sewing, home decorating, child development, family activities, nutrition and health, home care and budgeting. Extension agents available to answer questions/provide information. No fees, professional staffing.

Shrine Club

Provides specialized treatment for crippled or severely burned patients up to 18 years of age. There are 3 burn hospitals and 21 crippled children's hospitals across the country, all financed by the Shrine Clubs. The Burns Institute in Galveston, Texas and the Crippled Children's Hospital in St. Louis serve this area.

Through membership assessments, the East-West Shrine Game, the annual Shrine Circus, wills and bequeaths, funds are raised to support the hospitals. If a case is approved through the Shrine headquarters in Salina, a local person can receive treatment from one of the hospitals.

Anyone is eligible for service at no charge.

Professional staffing.

Social and Rehabilitation Services

SRS provides financial and medical assistance and social services to low income Kansans, mainly through office and home visits. Community educational programs can be arranged upon request. The range of services is fairly comprehensive, including services to the aged, delinquent youth, child care services, income maintenance, vocational rehabilitation, child management, family planning, and services to the

handicapped. SRS conducts abuse and neglect investigations for children and adults, as well as adoption services. Information and referral for other areas are offered.

Information and referral are provided without regard to income, as are abuse and neglect services. Other services are provided to low income individuals and family households.

Some services may require partial fee payment. Most services are provided free.

Professional, paraprofessional, trainee, and volunteer staffing.

Special Educational Services, USD # 383

This service provides educational services for handicapped children, including K-12 Educational Programs. Transportation is also provided.

People 5-21 years of age and resident of USD #383 are eligible at no charge.

Professional, paraprofessional, trainee, and volunteer staffing.

Speech and Hearing Center--KSU

Speech, language and hearing evaluation. Remedial and diagnostic services provided for stroke, laryngectomy, stuttering, language articulation, and hearing impairments.

Sliding scale fees are charged.

Professional and student staffing.

THE PROBLEMS, CONCERNS AND SERVICE NEEDS OF
FAMILIES WITH HANDICAPPED INFANTS AND PRESCHOOL CHILDREN

by

MARY JO SMITH BADEN

B.S.N., University of Minnesota, 1979

An Abstract of a Master's Report
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MASTER OF SCIENCE

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Abstract

Twenty maternal interviews and a literature review identified problems, concerns, and needs of families with handicapped infants and preschool children. The families appear to be experiencing a high level of stress and feelings of grief and loss. They need emotional support (counseling and parent groups), and specific services including an educational/developmental program for the affected child, access to information and child care assistance. Some difficulties encountered with family and community support networks were identified and are discussed. Implications for family life education are presented.