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THE ROLE OF THE SERVICE COORDINATOR

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PROMOTING EMPOWERMENT AND COPING IN FAMILIES WHO HAVE INFANTS AND TODDLERS WITH DISABILITIES: THE ROLE OF THE SERVICE COORDINATOR

By

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ABSTRACT

PROMOTING EMPOWERMENT AND COPING IN FAMILIES WHO HAVE INFANTS AND TODDLERS WITH DISABILITIES: THE ROLE OF THE SERVICE COORDINATOR

By

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Under Part H of the Individuals with Disabilities Education Act (IDEA), families of infants and toddlers with disabilities are entitled to a service coordinator to assist them in accessing and coordinating early intervention services. This study examines the role of the service coordinator in promoting a sense of empowerment and ability to cope as they work with families to access and coordinate such services.

The research design was comprised of both quantitative and qualitative methodologies. The relationship between parental ratings of service coordinator behaviors and parental perceived empowerment and ability to cope was examined through a secondary analysis of existing data from a survey of families receiving services under Part H in Michigan. In addition, 171 service coordinators were surveyed in order to determine the background characteristics (e.g., education, experience, inservice training, caseload) of these individuals. Finally, ten service coordinators across Michigan were interviewed in order to examine the relationship between the knowledge and beliefs of the service coordinators and how empowered and able to cope parents perceived themselves to be. The ten service coordinators chosen consisted of the five rated most favorably by families and the five rated least favorably by families in the Part H survey of families.

The quantitative portion of the study revealed that parents who rated their service coordinators' behaviors more favorably, perceived themselves as more empowered and able to cope. Only one background characteristic of the service coordinator was related to parental perceived empowerment and ability to cope. Increased experience as a service coordinator was predictive of parental perceived empowerment and coping.

Hypotheses were generated from the qualitative portion of the study that will serve as useful topics for further research. These hypotheses suggest that service coordinators rated more favorably by families (a) held a more positive view of families, (b) encouraged increased parental involvement, (c) viewed their roles more broadly, (d) were more aware of what families want or need from professionals, (e) were more aware of and used more empowering behaviors, and (f) engaged in more risk-taking behaviors, than the lower rated service coordinators.

ACKNOWLEDGMENTS

The completion of this dissertation is the end of a seven year journey for me. During those seven years I have experienced many life changes which have made the completion of this effort particularly difficult. It would have been even more difficult without the support of my friends. First of all I would like to thank my wonderful friend Marty, and my canine friend Mick. They were always there, willing to allow all the tantrums and tears and still continued to love and support me. A special thanks also goes to my friend and colleague, Dr. Kelly Rhoades-Dumler who not only provided much encouragement and emotional support, but also served as my qualitative research consultant on this project. A special thanks to my friend Jim Henry who helped me learn patience, to "live the questions", and to believe that I would finish this effort. I am very fortunate to have the number of good friends that I have, and I want to express my sincere appreciation to all of them, each of whom provided support in different ways. I would also like to thank the members of my committee, especially my Committee Chair, Dr. Tom Luster who spent many hours answering my never-ending list of questions. Last, but not least I want to say thanks to that determined core inside of me that allows me to persevere when things are tough. This has allowed me to take chances and to have experiences I might not otherwise have had. A thank you to my indomitable spirit!

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Chapter I

INTRODUCTION

All families experience stress as a part of their lives. Changes and hardships are a natural and predictable aspect of family life (McCubbin & McCubbin, 1987). In times of transition or when a crisis occurs families experience increased levels of stress to which they must adapt if the family system is to maintain equilibrium. The birth of a child with a disability can cause a crisis situation in a family.

Research indicates that many families who have young children with disabilities experience greater levels of stress than families with children who do not have disabilities (Bubolz & Whiren, 1984; M. McCubbin 1989; Dyson, 1991). The additional stress can result from increased demands on family resources such as time, energy, and money. Even if the family manages to meet the increased demands placed on the family system that result from caring for a child with a disability, the family is more susceptible to other sources of stress such as inflation, unemployment, or the problems of other family members (Bubolz & Whiren, 1984).

How a family responds to stress in general, will determine how its members respond to the stress of having a child with a disability. Each family is unique in terms of how they cope with stressful situations. A family's ability to cope with a stressful event is influenced by the historical period within which the family is living, the culture of the family, the economic conditions of society, the family's stamina and resistance, and the stage of the family life cycle (McKenry & Price, 1994).

A family's response to stress is its ability to cope. McCubbin and McCubbin (1987) believe that the function of coping is the maintenance or restoration of the balance between demands and resources. The authors define family coping as:

> ...the family's strategies, patterns, and behaviors designed to maintain and/or strengthen the organization and stability of the family unit, maintain the emotional stability and well-being of family members, obtain and/or utilize family and community resources to manage the situation, and initiate efforts to resolve the family hardships created by the stressor/transition (p. 11-12).

Families use many different coping behaviors or strategies to restore the balance between demands and resources and improve or maintain family functioning. Accessing necessary resources and viewing oneself as empowered and competent are ways that individuals and families cope (McCubbin & McCubbin, 1987). Family support initiatives are designed to strengthen individual and family functioning by providing families with needed resources and supports. In doing so, such initiatives work with families in ways that empower family members and assist them to become more capable and competent and thus able to act on their own behalf (Dunst, Trivette, Starnes, Hamby, & Gordon, 1993). If families are provided with needed resources and interacted with in ways that empower them to act on their own behalf, the possibility that they will be better able to cope with the demands of having a child with a disability will be enhanced.

An example of a family support initiative that operates from an empowerment philosophy is Public Law 99-457, a 1986 amendment to the Education of the

Handicapped Act (EHA), which added Part H (the Handicapped Infants and Toddlers Program) to the EHA. In 1991, the EHA was reauthorized as Public Law 102-119, and renamed the Individuals with Disabilities Education Act (IDEA). This law provides financial assistance to states to develop comprehensive, multidisciplinary, interagency systems of early intervention services for infants and toddlers from birth to three years of age who (a) demonstrate a developmental delay; (b) have an established condition with a high probability of developing a developmental delay; or (c) at the discretion of the states, are thought to be at risk for developmental delay as a result of various other factors.

Part H, known as *Early On®* in Michigan, places a strong emphasis on the family and mandates that services be provided in a family-centered manner. Because of its focus on family-centeredness, Part H is especially well-suited to promoting a sense of empowerment and ability to cope in families when implemented as it was intended. Many of the principles of Part H, such as a focus on family strengths, shared responsibility between families and professionals, and connecting families with information and resources, can be related to what families need to do in order to cope. For example, focusing on a family's strengths may help the family to reconceptualize the birth of the child with a disability in a way that promotes coping. Willingness on the part of the professional to allow families to be responsible for their own decisions and to help families experience success as a result of decisions they make can promote a feeling of competence and thus an ability to cope (Dunst & Trivette, 1988).

The principal focus of Part H is the provision of service coordination. Based on a case management perspective, the role of the service coordinator is very broad and includes multiple functions. The functions of the service coordinator include outreach and client identification, assessment, identification of resources, development of the Individualized Family Service Plan (IFSP), service implementation, monitoring of service delivery, and evaluation of service outcomes (Zipper, Hinton, Weil, & Rounds, 1993). The 1991 amendments to the IDEA state that the duties of service coordinators should encompass all the responsibilities formerly defined under case management. To view service coordination more narrowly may not promote the predominant purpose of service coordination which is to enhance the ability of parents to coordinate services for their own child (Zipper et al., 1993).

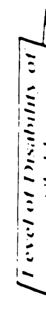
Enhancing the ability of parents to fulfill their parenting roles and meet the needs of their families can result from helping parents to perceive themselves as empowered and better able to cope with all the demands of having a child with a disability (Dunst, Trivette, & Deal, 1994c). In order to assist families to perceive themselves as empowered, service coordinators must be willing to engage in a family-centered approach which focuses on the child in the context of the family and on enabling families to act on their own behalf. In addition, service coordinators must be willing to work collaboratively with families. Collaborative relationships are based on mutual respect, understanding the perspective and role of the other person, and sharing of information (Zipper et al., 1993). There are a variety of specific skills service coordinators need in order to work collaboratively with families. In addition, there are specific help-giving behaviors that promote empowerment and coping (Dunst & Trivette, 1987).

Many professional training programs do not teach the skills necessary for effective service provision or coordination. Bailey, Simeonsson, Yoder, and Huntington (1990) report that course work related to working with families was one of the weakest facets of preservice education programs across several key disciplines involved in early intervention. Bailey, Palsha, and Simeonsson (1991) contend that despite the fact that the professional literature supports the principles of family-centered care, instituting family-centered practices will be a challenging endeavor. Changing university programs is difficult. Therefore, a meaningful investment in inservice and continuing education programs should be a critical priority for the field of early intervention (Bailey et al., 1990; Niemeyer & Proctor, 1995).

Purpose of the Study

Coping is the process in which the family engages as it attempts to adapt to a stressful event such as the birth of a child with a disability. As will be reviewed in Chapter II, many factors may impact a family's ability to cope. An increased sense of empowerment on the part of the parents is one of the factors that may impact the family's ability to cope (Dunst & Trivette, 1988). Figure 1 presents several of the variables which may impact coping and the proposed relationship among the variables. Although there are several variables, due to the limited scope of this study, it will focus on the relationship between the behaviors of the service coordinator and parental perceived empowerment and ability to cope. The other variables will be treated as control variables.

In order to assist families of young children with disabilities to feel empowered and help them cope with the additional stress they may experience, professionals must know how their own actions may affect families. More specifically, they must know what actions or behaviors on their part promote empowerment and coping. Some helping



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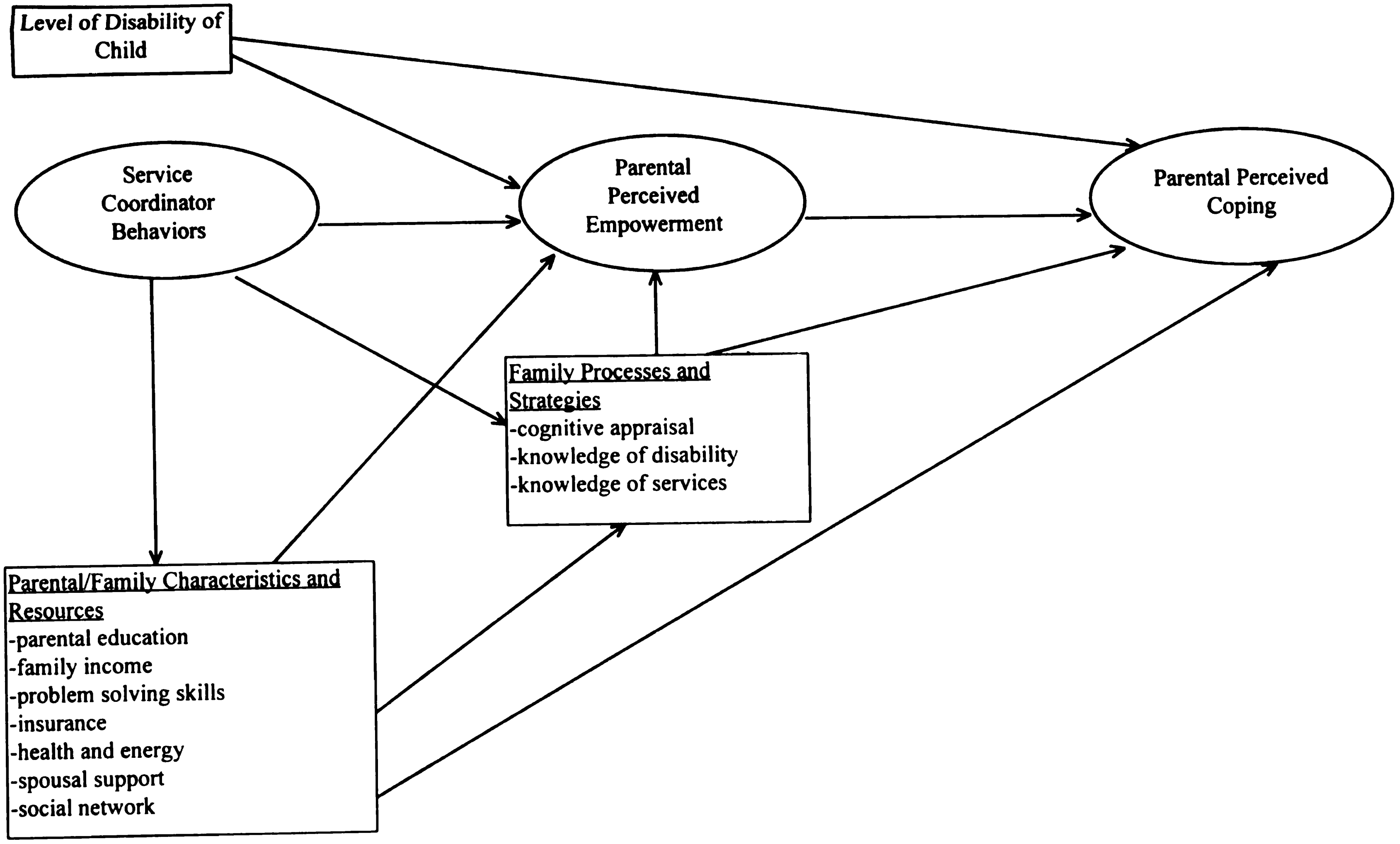

Figure 1. Relationships Among Variables That May Impact Empowerment and Coping

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behaviors on the part of professionals are more conducive to empowering and promoting coping than other helping behaviors. In fact, some helping behaviors may actually contribute to learned helplessness, dependency, and diminished self-esteem rather than empowerment and coping (Dunst & Trivette, 1987; Dunst & Trivette, 1988; Dunst, Trivette, & Deal 1988).

Families know what they want or need from professionals. Several studies have captured what families say they want or need from professionals (Able-Boone, Sandall, Stevens, & Fredrick, 1992; Bailey, Blasco, & Simeonsson, 1992; Garshelis & McConnell, 1993; Gamel-McCormick, 1995; Thompson, 1995). It is important that professionals know what families say they need and understand the relationship between what families say they need and how meeting such needs translates into empowerment and increased coping. Unfortunately, most professionals have had little or no training in working with families (Bailey et al., 1990; Bailey et al, 1991; Niemeyer & Proctor, 1995) or about help-giving behaviors (Dunst & Trivette, 1987).

Knowing what families say they need, and how specific help-giving behaviors promote coping, can help professionals be more effective. This study examines the relationship between the characteristics (e.g., knowledge, beliefs, behaviors, background) of one very specific type of professional, the service coordinator, and parental perception of empowerment and ability to cope. Figure 2 depicts the proposed relationship.

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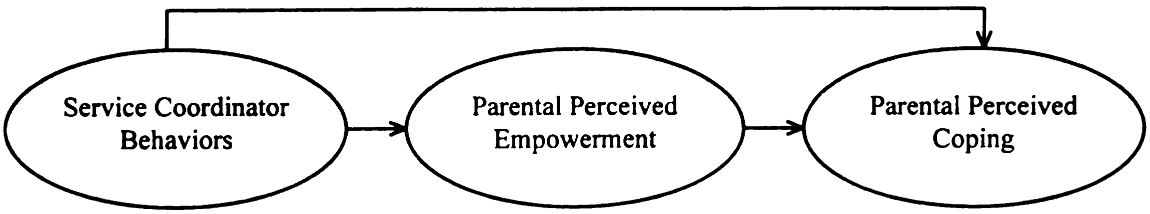

Figure 2. Primary Variables of Interest in Present Study

Statement of the Problem

This study examines the relationship between parental ratings of service coordinator behaviors and parental perceived empowerment and ability to cope. Secondly, the study quantitatively and qualitatively examines the differences between those service coordinators parents rate high on behaviors that families say they need and those service coordinators rated low on such behaviors. Specific characteristics of service coordinators examined are: (a) the behaviors they use when working with families and the impact of these behaviors on parental perceived empowerment and coping, (b) their knowledge of what families want from professionals and what empowers family members, (c) their view of families and of the role of service coordination, (d) their years of experience, (e) the number of hours they are contracted to provide service coordination, (f) the number of roles they are required to carry out, (g) the discipline within which they were educated (e.g., special education, nursing), (h) their level of education, (i) the amount inservice training they have received, and (j) the areas within which they received inservice training. The objective of the study was to address the following research questions.

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Research Questions

1. Are specific service coordinator behaviors, identified by families as those they need from professionals, related to parental perceived empowerment and ability to cope?
2. Do service coordinators who parents rate high on behaviors that families say they need from professionals have different training (preservice and inservice) than service coordinators parents rate lower on such behaviors?
3. Is there a relationship between the number of different roles a service coordinator is expected to perform, the amount of time allotted to doing service coordination, or the number of families for which the service coordinator provides service coordination and how parents rate the service coordinator on behaviors that families say they need from professionals?
4. Do service coordinators who parents rate high on behaviors that families say they need from professionals, have a different awareness of what families say they need than service coordinators parents rate lower on such behaviors?
5. Do service coordinators who parents rate high on behaviors that families say they need from professionals have a different view of families with whom they work (e.g., accept parents as equals, are comfortable with a blurring of roles) than service coordinators parents rate lower on such behaviors?
6. Do service coordinators who parents rate high on behaviors that families say they need from professionals prioritize duties/functions differently than service coordinators parents rate lower on such behaviors?

7. Do service coordinators who parents rate high on behaviors that families say they need from professionals have greater awareness of helping behaviors that promote empowerment and coping than service coordinators parents rate lower on such behaviors?

Conceptual and Operational Definitions

The key terms used in this study and how concepts were measured are defined as follows:

Ability to Cope: The family's feelings of being able to successfully manage the demands of having a child with a disability and continue to function effectively as a family. For the purpose of this study this concept is measured using selected items from the Questionnaire on Resources and Stress-Short Form Adapted (See Appendix E).

Disability: As defined for *Early On* Michigan (Part H of IDEA), this refers to the presence of a developmental delay or an established condition with a high probability of resulting in a developmental delay. Examples of conditions with a high probability of developmental delay include Down syndrome, physical or health impairments, and sensory impairments (see Appendix A).

Empowerment: The perception of the parent of being able to act on his/her own behalf and of having some measure of control over his/her life. This includes having the ability and opportunity to access and control needed resources, make decisions about and solve problems for one's family, and secure resources through effective interaction with others (Dunst et al., 1988). According to Koren, DeChillo, and Friesen (1992), and as used in this study, empowerment may be expressed as an attitude, knowledge, or behavior and may be present at differing levels. These levels include the Family, Service System, and Community/Political levels. For the purpose of this study all levels of empowerment were measured using the Family Empowerment Scale (see Appendix D).

Helping Behaviors: Types of assistance and the manner in which they are offered which either promote or inhibit a sense of empowerment (Dunst & Trivette, 1987).

Parent: The primary caregiver who completed the Family Survey.

Part H: A section of the Amendments to the Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act) enacted by the United States Congress in 1986, which provides for a system of early intervention services to infants and toddlers with disabilities and their families.

Service Coordinator: The person identified on the Individualized Family Service Plan to fulfill this role. The role of the Service Coordinator is to carry out the activities "to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program" (CFR 303.6 (a)[1], p. 40964). A more detailed description of service coordination can be found in Appendix B.

Service Coordinator Behaviors: The way in which the service coordinator interacts with the family when providing aid and assistance. For the purpose of this study this was measured using selected items from the *Early On* Family Survey (see Appendix F).

Assumptions

1. Service coordinators should work to promote a perception of empowerment and ability to cope in parents of infants and toddlers with disabilities.

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2. It is possible to measure empowerment and coping in individuals.

Overview

The need for a better understanding of the relationship between the behaviors of professionals who work with families who have infants or toddlers with disabilities and parental perceived and ability to cope was discussed in Chapter I. In Chapter II, literature relevant to this topic is reviewed. In Chapter III, the quantitative and qualitative methodologies employed in this study are discussed along with the research instruments used to study the variables of interest. The results of the use of the two different methodologies are discussed in Chapter IV. Chapter V includes: (a) a discussion of the findings resulting from the use of the two different methodologies; (b) a discussion integrating the findings from both methodologies; (c) limitations of the study; and (d) implications for practice, personnel development, and research in the area of working with families who have infants and toddlers with disabilities.

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Chapter II

REVIEW OF LITERATURE

The intent of this study was to examine the impact of specific behaviors of service coordinators on parents' perception of empowerment and ability to cope with the demands of having an infant or toddler with a special need. In addition, it examines what may contribute to the service coordinator's ability to engage in behaviors that may help parents feel empowered and better able to cope. In order to better understand the dynamics involved in helping parents feel more empowered and able to cope it is necessary to review the literature in the following areas: (a) Stress in families who have a child with a disability, (b) Coping in families who have a child with a disability, (c) The role of empowerment in promoting coping, and (d) Helping behaviors on the part of professionals that promote empowerment and coping.

Stress in Families Who Have a Child with a Disability

The varying stressors experienced by families who have a child with a disability have been well documented in the literature (Crnic, Friedrich, & Greenberg, 1983; McKinney & Peterson, 1987; McCubbin, 1989; Dyson, 1991; Floyd & Zmich, 1991; Able-Boone & Stevens, 1994). Such stressors may include increased demands on time, emotional energy, and financial resources (Bubolz & Whiren, 1984; Able-Boone & Stevens, 1994); disruptions in family life (Bristol, Gallagher, & Schopler, 1988); limited

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socialization opportunities (Able-Boone & Stevens, 1994;); restriction of career opportunities (McCubbin, 1989; Able-Boone & Stevens, 1994); and impacts on the marital relationship and parenting behaviors (Floyd & Zmich, 1991).

Although families who have a child with a disability experience a variety of different stressors, the body of literature examining whether or not these families experience greater levels of stress than families with children without disabilities is inconsistent. McKinney and Peterson (1987) found that although mothers of young children with a developmental disability rated their children as a greater stressor than mothers of children without a disability, the overall life stressor level for the mothers of children with disabilities was actually lower. Similarly, Meadows-Orlans' (1994) study of parents of infants who were deaf reported that these parents did not score significantly higher on measures of parenting stress and general life stress than parents of infants with normal hearing. Although Frey, Greenberg, & Fewell (1989) reported that the characteristics of the child (i.e., sex of child, communication skills) were associated with increased parenting stress, they also found that parents differed significantly as to the degree that they viewed their child's disability as a negative and stressful experience.

Dyson (1991) reported increased stress in a population of middle-class families with children with developmental disabilities. Even in the absence of economic and social obstacles, caring for a child with a disability was associated with high levels of parental stress. However, the families experiencing higher levels of stress due to their child with a disability did not differ significantly on general family functioning from families whose children did not have disabilities.

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McCubbin (1989) studied family stress and family strengths in single- and two-parent families who had a child with cerebral palsy. The results indicated no significant difference in degree of family stress in single- and two-parent families. The mean stress level in both family groups was described as moderate, based on a standardized weighting of life events. Single-parent families were found however, to be less able to meet financial commitments and were less optimistic about their financial future.

Numerous studies have examined the adaptation and coping strategies of families who have a child with a disability. Similar to the findings of Dyson's (1991) study, other research has found that having a child with chronic illness or a disability did not necessarily predict poor family functioning. Bristol et al. (1988) found that in spite of dramatic differences in the levels of severity of the children's disabilities, and in the levels of spousal support, the families who had children with disabilities and families who did not, had similar scores on measures of family functioning. Although Meadow-Orlans' (1994) study of parents of children who were deaf found that these parents did not exhibit greater stress than parents of children without hearing impairments, a sizable group of parents of children who were deaf scored high enough on the stress index used, to suggest they might benefit from counseling.

A comprehensive review of the literature regarding families with children who had mental retardation also determined that familial response to a child with mental retardation varied. The authors concluded that there must then be other factors that accounted for familial adaptation (Crnic et al., 1983). Supporting this finding, McCubbin (1989) found single-parent families to be more adaptable and flexible. When faced with a chal

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a challenge, these families appeared to respond to the challenge by altering patterns of leadership, assertiveness, and control.

Coping in Families Who Have a Child with a Disability

Coping is a process, rather than an outcome. It is the on-going attempt to achieve balance within a family system in order to facilitate organization and unity within the family, and promote growth and development of individual family members (McCubbin, & McCubbin, 1987; McKenry & Price, 1994). Successful adaptation to a stressful event requires the use of effective coping strategies.

Coping strategies or responses have been conceptualized in several different frameworks. For example, McKenry and Price (1994) list three types of coping responses sighted in the literature (Boss, 1988; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978). The three types of responses are: (a) direct action (e.g., acquiring resources, learning new skills), (b) intrapsychic (e.g., reframing the problem), and (c) controlling the emotions generated by the stressor (e.g., social support, use of alcohol) (p. 11).

McCubbin and McCubbin (1987) also provide a conceptual framework for categorizing coping behaviors, and emphasize that such behaviors can be a collective group action (e.g., family action) as opposed to just an individual action. The authors propose the following five ways through which coping may occur:

1. Employing direct action to reduce the number and/or intensity of the demands (e.g., placing a family member in an institutional setting, refusing a job promotion).

2. Employing direct action in order to acquire additional resources that are not presently available (e.g., taking an additional job, developing skills one does not presently possess).
3. Maintaining existing resources and allocating and reallocating as demands require (e.g., maintaining a social support network, promoting family cohesiveness).
4. Keeping tension associated with on-going stress manageable (e.g., exercising, meditating, engaging in family recreation activities).
5. Changing the meaning of the situation through cognitive appraisal (e.g., changing how one views the demands, viewing oneself or the family as capable of meeting the demands).

Rather than focusing on coping responses or behaviors, Lazarus and Folkman (1984) propose five categories of coping resources available to families. The categories include: (a) social network, (b) problem-solving skills, (c) general and specific beliefs, (d) utilitarian resources, and (e) health/energy/moral.

The presence of any type of disability in a child may be a stressor that requires families to employ on-going coping responses (Frey et al., 1989; McCubbin, 1989; Dyson, 1991; Able-Boone & Stevens, 1994) and to use a variety of resources. The greater the needs of the child, the greater the demands and thus the greater the response and resources required to cope. For example, parents of infants with severe needs report being nearly overwhelmed by the degree and type of new demands on their daily coping skills (Able-Boone & Stevens, 1994).

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Crnic et al. (1983) propose that the responses of families to stress involve the various coping resources available to both the individual and the family as a whole. The authors use an ecological perspective to describe "the family's coping resources and ecological environments as interactive systems that serve to mediate the family's response to stress" (p. 125).

Able-Boone and Stevens (1994) were unable to identify any "typical" patterns of coping when interviewing families with a child with a disability or a chronic health condition who had experienced a stay in an intensive care nursery. The authors inability to find a "typical" pattern of coping may be a result of the interaction between the family's coping resources and ecological environments as described by Crnic et al. (1983).

One coping strategy frequently mentioned in the literature is cognitive appraisal of the situation. Crnic et al. (1983) argue that the impact of a child with mental retardation on a family is related to the family members' cognitive appraisal of the stress situation and the family's coping resources, and that both are influenced by the ecological systems within which the family interacts and is acted upon. The authors cite a study (Watson & Midlarsky, 1979) which found mothers of children with mental retardation to have more positive attitudes about mental retardation than a group of mothers of nonretarded children of similar socioeconomic status.

Similarly, Floyd and Zmich (1991) reported that parents of children with mental retardation may attribute their difficulties managing the child to the child's cognitive limitations and poor social skills rather than blaming themselves or attributing it to their lack of competence. The expectation that children with mental retardation are difficult to manage helped parents maintain their own sense of competence and thus promoted adaptation. The authors also cite another example of how changing one's perceptions and expectations can promote coping. Parents observed by others to have relatively negative marital interactions, reported they were satisfied with their marriages. As long as expectations were low, the parents perceived themselves as satisfied and did not feel as if the quality of their marriage was a matter of concern. Although the authors recognized that a correlation between positive feelings about the marriage and adaptation to raising a child with mental retardation has been reported in the literature (Friedrich & Friedrich, 1981), they caution about the possible long term costs if the strain observed in the marital relationship continues to be ignored. Negative and ineffective problem-solving interactions have been found to be precursors to marital dysfunction, even when not associated with dissatisfaction. This would indicate that while cognitive appraisal may be an effective coping strategy in relation to short-term coping, it may not always be effective for long-term adaptation.

The families interviewed by Able-Boone and Stevens (1994) emphasized the need to learn to appreciate small achievements in their child's life and to focus on developmental gains as a way to move from one crisis to another. In addition, these parents focused on their love for their child instead of focusing on any negative aspects of having a child with a disability or chronic health condition.

Parental beliefs were also frequently mentioned as a way that families cope with having a child with a disability. Frey et al. (1989) reported parental beliefs to be the most powerful predictor of parent outcome measures (i.e., parenting stress, family adjustment, psychological distress) for both mothers and fathers. The authors examined the beliefs of mothers and fathers in relation to: (a) their comparative appraisal of having a child with a

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disability, (b) their self-rating of their coping efficacy, (c) their rating of their spouses' coping efficacy, and (d) their belief in their own personal control. The degree to which the parent viewed the child's disability in a more positive light, in comparison to other people, other times, and other possible situations (i.e., comparative appraisal) was moderately to strongly related to all three parenting outcomes measures for both mothers and fathers. Mothers and fathers who viewed themselves as better able to cope also demonstrated better outcomes on all three measures. In addition, mothers who viewed their spouses as better able to cope displayed better outcomes on all three measures. High personal control in mothers was associated with more favorable outcomes on measures of parenting stress and psychological distress, but not with family adjustment. High personal control in fathers was associated with better outcomes on all three measures. A particularly strong association existed between low personal control in fathers and psychological distress.

Dyson (1991) reported that families who had a child with a disability emphasized achievement and moral-religious beliefs, and valued set rules and procedures for handling family life more than families who did not have a child with a disability. Reliance on faith and a day-to-day coping mentality were coping strategies mentioned in a study by Able-Boone and Stevens (1994).

Orr, Cameron, and Day (1991) added support for the influence of parental belief systems on ability to cope. In their study they found that the effectiveness of resources in reducing stress in families who have a child with mental retardation is dependent on how the parent defines and construes the child's needs, functioning level, behavior problems, and other characteristics. The authors propose that some families are able to reframe their

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child's disability into something positive, or at least routine. Orr et al. (1991) use this information to issue a caution to professionals regarding what can be assumed to be stressful for a family. The authors cite Dunst et al.'s (1988) proposition that unless the family indicates that a need exists, there may not be a need, regardless of how the professional appraises the situation. A child is not a stressor unless the family views the child as such.

Social support is another frequently identified factor that helps families cope (McKinney & Peterson, 1987; Bristol et al., 1988; Frey et al., 1989; Able-Boone & Stevens, 1994; Meadow-Orlans, 1994). Studies considering social support include those that examine the support of friends, extended families, and spouses.

In their study of mothers and fathers of young children with disabilities, Frey et al. (1989) found social network (i.e., social support and network criticism) and family adjustment to be positively related. However, social network was not related to parenting stress or the psychological distress of mothers. In addition, the important aspect of the social network was different for mothers and fathers. This study included criticism from the social network in their analysis. The family adjustment of mothers was improved when social support was higher but not related to the amount of criticism. In fathers, family adjustment was improved if there was low criticism, and the criticism was not related to the amount of support. A relationship between the psychological distress experienced by fathers and social network was primarily due to the influence of criticism rather than support. This would indicate that mothers benefit more from social support even if there is criticism in that support network. Fathers, on the other hand, benefit more from social support when criticism is less or not present.

Parents reported the reliance on extended family and professionals as a mechanism for coping (Able-Boone & Stevens, 1994). This reliance may include obtaining help with the caregiving for the child with a disability and having others to talk with about the many family stresses and needs and the special needs of the child with a disability.

When studying parents of children with hearing impairments, Meadow-Orlans (1994) examined the relationship between social support and parenting stress in both mothers and fathers. The author reported a significant negative relationship between parenting stress and social support for mothers. The relationship was marginally significant for fathers.

Contrary to much of the literature, in a study of mothers of children with disabilities, McKinney and Peterson (1987) reported no differences in mean level of child-related stress or stress reaction (i.e., mood disturbance, depression, maternal sense of competence) between mothers who had a high level of social support from outside the home and those with a low level of social support. In addition, this study considered the effects of spousal support on mean level of stress and stress reaction. An interaction between spousal support and another of the predictor variables, perceived control, was identified. Subjects in the high spousal support, high perceived control group had lower stress response scores than subjects in the low spousal support, high perceived control group. The two low perceived control groups obtained scores that fell between these two groups for all measures of stress reaction.

Bristol et al. (1988) found instrumental and expressive support from a spouse to be the best predictor of how mothers of young children with disabilities functioned in terms of depression, marital adjustment, and parenting. Additionally, the authors found that expressive support from one's spouse was the best predictor of parenting for both fathers and mothers in families of young children with disabilities. However, in order for the support to be effective, the support must be extended in a manner congruent with the spouse's needs and expectations for support.

The Role of Empowerment in Promoting Coping

Part H of IDEA is an example of a family support program that is designed to assist families who have an infant or toddler with a disability. According to Dunst et al. (1993), citing U.S. House of Representatives Report 99-860 of 1986, Part H was designed "specifically to meet the needs of infants and toddlers with special needs and their families by enhancing the capacity of parents to effectively perform their child-rearing roles" (p. 9).

When considering the family from a human ecological perspective, the importance of improving parent child-rearing roles becomes clear, as the impact of child-rearing roles as a context which impinges on the development of the infant and toddler with a disability is explained. From an ecological perspective, Bronfenbrenner (1989) defines human development as:

> "...the set of processes through which properties of the person and the environment interact to produce constancy and change in the characteristics of the person over the life course" (p. 191).

The child-rearing roles of the parent are one of the properties of the environment that interact with the characteristics of the child to ultimately determine the child's development.

The ability of parents to perform their child-rearing roles can be affected by stress (Dyson, 1991). Crnic et al. (1983), citing Rabbin & Streuning (1976), report that stress has been related to minor and major health problems, chronic illness, and psychiatric illness such as anxiety and depression. Such conditions may lead to environments that are not optimal for the development of the child. Frey et al. (1989) cite a longitudinal study by Frey, Fewell, Vadasy, and Greenberg (1989) that found both parenting stress and family adjustment to be predictors of subsequent child development.

Floyd and Zmich (1991) report poor marital problem solving skills as a result of stress. The authors explain that poor marital problem solving is likely to affect parent-child relationships because marital difficulty affects the parents' ability to provide the degree of warmth and control in interactions with their children that are necessary for optimal child development.

An important aspect of helping families improve their ability to perform their child-rearing roles is the promotion of coping. Part H of IDEA, with its emphasis on family-centered service delivery which encompasses the philosophy of enabling and empowering families, is especially well-suited for helping parents of infants and toddlers who have a disability, cope. In order to do so, when working with families, it is important that professionals work from an enabling and empowering perspective. Considerable evidence exists that different types of help and assistance and the way in which they are offered, can have either empowering or diminishing results. From a family systems' perspective, it is the families' needs, intrafamily resources, extrafamily resources, and help-giver behaviors that interact to directly and indirectly influence child, parent, and family functioning (Dunst & Trivette, 1987).

It is particularly important that professionals work from an enablement and empowerment perspective if they hope to promote coping in families. According to Trivette, Deal, and Dunst (1986), to empower families means to conduct intervention in a manner that insures that "family members acquire a sense of control over their lives as a result of their efforts to get needs met" (p. 260). The provision of help by professionals is contingent on families playing an active role in carrying out mutually agreed upon interventions. Families must also acquire a wide variety of competencies that help them mobilize their own support networks in order to get their needs met (Dunst & Trivette, 1986). Citing a previous Dunst (1985) article, the authors propose that working with families in a manner that meets the conditions stated above promotes a sense of personal well-being on the part of family members and positively influences family functioning.

Dunst, Trivette, and LaPointe (1992) have described how the concept of empowerment can be conceptualized as perceptions. As a perception, empowerment is described as a variety of "*attributions and beliefs* that reflect a *sense of control*" (p. 118). The authors explain that in a previous study by Dunst (1991), the researcher found that encouraging the active participation of parents in all aspects of the process of building a resource network produced greater changes in self-efficacy than an intervention that focused on the professional as the mobilizer of resources. In a study of family-centered early intervention program models, Trivette, Dunst, Boyd, and Hamby (1995) found that different help-giving models differentially influenced participants in human service programs. Specifically, the authors found that different help-giving models differentially affected the sense of self-efficacy and personal control those seeking help experienced. Parents in programs in which there was frequent contact with a help-giver who engaged in empowering, help-giving behaviors reported a greater sense of personal control.

The perception of a sense of control or self-efficacy can be viewed as a personal resource that promotes coping. McCubbin and McCubbin (1987) describe self-esteem, or a positive judgment about self-worth, as an "intangible" resource. The authors also discuss the importance of "a sense of mastery" (p. 17), which is believing that one has some control over one's life, as an important personal resource that promotes coping. According to McCubbin and McCubbin (1987), both self-esteem and a sense of mastery have been named by many researchers in the area of stress as the most important factors in the process of stress and coping. This is thought to be due to the fact that the presence of both are one of the most critical characteristics for "active, effective efforts at managing demands" (p. 18). In discussing successful system (i.e., family) adaptation to a stressor, the authors propose that to successfully adapt, efforts to cope must be directed at system maintenance. Such maintenance is delineated as maintaining the integration, morale, and member self-esteem of the system.

Empowering parents also promotes coping by increasing another personal resource the family possesses. Knowledge and skills obtained from education, training, and experience are identified by McCubbin and McCubbin (1987) as one of the most important personal resources a family may use to adapt to a stressor. In addition, the authors state that coping can involve direct action to acquire additional resources. When professionals work from an enablement and empowerment perspective they create opportunities for parents to learn new competencies (i.e., knowledges and skills). The professional does not mobilize resources for the parent, but creates opportunities for the parent to acquire the necessary competencies to obtain his/her own resources (Dunst & Trivette, 1987). These new found abilities can be viewed as additional personal resources which may assist the family in their efforts to cope.

How Professionals Can Promote Empowerment and Coping

In the previous section it becomes apparent that how professionals work with parents has the capacity to help parents perceive themselves as empowered and better able to cope. As Sokoly (1994) found when reviewing the mental health literature for her study addressing parent-professional relationships and empowerment, there has been little research that attempts to specifically relate parent-professional interactions and empowerment. According to Sokoly (1994) one exception is a study by Kalyanpur and Rao (1991) of low-income, black mothers which explored the perceptions of these mothers regarding the characteristics of empowering relationships. The authors defined two types of parent-professional relationships. The first they call exclusionary or unempowering relationships which were characterized by disrespect, a discounting of parenting style, and a focus on deficits. The second style they referred to as empowering relationships which were characterized by a responsiveness to the needs of the mothers and a reciprocal, supportive approach.

A series of three studies which more specifically depict the relationship between help-giver behaviors and empowerment was carried out by Dunst, Trivette, Boyd, and Brookfield (1994a). The three studies involved over 1300 parents (mostly mothers) of young children (birth to six years of age) and focused on the relationship between program models and parental appraisal of self-efficacy and specific types of help-giving behaviors and parental appraisal of self-efficacy. The authors found what they called a "remarkedly powerful association" (p. 220) between the kinds of practices used by program staff and parental appraisals of self-efficacy. Parents who worked with staff who used empowering help-giving behaviors perceived themselves as better able to secure the supports and resources they needed from the help-givers and the help-giving programs.

When examining the relationship between the role of professionals and parental empowerment and coping, it is important to keep in mind that it is not possible to actually empower another human being, but that families can be assisted to empower themselves so that they are able to make the necessary changes to achieve the quality of life they desire (Singh, 1995). This is why it is important to keep in mind that empowerment, as used in this study, refers to a perception held by the parent. The way in which the professional acts can influence how the parent views him/herself (Dunst and Trivette, 1994; Trivette et al., 1995). Singh (1995) suggests that professionals can help both themselves and others to gain positive control over their lives and improve their quality of life.

Cochran and Woolever (1983) believe that the concepts of power and control are central to the empowering process. Parents become more active when they perceive that they have some control over their own lives and those of their children. Sokoly (1994) supports this by citing Moroney (1986), who proposes that promoting family empowerment can only be achieved when professionals move away from paternalistic, pathologically oriented views towards ones that emphasize shared responsibility and mutuality.

Examining what the empowering parent-professional relationship looks like is helpful when considering what professionals must do if they hope to help parents perceive themselves as empowered and better able to cope. The terms "shared responsibility" and "mutuality" as used by Moroney (1986), and cited by Sokoly (1994), are two important descriptors of empowering relationships. In her study of parent-professional relationships Sokoly (1994) found a "general collaborativeness factor" as the characteristic of professionals that accounted for the greatest amount of variance in a collection of characteristics most strongly associated with parental empowerment. The author also discusses the need for both partners to give and receive. This is consistent with the view held by Dunst and Trivette (1987) that an effective help-giver offers help that can be reciprocated and allows for reciprocity and the "repaying" of the help-giver. An example of such reciprocity or repaying might be the help-giver allowing the help-seeker to provide information (e.g., a name of a person who can do something for the help-giver) or a service (e.g., share his/her experience with another parent with whom the help-giver is working) to the help-giver.

In a survey designed to acquire information about specific characteristics of parent-professional relationships, Dunst, Trivette, and Johanson (1994d) developed a categorization scheme for organizing the major characteristics of parent-professional partnerships. The results indicated that such characteristics could be broken into four categories: (a) beliefs (e.g., trust, mutual respect, honesty, acceptance, mutually supportive); (b) attitudes (e.g., caring, understanding, empathy, positive stance, humor);

(c) communicative style (e.g., open communication, active listening, openness, understanding, information sharing); and, (d) behavioral actions (e.g., showing mutual respect, openness, flexibility, shared responsibility, mutual support, reciprocity, dependability).

In addition to the need for the parent-professional relationship to possess certain characteristics, it is necessary for the professional as help-giver to have certain beliefs and act in particular ways. Dunst and Trivette (1989) recommend that help-givers are more apt to help others perceive themselves as empowered if they act in the following manner:

1. Assume a positive and proactive stance with families.
2. Emphasize the families' responsibility for solving problems and meeting needs.
3. Assume that all families can understand, learn, and manage their own lives.
4. Build upon family strengths.
5. Work with families in a proactive rather than reactive manner.
6. Promote the development of competencies within the family.
7. Emphasize helping families identify and prioritize their needs from the families' perspectives of those needs.
8. Encourage active participation.
9. Use partnership and collaboration as the basis for helping families become more competent.
10. Provide families with the information they need to make informed decisions.

11. Accept and support the decisions families make.

Dunst and Trivette (1987) also report that in order for the professional, in the role of help-giver, to be effective at helping parents perceive themselves as empowered it is important that the professional possess a particular help-giving style. The authors propose the following twelve characteristics of an empowering help-giver:

1. Displays a sense of caring, warmth, and encouragement.
2. Is sensitive to verbal, nonverbal, and paraverbal messages used by the help-seeker.
3. Acts in a way in which locus of decision making clearly resides with the help-seeker.
4. Offers aid and assistance consistent with person's culture.
5. Offers help that is compatible with help-seekers assessment of his/her need.
6. Offers help in which the costs of accepting do not outweigh benefits.
7. Is willing to engage in reciprocal help-giving.
8. Bolsters the help-seekers by helping the individual experience immediate success in solving problems and meeting needs.
9. Promotes the use of natural support networks instead of relying heavily on professional support.
10. Conveys a feeling of cooperation and shared responsibility.
11. Promotes the acquisition of competencies that decrease need for help.

12. Helps recipient view self as an active agent, who either solves own problems and meets own needs or plays a significant role in doing so.

In addition to possessing particular beliefs, behaviors, and a help-giving style (Dunst & Trivette, 1987; Dunst & Trivette, 1989; Trivette et al., 1995) it is important that professionals ensure that certain events occur when helping families. For example, it is important that professionals provide opportunities for parents "to feel powerful and to exercise that power responsibly" (Cochran & Woolever, 1983, p. 230). The authors believe that the first step in helping parents to perceive themselves as empowered is to help parents develop a more positive image of the parenting role. Similarly, Kalmanson and Seligman (1992) emphasize the importance of working relationships that enhance the parents' recognition that it is their efforts that are ultimately the most important to their child.

It is also important that professionals allow and facilitate the active participation of parents. Dunst et al. (1992) cite an earlier Dunst (1991) study in which the researcher found a relationship between parental self-efficacy and their active participation. Specifically, the author found that when enabling experiences were used that encouraged the active participation of parents in all aspects of resource development, parents demonstrated greater changes in self-efficacy.

In conjunction with encouraging active participation of parents, it is important that the professional serving in the capacity of help-giver refrain from doing everything for the family. Taking over the family's responsibilities can lead to the family becoming a passive recipient and can have harmful consequences as the family's natural support network is displaced. Consequences may include a decrease in self-esteem, an increase in dependency, and a sense of helplessness as opposed to a perception of empowerment (Trivette, Deal, & Dunst., 1986). The authors suggest that to the extent possible, aid and assistance should be contingent on the family playing an active role in carrying out efforts to achieve mutually agreed upon goals.

The frequency of contact between the professional and the family is also important. In a study of the relationship between help-giving behaviors and parental perceived control in families of young children with disabilities, Trivette et al. (1995) reported that frequent contact with a help-giver who engaged in empowering help-giving practices resulted in a greater sense of personal control on behalf of the parents.

Summary

In summary, working in an manner that empowers family members is important because it helps to promote family coping. Doing so requires that (a) parent-professional relationships possess certain characteristics, (b) professionals providing help have certain beliefs and specific help-giving skills, and (c) professionals ensure that certain events occur during the intervention process. The responsibility for developing such professional competencies will lie with personnel preparation programs. The results of this study will contribute to what is known about the relationship between the characteristics of those professionals who are in the best position to help families perceive themselves as empowered and better able to cope (i.e., the service coordinator) and actual parental perceived empowerment and coping.

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Chapter III

RESEARCH METHODOLOGY

The purpose of this study was: (a) to identify specific service coordinator behaviors that promote a perception of empowerment and ability to cope in parents of infants and toddlers with disabilities, (b) to explore the characteristics of service coordinators, and (c) to explore the relationship between service coordinator behaviors and parental perceived empowerment and ability to cope.

This study employed both quantitative and qualitative methodologies. The combination of the two methodologies provide a "depth of perception or a binocular vision that neither can provide alone" (Bobbit, 1990, p. 4). The use of a quantitative design allowed the examination of the experiences and competencies of a greater number of families and service coordinators. The addition of the qualitative component allowed a closer look at the specific characteristics (i.e., knowledge, beliefs, behaviors, background) of the service coordinators and contributed to an increased understanding of the relationship between service coordinator characteristics and parental perceived empowerment and ability to cope. The specific research questions can be found in Chapter 1.

This chapter is divided into the following segments: (a) sample selection, (b) research designs and procedures, (c) research instruments, and (d) procedures for data analysis.

Sample Selection

Three different samples were used in this study. Each of the samples is defined below.

Sample for Quantitative Portion of Study

The quantitative portion of the study involved two different samples. The first consisted of 332 parents of children from birth to three years of age who were receiving services through *Early On* Michigan. Each year since 1993, a Family Survey, designed and administered by the *Early On* Evaluation Project at Wayne State University, College of Urban, Labor, and Metropolitan Affairs (CULMA), is sent to a sample of families whose infants or toddlers are receiving services through *Early On* Michigan. This project is funded by the Michigan State Board of Education through Part H monies allocated by the federal government to the Michigan Department of Education (MDOE).

In 1996, one of three different versions of the Family Survey (i.e., long version, short version, transition version) was sent to all families listed on a database maintained for the MDOE. Prior to receiving a survey in the mail, each family was provided with a stamped, addressed postcard allowing them to notify the Evaluation Project that they did not wish to receive and complete a survey. This study was based on responses obtained from the long-version of the survey.

A total of 890 families received the long-version of the survey. A total of 332 families (37.3%) completed and returned the survey. These are the individuals that make up the sample for the first part of the quantitative portion of the study.

The second sample consisted of all the service coordinators who provided service coordination to the families who completed and returned the long version of the Family Survey (n=169). Two service coordinators for whom families had returned the short version of the Family Survey met the established criteria and were chosen for the qualitative portion of the study and were also asked to complete the survey. This was done so that complete demographic information on these two service coordinators would be available. They were added to the sample for a total of 171 service coordinators. A further description of the sample is provided in the Chapter IV. These individuals received a questionnaire regarding service coordinator demographic information and additional characteristics (see Appendix C).

Participants in the Qualitative Portion of the Study

The participants for the qualitative portion of the study consisted of ten service coordinators chosen from the 171 service coordinators originally identified for the quantitative portion of the study. The ten selected consisted of the five whose behaviors were rated most favorably by parents on the Service Coordination Scale (SCS) of the Family Survey, and the five whose behavior was rated the least favorably by parents. In order to be included in this portion of the study, a service coordinator had to be rated by at least three families. This was to insure that a service coordinator was not rated as low or high by only one family or rated low by one family and high by another.

Using the criteria of three surveys for each service coordinator, it was possible to identify only 18 service coordinators from only the long version of the Family Survey. Therefore, a list of the service coordinators and SCS ratings from the short version of

Family Survey were also obtained. This list of service coordinators and SCS ratings was added to the list from the long version of the survey for a total of 109 service coordinators with at least three surveys returned. From this list, 69 service coordinators had at least three SCS ratings by families without missing data. A mean SCS score was obtained for each of the 69 service coordinators. From this list the top five rated and lowest five rated were chosen to be interviewed. Selected demographic information on the ten service coordinators is reported in Chapter IV.

Research Design and Procedures

This study consisted of both quantitative and qualitative methodologies. Each of the two methodologies will be discussed separately.

Quantitative Design

The quantitative portion of this study was comprised of two different components. The first was a secondary analysis of portions of the 1995-96 *Early On* Family Survey data. Utilizing these data, the relationship between specific service coordinator behaviors and parental perceived empowerment and ability to cope were examined. The second component consisted of a short questionnaire regarding demographic information and additional characteristics (e.g., preservice and inservice training, years of experience, number of different duties/roles) of service coordinators which was sent to 171 service coordinators selected for this study. A description of each of the components follows.

Secondary Analysis of Family Survey

The *Early On* Family Survey, administered by CULMA at Wayne State University, is sent each year to the families of infants and toddlers who are eligible for early intervention services through *Early On* Michigan. This survey was first administered in 1994 and is one component of a multi-faceted evaluation strategy targeted at stakeholders and designed to examine the degree of implementation and family satisfaction with Part H efforts in Michigan. It also provides information regarding the impact of Part H on families and on the service delivery system.

The content of the original 1994 Family Survey was determined with input from stakeholders who were members of the State Interagency Coordinating Council, a Governor appointed advisory body to *Early On* Michigan. The 1996 version of the survey was once again reviewed by stakeholders and input again incorporated into the final version of the survey in an effort to make the survey as family-centered as possible while still protecting the integrity of the research instrument.

The content of the survey includes the use of several previously existing assessment scales. In general, it includes questions concerning (a) the characteristics of the respondents, (b) the characteristics of the respondents' children, (c) the family's experiences with *Early On,* (d) the family's satisfaction with the quality of service they have received, (e) the family's network of informal supports, and (f) levels of respondent perceptions of stress and empowerment (Lobb, Jurkiewicz, & Thompson, 1995). A description of each of the individual scales contained within the Family Survey, used in this study, follows.

<u>Family Empowerment Scale</u>. Measuring empowerment has proven difficult for researchers (Dunst et al., 1992; Koren et al., 1992; Thompson, Lobb, Elling, Herman, Jurkiewicz, & Melesky, in press). To date, there are only a limited number of studies that attempt to measure empowerment quantitatively. One reason for this is that

empowerment is frequently described as many different entities (e.g., process, state of being, individual vs collective characteristic, attitude) (Koren et al., 1992).

The level of parental empowerment was measured in the Family Survey using the Family Empowerment Scale (FES) developed by Koren et al. (1992) (see Appendix D). According to the authors, this was the only empowerment scale designed to be used as a general empowerment measure that focuses on empowerment in families whose children have disabilities. The Evaluation Project chose this instrument for this very reason. It was the only such instrument available at the time the Family Survey was designed (Lyke Thompson, personal communication, June 1996).

The FES focuses on different facets of empowerment as possible changing states rather than as a static condition or process. It assesses two dimensions of empowerment: (a) level of empowerment, and (b) the way in which empowerment is expressed. The instrument consists of 34 statements that are rated on a 5-point Likert-type scale (1 = not true at all, 5= very true). The items are divided into three categories that reflect empowerment in terms of: (a) Family; (b) Service System; and, (c) Community/Political (Koren et al., 1992). A subscale score may be obtained for each of the three different levels of empowerment. Both a total score for the FES and subscale scores for the different levels of empowerment were used in the analysis for this study.

Koren et al. (1992) conducted numerous analyses on this instrument to determine reliability and validity. In terms of reliability, the authors obtained Cronbach's alpha coefficients for the three subscores (i.e., Family, Service System, Community/Political). The coefficients ranged from .87 to .88. In terms of test-retest reliability the analyses revealed Pearson correlations ranging from .77 to .85 (Family=.83, Service System=.77, Community/Political=.85) when administered a second time to families three to four weeks after the initial administration of the instrument. Due to the fact that "a completely reliable measure of empowerment might still show instability across time due to real changes in how empowerment is manifested or experienced" (Koren et al., 1992, p. 313) the authors believed that such correlations provided some support for the stability of the various subscores over a short period of time. Using data that resulted from the administration of the 1995 *Early On* Michigan Family Survey, Thompson et al. (1996) found all three subscores to be highly reliable and internally consistent. The authors reported standardized alphas for the various subscores that ranged from .84 to .86.

In terms of validity, Koren et al. (1992) conducted several analyses on their instrument. An independent item ratings analysis was conducted at two levels. The raters were faculty from the Graduate School of Social Work or individuals who provided services to families and children. All raters held advanced degrees in the social or behavioral sciences. None of the raters had previous knowledge of the relationship between the various items and the conceptual framework. The first analysis was an examination of agreement among raters. Kappa coefficients for multiple raters were computed for each of the three categories of the Level of Dimension, and across all categories. The coefficients for each of the categories were: (a) .83 for Family, (b) .70 for the Service System, and (c) .77 for Community/Political, with an overall coefficient of .77.

The second analysis was conducted to assess agreement with the original item classification scheme. To do so, the authors computed kappa coefficients between each rater and the item classification scheme across categories of the Level of Dimension.

This analysis revealed kappa coefficients ranging from .47 to 1.00, with 84% of the coefficients exceeding .75, and an average coefficient of .83.

The authors state that the results of these two analyses "provide support for the correspondence of FES item content to the constructs underlying the instrument" (Koren et al., 1992, p. 314). A factor analysis was also completed. The authors found that although the analysis produced factors that were independent or uncorrelated when using an orthogonal model, the subscores of the three categories were not independent. The Family subscore had zero-order correlations with the Service System and Community/Political subscores of .77 and .63 respectively. The Service Systems subscore had a correlation with the Community/Political subscore of .71. This led the authors to propose that this was evidence of the distinctiveness of the item groups that constitute the various level categories and not an indication that the categories or subscores were independent of each other. Koren et al. (1992) also tested the construct validity of the FES. An analysis of groups of parents was completed only for the Community/Political subscale. The results indicated some level of validity for the FES subscores in their ability to discriminate between groups of parents who differ in their participation in activities that are of a community nature. The issue of the ability of the subscores to differentiate groups of parents as to activities that relate to empowerment in terms of the Family or Service System was not addressed because the data obtained were not adequate to allow for such an analysis.

A study of the FES conducted by Singh, Curtis, Ellis, Nicholson, Villani, and Wechsler (1995) with 228 families who had children with serious emotional disturbance or attention deficit/hyperactivity disorder found the instrument to have "robust psychometric properties" (p. 85). The authors describe it as a tool that mental health and other service delivery personnel can use periodically to determine the changing status of empowerment in specific families. However, these researchers caution that little data exists as to the cultural appropriateness of the items contained within the FES. It is unknown whether or not the scale is as effective as a measure of empowerment in families of diverse backgrounds (i.e., racial, ethnic, cultural) as it is for the White, middle-class population with whom it was developed (Singh et al., 1995).

Questionnaire on Resources and Stress. Parental stress and coping are measured in the Family Survey using items from the Questionnaire on Resources and Stress-Short Form Adapted (QRS-SFA). The original QRS-SF was developed by Holroyd (1982) and adapted by Salisbury (1986). The Evaluation Project opted to eliminate the Cognitive Impairment scale from the QRS-SFA because the content of this scale was not appropriate for many of the families who would complete the Family Survey. The six scales included in the Family Survey are: (a) Child Characteristics, (b) Family Disharmony, (c) Family Pessimism, (d) Financial Stress, (e) Lifespan Care, and (f) Physical Limitations. The items are presented in a true/false format which alternate in terms of which response indicates stress or coping. Responses that indicate stress were scored as 0 while those that indicate a lack of stress were scored as a 1.

For the purposes of this study 25 items were selected from the QRS-SFA as it was included in the Family Survey by the Evaluation Project (see Appendix E). These items were chosen based on two criteria: (a) the items apparent face validity in terms of being an indicator of a possible source of stress in families, and (b) the appropriateness of the item to families who have infants and toddlers with disabilities. For example, the

Physical Limitations scale contained items which were not thought to be relevant to families with infants and toddlers with disabilities (e.g., Wheelchairs or walkers have been used in our house). The 25 items included some items from each of the six scales incorporated into the Family Survey. A total score obtained from the 25 items was used in the analysis.

According to Salisbury (1985), the original QRS is viewed as an objective, general measure of family coping and adaptation. In addition, further data exists to support the QRS-SFA as a useful tool for discriminating among the varying levels of stress in families who do and do not have children with disabilities (Salisbury, 1986). In a study designed to develop a psychometrically stronger version of Holroyd's 1982 version of the QRS-SF, Salisbury (1986) reported Kuder-Richardson-20 reliability coefficients within acceptable limits that ranged from .65 to .84, with an overall reliability coefficient of .76.

Using data from the 1995 *Early On* Family Survey, Thompson et al. (in press) determined the reliability of the QRS factors. For their analysis, the authors used only four of the six subscales (i.e., family pessimism, family disharmony, child characteristics, and financial stress). The results indicated standardized alphas of .36 for family pessimism, .55 for family disharmony, .62 for child characteristics, and .77 for the financial stress factor.

Service Coordination Scale. The Family Survey also includes a number of statements regarding the family's service coordinator (see Appendix F). Several of these items are part of other scales within the Family Survey. For the 1996 version of the Family Survey an additional set of 14 statements regarding service coordinator behavior (item 22a-n) was added. Items 21 through 27 comprise the Service Coordination Scale to be used for this study.

The responses to the 14 statements included in items 22a-n allow a more in-depth look at parental perceptions of the behaviors of service coordinators across Michigan. The 14 statements were developed primarily from the results of a study by Thompson (1995). In this qualitative study of families who had young children with disabilities, the author examined previously obtained data from a survey in which families were asked six questions about their perceptions of existing early intervention service systems. The three questions which provided data relevant to the development of the 14 statements were:

1. What is most important for early intervention service providers to know about working with families?
2. What do families need most when they discover that their infant or toddler has special needs?
3. If you could talk to the administrators of the service system in your county,
    a) What would you tell them about their agencies and services?
    b) What should they know about the families who receive services from these agencies (p. 36-37)?

In the final analysis of responses to all six questions, Thompson (1995) identifies three conceptual categories of behavior that relate to the ability of families who have young children with disabilities and service providers to "shape a future" for the family. The three categories are: (a) Family Reacting-Provider Caring, (b) Family Connecting-Provider Connecting, and (c) Family Persisting-Provider Guiding.

It is possible to relate most all of the items in the SCS to Thompson's (1995) categories although some items fit in more than one category. It was not possible to relate three items (22c, 26, and 27) directly to the author's categories . Each item that can be related is indicated in the description of each of the categories that follows.

The Family Reacting-Provider Caring category deals with the family's response to finding out that their child has a disability and the family's need to have professionals consider and understand their intense reactions. Families want professionals to offer support and help in ways that are sensitive to the intense emotions of the families. They want professionals to demonstrate caring by accepting them where they are and by listening to them tell their stories about what it is like to have a child with a disability (Thompson, 1995). The items from the SCS which correspond to this category are items 21, 22a, 22e, 22g, 22j-m, and 25.

The Family Connecting-Provider Connecting category involves actions and behaviors on the part of both families and professionals. Families expressed the need to be connected to "information, resources, to services, to opportunities to learn, and to other families in similar circumstances" (Thompson 1995, p.64). They expect professionals to help them connect so they can get their needs met. This requires that professionals are also able to "connect" with one another. Families view the professional as the access point for making connections (Thompson, 1995). The items from the SCS which correspond to this category are items 22b, 22d, 22h, 22n, 24, and 25.

The Family Persisting-Provider Guiding category relates to the need of families to continue seeking information, understanding, and appropriate services, which families see as never ending. Families felt a need to become the primary investigator and consumer experts, and to learn how to be the primary member of the team that has responsibility for making decisions about their child or family. In this process they want professionals to help "guide" them through this process. They want a professional who will "explain, clarify, interpret, and help them evaluate" (Thompson 1995, p. 68) all the information they obtain as they persist. This category reflects the type of relationship families prefer to have with professionals (Thompson, 1995). The items from the SCS which correspond to this category are items 22f, 22g, 22i-m, 23, 24, and 25.

Thompson's (1995) categories, which reveal what parents say they want and need from professionals, are reflective of Dunst and Trivette's (1987) conceptualization of empowering help-giving behaviors. The authors discuss the need for professionals to "display a sincere sense of caring, warmth, and encouragement" (p. 451) and to be sensitive to "verbal, nonverbal, and paraverbal messages" (p. 452) of the help-seeker. In addition, the authors relate the need for a help-giver who "conveys a sense of cooperation and joint responsibility (partnership)" (p. 452) and that engage in help exchanges that "promote participatory decision making and shared responsibility" (p. 453). It would seem that if, as service coordinators, professionals would simply ask parents of young children with disabilities what they want and need and then respond in that manner, parents could more readily be helped to perceive themselves as empowered and able to cope.

Using the actual responses of families which were included in Thompson's (1995) study and information obtained from the literature on positive and negative helping behaviors (Cochran & Woolever, 1983; Dunst & Trivette, 1987, 1988, 1989) the 14 statements were identified which fit within the three categories identified by Thompson. Additional items concerning the behavior of the service coordinator, already included in the Family Survey, were also representative of the results of Thompson's study and were included in the data analysis for the present study as a part of the Service Coordinator Scale. The items in the scale are scored on Likert-type scales (1 through 5). However, the items have different response categories. Each item was standardized prior to obtaining a total score for the scale. For the purpose of this study a response of 5 was interpreted as indicating the most positive service coordinator behavior and a 1 was interpreted as indicating the least desirable behavior. Two items (21 and 22c) were reverse scored for the purpose of analysis.

Service Coordinator Questionnaire

The second quantitative component of this study consisted of a short questionnaire which was mailed to the 171 service coordinators selected for this study. The questionnaire was designed specifically for this study and contained questions requesting demographic information and the background information (e.g., preservice and inservice training, years of experience, number of different duties/roles) of the service coordinators. A copy of the Service Coordinator Questionnaire can be found in Appendix C. The responses from this questionnaire were used to determine if there was a relationship between service coordinator characteristics and how parents rated the service coordinators on the SCS and parental perceived empowerment and ability to cope.

Qualitative Design

A qualitative design was especially appropriate to the exploratory nature of this study. The focus of this study was to better understand and explore the interface between service coordinators and the families they serve. The intent of this portion of the study was to do as Glaser and Strauss (1967) suggest and generate theoretical ideas and hypotheses about this interface. The quantitative design tested a hypothesis regarding service coordinator behaviors and family perceived empowerment and ability to cope. The qualitative design sought a deeper understanding of this relationship.

The qualitative component of this study consisted of interviews with the ten service coordinators selected based on parental ratings of these service coordinators' behaviors on the Family Survey. The five service coordinators who received the highest parental ratings on the SCS and the five service coordinators who received the lowest parental ratings on this scale were interviewed and their responses compared. The intent of the interviews was to discover what was different about the knowledge, beliefs, or behaviors of the two groups of professionals and how this impacts how these individuals work with and are viewed by families and thus the service coordinators' ability to promote a parental perception of empowerment and ability to cope. An open-ended interviewing technique was used in order to allow the researcher to "access the perspective of the person being interviewed" (Patton, 1990, p. 278) instead of forcing the interviewee to respond to preconceived categories. As it was not possible for the researcher to observe these individuals in action, interviewing allowed the researcher to obtain information otherwise unattainable (Patton, 1990) which added considerable depth to this study.

Interview questions addressed the following areas: (a) prioritization of job duties, (b) view of family involvement in the process of service coordination, (c) awareness of what families say they need from professionals, and (d) awareness of what types of helping behaviors promote rather than inhibit a perception of empowerment and ability to cope.

The format for the interviews was what Patton (1990) refers to as a Standardized Open-Ended Interview. This style of interview allows the researcher to obtain the same information from each of the individuals interviewed. The interview questions were written out in advance and each participant was asked essentially the same questions. Each question also included a set of probes that could be used. This style of interview was chosen because its basic intent is to minimize interviewer effects. In addition, it is systematic and reduces the necessity for interviewer judgment during the interview (Patton, 1990). Appendix G contains the Interview Guide.

Each interview lasted approximately one hour and occurred primarily at the service coordinator's place of employment. One service coordinator chose to meet at a community college in a town she was visiting, near her home. Interviews were audio-taped. Each interview began with reassurance regarding confidentiality and obtaining the signed consent form. The ordering of the questions was intentional. The first questions encouraged the individual to talk descriptively and required less reflection as to their specific knowledge and beliefs. Initially the service coordinators were asked to "tell me about your job as a service coordinator" and allowed to speak about anything they wished. Once the individual had begun to relive the experience of service coordination more specific questions regarding opinions, feelings, and beliefs were asked. A question regarding additional skills the coordinators felt they may need occurred later in the interview. This allowed a rapport to develop between the interviewer and the individual being interviewed before they were asked to reveal areas in which they felt they needed to develop further skills (Patton, 1990). The length of the participants' responses to the questions varied. Some provided in-depth responses and some had difficulty answering specific questions. Whenever a participant had difficulty answering a question, probes were made by the researcher. All questions on the guide were asked of each participant. At times, participants answered a question before the question was asked. If this happened, the question was not asked again and the researcher indicated that that question had already been covered.

Immediately following the interview, the observations of the interviewer were recorded in a journal. Babbie (1989) suggests that interviewers who question individuals face-to-face are able to make important observations in addition to obtaining responses to the questions asked during the interview. Patton (1987) agrees that a face-to-face interview also involves observation. He proposes that the interviewer must also be skilled at observation in order to read nonverbal messages, be sensitive to how the setting may affect what is said, and attuned to the subtleties of the interaction and relationship between the interviewer and interviewee. Elements observed during the interview included such factors as the existence and/or appearance of the office of the service coordinator, impressions of service coordinator's appearance and personality (e.g., warmth, openness), ability to communicate effectively, and willingness to talk about the subject matter. Observations were separated into objective descriptions and the subjective impressions of the interviewer in order to preserve objectivity during data analysis (Rhoades, 1994). Babbie (1989) supports the need to separate the two and proposes that researchers should include what they "know" has happened as well as what they "think" has happened and that these different types of notes be identified as specifically what they are (i.e., objective or subjective observations). A format developed by Rhoades (1994) was used for recording objective observations and subjective impressions that result from the interview process (Appendix H).

Each interview was transcribed verbatim as soon as possible after the interview. A person was originally hired to transcribe the tapes, but terminated the agreement after the completion of three tapes, due to a serious illness in the family. The researcher then completed the task of transcribing the tapes. The transcriptions were then printed out and each transcribed interview was numbered according to the order in which the interview had occurred (P1-P10). Three copies were made of each transcribed interview. One was placed in a three-ring binder for analysis, one was stored in the home office of the researcher, and one was stored in a locked drawer at the researcher's place of employment.

Data Analysis

As previously explained, this study included both quantitative and qualitative methodologies. This discussion of how data obtained for each of the research questions were analyzed is once again divided into sections based on the methodology utilized.

Quantitative Analysis

The data analyses for the quantitative portion of the study was completed using the Windows 6.1 version of the Statistical Package for the Social Sciences (SPSS). Descriptive statistics were used to determine the distributional characteristics of the variables. In addition, as the SCS had never been used before, no information regarding its psychometric properties existed. The internal consistency of the items within this scale were examined using the Reliability Analysis function of the SPSS software. Each of the items were standardized prior to analysis. The analysis yielded good reliability with a standardized alpha of .93. When the test was repeated, omitting item 22c, the standardized alpha increased to .94. A discussion of the analysis for each of the research questions that are a part of the quantitative design follows.

Research Question #1 was examined using a correlational design. Correlations were computed to determine the relationship between the predictor variable (service coordinator behaviors) and the outcome variables (parental perceived empowerment and ability to cope). In addition, the relationship between the service coordinator behaviors and the three levels of empowerment (i.e., Family, Service, Community/Political) were explored. A t-test for independent samples was used to determine differences between male and female respondents. Zero-order correlations on the variables of interest for just the fathers were computed and are reported in Table 8 in Appendix I. Due to the small number of fathers responding (n = 15) no further analyses could be completed. Multiple regression analyses were used to examine the effect of service coordinator behaviors on parental perceived empowerment and ability to cope while controlling for demographic variables that were found to be significantly correlated with either the predictor or outcome variables.

Three items on the Service Coordinator Questionnaire were used to address Research Question #2. The first item (#5) asked service coordinators to identify the area within which they received their degree(s) (e.g., education, social work) and the different degrees they had received. Items #6 and #7 asked in which areas, identified in the literature as particularly necessary to working in a family-centered manner (Bailey, Farel, O'Donnel, Simeonsson, & Miller, 1986; Bailey, Simeonsson, Yoder, & Huntington, 1990), the service coordinator had received either inservice training (Item #6) or college/university course work (Item#7). The number of hours identified in each of these items (i.e., total inservice hours, total semester hours) were totaled prior to analysis. For Item #7, term hours were converted to semester hours to determine total number of preservice hours. In addition, the number of different areas of inservice for each service coordinator were totaled for Item #6. Correlations and one-way analysis of variance were computed to examine the possible relationship between the education (i.e., preservice and inservice) of service coordinators and how they were rated by parents of infants and toddlers with disabilities. A t-test for independent samples was used to examine differences in how parents rated female and male service coordinators.

For Research Question #3, correlations were computed to examine the possible relationship between characteristics of the service coordinators and how parents rated the service coordinators. Characteristics of the service coordinators included for this analysis were: (a) number of years working with families, (b) number of years providing service coordination, (c) number of hours contracted to work per week, (d) number of hours contracted for service coordination, (e) number of families on service coordination caseload, and (f) number of roles fulfilled by service coordinator.

Qualitative Analysis

Miles and Huberman (1994) define qualitative analysis as three activities that flow concurrently. The three activities are data reduction, data display, and drawing conclusions/verification. Because the three activities occur concurrently, the strategies used in this study can best be explained as they occurred and not as separate functions.

Data Management and Initial Analysis

Immediately following each interview, the researcher listened to each of the tapes and wrote several pages summarizing what the service coordinator had to say. This allowed the researcher to begin developing a tentative coding framework by identifying possible concepts and themes to be explored during subsequent coding of the data. At this point, the researcher also began to generate a list of possible differences among the various service coordinators. This activity proceeded while all of the interviews were being completed and transcribed. During the transcription of the interviews the researcher also began to add to and re-configure the list of possible concepts, themes, and categories.

Once all the interviews were transcribed, a copy of each transcribed interview was given to two parents of children with disabilities who were hired as objective readers. These two individuals were paid a stipend of $50.00 each and instructed to read all the interviews and then to divide the ten interviews into the five service coordinators they felt were rated most favorably by families and the five they felt were rated least favorably by families. They were also asked to make comments as to why they rated each service coordinator as they did. In addition, a professional colleague of the researcher, with a Ph.D. in Family and Child Ecology, and an emphasis in Family Studies, was asked to randomly choose two of the transcribed interviews (one from the higher rated group and one from the lower rated group) and to do the same as the parents. She chose Interviews 6 and 10 and did not know how each was rated. This step was taken to verify the objectivity of the study and is what Lincoln and Guba (cited in Marshall and Rossman, 1989) refer to as *confirmability*. By showing that the findings of the study could be confirmed by another, the evaluation is removed from some "inherent characteristic of the researcher (objectivity) and placed on the data themselves" (p. 147). This strategy was used to confirm that it was possible to tell that there was something different about the service coordinators based solely on what they had to say.

Coding of the transcribed interviews began by summarizing each paragraph on the blank page adjacent to the interview text. This allowed the researcher to go back to the text and more quickly locate the information as analysis proceeded. Following the completion of these summaries, the detailed coding of each transcript began.

All data were coded by hand by the researcher. In order to avoid forcing the data to fit a predetermined set of codes, the researcher used a more inductive approach based on techniques described by Strauss and Corbin (1990). In this approach data are reviewed, line by line within a paragraph, and labels or categories are generated and written next to the text. Next, the labels are reviewed and more abstract categories are generated and attributed to more than one incident or observation (Miles and Huberman, 1994). The research began with a tentative list of concepts and categories that had emerged from listening to the tapes immediately following the interviews and from immersion in the related literature. As coding of the text proceeded, the concepts were placed within categories and categories were re-organized. This process resulted in the

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researcher ultimately generating a list of 29 questions that needed to be answered regarding the service coordinators in order to respond to the four qualitative research questions. These questions were combined with the interview questions that directly related to one of the research questions for a total of 34 questions. A list of the these questions can be found in Appendix J.

After coding each of the interviews, one page summaries of the most noticeable characteristics of each service coordinator were written. This helped the researcher to gradually reduce the amount of data and continue to identify the similarities and differences among the service coordinators.

In order to identify the answers to the 34 questions and to organize the data so that it was manageable, a matrix was developed. Each of the 34 questions was entered as a category down the left side of the matrix. For example, the question that asked, "What is the scope of the service coordination provided by this service coordinator?" was entered into the matrix as "Scope of Service Coordination". In addition, as the coded data were reviewed for assignment to the matrix, four additional categories were identified and added to the matrix. These were Attitude Toward Paperwork, Learn by Doing, Flexibility, and Pride in Program. A number which represented each of the ten service coordinators (the number that corresponded to the order in which they were interviewed) was entered across the top of the matrix (i.e., P1-P10). The service coordinators were grouped within the matrix, according to how they were rated by families (i.e., high or low). This allowed the researcher to look for visual patterns in the data such as simply the amount of information supplied by a particular service coordinator. A sample of the matrix can be found in Appendix K.

A display, such as a matrix, is valuable for visually presenting "information systematically, so the user can draw valid conclusions and take needed action" (Miles & Huberman, 1994). As the authors suggest, the matrix provided a display that was focused enough to allow the researcher to see the full data set in one location and that was systematically arranged so the research questions could be answered. The full data set in the matrix did not include all the interview data, but rather, those comments that answered the question that originally generated the category that was entered into the matrix.

The entries of data into the matrix were what Denzin (1989) and Gertz (1973) as cited by Miles and Huberman (1994) refer to as "thick" (p. 241). This type of data present the context well and reveal intentions and meanings. Paraphrasing of text and direct quotes were used as opposed to summary judgments or global ratings. Data that are more dense such as this, increases the usefulness of the data (Miles & Huberman, 1994). The number of the page from which the text was obtained was also included to enable the researcher to go back to the data for a more detailed look when drawing conclusions.

After entering the data for each service coordinator into the matrix, the researcher once again wrote a short summary (six to ten lines) regarding the service coordinator. These summaries consisted of listing the characteristics of the service coordinator that were most obvious after being immersed in the data from a specific interview. Once again, this helped the researcher to confirm or reconsider previous thoughts about the similarities or differences between the higher and lower rated service coordinators.

The next step, once all data were entered into the matrix, was to begin to examine the matrix. This began with what Miles and Huberman (1994) call a “squint analysis” (p. 242) which consists of simply looking down rows and across columns to see what is apparent immediately. Next, themes or similarities in comments across interviews were color coded. It became apparent at this point, that in order to answer the four research questions, categories would have to be combined and then examined. Codes were further delineated by adding what Strauss and Corbin (1990) refer to as the dimension of the code. This consists of locating the property of the concept along a continuum. For example, Scope of Service Coordination was again coded from Broad (including other agencies in the community) to Narrow (limited to educational services only).

From examining the matrix at this point, it was possible to confirm the themes that existed in the data and to begin to generate some tentative hypotheses regarding the differences between the two groups of service coordinators. The researcher now felt the need to seek out another person to act as what Marshall and Rossman (1989) refer to as a devil’s advocate who could critically question the tentative hypotheses that were emerging. This role was played by the same professional colleague who had read and rated two of the interviews previously. The researcher showed this individual the matrix without identifying which group of service coordinators were which and asked her to focus on specific categories and to indicate what she saw in the display. This feedback confirmed the tentative hypotheses that were beginning to develop and provided ideas for further exploration of the data.

Although the matrix, as it presently existed allowed the researcher to respond to Research Questions #5 and #6, it now became clear that further coding and data reduction were necessary in order to be able to respond to Research Questions #4 and #7. At this point two existing theoretical frameworks were applied to the data. The first framework was from Dunst, Trivette, Davis, and Cornwall (1994b) and was based on Dunst and Trivette's (1987) enablement model of help-giving. The second was Thompson's (1995) grounded theory regarding what families say they need from professionals. Using these two frameworks, coding schemes were devised and the data were once again coded.

Color-coding was used to code the data in the matrix according to the Dunst's et al. (1994b) model. This model includes: (a) prehelping attitudes and beliefs, (b) help-giving behaviors, and (c) posthelping responses and consequences. A color was assigned to each of the three categories within the framework. Each line of text within the matrix was then compared to each of the categories and highlighted with the designated color if it was determined to belong to that category.

Using Thompson's (1995) framework, copies of the transcribed interviews were then coded using a designated color and assigned a letter(s) which represented a category from the framework. The codes used were: C for Caring, Cn for Connecting, G for Guiding, P for Persisting, CF for Caring about the Future, CNF for Connecting to the Future, GF for Guiding for the Future, PF for Persisting toward the Future, and GPF for Guiding to Persist in the Future.

After completing the coding using Thompson's (1995) framework, an additional, small matrix was created in the same manner as the original matrix, but included only the categories from Thompson's framework along the left side and the service coordinator's across the top. Once again this allowed the researcher to view a large amount of data at one time.

Final Data Analysis

Once the matrices were finalized, the analysis was easily completed. During the process of coding and organizing the data, themes had begun to emerge and were recorded. The first step in completing the analysis was to finalize the development of each of the themes. These themes were those concepts or experiences mentioned by or common to both groups of service coordinators. A decision rule was established that a majority (six out of a possible ten) service coordinators must have mentioned the concept or experience before it was included in the final analysis.

Next, each of the individual research questions was addressed. During the process of coding and condensing data, a tentative list of differences between the two groups of service coordinators had been generated. In order to confirm or deny such differences and respond to the research questions, it was necessary to utilize several categories within the matrix. The specific categories used to answer each question are delineated in the following chapter which presents the results of the analysis. A decision rule was set that three of five (a majority) of one group (lower or higher rated) and no more than one individual in the opposite group, must demonstrate the knowledge, belief, or behavior under consideration for a determination to be made that a difference existed. As the differences were identified, text was written to explain them. As Miles and Huberman (1994) explain, writing leads to reformulation, additional clarity, and ideas for further analysis. Initial hypotheses were compared to initial summaries describing each service coordinator which were written during the entire process of analysis, to the notes generated immediately following each interview, and to the comments of the objective readers. Alternative explanations were considered. Once the hypotheses were generated, "genuinely representative exemplars of the conclusions" (Miles & Huberman, 1994, p. 243) presented were identified. The authors propose that if such exemplars cannot be found then the hypotheses must be revised.

Identifying Negative Instances

While looking for evidence in the data to verify proposed relationships, it is necessary to also look for instances which do not fit the hypotheses. Such instances help the researcher to qualify original statements of relationship. They do not necessarily negate the proposed relationship, but rather they may add additional information and clarity (Patton 1990; Strauss & Corbin, 1990). In any case, such instances must be identified and carefully examined (Berg, 1995).

In this study, all negative instances were noted as they were identified. There were no instances of an entire case (i.e., a service coordinator) being a negative instance. Rather, a lower or higher rated service coordinator may have demonstrated a knowledge, attitude, or behavior that was predominantly found in the alternately rated group of service coordinators. For example, Participant #6, one of the lower rated service coordinators, appeared to view her role as a service coordinator more broadly as did the higher rated group. However, this one instance, when considered in the context of all the other negative aspects of this service coordinator's work experience (e.g., little or no support, little connection in community) became negligible. A decision rule was set that not more than two negative instances could be identified before the hypotheses was discarded or reformulated. No hypotheses were discarded or reformulated based on negative instances identified. However, notable negative instances are noted and discussed in Chapters IV and V. The results of the final analysis are presented in Chapter IV.

Chapter IV

RESULTS OF DATA ANALYSIS

This study was designed to examine the relationship between parental ratings of service coordinator behaviors and parental perceived empowerment and ability to cope. In addition, it examined whether or not service coordinators who are rated most favorably by families, differ from those rated less favorably. The study utilized both quantitative and qualitative methodologies. The results of each of the different analyses will be reported individually within this chapter.

Results of Quantitative Analysis

The results of the quantitative analysis will be reported first and will be reported by the various Research Questions (Research Questions 1, 2, and 3). Because the various questions involved different samples, the samples will be explained in relation to the specific Research Question.

Research Question #1

1. Is there a relationship between particular service coordinator behaviors and parental perceived empowerment and ability to cope?

Sample

The sample included in this portion of the study consisted of families of infants and toddlers with disabilities who returned the long-version of the *Early On* Family Survey administered by the College of Urban, Labor, and Metropolitan Affairs (CULMA) at Wayne State University. The respondents consisted of 332 individuals, 307 females (95.3%) and 15 males (4.7%). The respondents ranged in age from 15 years to 66 years (mean=31.4 years).

Families in the *Early On* system are allowed to self-identify their ethnicity from a choice of seven categories (i.e., American Indian/Alaskan Native, Asian/Pacific Islander, Black/Not of Hispanic Origin, Hispanic/Not of Black Origin, European American, Middle Eastern American, and Multi-Ethnic American). This information is not requested on the Family Survey, but is obtained from another grant administered by the Michigan Department of Education. This grant is responsible for collecting and reporting demographic data for the families in the *Early On* system. The ethnicity of the respondents was predominantly European American (236 respondents or 79.5%). Thirty of the respondents (10.1%) reported themselves as Black/Not of Hispanic Origin, nine (3.0%) as American Indian/Alaskan Native, eight (2.7%) as Multi-Ethnic American, six (2.0%) as Asian/Pacific Islander, five (1.7%) as Hispanic/Not of Black Origin, and three (1.0%) as Middle Eastern American.

The number of years of education reported by the respondents ranged from 10 years to 20 years (mean = 13.6 years). Family income ranged from $10,000 or below to $75,000 or above (mode = $10,000 or less) with 44.3% of the respondents reporting that they worked either part-time (22%) or full-time (22.3%). Selected demographic information is reported in Table 1.

The age of the children of the families included in the sample ranged from a few months to three years of age. Sixty-eight (20%) of the children were from birth to one year of age, 129 (39%) were from one year to two years of age, and 132 (40%) were from two to three years of age. Three of the children (1%) did not have an age reported. There were 156 female (47%) and 175 male (53%) children. Information regarding the specific disability of the child was not requested.

Bivariate Analyses

Correlations were computed to determine the relationship between the predictor variable (service coordinator behaviors) and the outcome variables (parental perceived empowerment and ability to cope). A significant positive relationship between the behaviors of service coordinators and overall parental perceived empowerment was found ($r = .31$, $p < .000$). Parents who rated their service coordinator more favorably on behaviors that families say they want from professionals, perceived themselves as more empowered. The relationship between service coordinator behaviors and each of the three levels of empowerment (i.e., Family, Service, and Community/Political) was also found to be significant (rs = .24, .33, and .26 respectively, $p < .000$). Parents who perceived their service coordinator more favorably tended to receive higher scores at each of the levels of empowerment. Parents who had children with more severe disabilities perceived themselves as less empowered within the family unit ($r = -.14$, $p < .05$) than

Table 1 - Selected Demographic Information on Sample for Research Question #1

Variable	Number	Percent	Mean (SD)
Gender of Respondent			
Female	307	95.3%	
Male	15	4.7%	
Age of Respondent			31.4 years (7.7)
Education of Respondent			13.6 years (2.1)
Employment of Respondent			
Full-time	73	22.3%	
Part-time	72	22.0%	
No-work outside of home	183	55.8%	
Ethnicity			
European American	236	79.5%	
Black/Not of Hispanic Origin	30	10.1%	
American Indian/Alaskan Native	9	3.0%	
Multi-Ethnic American	8	2.7%	
Asian/Pacific Islander	6	2.0%	
Hispanic/Not of Black Origin	5	1.7%	
Middle Eastern American	3	1.0%	
Income			
< $10,000	65	20.6%	
$10,000 to < $35,000	133	42.2%	
$35,000 to < $75,000	91	28.9%	
$75,000 or more	26	3.3%	
Presence of Partner/Spouse			
No Partner/Spouse	30	13.8%	
Partner/Spouse Present	187	86.2%	

parents who had children whose disability was not as severe. In addition, parents who had a partner or spouse perceived themselves as more empowered when interacting with service providers ($r = .12$, $p < .05$). Although statistically significant, these relationships were modest in magnitude.

A t-test for independent samples indicated that female respondents perceived themselves as significantly more empowered than males ($p = .04$). Females also perceived themselves as more empowered at the Service level of empowerment than males ($p = .02$). This may be due to the fact that mothers are the parent who most often interact with personnel at the Service level (e.g., medical personnel, educational personnel). There was no significant difference in perceived empowerment between females and males at the Family or Community/Political levels of empowerment.

The analysis revealed no significant correlation between service coordinator behaviors and parental perceived ability to cope. However, several other variables were found to be significantly correlated with parental perceived ability to cope. Parents who reported more family income perceived themselves as better able to cope ($r = .27$, $p < .001$) as did those with more education ($r = .19$, $p < .01$). The level of disability of the child also impacted the parents' perception of their ability to cope. As the level of disability increased, the parents reported more difficulty coping ($r = -.35$, $p < .001$).

The analysis also revealed a significant relationship between parental perceived empowerment and ability to cope ($r = .29$, $p < 001$). Parents who perceived themselves as more empowered also perceived themselves as better able to cope. This was true at all three levels of empowerment (Family, $r =.38$, $p < .001$; Service, $r = .24$, $p < .001$; and

Community/Political, r = .15, p < .01). Relationships among the control, predictor, and outcome variables are shown in Table 2.

Multiple Regression Analysis

Multiple regression was used to control for demographic variables which were significantly correlated with either the predictor or outcome variables. The first analysis examined the relationship between service coordinator behaviors and parental perceived empowerment. Factors entered into the first regression equation included the level of disability of the child, parental education and employment status, gender and income of parent, and parental ratings of service coordinator behaviors. Only two factors were found to be predictive of parental perceived empowerment. More positive ratings by parents of their service coordinators predicted higher levels of parental empowerment. In addition, parents who rated their children's disability as less severe, perceived themselves as more empowered than parents who considered their children to have more severe disabilities. Fourteen percent (14%) of the variance was accounted for by the model. The results of this analysis can be found in Table 3.

Table 2 - Relations Among Control, Predictor, and Outcome Variables

	Income	Education	Gender	Marital Status	Level of Disability of Child	Number of Children in Family Receiving *Early On* Services	Age	Service Coordinator Scale	Parental Perceived Empowerment	Family Level Empowerment	Service Level Empowerment	Community/ Political Level Empowerment	Parental Perceived Coping
Income	1.00												
Education	.52***	1.00											
Gender	-.04	.06	1.00										
Marital Status	.45***	.21***	-.05	1.00									
Level of Disability of Child	.20***	.16**	-.04	.03	1.00								
Number of Children	-.09	-.14*	.07	.03	-.02	1.00							
Age	.40***	.33***	.10	.24***	.02	.05	1.00						
Service Coordinator Scale	-.27***	-.15*	-.08	.01	.14*	.12	.01	1.00					
Parental Perceived Empowerment	.07	.02	-.11*	.09	-.09	.06	.07	.31***	1.00				

*p < .05 ** p < .01 ***p < .000

Table 2 (Cont'd)

	Income	Edu-cation	Gender	Marital Status	Level of Disability of Child	Number of Children in Family Receiving *Early On* Services	Age	Service Coordinator Scale	Parental Perceived Empower-ment	Family Level Empower-ment	Service level Empower-ment	Community/ Political Empower-ment	Parental Perceived Stress
Family Level Empower-ment	0.03	0.01	-0.09	0.09	-.14*	0	0	.24***	.84***	1			
Service Level Empower-ment	.05	.03	-.13*	.12*	-.09	.07	.04	.33***	.89***	.72***	1.00		
Com-munity/ Political Level Empower-ment	.09	.04	-.07	.02	.01	.08	.14	.26***	.84***	.50***	.61***	1.00	
Parental Perceived Coping	.27***	.19**	-08	-10	-.35***	-.06	.13*	.08	.29***	.38***	.24***	.15**	1.00

*p < .05 **p < .01 ***p < .001

Table 3 - Predictors of Parental Perceived Empowerment

Predictor Variable	Standardized Beta (β) (n = 297)
Level of Disability of Child	-.20**
Service Coordinator Behaviors	.28***
Full-time Employment of Parent	-.01
No Employment Outside of Home by Parent	.15
Gender of Parent Responding	-.10
Education of Parent	.08
Income of Family	.04

p < .01 ***p < .001 $R^2 = .14$ $F_{(7, 189)} = 4.51$*

The second multiple regression analysis was used to determine which variables were predictive of parents' perception of their ability to cope. In this equation the seven predictor variables from the previous regression analysis were entered into the equation. In addition, parental perceived empowerment was entered as a predictor variable. Parental perceived ability to cope was used as the outcome variable. Five variables were found to be predictive of parental perceived ability to cope: (a) income and education of the parent, (b) level of disability of the child, (c) parental ratings of service coordinator behaviors, and (d) parental perceived empowerment. As with the bivariate analyses, increased income, education, and parental perceived empowerment were predictive of an increased perception of ability to cope. Having a child who had a severe disability was again predictive of a decreased perception of an ability to cope. The predictor of parental perceived ability to cope that emerged as a result of the regression analysis, but was not significant in the bivariate analyses, was the parental ratings of the behaviors of the service coordinators. The regression analyses were consistent with the view that parental ratings of their service coordinator have both a direct and an indirect effect on parental perceived ability to cope. How parents feel about the treatment they receive from their service coordinators predicts how empowered parents perceive themselves to be. Feeling more empowered, in turn, helps parents of infants and toddler with disabilities to perceive themselves as better able to cope (see Figure 3). Overall, the model accounted for 41% of the variance in perceived coping. Predictors of Parental Perceived Coping are included in Table 4.

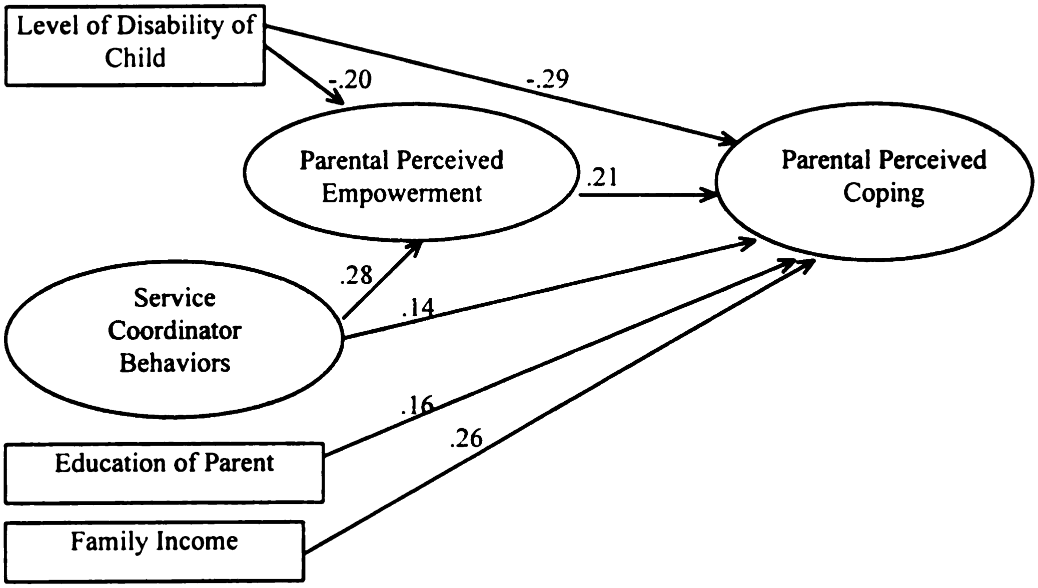

Figure 3. Path Model: Effects of Service Coordinator's Behaviors

Note: Only significant Paths ($p < .05$) are included in the model. Standardized regression coefficients are presented on the paths.

<u>Research Questions #2 and #3</u>

2. Do service coordinators who parents rate high on behaviors that families say they need from professionals have different training (preservice and inservice) than service coordinators who parents rate lower on such behaviors?

3. Is there a relationship between the number of different roles a service coordinator is expected to perform, the amount of time allotted to doing service coordination, or the number of families for which the service coordinator provides service coordination and how parents rated the service coordinator on behaviors that families say they need from professionals?

Table 4 - Predictors of Parental Perceived Coping

Predictor Variable	Standardized Beta (β) (n = 297)
Level of Disability of Child	-.29***
Service Coordinator Behaviors	.14*
Education of Parent	.16*
Parental Perceived Empowerment	.21*
Income of Family	.26***
Full-time Employment of Parent	-.61
No Employment Outside of Home By Parent	-.11
Gender of Parent Responding	-.09

$^{*}p < .05$ $^{***}p < .001$ $R^2 = .41$ $F_{(8, 188)} = 15.98^{***}$

Sample and Survey Data

The sample for this portion of the study consisted of 100 service coordinators within the state of Michigan who returned a survey regarding their present positions, training, and background. These individuals were chosen because families, to whom they provided service coordination, had rated their behaviors when completing the long version of the Family Survey. The sample consisted of 94 females and six males. The number of years these individuals had worked with families in some capacity, ranged from a minimum of one year to a maximum of 25 years (mean = 10.6 years). The number of years these individuals had been providing service coordination to families ranged from zero to 15 years (mean = 4.5 years). The zero was due to one individual reporting that he had never provided service coordination to families, even though he was identified as the service coordinator for the family. The number of families on these individuals' caseloads ranged from zero to 275 families (mean = 23 families). Again, one individual reported not doing any service coordination and one reported doing only service coordination, for 275 families.

The service coordinators reported that they were contracted to work from 16 hours to 40 hours per week (mean = 34.5 hours). Forty individuals (42.6%) reported that their employment contracts did not specify a particular number of hours for just service coordination (separate from other duties). The majority (55.3%) reported that their employment contracts specified from one to five hours per week for providing service coordination. In addition, two individuals reported that they were contracted for 10 and 30 hours a week, respectively, to provide service coordination, and six individuals did not respond to the question.

The service coordinators were asked to report the number of roles they are required to perform in their positions. The majority of the respondents (38.8%) reported that they are required to fulfill at least two roles (at least one in addition to being a service coordinator). The most frequent second role was as a direct service provider. Only five (5.1%) reported service coordination as their only role.

Several questions on the survey these individuals completed dealt with their preservice and inservice training. Thirty-nine percent of the service coordinators held degrees in the field of Special Education. The next most frequently held degree (14%) was in the field of Public Health. Fifty-two percent (52%) had obtained a Master's degree and another 41% held a Bachelor's degree. The number of hours of inservice training received by these individuals ranged from six hours to 700 hours (mean = 172.5 hours). Twelve possible areas of inservice training (e.g., typical infant development, family assessment, family-centered practices) were included in the survey. The minimum number of areas of inservice attended by a respondent was two and the maximum was twelve (mean = 8.8 areas). The number of hours of course work the respondents had completed in areas related to working with infants and toddlers with disabilities and their families ranged from zero to 94 hours (mean = 17.7 hours). Additional information about the service coordinators' preservice and inservice training can be found in Table 5.

Research Question #2

Correlational analysis was used to examine the relationship between the training (preservice and inservice) of service coordinators and how they were rated by parents of infants and toddlers with disabilities. No significant relationship was found between either the number of hours of course work or hours of inservice in the area of infancy and working with families and the way in which parents rated the service coordinators. When training was examined in terms of the number of different areas (e.g., typical infant development, family assessment) in which a service coordinator had received inservice training, the relationship between the number of different areas of inservice and how parents rated the service coordinators approached significance ($r = .20$, $p = .056$).

A one-way analysis of variance was used to examine the relationship between the area within which the service coordinator held a degree (e.g., special education, social

Table 5 - Service Coordinator Educational Background and Training Information

Variable	Percent	Mean (SD)
Degree		
Bachelors	41%	
Masters	52%	
Doctorate	1%	
Other	6%	
Degree Program		
Special Education	39%	
Public Health	14%	
Social Work	9%	
Occupational Therapy	9%	
Speech and Language	9%	
Physical Therapy	8%	
Early Childhood	4%	
Psychology	1%	
Other	7%	
Semester Hours of Course Work in Infancy or Working with Families		17.7 (19.3)
Hours of Inservice		172.5 (180.4)
Number of Different Areas of Inservice Training Regarding Infancy and Working with Families		8.8 (2.6)

work), the degree held (e.g., Bachelors degree, Masters degree) and how the service coordinators were rated by parents. No significant differences were found based on the area within which the service coordinator held a degree or the degree held by the service coordinator. In addition, a t-test for independent samples indicated no significant difference between how parents rated male and female service coordinators.

Research Question #3

Correlational analysis was once again used to examine the relationship between various characteristics of the service coordinators and how parents rated the service coordinators. Characteristics of the service coordinators included: 1) number of years working with families, 2) number of years providing service coordination, 3) number of hours contracted to work per week, 4) number of hours contracted for service coordination, 5) number of families on service coordination caseload, and 6) number of roles of service coordinator. The only significant predictor of how parents rated the service coordinators was the number of years the service coordinators had been doing service coordination. There was a positive relationship ($r = .28$, $p < .05$) between the two variables. More experience as a service coordinator results in one being rated more favorably by parents.

Results of Qualitative Analysis

The purpose of the qualitative analysis was to examine more closely the interface between service coordinators and the families they serve, revealing a deeper understanding of this relationship and how it contributed to families feeling more empowered and better able to cope. The raw data consisted of transcribed interviews from ten service coordinators across the state of Michigan. The results of this analysis are organized by the four qualitative research questions. Prior to discussing these results, two other topics are discussed. First the results of having objective individuals read and rate the service coordinators is introduced. Second, the general themes that emerged regarding the experience of providing service coordination are presented. A description of the ten service coordinators interviewed follows.

Participants

The participants consisted of ten service coordinators who provided this service to the families who returned either the long or short version of the *Early On* Family Survey. The ten service coordinators interviewed for this study included the five rated most favorably and the five rated least favorably by these families. All of the service coordinators were females. The mean scores on the Service Coordinator Scale for the five higher rated service coordinators ranged from 4.62 to 4.71 on a 5-point Likert-type scale (mean = 4.67). The mean scores for the five lower rated service coordinators ranged from 2.82 to 3.36 (mean = 3.20). Selected demographic information is reported in Table 6.

Table 6 - Selected Demographic Information of Qualitative Participants

Characteristic	Number	Percent	Mean
Number of Years Working with Families			
Lower Rated			6.9 years
Higher Rated			9.4 years
Number of Years Providing Service Coordination			
Lower Rated			3.4 years
Higher Rated			4.6 years
Degree Area			
Special Education (and Early Childhood)	5	50%	
Occupational Therapy	2	20%	
Public Health Nursing	1	10%	
Family and Child Ecology	1	10%	
Human Services (and Child Development)	1	10%	
Degree			
BA/BS	5	50%	
MA/MS	4	40%	
Other	1	10%	

Input From Objective Readers

Two mothers of children with disabilities, who have also been involved in training service coordinators, read and rated all of the ten transcribed interviews. This was done in order to confirm that it was possible to differentiate the service coordinators (higher and lower rated) based on what they said in the interviews. The two parents were asked to read each interview and then place that service coordinator in one of two groups, those rated higher by families and those rated lower by families. Each of the two parents placed eight of the ten service coordinators in the correct group.

A professional colleague of the researcher randomly selected two of the interviews and rated them. This individual has a Ph.D. in Family and Child Ecology, with an emphasis in Family Studies, and also has experience in conducting qualitative research. This reader also rated the two randomly selected interviews correctly and indicated that she had no difficulty doing so.

The comments from all three objective readers, regarding why they rated each of the service coordinators as they did, clearly reflect the results of the in-depth analysis of the interviews by the researcher. For example, the parents commented on the difference in how caring, compassionate, and honest the higher rated service coordinators were. They noted differences in how aware the service coordinators were as to what is important to families, such as the need to listen and to connect families to the information and resources families need. Also mentioned was the difference in the degree of connection the service coordinators had within their communities which allowed them to better connect families to much desired resources. The parents also recognized the difference between the higher and lower rated service coordinators in terms of the amount of support available to these individuals. The professional reader noted the fact that the higher rated coordinator "welcomes challenges" while the lower rated coordinator expressed much frustration and seemed to be "bordering on burnout".

Emerging Themes Regarding Service Coordination

In qualitative analysis, themes are useful in describing the conditions of the social context being studied. The themes that emerged from the data seemed to reflect how service coordinators viewed their roles and what their general knowledge was about working with families. To be considered a “theme” such information had to occur in the majority of the interviews (i.e., at least six out of a possible ten) and not be a result of a specific question during the interview. The researcher will first present a description of the service coordinators’ view of their roles and then report information that provides insight into their knowledge about working with families.

The ten individuals interviewed generally viewed their role as a service coordinator in a positive light. The comments ranged from “I love it” to “time consuming”, to “frustrating”, to “overwhelming”, to “very rewarding”. Even those who were most positive about this role mentioned how time consuming it was. Participants often alluded to giving out their home phone numbers and taking calls in the evenings and on weekends and holidays. Several also mentioned evening and weekend meetings.

Paperwork was a component of this role that was viewed unfavorably by all. The length of the Individualized Family Service Plan (IFSP) was of particular concern. Some expressed concern that the length of this document was not family-centered and caused parents to question why they were pursuing services through *Early On*. In general, the IFSP was seen as an “event” that occurred or as a “document” to be completed and not as a process to be used to create, record, and modify the family’s plan of service.

The systems within which the service coordinators worked varied in terms of their configurations and in terms of how family-centered they were. Despite the fact that the lead agency for *Early On*, the Michigan Department of Education and the State Interagency Coordinating Council (SICC), both actively promote the concept that families should be allowed to choose their service coordinators, this was not occurring in the systems where the service coordinators interviewed were employed. In nine of the ten service areas, the families had no, or at best limited, choice as to who their service coordinator would be.

The service coordinators mentioned issues of personal safety as one of their greatest concerns, as they are required to provide services in a number of different environments each day. Safety issues included unsafe environments within which drugs and/or guns may be discussed or present, or where large, aggressive dogs were present. The service coordinators generally felt safe with the immediate family members with whom they had developed a relationship, but mentioned feeling threatened by others present in the home when they visited. These concerns were expressed clearly by one of the participants:

> The only times that I've, and there's only been a few, when I've felt uncomfortable, and it hasn't been the family, per se, that I've been working with, it may be a family friend or an extension of their own family, like extended relatives, that may be in the household that are physically threatening. Or I felt uncomfortable because either somebody was making advances....Or I've gone into neighborhoods where, before I've gotten in the house, you know it's not been a real safe neighborhood (P10).

Working under such conditions can be highly stressful. One way of dealing with such stress is to talk about it with another person such as a colleague. The need for such support was discussed by all but one of the service coordinators. The one service coordinator who did not specifically mention the presence or absence of such support, but yet clearly implied that she had no such support and her frustration with the job, did reflect on the process of the interview and say:

> As a matter of fact, just kinda even talking about it kind of makes you feel good. "Oh, I do, do that!" I haven't had a chance to tell anybody lately that I think my strength is that (P6).

One of the foremost principles of a family-centered model of early intervention as proposed by Dunst et al. (1994c) is viewing the family, and not the child as the unit of intervention. This view is consistent with systems's theory and supported by Bronfenbrenner's (1989) definition of human development as the "....progressive, mutual accommodation, *throughout the life course*, between an active, growing human being, and the changing properties of the immediate settings in which the developing person lives..." (p. 188). Six of the ten service coordinators actually stated this view and two others implied the belief in this concept through other discussions. However, the three lower rated service coordinators who stated this view, did not reflect this in their actual delivery of services as it was clear that their primary unit of focus was working with the child. One in particular expressed this view by lamenting the presence of other family members when she was trying to work with the child and actually stating "this is my time to work with their child" (P1). It seems that although many of them knew they should be focusing on the entire family they were still struggling with their need to "teach" the child. The higher rated service coordinators consistently demonstrated their view of the family as the unit of intervention as they placed their emphasis on strengthening and supporting the family and not just developing the skills of the child.

Families with young children with disabilities want service providers who recognize that all families are unique (Thompson, 1995). Eight of the ten service coordinators interviewed indicated that all families are different. This "uniqueness" included different aspects of the family. For example, some families preferred the focus of early intervention to be on the child, as opposed to the family. Families varied in terms of what they prioritized as needs. In addition, some service coordinators recognized that

families are in different places in terms of grieving the loss of the "perfect" child they thought they would have. The uniqueness of families was captured well by the words of one service coordinator when she said:

> I think the families I work with are just like any other families that we would find anywhere. I mean, just like my family. I don't think...There isn't a typical, stereotypical family that you would see. I think they come in all sizes, shapes, colors, and family backgrounds (P10).

This uniqueness affects how willing or able the family is to participate in early intervention. Families with young children with disabilities themselves, report that often they are not "ready" for any early intervention services or for particular aspects of early intervention (Thompson, 1995). Six of the ten service coordinators indicated an awareness of the need for families to be "ready". This readiness factor varied from the need to "get them ready to see what's really going on with their child" (P7), to the parent's readiness to accept early intervention and the need to "get them over that hump" (P1), to the parent's readiness to meet and talk with another parent who has a child with a similar disability as evidenced by one of the participants as she discusses her need to use parents to talk with other parents more often:

> I probably don't use it as much as I should, or could, but I also want to figure out where the parents are at, if they're ready to handle something like that (P8).

The service coordinators also had similar methods of "assessing" this readiness in families. Although some did ask families directly what they wanted, all the coordinators mentioned their need to indirectly determine where the family was at in terms of readiness. This behavior seemed to be consistent with what Dunst and Trivette (1994) describe as the effective help-giver's "sensitivity to verbal, nonverbal, and paraverbal messages displayed" (p. 167) by the person seeking assistance. This sensitivity allows the help-giver to offer, rather than wait for help to be requested. One higher rated service coordinator, in particular, reflected this sensitivity. She was discussing her conversation with a grandmother about why the daughter-in-law was not making the grandson wear his hearing aids. The service coordinator offers the grandmother three possible reasons for the daughter-in-law's behavior. These hypothetical reasons indicate the service coordinator's awareness of possible hidden messages in the behavior:

> And so, we just kinda talked about that and I'm gonna have to get with the family and see where they're coming from, but you just listen and you find out where they're [at], cause it could be any one of those options, it could be "She's telling me I have to have this kid wear the hearing aids, so I'm not gonna do it!" Or, it could be, "Oh man, he looks just so ugly with those hearing aids on, I just can't make him, and he's really deaf when he has those on." Or, three, "I just don't want to hassle with the darn things." And I think you just have to watch for non-verbal communication and you have to listen. Action speaks so much louder than words (P9).

Another common theme, mentioned by seven of the ten coordinators, was the need to prepare the family for the future in some way. Thompson (1995) reported that families have a need to be able to define a future. Thompson provides an example from a survey completed by a parent which said "I need a plan for my child's future so I could have a plan for mine" (p. 90). The service coordinators appear to recognize this need. Concurrent with this theme, was the need to prepare the families for their need to advocate for their children's needs within the educational system. Four of the ten service coordinators specifically mentioned that families and children could not expect to be treated as well, once they entered the traditional educational system. Much emphasis was placed on developing the family's advocacy skills for the future as is indicated in the following excerpt:

> To be their own advocates. Because we won't be with them for a lifetime...To check into things for their children. For example, later on when we're not going to be there and they're going into various classroom programs. To make sure that if they see a concern to question it or to follow-up and make some kind of resolution that they feel is acceptable. To be their child's advocate (P10).

One of the principles of effective help-giving behavior proposed by Dunst and Trivette (1994), citing Hobbs (1975) and Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne, & Weeks (1984) is the promotion of the help-seekers' use of the families' natural support networks. One example of such a support is connecting families who have a child with a disability to one another. These families often feel alone and have a need to meet other families so they can see how others like themselves have learned to adapt. These families expect their service providers to understand and support this need (Thompson, 1995). Eight of the ten service coordinators interviewed mentioned the need for families to connect with one another. They recognized that such a connection needs to occur for a variety of purposes. One important reason is so that families who have children with disabilities do not feel so alone. In addition, families are often the best source of information for one another. One of the coordinators spoke of asking families to talk to other families because they knew more about the child's condition than she did:

> I have some parents, I have one, their child has a seizure disorder, she knows more about seizures, I use her as my resource and say, "Do you mind talking to this other parent? I can't remember that stuff, and you...." (P9).

Although the majority of the service coordinators referred to the need to connect families with one another, none of them mentioned the need to encourage families to identify and use other natural supports (e.g., friends, extended family, support groups) as opposed to focusing on the identification of formal services to meet the families' needs. This is consistent with Thompson et al.'s (1996) study of families with infants and toddlers with disabilities in Michigan. The authors report that despite a number of informal sources of support available to families in the State, "Only occasionally are there organized efforts on the part of service coordinators to actively engage the informal support systems apparent" (p. 2).

This portion has focused on general aspects of providing service coordination to families as reported by the majority of the service coordinators interviewed. Next, each of the four qualitative research questions will be addressed individually.

Research Questions

The qualitative design addressed four individual research questions. A discussion of each of the qualitative research questions follows.

Research Question #4.

4. Do service coordinators who parents rate high on behaviors that families say they need from professionals, have a different awareness of what families say they need than service coordinators parents rate lower on such behaviors?

Two questions were asked during the interviews to gain information to answer this question. The two questions were:

1. What do you think families want/need from professionals?
2. What do you think a service coordinator can do to make a positive contribution to the lives of families who have an infant and toddler with a disability?

However, in reviewing the interviews it was apparent that the information necessary to answer Research Question #4 was scattered throughout each interview and not simply given in a response to each of the two interview questions. Therefore, each of the interviews were re-coded using Thompson's (1995) framework for explaining the relationship between what families need and what they want from their service provider and a matrix was developed. Thompson's framework included the concepts (in bold face) of service coordinators demonstrating **caring** behavior, **connecting** the family to the information and resources they need, and **guiding** the family as the family **persists**. As the interviews were once again read, coded, and information entered into the matrix it became apparent that the higher rated service coordinators were more aware of the need for or actually demonstrated increased evidence of **caring** behavior, the ability to **connect** families, and more active **guiding** of the family. The service coordinators revealed both conscious and intuitive knowledge of these concepts. Each of the concepts will be discussed individually and examples from the interviews provided.

Caring. This concept refers to the service coordinators' response to families as the families attempt to come to terms with the reality of their new lives with a child with a disability. Some of the terms used by parents in Thompson's (1995) study include non-judgmental, someone to listen as they talk and process, support, hugs and positive comments, and listening to the family's goals for their child. In addition, families wanted service providers who were accepting, sensitive, honest, dedicated, and accessible (Gamel-McCormick, 1995; Thompson, 1995). They want individuals who are willing to work with the whole family and not just the child. In general, much of the concept of caring focuses on allowing the family to be as they are at this time and on supporting them as they begin their efforts to adapt to this new occurrence in their lives. The following excerpts from the interviews with the higher rated service coordinators reflect this concept as defined by families:

> ...once they begin to trust you, in that you are in there for the best of them you're not in there to take their kids away, you're not in there to look to see how clean their house is, you're not in there to put their relationships under microscopes just because they're not married....Once you've established that trust that you're not there to make judgement, you're there to do whatever they need. Then I think the relationship moves to support (P4).
>
> ...when you're in there you just talk to them a little about what their child is like and what they would like to see go on. What their goals are because so many times, you know, their goals are different than what ours would be. So that's very nice because that gives us an idea of um, where they're at and what they want to see for their child... (P7).
>
> I think they just need to feel that whoever is in there really cares. That they are legitimate, that they are genuine when they go in there and that the purpose is to help them (P8).
>
> And I just hugged her and we both started crying. So, you know, it's loving, it's a very loving, warm, you have to, I think to do this job you have to like being with people....very often it's very down. You have, you see kids progress and you're really excited, then you have other children who have progressive problems and you can barely take yourself to the house because you're sad....you grieve with the parent (P9).

In contrast to the higher rated service coordinators, four of the five lower rated service coordinators actually demonstrated instances of uncaring or judgmental behavior. For example, one service coordinator clearly demonstrated that she did not understand the family's desire to have her work with the whole family and not just the child:

> I have one family that has a very small home and I've talked with my team members lately because I don't feel like I'm able to do what I need to do with this little girl because there are six to eight other people in the very small living room when I'm trying to work with her and it's just chaotic and we're trying to decide if I should call the day before and say I need just Mom to be there. And so, is that going to work out tomorrow or do we need to schedule another time when brother

> who goes to kindergarten...babysitter who comes into the house with one to three children is not going to be, you know (P1).

Although one service coordinator actually said that she needed to be non-judgmental her words indicate that by doing this, she thinks she's "doing them a favor":

> I try to not have any attitudes about, you know, "Get your act together," or, I really try to just come to their level and respond to them and not be judgmental. I think that's the biggest favor I can do them, because everybody has their rank in life and, just as I'm so familiar with mine and come from my perspective, they're very comfortable with theirs', no matter what it looks like to me. That's their life and this is their problem (P5).

When coding the interviews, more examples of empathic behavior were found in the discussions with the higher rated service coordinators. For example, one of the higher rated service coordinators explained why she is flexible about where she meets with families:

> Some of those [meetings] are at child care centers. Some of those are at the parent's work place, just to speak with Mom, but, maybe it's a service that she needs, that, you know, doesn't directly affect the child, but mental health counseling, or those kind of issues, that sometimes Mom is more comfortable meeting at work because Dad is not involved, isn't there, the kids aren't there...she isn't going to fall apart in front of the kids (P4).

Another service coordinator conveys her ability to understand what it is like to have a child with a disability after working with families for over 20 years:

> Well, I think they want someone to listen to them. Cause in their family, they [family members] always have something to say, and their neighbors don't know anything about what they're going through. And I think they want someone that's gonna listen to them, want someone to acknowledge that it stinks....It's tough. It's nothing that we would ask for, is it (P7)?

Families also emphasized the need for the service coordinator to be accessible to the families when they have a need for the services (Gamel-McCormick, 1995; Thompson, 1995). Four of five of the higher rated service coordinators reflected this increased accessibility. This was demonstrated in their willingness to give out their home phone numbers and to meet with the families during evening hours and possibly on weekends. The following excerpts from the interviews with two of the higher rated service coordinators reveal their increased accessibility:

> I give people my home phone number and I do get a lot of calls. And I feel attached to them, I feel that's part of my responsibility....I do nighttime visits too cause I have parents that work and I have made a choice for myself that I would do night visits (P9)

> Um, if something does arise, where there are problems we do come in early and we do stay late. I mean, our job description, we get phone calls at home, um, we get phone calls on the weekend and on holidays. I mean there is no real time constraint (P10).

Only one of the lower rated service coordinators mentioned doing evening home visits, although this was not typical for her. The remainder talked in terms of typical work days (e.g., 8:30 a.m. to 3:30 p.m.). In fact, one of the lower rated service coordinators actually stated her negative views on giving out her home phone number and working on weekends, although she was willing to check her voice mail when convenient for her:

> Um, we have teachers, in my opinion, who very much take this job home with them. They give all families their home phone number. They're available on weekends and vacations, it doesn't matter. They are like a member of the family almost. That isn't the way I can personally operate....So we have a great system this year for the first time with pagers and voice mail. A family can call us 24 hours a day and get our voice mail. So I check my voice mail whenever it's convenient for me. I get back to them as soon as I can, but I never give out my home phone number (P1).

Connecting. Connecting, as used by Thompson (1995) refers to "connecting families to information, to resources, to services, to opportunities to learn, and to other families in similar circumstances" (p. 64). Analysis of the interviews indicated that the higher rated service coordinators were superior to the lower rated service coordinators in two aspects of connecting. First, they were more aware of the family's need to be connected with information and resources. One important type of information families want is about their child's specific disability. In addition, they want information that is accurate and they want help interpreting and using this information (Gamel-McCormick, 1995). This was clearly recognized by the higher rated service coordinators. For example:

> I think the first thing is to get them as much information as they're able to handle about the condition. And to make sure that they're getting accurate information. And help them deal with this....But I think resources are the key (P8).
>
> Because part of what I do is bring lots of information....and we then talk about topics and things they want to know....I try to research and get information that is critical for them understanding their child and their child's disability (P9).
>
> To help them understand what, like if they had cerebral palsy, what that means or how, I know a lot of times, especially in the young, it's very important for parents to know "How did this happen?"(P10).

Understanding of the need to connect families with resources was evident in the following excerpts from the interviews with the higher rated service coordinators:

> I'm the resource finder for the families (P4).
>
> ...if they need a nutritionist or you pull in the speech and language person, if they need someone from CMH you will get someone who is a mental health specialist and that's, that's the kind of coordination....and helping them with subsidy applications, respite applications, um, maybe hooking them up with H. School for the Blind, those little things that we do (P7).
>
> ...knowing what programs are out there and making sure parents are aware of that so if they choose to have a particular service, that they know of it, they know how to access it (P10).

The second way in which the higher rated service coordinators differed from their lower rated counterparts, is in their degree of connectedness within the community itself. Families want early interventionists who communicate with each other and who are able to put them in touch with other programs, agencies, and informal resources that can help them meet their goals (Gamel-McCormick, 1995). The higher rated service coordinators placed more emphasis on networking within their communities and as a result, were better connected to resources that families want and need. This increased connectedness allowed the families with whom these service coordinators worked to have greater access to the resources they needed. One higher rated service coordinator expressed this especially well:

> I think one of the things you need most for service coordination is, you have to have contacts within the community. I think that's extremely important....And you have to have some contacts so that if the system fails you, or the person that you're supposed to contact the first time, doesn't work out, you can go behind the scenes and pull some strings and get what you want (P10).

Guiding. Thompson (1995) defines guiding as the families' "perceptions of a preferred relationship with the provider and of their own sense of family ability and potential" (p. 68). The author proposes that families recognize the expertise of the professional, but at the same time recognize their own strengths and abilities. It is their hope that the professional will interact with them in a responsive manner and include them as essential members of the early intervention team as the families undertake their journey (Gamel-McCormick, 1995). Families want their providers to explain, clarify, interpret, and help them evaluate information. They want to be able to feel comfortable about asking for and receiving help. If the provider is their sole contact, they expect that person to have information beyond their specific discipline (e.g., nursing, education). They want help getting through this difficult time. They want to know what to ask, what is available, and how to get it (Thompson, 1995).

All of the higher rated service coordinators demonstrated more active involvement in guiding the families along their journey. The following excerpts from two of the coordinators in this group, best illustrate such active involvement as they actually engaged families in problem solving and goal setting:

> It empowers people. It empowers them. If you can set a goal and get to it, you have become a success. And every time you are successful, you become more successful. Power builds on success, not on failures. So if I set your goals, then you're simply responding to some demands. That is not appropriate. I don't want anyone only to respond to my demands. I want you to figure out what it is, and then I'm going to point you in the right direction, or set you up to get to that (P4).
>
> No, I think they have their own way of dealing with things. But maybe the acceptance of how they get to that goal that, in effect, I will accept how you get to that as long as it's legal....I don't say, "I want you to do this, this, this, and this." I say, " I would like you to do this. Here's some ideas. Now you figure out how you're going to be able to do that." I'd rather give them, they have to figure out how they can handle that. How they're going to deal with it. How they're going to accomplish it. And I also tell them, you can do this. This is an attainable goal (P8).

Knowing when to provide information or suggestions, the manner in which it is explained, and the amount of information are important aspects of guiding (Thompson, 1995). The higher rated service coordinators appeared to be more sensitive to these aspects of guiding. The following excerpts taken from the interviews with the higher rated service coordinators exemplify understanding of these concepts:

> "Do you want to do it now or do you want to wait until we work with, you know, giving her some sounds and experiences with it?" The family will say, "Well, wait." "Ok, I agree." So you kinda get their input then you either agree with it or disagree with it and if you disagree with it you kinda work with them to hold their hand until they find out it may be something different they want to do. But I'm not real good at going in and telling them this is what they have to do (P7).
>
> Because part of what I do is bring lots of information...it's kind of like you're giving, you have to look at the adult as a learner, you have to know some adult learning styles and they want to know if it's pertinent to them right, you know, they learn, they don't just learn to learn, they learn because it's pertinent....And so

> it's like a lesson for that. I might use visuals, I use visuals most of the time, I'm a visual [person], but I also use like a little lecture, mini-lecture, visuals, videos. I bring those videos into the home and we watch a video together and discuss it (P9).

In contrast, only one of the lower rated service coordinators recognized the need to present the information in a way the families could understand, but her attitude toward doing so when writing an IFSP was negative, as is evident in the following excerpt:

> It's difficult for me because they [school district] want everything de-professionalized. That's, you know, I can write a great goal, professionally, but it's very hard for me to come down (P5).

The higher rated service coordinators also had more of a orientation towards preparing the family for the future, helping the system move toward equilibrium. Thompson (1995) refers to this as "Guiding for the Future" (p. 79). This was apparent in the interviews as the service coordinators discussed what they do that helps restore the family's sense of hope. The following excerpts captured the essence of this concept:

> ...you kind of support them and you care....you indirectly kind of lead them to, "This is your child, this is what your child can do, enjoy this. Who knows how he'll blossom! But if you feel good about what you're doing for him, that's, he'll do the best he can" (P7).

> I think when they're able to follow through on their own and they know that they've done a good job. I keep going back to this one family, but, this is the family where the little guy was two months old and had to have a traech, and he had that for almost two years, and this mother had to learn how to take care of this. There was lots of respite services in there because she was having difficulty coping, and people were questioning how she was doing things. She needed to know she was doing ok. She needed to know she was doing it right. And she also needed to know that he could get better. And that the quality of life could be the very best that he could have (P8).

A remarkable example of a dedicated, skilled service coordinator's willingness to guide the family was revealed by one of the higher rated service coordinators as she related her efforts to help families whose child had a very limited life expectancy:

> I've had two babies die during care, while I was their service coordinator and we just identified an infant with CF [Cystic Fibrosis] who probably isn't going to be around long. She was identified at birth with CF, so it's kind of rare. And she is a three month old and she's, I was just there yesterday and now she's got a big bronchial infection. So, she looks, to me it just breaks my heart and I have a hard time knowing what to say, you know, how far do you plan with this Mom? And I was involved with a Mom who was making funeral arrangements before the baby died. She knew the infant wasn't going to live much longer (P4).

Thompson (1995) discusses the family's need to "Persist" and that this is the focus of the service provider's guidance. In analyzing the ten interviews it became evident that the service coordinators depict two different reasons for guiding. The first seems to reflect the concept of guiding the family as they struggle to regain a sense of hope and re-establish equilibrium in the system, as described above. The second seems to be guiding the family to continue to persist in the future. This behavior was evident in all five of the higher rated service coordinators and would indicate that these individuals understood the family's need to persist in order to move forward. Thompson (1995) states that families will persist whether or not the service provider supports this task. If the service provider does not support the family's need to persist, conflict may result and the family's ability to progress in their efforts to shape a future may be endangered.

Although two of the lower rated service coordinators also mentioned the need to guide the families to persist in the future, all five of the higher rated service coordinators talked of this need. In addition, they mentioned this concept more frequently and in more depth. The following examples from the interviews with the higher rated service coordinators reveal their understanding of the need to guide families to persist:

> A lot of their skills have to be dealing with doctors and nurses--asking the right questions and so they get a second opinion or shouldn't they, should they accept that. And you can't say "I don't think so." You can just say, "Sometimes other parents have done this and you may want to do this...." or "this doctor often will

> say this about kids, you may want to go somewhere else." You have to be real careful that you're not giving medical advice, you know, that's really bad. But you need to give them skills to ask the right kind of questions maybe and, I want them to leave early intervention, you want them to be able to like schools, but to be able to do coordination for themselves--maybe not accept everything people are going to say to them...you can always say, "Hey, I'm not comfortable with this, let me think about it (P7).
>
> For this gal...we told her, and I can remember the day we did that because we put it down in black and white for her, and we said, you know, this is where you started, way down here, you remember that because they remember how negative they were. And you've come all this way. So if you put it on a chart from one to 100, and you've gotten all the way to 50, but you still have to go higher...And we almost put it in a graphic form that she could see in black and white, and where we wanted her to go (P8).
>
> To be their own advocates. Because we won't be with them for a lifetime....To check into things for their children. For example, later on when we're not going to be there and they're going into various classroom programs. To make sure that if they see a concern to question it or to follow-up and make some kind of resolution that they feel is acceptable. To be their child's advocate (P10).

In summary, the higher rated service coordinators could be described as more "in sync" with the families. The higher rated service coordinators recognized the family's need to have someone who demonstrated caring, empathic behavior. They communicated with families in a more direct, honest manner and were less judgmental than the lower rated service coordinators. The higher rated service coordinators were better able to connect families with the information and resources they needed and to more actively guide families as the families continued on their journey toward building a future for themselves. The higher rated service coordinators recognized that, in order for families to build their future, they would have to have the skills to persist in obtaining what they needed for their child. The higher rated service coordinators recognized this need and more actively encouraged the families to develop the skills they would need to persist once they left the early intervention system.

<u>Research Question #5</u>:

5. Do service coordinators who parents rate high on behaviors that families say they need from professionals view their families differently (e.g. accept parents as equals, are comfortable with a blurring of roles) than service coordinators that parents rate lower on such behaviors?

There were no specific interview questions developed in regards to Research Question #5. The researcher felt that this information might emerge as participants attempted to answer the other interview questions. Appropriate pieces of data in the interviews were coded as "View of Families" and a category named "View of Families" was entered into the matrix. All instances from the interviews which depicted the service coordinators' attitude toward, or perception of families was entered into the matrix under this label. Examining the matrix revealed that the higher rated service coordinators viewed families in a more positive light than the lower rated service coordinators. Examples from both groups of service coordinators will be used to demonstrate the difference in their attitudes that became apparent when scrutinizing the matrix. A selection from the interview of one of the higher rated service coordinators seemed to capture the positive view of that group as a whole:

> But I just won't give up on them because my basic premise is that God didn't create any junk and there is good in every human being, no matter how awful they are. And you just have to work real hard sometimes to find that good (P8).

All of the service coordinators recognized that families have differing levels of abilities and some are more capable than others. However, the higher rated service coordinators were more apt to view families who had great difficulty doing what needed to be done to meet their own needs as "innocent victims of prior experiences" and "... not responsible for their problems" (Dunst & Trivette, 1987, p. 449). This was best reflected in the following excerpt:

> I think we need to respect where they are and find their strength, and emphasize that, because so many of them have been so bombarded by different agencies and put down. So much negative things have happened in their lives, and that's why we're in there in the first place. Because, something good has not happened, or something hasn't happened the way it should have happened (P8).

Another service coordinator demonstrated this same view as she discussed a mother calling her and admitting she could not do what was right for her child, and ultimately making the decision to relinquish her parental rights:

> And so she turned the child over to foster care....some of it, I think, was recognition, or was pressure from outside sources....She couldn't choose at this point to not do that stuff. She was caught in a party trap....She would call me and she would say, "You know, it's four o"clock in the afternoon, I can't take care of this baby tonight, I can tell you that right now," and so then we would put it into emergency foster care....I couldn't find a way to empower her to get away from her outside influences (P4).

Service coordinators in both groups mentioned that some families will take advantage of you. The following two examples are from the lower rated service coordinators:

> And then we'll all have the same approach, we're all working together. You know, these types of families can pit agencies or staff against each other, and you know, we're aware of that (P2).
>
> Some families, they take advantage of you. You know what I mean? And so you really, your role becomes that of being a facilitator....you just, you have to be careful because some people will just use you to get everything done and then you're really, they're not any better off when you leave (P5).

Although one of the higher rated service coordinators relayed essentially the same piece of information, her view of the family was more accepting:

> You always have to think, "Yeah, yeah, you're taking advantage of me"....Sometimes I feel like I get taken advantage of, but I have to let go of that because, I know that they're not, they don't mean to take advantage of people, they just can't manage their resources right now (P4).

Another area of difference between the two groups of service coordinators was their view of how capable families are. Once again, the higher rated service coordinators talked about families in terms that reflected their belief that these individuals were very capable as the following passages indicate:

> I think they just need some help in organizing their lives and setting priorities. And identifying their own personal resources. Sometimes families don't realize what they do have. If you start to point it out to them they feel better (P4).
>
> That they can do it, that sometimes maybe they need the support, but they're the one in charge and they can do it (P8).
>
> ...and I'm like, hey, they're the advocates, they know. They know what they want because they know him best (P9).

Having the view that parents are capable also seemed to lead to greater parental involvement in the early intervention process as discussed by two of the higher rated service coordinators:

> ...then I'll go find out information, or they'll say, "I heard about this," and I'll say, "Well, will you find out for me because I could use that with another parent." So we just kind of, I mean roles aren't clearly defined, it's more like a family relationship, it's whoever has the access to the information that's needed is the one that'll get it (P9).
>
> It's more or less a partnership that, right from the start, the way we do assessments ....The fact that we go through and do the assessments with the parents...we've made the process where they are completely involved. We ask them questions because we consider them to be the most knowledgeable about their child (P10).

One of the higher rated coordinators even uses two more experienced parents to help her in her interactions with families:

> We have a, [first parent's name] is in on this. But we have a families court network....And she and [second parent's name] run that on a monthly basis. And they, I also use [first parent's name] as my, what used to be called the ombudsman position....to talk to a family....And between that and attending a lot of meetings that they do, I think they're very knowledgeable about the various resources in this state, and even in the nation (P8).

Another of the higher rated service coordinators enlisted the help of families to survey other families so information could be gained without the families being influenced by any of the professionals:

> I had two parents that I had do the survey because I didn't want them to be influenced by any of us....And then we had the questions and we inserviced the two parents with regard to what to ask and that they were just to write down and we didn't want to know names or anything on this, we just wanted information (P9).

In summary, it was clear that the higher rated service coordinators held a more positive view of families. Their view was consistent with what Dunst and Trivette (1987) refer to as the compensatory model of helping originally proposed by Brickman et al. (1982, 1983). In this model, the help-seeker is not blamed or held responsible for their problems, but are held responsible for solutions. This model emphasizes development of self-sustaining behaviors and a sense of self-efficacy. As a result, the help-seeker is more likely to relate their success to their own behaviors. The predominant consequence of this style of help-giving is that the help-seeker experiences increased competence and a sense of increased well-being and ability to cope. The results of the analysis of the data for Research Question #5 are consistent with the quantitative portion of this study. Service coordinators who have more enabling behaviors are associated with families who perceive themselves as more empowered and able to cope. The reason for this could be the model of helping which the service coordinator employs.

Research Question #6:

6. Do service Coordinators who parents rate high on behaviors that families say they need from professionals prioritize duties/functions differently than service coordinators who parents rate lower on such behaviors?

The ten service coordinators were asked a specific question regarding prioritization of their efforts. The participants were asked to describe one of their typical days. In light of the fact that everyone experiences time crunches, how do they decide what has to get done in a day?

As a result of coding the interview data, a category entitled "Priority" was entered into the matrix. However, it was necessary to use additional categories included in the matrix in order to answer Research Question #6. It was necessary to also examine the categories labeled, View of Role, Point of Focus, and Who's in Charge. Once the data contained in each of these categories were examined, it was apparent that the higher rated service coordinators prioritized differently. The higher rated service coordinators prioritized their home visits with families or as one service coordinator said, "Anything that involves a child or family is a priority" (P4). It was also evident that they prioritized the needs of families over their own needs. For example, a lower rated service coordinator prioritized making home visits in one portion of the county "What I try to do is a district a day"(P1) and her need to sing with the child, "And then I always sing with them at the end" (P1). This seemed to reflect her need to meet her own needs as opposed to the needs of the families. In contrast, three of the higher rated service coordinators related how they do whatever needs to be done, based on the needs of the families:

> Well, it's kind of like triage. It depends on what is the greatest need for which client. How soon does this need to be taken care of. How much in crisis is this family (P8)?
>
> The home visit has to get done. Plus whatever phone contacts you have to make. But the bottom line is the home visit--it still takes the primary focus. Then you, you just stay late! Till you get what you need to done (P9).
>
> Huh! Lot of times you end up putting out fires....I try to put out the fires first but I also try to stay on top of my weekly caseload so that is my first priority is to troubleshoot, first of all I'm responsible for making X-number of home visits and these people have already signed up....If there becomes a real big problem and it's critical issues, somebody's hospitalized and they need X-things fast...I will call and say to the family I'm supposed to go and visit, "Do you mind if I'm a few minutes late or would you like to reschedule...so and so is having a crisis" (P10).

Paperwork was something that the higher rated service coordinators did on their own time (after hours) or during a time when an appointment was canceled. This attitude is apparent in the following passages:

> Anything that involves paperwork is either bottom of the list or it goes home. I do it at home. Simply because you have to get it done, of course, but you can't do it in place of (P4).
>
> And then you drop prep time a lot if there's IFSPs or IEPs and go to that....There are prep things, but I don't really get hung up on that because there will be slots during the day when people don't show up with kids, so you just move things around (P7).

In contrast, the lower rated service coordinators prioritized paperwork and were much more concerned about getting it finished:

> Well, we knew we had to get the paperwork done, so usually what I would do is, when it was time to do an update or a new IFSP, which it seemed like there was always one or the other needing to be done....I would take it out during my home visit and do it with the family then (P2).
>
> The paperwork is important (P3).

One of the lower rated coordinators actually defined her role as a service coordinator in terms of paperwork:

> My role as service coordinator is the one who keeps track of the paperwork...(P5).

When Research Question #6 was originally conceived, its focus was on what service coordinators decide to do first in a given day. What is most important to them? As the data were reviewed, the researcher became aware that to really understand how service coordinator's prioritize it was necessary to take into account what this researcher had labeled their "Point of Focus" and what they view as the "Scope" of service coordination. What do they see as the point of impact for early intervention, the child or the family? How broadly do they view their role as service coordinator? Are they the teacher or therapist who works with the child or the person who is a resource to the entire family? Are they the person who does the paperwork, as stated by one of the lower rated service coordinators? All of this is believed to enter into decisions regarding how service coordinators prioritize their time.

As previously stated, six of the ten service coordinators mentioned the need to consider the child in the context of the family. However, when the data were examined it became evident that the two groups of service coordinators viewed their point of focus differently. Four of the five lower rated service coordinators indicated that their first priority was the child. They viewed their function as primarily educating or doing therapy with the child. When working with parents it was often to educate them so they could do the actual therapy with the child. The following excerpts reflect that point of view to varying degrees:

> ...this is my time to work with their child, we don't need any distractions (P1).

> And I typically, because I don't have a lot of time to see these babies individually, I really rely on the parent a lot to, I will educate them on some things that they can

> do at home. And then just kind of, you know, from week to week, find out how those things work and then adjust that (P2).
>
> Well, the most important thing that gets done every day is that I try to see my students first....We would take activities out and encourage the kids to work on their goals....A lot of the time you've got your hands over here, but your head is looking a different way. But the kids expect you to be down on the floor, playing with them, while the parents want to bend your ear a little bit and let you know what's going on (P3).
>
> Anyways it's [service coordination] not that different from what I do regularly. Part of my intervention is family education, you know, discussing with the family the entire time I'm treating the child (P5).

In contrast, all of the higher rated service coordinators viewed their point of focus as the family or the child and family. For example:

> I mean every family is very, very different. Cause you have some relationships where it's just going in and work with their kid and they'll, they're busy or something. Then you have some where they're there all the time and you know everything about the family. I had one where I hardly ever saw the child. The mother was so needy....because the Mom was the main person (P7).
>
> ...the philosophy we embrace here is the same as the SKI-HI Institute, in that we, this is a parent-focused program, it is not a child-focused. We do not go in and do therapy and work with the child. We go in and discuss topics, different things, or if the parents get a report from a physician they don't understand we take that report, we find out the information from whoever, we connect them with resources and our primary function is parent-focused or parent-directed, not like going in and doing speech or...(P9).

The higher rated service coordinators also had a broader view of the scope of their role as service coordinator. They viewed their role as basically encompassing whatever needed to be done. The following account by one of the service coordinators as she dealt with a distraught teen mother exemplifies this view:

> It's literally whatever that, you identify as a need for that parent. I told S.C., my supervisor, "I want combat pay!" I was called at home by some 17 year-old Mom...she called me at 10 o'clock one night and she said, "I just can't handle it", she'd only had the baby home like three days. "I can't handle this", she's just in a panic. I said, "Ok, I'll be there in just a few minutes." I get out of my pajamas,

> into the car, drive eight miles to her house, and she's sitting on the couch and she's just sobbing, and the baby's in the bedroom just wailing....So I pick up this baby who was starving to death. Immediately the child latches onto my cheek...I said, "Well, you know I think he's just hungry"....Well, she was nursing this baby, once or twice a day. And that's it. No one told her newborns nurse six or ten times a day....So I literally had to sit on the couch and help her feed this baby. Which I said, "This isn't in my job description!" I don't think that anyone ever said that you will manually breast feed a baby (P4).

The higher rated service coordinators also viewed their role as coordinating all services with which the family may be involved and locating any resources the family might need. As can be seen by the following examples the higher rated service coordinators viewed their role broadly:

> Hospice is a big part of it. Recently we've had some very medically fragile kids, so that's an agency that hasn't really been a key player, but is playing a key role now with some of our families--and to integrate that with families has been real nice...(P4).

> ...if they need a nutritionist or you pull in the speech and language person, if they need someone from CMH you will get someone who is a mental health specialist and that's, that's the kind of coordination....and helping them with subsidy applications, respite applications, um, maybe hooking them up with H. School for the Blind, those little things that we do (P7).

> I think that's probably the number one thing that is important for a service coordinator is to know resources. Community resources and resources out of the community, you know, Ann Arbor, Detroit, John Hopkins, Ketogenic Diet....I have this one little child that I work with that's on a drug from Canada. Now, how she got on this one drug, we found this one particular physician that really is into infantile spasms. We had to do some research (P9).

The lower rated service coordinators viewed their role as more limited. Three of the five limited it to predominantly education services only:

> I see myself as coordinating the home visit. The PT goes and does PT. And the speech therapist does speech therapy, and the OT does OT....I try to coordinate that....For me it's not a lot of working with other agencies. But, again I could have one family out of 15 or 20 that really needed agency help. So that isn't, I'm just saying it's not the majority of my time (P1).

> But as far as coordinating other services, the way we would do it, is we would go out and talk to the family and if other things came up, other specialty areas, we would try to let the other therapist know, you know, that that family needed more help from them or something like that. Or they would give us suggestions, and we would take them back. I think it was hard to coordinate it even amongst our own staff, let alone try to coordinate it with other agencies (P2).

> If the children have a lot of outside agency concerns, I refer them out cause I'm the educational facility and if there's a lot of needs as far as respite, or um, other CMH, generally what we'll do is refer them to a professional service coordination, you know. So I may take a child on and then decide, this is becoming too encompassing, I don't have the scope that this family needs and I'm gonna refer to somebody else. Then I do that (P5).

In summary, the higher rated service coordinators prioritized their duties/functions differently than the lower rated service coordinators. The higher rated service coordinators were more apt to prioritize the family's needs over their own needs. They also prioritized interactions with the families over everything else (e.g., paperwork, meetings, staff development). In contrast, the lower rated service coordinators tended to place more emphasis on meeting the paperwork requirements. The higher rated service coordinators were less "education" focused and prioritized working with the family to meet its needs as a unit as opposed to concentrating on meeting just the needs of the child. Consistent with this belief, the higher rated service coordinators viewed their role more broadly and basically helped the families obtain and coordinate any services they needed. The lower rated service coordinators focused predominantly on education services.

<u>Research Question #7</u>

7. Do service coordinators who parents rate high on behaviors that families say they need from professionals have greater awareness of helping

behaviors that promote empowerment and coping than service coordinators parents rate lower on such behaviors?

Two questions from the interview guide were aimed at answering Research Question #7. These questions were:

1. What do you think a service coordinator can do to make a positive contribution to the lives of families who have an infant or toddler with a disability?
2. What do you think helps families of infants and toddlers with disabilities feel empowered and better able to cope?

Once the data were coded and entered into categories within the matrix, it became apparent that the answer to Research Question #7 was best answered by examining ten of the categories that emerged during coding. The ten categories were: (a) Awareness of Help-Giving Behaviors, (b) Relationships with Families, (c) Positive Contribution, (d) Who's In Charge, (e) View of Role, (f) View of Families, (g) Desired Outcome for Families, (h) Important Responsibilities for Service Coordinator, (i) Awareness of What Empowers, and (j) Skills Families Should Learn. Each of the ten categories was re-coded using Dunst et al.'s (1994b) framework of enabling principles. The framework includes three clusters of factors that contribute to effective help-giving and promote a sense of family empowerment. The three factors are: (a) prehelping attitudes and beliefs, (b) help-giving behaviors, and (c) posthelping responses and consequences.

As a result of the analysis, it was apparent that the higher rated service coordinators were aware of or actually employed more enabling attitudes and behaviors that increased the probability of positive consequences for families. Some examples of the attitudes and behaviors of the service coordinators were presented in Research Questions #4 and #5 and further examples will not be included here. For example, in Research Question #4 it was found that the higher rated service coordinators were aware of the need to be or were more caring and honest and employed a more empathetic style. Research Question #5 found that they viewed families as more capable and held high expectations for the families to become competent.

Along with being more caring, honest, and empathic, the higher rated service coordinators employed a cooperative helping style that conveyed what Dunst et al. (1994b) call a sense of joint responsibility or partnership with families. For example:

> It's to build a relationship. Not just to be a professional in that house, with that family, because you are in their house....I think a service coordinator needs to become a partner. And needs to build a relationship. And while you can't always take your work home, if you're not taking your work home, you probably aren't really invested in that family (P4).
>
> But I think if you teach them [their rights] they're much more, they're happier, they're easier to deal with if you're very honest with them instead of trying to shut them out of your private teacher world or something. So, yeah, I kinda treat them like I want to be treated (P7)!
>
> I think I do a lot of listening. And that's probably my first step in a relationship. It's kind of give and take (P8).
>
> And I say to the parents, "If I provide you with information regarding vision and visual development do you feel that would be appropriate?" "Well, yeah, that's appropriate." "Another thing I can do is show you some things to stimulate his vision, but you're gonna have to try some of these things because if you don't try them, it's not gonna work, cause me coming in and just showing you one time and then leaving is not gonna make it" (P9).

One of the higher rated service coordinators even mentioned how she wished all partnerships with families were equal but recognized that this may not be possible:

> I'd like to say that all partnerships are equal but I would be telling a falsehood because it's not true. We have some parents that are very limited, either

> emotionally or mentally...developmentally disabled....You try to give them as much responsibility as you think they can accept....it's dependent on their levels. Their intellectual and emotional levels at that time....I try to get a feel for what they're capable of. You know, maybe I'll try it the first time and see if it works, and if it doesn't work, you try a different way (P10).

In reviewing the Relationship category of the matrix it was apparent that the higher rated service coordinators talked more about their relationships with families. There was more description of the feelings involved and the quality of the relationships. They seemed to recognize the importance of the relationship in helping families help themselves.

Dunst, et al. (1994b), citing Brickman (1982), propose that a compensatory model of help-giving is more likely to be effective in empowering the help-seeker. This model places emphasis on the help-seekers' responsibility for acquiring competencies and de-emphasizes the help-seekers' responsibility for their problems. The higher rated service coordinators demonstrated this model of help-giving in that they provided aid and assistance in a manner that was intended to empower. In doing so, they were more apt to put themselves at the disposal of the family and thus ask the family what they wanted rather than to tell the family what to do. The following examples reflect this behavior:

> Usually I wait for their lead. If someone had said to me that this Mom, you know, they saw this Mom on the street and she was really having a hard time, I might have called her and just said, you know, "Is there something I can help with?" (P4).
>
> I'm not sure [what I do that's different]. I think maybe I want to find out where they're coming from as opposed to "Here I am and this is what I need done" (P8).
>
> I have a family who's going to be moving and they wanted some, they wanted to know some programs out East, a hearing impaired program. And I said, "What do you want me to do for you?" (P9).

In addition, the higher rated service coordinators placed more emphasis on the family members' responsibility for acquiring the skills to solve their own problems and meet their needs:

> But then I try to taper that off as time goes on to make them just more resourceful of themselves--because my goal is to give them the resources and to help them learn how to access those resources. Not to do it for them....So my role became more to make them independent....So we set some goals...then we review how we got to those goals, or how we didn't get to those goals, and maybe the goals have changed (P4).
>
> ...to be able to do coordination for themselves....You have to teach them how to get equipment, where to get their equipment by themselves, they won't always have therapists to get it for them like the nice people here do it....And they just, you know, how to get information on their own--coordinator kind of things (P7).
>
> I think the end result is that it is rewarding because you are helping and also empowering these people to get things on their own. You're just there to kind of help them to see what they need to do. But they're in charge....Break down the barriers so that you can get them to follow thorough. So they have to say they can do it too. Or there's no sense, saying, "Ok, I want you to do this." Then you have, I guess qualified everything, "can" you do this? Are you going to be able to do this this week?....And if they can't, then ok, well, why not? Ok, so these other things are in the way, so what do we do about getting these other things out of the way (P8)?

By providing aid and assistance in a manner intended to empower and by placing emphasis on family members' responsibility for developing skills, the higher rated service coordinators employed one of the most important aspects of effective help-giving which is promoting the development of effective behavior that leads to greater independence (Dunst et al., 1994b). Although the lower rated service coordinators also had some expectation for families to assume responsibility for meeting their own needs, the expectation was not as great. One of the service coordinator's intent was for the parents to "do as much as they can" (P1) and another said that having the family take on the responsibility for making their own calls, for example, was "what you kind of hope for"

(P3). For another, the focus was on teaching the parents "what they need to know in their own circumstance, and not necessarily what's available" (P5) with no mention of parents learning specific skills other than how to do therapy with the child.

Not only must the help-giver provide assistance in a manner that promotes competence, it is also important that the help-seekers view themselves as actively involved in producing the outcome (Dunst et al., 1994b citing Bandura, 1977). The higher rated service coordinators worked with families in a way that allowed family members to be actively involved in the process and to view themselves as actively impacting the outcome. Two of the higher rated service coordinators explained how they helped family members develop this positive view of themselves:

> If I think that Mom is going to follow through, or if I hope that she's going to follow through, I try to set up a situation so she can do it easily. Make her successful at it at the beginning, and then as we go down the road, she can deal with it. She may have to go over a few more bumps to get what she wants, but she can deal with that. [In] the beginning I try to set it up so I know she's going to be successful (P4).

> "Ok, this is what you want. Ok. In order to do that this is what we have to do and I want you to do this, this, and this, and I will make this come out ok." But never carry them completely, they have to follow through, take some responsibility. But in the end you have a result. Hopefully a positive result. But some sort of conclusion of or closing of, "This is what we did and this is what happened. We had a result. Because of that thing, you feel good about it." Because so many of them start something and it never quite gets done. And we make the appointment but we never get there. Well, this time we made the appointment and we got there....I think when they're able to follow through on their own and they know that they've done a good job (P8).

A third higher rated coordinator viewed families as capable of teaching other families and mentioned how this helps families perceive themselves as empowered:

> And to help other parents. Sometimes that's important. It's a way to make them feel good about themselves. And you know you've succeeded when you see them in playgroup with another parent and they say, "Oh, I've had that problem and this

> is what I did"....We teach them and they teach somebody else. And they always say, you learn best by teaching someone else (P10).

In order for help-giving to be the most effective, the locus of decision making must lie with the help-seeker. The help-giver must make it clear that help can be refused and must support the decisions of the help-seeker (Dunst et al., 1994b). The higher rated service coordinators more often described the need to allow the family to be in charge. Even though it was sometimes difficult, they realized that ultimately the decision is up to the family. The following excerpts demonstrate this view:

> And with some Moms it's a "Do you want...", because some parents don't want, it's like accepting something that they feel like is not necessary (P4).
>
> They [family] really have to be the one, because you can sit in there and talk till you're blue in the face, and if they're not buying it, you've lost them. So they have to buy into it, they have to agree (P8).
>
> And I explained initially, like I always do with all my families, these are your options....And it came down to, they wanted to start with the place that I, personally, considered to be not my first choice for this little girl had I been her parent. And I try really hard to not say anything and not sway them in one direction or the other (P10).

In summary, the higher rated service coordinators were more aware of and employed helping behaviors that promote a sense of empowerment and ability of cope than the lower rated service coordinators. When specifically asked what empowers parents they were more able to describe effective help-giving behaviors. They also emphasized the development of effective behaviors, on the part of family members, that guided families toward increased independence. They employed a more caring, honest, empathic style and emphasized working in partnership with families. In doing so, they allowed families to make their own decisions, and supported such decisions. They put themselves at the disposal of the family and provided aid and assistance in ways that were intended to empower. They demonstrated greater expectations for families to acquire the skills necessary to solve their own problems and meet their own needs. They provided opportunities for family members to be actively involved, experience success, and view themselves as active agents in the attainment of goals.

Additional Differences Between Higher and Lower Rated Service Coordinators

During the process of examining the categories in the matrix to answer the specific research questions, three other differences between the higher and lower rated service coordinators were noted. First, the higher rated service coordinators were more willing to take risks. Four of the five higher rated service coordinators demonstrated examples of attitudes or behaviors that could be identified as "risk-taking". The fifth service coordinator demonstrated evidence of a risk-taking attitude or behavior through her willingness to do whatever families want, and being so open in her communications with families. There was only one limited instance of a possible risk-taking attitude or behavior in the lower rated service coordinators. The following are examples of the risk-taking attitudes or behaviors discovered in the interviews with the higher rated service coordinators:

> You have to make mistakes in order to learn what you need to know (P4).
>
> So you really have to be someone who's flexible, who doesn't say, "This is how it's done." You have to be able to think of it as kind of an adventure. But that's, it's kinda your attitude. You have to have a real open attitude....if you just go in and if you don't have these pre-set ideas, something works out! It usually turns out well (P7).
>
> It's risk-taking. And sometimes it doesn't come out the way you want it to, but a lot of times it's a, you'll see a change, you'll see things get better, because you took that one step that maybe somebody else just wasn't willing to do. And you've got to do that (P8).

> You know, maybe I'll try it the first time and see if it works, and if it doesn't work, you try a different way. Just like with the kids (P10).

The second way in which the higher rated service coordinators differed from the lower rated coordinators was in their perceptions of being supported in their positions. Four of the five higher rated service coordinators appeared to feel very supported by their colleagues. The colleagues were either in the system within which they were employed, or a result of professional relationships developed across systems (e.g., education, public health).

In contrast, although the lower rated service coordinators mentioned the need for support, the support systems available appeared to be more tenuous. Either the support was not there, or they spoke of their support systems with less enthusiasm. One of the lower rated service coordinators stated that, until recently, she did not have the support she needed when required to go into a home where she did not feel comfortable:

> I don't think there was something in place. I think that was something that [the school district] was working on about that time and now has a plan...(P1).

Another lower rated service coordinator talked about having opportunities to meet with other professionals on a somewhat regular basis, but said:

> It's a worthwhile thing even though you leave it frazzled (P5).

This led the researcher to conclude that this possibly was not a support if it caused one to leave feeling frazzled. A third, lower rated service coordinator, did not even have a core group of people with whom she could interact and obtain support. Throughout the interview a source of support was never mentioned. This same service coordinator often spoke of her frustration with her job and was the one who mentioned that it felt good just to have a opportunity, during the interview, to talk about what she thinks she does well.

The higher rated service coordinators emphasized the importance of their opportunities to interact frequently, brainstorm new ideas, and problem solve with other supportive individuals. The following are examples of their comments:

> So there's kind of a brainstorming at the direct delivery level....So you don't have to necessarily bring in another person, that professional is giving another professional some guidelines....now they know that person so now they've established a professional relationship they can always call that person....So that's been a nice connection (P4).
>
> I rely on certain people for support when things get tough to kinda bounce things off of. And one of those is C. I have a very close relationship with C....for the most part she's just always there. I also have a supervisor, our Director of Nursing, that I, is very, very understanding. Another supervisor, I'm very close with. And so I use these people to kinda, and I, I tend not to stuff things, I tend to get them out and talk about them and dump them (P8).
>
> ...you know, if there's something I'm having trouble with I have three wonderful people that I can come and say, "Ok you guys, I'm having a problem, what do you think? What can I do? I've tried everything and it's not working! Help me!" You know, and sometimes they'll say, "Well, why don't you try this?" "Ok, that's a good idea." Or they might say, "D., you've tried everything, there's nothing else you can do, you just have to ride it out."
>
> You have to have some kind of support system. I'm very fortunate that I have three other people that are excellent. We all are good at different things. We work well together, and if you have a question you go to so-and-so and say, "Hey, do you know anybody in this community, or this agency, or have you ever dealt with this particular problem with a child before? And what has been the solution, or can we brainstorm some different ideas? This is what I've already tried"....We've always talked about, we have the same vision. We all like to do things sort of the same....If you have some people that you can bounce ideas off of...(P10).

The level of support may also have affected the service coordinators attitude toward the programs of which they were a part. One of the categories entered into the matrix that emerged from the initial coding of the interviews was Pride in Program. All five of the higher rated service coordinators mentioned on at least two occasions, aspects of their program or county about which they were pleased or proud. The following are a sample of some of the comments from the higher rated service coordinators:

> We had um, a kind of milestone happen oh, a month or so ago. We had a meeting with all of our, the entire PPI staff....We had a workshop and we brought in all the other agency Directors and we talked about *Early On*....the fact that 100% of the agencies sent the Director or a designee, a fairly high designee....No one absent. Every county, every agency was represented....We were real pleased (P4).
>
> I'm proud of this program, it's been very nice....This has been a real nice program...(P7).
>
> And I think probably our county is probably pretty progressive. I think that C. has done a really terrific job of trying to get these other agencies involved....And it's still got lots of room for growth. We have one case in particular that was very, very successful in this county, and I was the service coordinator on that, and it was an *Early On* case...and so the ISD was involved, and all the agencies were involved. Some of the children had been placed in foster care at one point or another. This mother had been in Families First and just gone the whole gamut....And it feels good even now, because she will call back and be making decisions that are the right thing to do (P8).
>
> And we are lucky in that the four of us really do share that vision and so it really makes for a nice program here. We have a really, and I, not just think, but we really, we really work cooperatively as a team. We're really a good team....and I'm really proud of what we do here, I think we've made a real concerted effort to do that [get parents into the school] (P9).

Summary of Qualitative Analysis

The qualitative portion of this study examined more closely the interface between service coordinators and the families they serve. The analysis revealed a deeper understanding of this relationship and how it contributes to families feeling more empowered and better able to cope.

Analysis of the interviews with the ten service coordinators revealed that the service coordinators rated more positively by families were more aware of and demonstrated the behaviors that families say they want and need. They viewed families in a more positive light and worked with families in partnership. The higher rated service coordinators prioritized their interactions with families over all other aspects of their job. They focused on the family as the unit of intervention and viewed the scope of their role more broadly. Finally, the higher rated service coordinators were more aware of and demonstrated the use of what Dunst et al. (1994b) refer to as enabling help-giving behaviors which result in the help-seeker feeling more empowered.

The results of the qualitative analysis support the results of the quantitative portion of this study. The combination of the two analyses help to further explain the intricacies of this important relationship. Further discussion of the implications of these findings will be presented in Chapter V.

Chapter V

SUMMARY, DISCUSSION, IMPLICATIONS

This chapter presents (a) a summary of the study; (b) a discussion of the findings; (c) limitations of the study; and (d) implications for practice, personnel development, and research in the area of working with families of infants and toddlers with disabilities.

Summary

This study had two purposes. First, the intent was to examine the relationship between parental ratings of service coordinator behaviors and parental perceived empowerment and ability to cope. The second purpose was to explore the possible differences between those service coordinators rated high on behaviors that families say they need and those service coordinators rated low on such behaviors. The information obtained from this study is needed in order to design effective preservice and inservice education programs to assist service coordinators in their efforts to work effectively with families of infants and toddlers with disabilities.

This study focused on the service coordination provided, as a result of Part H of IDEA, to families of infants and toddlers with disabilities. One of the original intents of this portion of the legislation was to "enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities" (Zipper et al., 1993, p. 12). In order to enhance the family's ability to meet the needs of their child, it is important that individuals providing aid and assistance to families work from a family system's perspective and deliver their help-giving efforts in an enabling and empowering manner. Of all the various components of an intervention model, it is the help-giver's role that is the most important aspect of determining if the help-seeker (i.e., families) feel themselves to be enabled and empowered. If help-giving efforts are not delivered in this manner, it is possible to actually make the help-seeker more dependent and less empowered (Dunst & Trivette, 1987).

This study employed both quantitative and qualitative methodologies. For the quantitative portion of the study, two sources of data were utilized. First, data resulting from a survey of 332 families who had infants and toddlers with disabilities, by CULMA at Wayne State University, was analyzed. Specifically, the data were examined for a possible relationship between how parents completing the survey rated their service coordinators and how empowered and able to cope those parents perceived themselves to be. Secondly, data resulting from a survey of 100 service coordinators, who provided service to the families surveyed by Wayne State University, was analyzed. The data were examined for the possible relationship between the training and characteristics (e.g., number of years working with families, number of families on caseload) of the service coordinators and parental ratings of the service coordinators on behaviors families say they need from professionals. Three research questions were tested using correlation coefficients, one-way analysis of variance, t-tests, and multiple regression. Data related to the samples were also analyzed.

For the qualitative portion of the study, the five service coordinators rated most positively and the five rated least positively by the parents completing the survey of families, conducted by Wayne State University, were identified and interviewed, using Patton's (1990) Standardized Open-Ended Interview process. Interviews were audio taped and transcribed and the data were then analyzed using a combination of qualitative methodologies. Four research questions were the focus of the qualitative analysis.

Discussion of the Findings

The summary of the quantitative analysis will be discussed first, followed by the summary of the qualitative analysis. Finally, a synthesis of the results from both portions of the study will be presented.

Discussion of Quantitative Analyses

The quantitative portion of this study consisted of three research questions. A discussion of each of the research questions follows.

Research Question #1.

The parents who responded to the survey perceived themselves to be more empowered and better able to cope when they felt their service coordinators were demonstrating more of the behaviors that families say they need from professionals. The results of the path analysis suggested that the behaviors of the service coordinators impacted the families' perception of their empowerment directly and their perception of their ability to cope indirectly and directly.

The finding that the service coordinators were able to directly impact the parents' perception of empowerment as a result of their behaviors, is consistent with Dunst and Trivette's (1987) proposed enablement model of help- giving. The service coordinators, rated more favorably by families, demonstrated behaviors that were consistent with those described in the enablement model. For example, parents rated these service coordinators high on behaviors that correspond to what the authors refer to as displaying a genuine sense of caring, warmth, and encouragement. The higher rated service coordinators were able to recognize when families were ready for assistance and offered assistance in a manner that respected the family's beliefs and right to privacy. They supported the family in making their own decisions.

A finding that was inconsistent with the enablement model of help-giving was that the higher rated service coordinators were also rated by parents as more apt to make decisions for the family. However, when the internal consistency of the Service Coordination Scale was determined, this item did not correlate with the other items in the scale and was removed from the scale.

The service coordinator behaviors that impacted the parents' perception of empowerment also impacted their perception of their ability to cope. The parents' coping ability was impacted both directly and indirectly by the behaviors of the service coordinators. The indirect effect was through empowerment. The more empowered parents perceived themselves to be, the more they perceived themselves as able to cope.

Both the direct and indirect effects of the service coordinators' behaviors on the parents' perception of their ability to cope can be explained through McCubbin & McCubbin's (1987) T-Double ABCX Model of Family Adjustment and Adaptation. In this model, the authors discuss the strengths, resources, and capabilities of the family. One way families cope with a stressor, according to the authors, is to increase the personal resources within the family.

By working with families from an enablement and empowerment perspective, as proposed by Dunst & Trivette (1987), the service coordinators are able to indirectly impact the family's ability to cope by helping them to increase their personal resources. For example, one personal resource that McCubbin and McCubbin (1987) propose that families use in their efforts to cope with a stressor is "a sense of mastery" or a belief that they have some control over their lives. This belief that one has control over one's life is an important component of definitions of empowerment (Dunst & Trivette, 1987; Dunst et al., 1992).

Working from an enablement model would also help to increase what McCubbin and McCubbin (1987) believe is another important personal resource--self-esteem of individual family members. The authors define self-esteem as "a positive judgment about one's self-worth" (p. 17). An important aspect of the enablement model is to deliver aid and assistance in a manner that helps recipients view themselves as active agents who are no longer in need of help, and are responsible for the changes that have occurred. Viewing oneself as capable of producing such changes could help one to have a more positive view of oneself. These two examples illustrate how service coordinators' behaviors can increase the personal resources within the family which, in turn, increases the parents' perception of empowerment and thus leads them to perceive themselves as better able to cope.

The service coordinators' behaviors were also directly related to the families' perception of their ability to cope. This too could be a result of increasing a personal resource within the family such as the knowledge and skills of the family members (McCubbin & McCubbin, 1987). This may occur through the information provided to the families by the service coordinator or by introducing the family to other families who have had a similar experience.

Coping also includes a number of actions on the part of the family to maintain or restore the balance between demands and resources such as acquiring resources not previously available to the family (McCubbin & McCubbin, 1987). Working from an enablement perspective, the higher rated service coordinators added resources to the family in terms of helping individuals in the family to develop what the authors refer to as self-reliance skills. Dunst and Trivette (1987), citing Skinner (1978), refer to such skills as effective behaviors that decrease the family's need for help, thus making them more capable and competent.

The higher rated service coordinators also promoted coping in additional ways. They helped families to identify their strengths and needs and added resources to the family by helping them obtain the services necessary to meet their needs. In addition, the service coordinators helped families do what McCubbin and McCubbin (1987) refer to as managing the tension within the family. Open expression of emotion and affect in a responsible manner is one example the authors give of how families relieve the tension. Reviewing the individual SCS items revealed that families rated the higher rated service coordinators more positively on survey items such as letting parents know their feelings were ok, helping parents see that their child's condition was not their fault, and encouraging parents to talk when they needed to do so (see Appendix L).

The results of the quantitative portion of this study are consistent with other studies of the relationship between professional behavior and parental empowerment and ability to cope. Thompson et al. (1996) concluded that how service coordinators interact with families of infants and toddlers with disabilities, is an important predictor of family empowerment and ability to cope. Sokoly (1994), in a study of parents of children with mental impairment, found that the qualities that characterize a collaborative parent-professional relationship (e.g., mutual respect, joint decision making, satisfaction with professional contact) were related to characteristics of parental empowerment (e.g., efficacy, control, and knowledge). As Dunst et al. (1988), citing their previous work, have concluded, it is not just a matter of whether or not needs are met that determines whether or not families are enabled and empowered, but rather, the manner in which resources are mobilized and support given.

In addition to relating the behaviors of the service coordinators to parental perceived empowerment and ability to cope, this study delineates some of the specific behaviors associated with parents perceiving themselves as empowered and able to cope. Furthermore, the results indicate that families do know what they need from professionals. As the list of behaviors in the survey, on which the service coordinators were rated, were taken from family accounts of what they want or need (Gamel-McCormick, 1995; Thompson, 1995; Sokoly, 1994; Able-Boone et al., 1992; Bailey et al., 1992) the results indicate that families know what will help them feel empowered and better able to cope. Professionals need to listen to parents and to learn from them.

This study also found a difference in how empowered parents perceived themselves to be based on gender and the presence of a spouse/partner. Females perceived themselves to be more empowered overall, and specifically more empowered than males when it came to dealing with the service delivery system. This may be a result of females being the family member who traditionally interacts with service systems (e.g., schools, medical services) more frequently. This finding should be viewed with appropriate caution because the sub-sample of males was very small. In addition, the presence of a spouse or partner resulted in a parent feeling more empowered when interacting with such systems.

Research Question #2

The training that a service coordinator received was not related to how parents rated service coordinators. This was true for the amount of training (i.e., degree obtained, hours of course work or inservice) as well as the areas within which the degree was obtained (e.g., special education, public health) and the areas within which the service coordinator had received inservice training.

The only variable that approached a significant relationship with how the parents rated the service coordinators was the number of different areas within which the service coordinator had received inservice training. This may reflect that those who have received training in more of the 12 possible areas of inservice training specified on the survey, have a better chance of having received training that dealt specifically with issues related to working with families (i.e., family assessment, family-centered practices, family intervention, service coordination, advocacy, and adult learning styles). As Bailey et al. (1986) suggest, professionals who know about infant development and how to impact development will likely do a good job as long as they only work with the infant. When the same professional attempts to interact with the family system, different skills are needed. Only recently, have preservice programs begun to have parents involved in personnel preparation and to provide opportunities for students to spend time with families in their homes. This trend is in contrast to Bailey et al.'s (1990) findings that early intervention students had only minimal contact with families (Capone & Divenere, 1996).

Research Question #3

How families rated their service coordinator was not related to (a) the number of years a service coordinator had worked with families, (b) the number of hours the service coordinator was contracted to work per week, (c) the number of hours contracted specifically for service coordination, or (d) the number of families on the service coordinator's caseload. The only service coordinator characteristic related to parental ratings of the service coordinator, was how long the service coordinator had been doing service coordination. Professionals who had more experience providing service coordination were rated more favorably by parents than those with less experience.

The fact that the number of years a professional has worked with families, in general, did not impact how families rated the professional, while the number of years that that individual had provided service coordination did impact parental ratings, is an interesting finding. This would seem to reflect the uniqueness of the service coordination role as defined under Part H of IDEA. This uniqueness relates to the family-centered approach that is required by legislation. Not only does this law require that services, one of which is service coordination, be provided, it requires that professionals "work in partnership with parents to design early intervention services that respect and support family-identified priorities for their child with a disability..." (Capone & Divenere, 1996, p. 222). Furthermore, the service coordination role requires that the professional in this position work in a collaborative manner with other professionals, as well as families, to meet the needs of the family (Zipper et al., 1993). The focus on parent-professional and professional-professional relationships is far different from the child-focused role for which most early intervention personnel have been prepared (Bailey, 1989; Bailey et al, 1991; Niemeyer & Proctor, 1995; Capone & Divenere, 1996).

The qualitative portion of this study supports this quantitative finding that service coordinators become better at what they do through experience as a service coordinator. According to the service coordinators interviewed, the way they learned to become parent-professional and professional-professional collaborators was through "on-the-job" training. Such training consisted of trial-and-error efforts, learning from and with families and other professionals, and inservice opportunities.

Discussion of Qualitative Analysis

Four research questions regarding the differences between the awareness and philosophies of the service coordinators rated most favorably by parents and those rated least favorably was the focus of the qualitative portion of this study. This portion of the study will be presented in terms of hypotheses that were generated from the data. These hypotheses will provide useful guides for further research into the relationship between service coordinators and parental perceived empowerment and ability to cope.

The quantitative portion of the study revealed that service coordinator behaviors could be related to parental perceptions of empowerment and ability to cope. Furthermore, it indicated that parents perceive service coordinators as either possessing or not possessing certain behaviors that families say they need. The intent of the qualitative portion of the study was to examine in more depth a sample of service coordinators in order to generate more information as to the knowledge and beliefs they hold and the behaviors they use that relates to greater parental perceived empowerment and ability to cope.

Theoretical Frameworks Used In Qualitative Analysis.

Two different frameworks were utilized to code and analyze the interview data. These two frameworks were Thompson's (1995) grounded theory regarding what families say they want or need from professionals and Dunst and Trivette's (1987) enablement model of help-giving. Applying these two frameworks to the data revealed numerous differences between the higher and lower rated service coordinators. These differences included their view of families, their knowledge base, and how they went about doing their jobs.

Hypotheses Generated From the Data

In general, the higher rated service coordinators were more aware of or demonstrated more instances of the behaviors that families in Thompson's (1995) study of families of young children with disabilities say they want or need from professionals. The higher rated service coordinators also demonstrated more of the enabling attitudes and used more of the enabling behaviors that Dunst and Trivette (1987) have found to result in increased parental empowerment. The summary of the differences between the two groups of service coordinators will be presented in terms of hypotheses as opposed to answers to questions. That is to reflect the intent of the four qualitative research questions which was to reveal more in-depth information regarding the relationship between service coordination and parental empowerment and coping. The hypotheses and a discussion of the differences in the higher and lower rated service coordinators attitudes, knowledge, and behaviors follow. It would seem most appropriate to begin with the service coordinators' view of the families with whom they worked.

1. **Service coordinators rated higher by parents on behaviors families say they need from professionals have a more positive view of families.** Although all of the service coordinators recognized that families have differing levels of ability, the higher rated service coordinators appeared to be more accepting of those who had greater difficulty doing what they needed to do. Their view of families was consistent with Dunst and Trivette's (1987) enablement model of helping, in that they emphasized the family's responsibility for acquiring the competencies necessary to solve its own problems and attain its own goals, as opposed to viewing the family as responsible for causing its own problems.

Even when individuals in both groups of service coordinators mentioned something that could be construed as a negative view of families, the higher rated service coordinators appeared to be more accepting of that aspect of families. For example, although some of the service coordinators in both groups mentioned that families would take advantage of you, the higher rated service coordinator who said this appeared to be more accepting of this fact and said that "they [families] don't mean to take advantage of people..."(P4).

Consistent with the enablement model of helping (Dunst & Trivette, 1987), the higher rated service coordinators viewed families as more capable than the lower rated service coordinators viewed them. In the enablement model, families are presumed to be competent and when provided with opportunities to do so, able to meet their own needs. Emphasis is on promoting and strengthening family functioning by facilitating the acquisition of new skills. The higher rated service coordinators viewed families as capable of learning new skills and as having the ability to even help others.

2. **The higher rated service coordinators encouraged increased parental involvement in the early intervention process**. The more positive view of families held by the higher rated service coordinators appeared to result in increased parental involvement. Parents were involved in the assessment process, asked to obtain information for the service coordinators, and even held official positions designed to assist other families. This too is consistent with Dunst and Trivette's (1987) enablement model within which help-giving occurs in a "co-operative, partnership approach that emphasizes joint responsibility" (p. 451). Actively involving parents is also a useful way of helping parents cope. It can help restore positive feelings about themselves and enhance their self-esteem (Cahners, 1981; McCubbin & McCubbin, 1987).

3. **The higher rated service coordinators viewed their roles more broadly and as a result prioritized their efforts differently**. Another area within which the two groups of service coordinators differed was in how they viewed their roles. This was true in terms of how broadly they viewed the scope of service coordination, where they focused their intervention efforts, and how they prioritized their time.

The higher rated service coordinators viewed the scope of service coordination more broadly and were less "education" oriented. They viewed their role as coordinating any services the families needed, as opposed to coordinating only educational services. They were more apt than the lower rated service coordinators to put themselves at the disposal of the family. This is an important aspect of Brickman's (1982) compensatory model which is the basis for Dunst and Trivette's (1987) enablement model of helping.

In contrast, the lower rated service coordinators were more traditionally education focused. They talked in terms of coordinating educational services such as occupational therapy, physical therapy, etc. Again, this may reflect their discomfort with their new roles or their lack of understanding of the role of service coordinator.

The higher rated service coordinators emphasized working with the family as opposed to working directly with the child. They recognized the need to work with the child in the context of the family. This view is supported by systems theory and in particular, Bronfenbrenner's ecological theory of development. Bronfenbrenner (1989) proposes that the development of the individual is a result of interactions which occur between the individual and the environment over the life course. Bronfenbrenner's theory is the basis of Dunst et al.'s (1988) assertion that the chances of making a significant positive impact on the development of the child, and all other family members, are improved when the unit of intervention is the family and not just the child.

Although many of the lower rated service coordinators voiced their belief that the child should be served in the context of the family, further analysis of the interviews indicated that their practice did not reflect what they said should happen. This may be a result of the fact that the family-centered approach of Part H of IDEA is very different from the traditional child-centered philosophy of the past and requires early interventionists to adjust their methods of providing services. Only recently have such individuals begun to receive the training necessary to work with families (Capone & Divenere, 1996) and they may continue to perceive themselves as better at and feel more comfortable working with children (Bailey et al., 1991; Boone, Moore, & Coulter, 1995). Such child-centered intervention could also be family-centered, if it is the family's desire that the focus be on the child. However, before making such a decision, the family must know that focusing strictly, or partially, on family needs is also an option (McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995). However, when the lower rated service coordinators' interactions with families and the design of their respective programs were viewed as a whole, it appeared that this and many other decisions regarding the intervention were more apt to have been made by professionals in these relationships rather than the families with whom they worked. One factor that may have contributed to this was the tendency of the lower rated service coordinators to prioritize their own needs over that of the family.

The higher rated service coordinators prioritized their interactions (e.g., home visits, phone calls) with families over all other activities. In contrast, the lower rated service coordinators talked more about their concern that the paperwork be completed. Concern with paperwork and other activities could impact on relationships developed with families. One of the outcomes of such a focus might be being late for, canceling, or constant rescheduling of appointments with families. Also, focusing on the completion of paperwork while interacting with the family might affect the quality of the relationship developed with the family. In a study of families and service coordinators, the authors found that service coordinators being late for visits with families and distractions during visits with service coordinators were two variables the interviewees felt interfered with the development of effective relationships (Dinnebeil & Rule, 1994).

4. **The higher rated service coordinators were more aware of what families want or need from professionals and this awareness translates into behaviors that reflect what families say they want or need.**

The birth of a child with a disability requires the family to redefine who they are and what is possible for them so that they can begin to envision a future for the child and the family (Thompson, 1995). The higher rated service coordinators recognized the family's struggle to understand what it means to be a family with a child with a disability and as a result, demonstrated more caring, empathic behavior. Consistent with their more positive view of families, they were less judgmental than the lower rated service coordinators. In their interviews, the higher rated service coordinators provided more examples of direct, honest communication with families. They recognized the need to be available to families when the families needed them and that this may not always be between 8:00 a.m. and 3:00 p.m., Monday thru Friday. These attitudes and behaviors seemed to set the tone for the parent-professional relationship and to allow the service coordinators and families to engage in mutual problem solving. Important components of collaborative parent-professional relationships are mutual respect and understanding of the other's perspective and role (Zipper et al., 1993 citing *Focal Point*, 1987). Through their positive attitudes and caring behaviors, the higher rated service coordinators appeared to set the stage for mutual respect and understanding to develop. This information supports the need for professionals who will be doing service coordination to have a thorough understanding of family systems and what often happens to such systems with the birth of a child with a disability (Zipper et al., 1993). They also need to understand what is required in order to develop collaborative parent-professionals relationships. This understanding is crucial to interacting with families in a way that promotes the development of mutual respect and caring so that the parent and professional can work together most effectively on behalf of the child and family.

An important aspect of service coordination is connecting families with the resources they need. These resources may include information, services, financial support, opportunities to learn, and other families in a similar circumstance (Able-Boone et al., 1992; Bailey et al., 1992; Garshelis & McConnell, 1993; Gamel-McCormick, 1995; Thompson, 1995). The higher rated service coordinators in this study appeared to be better able to connect the families with the resources they needed. This enhanced capacity to connect families seemed to be a result of several factors. First of all, the service coordinators were more aware of the family's need to be connected with resources. They went to greater lengths to get families the information they wanted and to help the families understand this information. They recognized the need for families to interact with and support one another and provided opportunities for this to occur.

The service coordinator is responsible for informing the family about available advocacy services, helping the family locate appropriate services, and assisting the family to access necessary services. In order to do so, the service coordinator must have current knowledge of "local, state, and national resources, eligibility requirements for services, and ways of accessing such services (Zipper et al., 1993, p.27). The higher rated service coordinators appeared to be better able to connect families because of the degree of connectedness they themselves experienced. They talked of their need to stay current, the research they do on a state and national basis when necessary, and helping families to access information through the Internet. They placed greater emphasis on networking within their communities and as a result, they appeared to be more connected to the resources that families want and need. They talked more about meeting and talking with others and how to get things done if the system originally fails in meeting the needs of the family. Often in early intervention, there is talk of the need to "collaborate" with other service providers, but it is not often related to how doing so can translate into improved access to information and services for families. The higher rated service coordinators' connections and their ability to connect families are an example of how such collaboration can be helpful to families.

Families prefer a particular type of relationship with professionals as they attempt to get their needs met. Families prefer to be "guided" by the professional. Although families recognize the expertise of the professional, they also recognize their own strengths (Thompson, 1995). They want professionals who will interact in a responsive manner and include them as integral members of the team (Gamel-McCormick, 1995). The higher rated service coordinators appeared to work from this perspective. They asked families questions about what the family wanted. They had a sense of when to provide information or suggestions in a manner that families could understand and in a manner families could accept. This could be related to their more empathic way of interacting with families and their tendency toward honest, direct communication.

The higher rated service coordinators appeared to engage families more directly in the process of meeting the family's needs. For example, families were actively engaged in problem solving and goal setting. This seemed to be related to the service coordinators' more positive view of families. Because they viewed families as capable of doing for themselves, they actively guided families towards such independence. Consistent with their belief that families could be more independent, the higher rated service coordinators seemed to place greater emphasis on preparing the family for the future. This is what Thompson (1995) calls guiding the family for the future. By guiding the family in such a way, the service coordinator helps the family regain a sense of hope. The family begins to see what is possible for their child and for them as a family. This in itself is a form of coping. McCubbin and McCubbin (1987) refer to this as changing the meaning of a situation to make it manageable. If the family perceives itself as having the skills to meet the demands of the future then it can view the situation as manageable.

In guiding the family, the focus of the professional's guidance must be in helping the family to persist in its efforts to define its future and get its needs met (Thompson, 1995). The higher rated service coordinators recognized the family's need to persist and actively engaged in efforts to help families develop the skills they would need to do so. The higher rated service coordinators' acceptance of the family's need to persist could explain why families rated these service coordinators more favorably. Thompson's (1995) research concluded that families will persist whether or not the professional supports this task. The author suggests that when professionals do not understand the family's need to do so and support this task, conflict between the family and the professional can occur and ultimately the family's efforts can be compromised. Because these service coordinators understood and supported the families they served in their efforts to persist, there may have been less conflict in the relationships and the families may have perceived the service coordinators more positively.

5. **The higher rated service coordinators were more aware of and used more behaviors that promote a perception of empowerment and ability to cope**. The enablement model of help-giving proposes that the attitudes and beliefs, behaviors, and posthelping responses and consequences of the help-giver's behaviors can promote family empowerment (Dunst et al., 1994b). The higher rated service coordinators appeared to

possess more of the attitudes and beliefs associated with the enablement model. In addition, they appeared to be more aware of what behaviors on their part could help families perceive themselves as empowered.

Many of the characteristics of the help-giver proposed by the enablement model have already been attributed to the higher rated service coordinators. For example, they had a more positive view of families. They used more caring, empathic, non-judgmental behaviors. They engaged family members actively in the process of obtaining the resources necessary to meet the needs of the family and assisted families in their decision-making efforts. These characteristics relate to four aspects of the enablement model. One is conveying a sense of joint responsibility for meeting the needs of the family. The second is the emphasis on the family learning effective behavior that leads to greater independence and the third is the family viewing itself as responsible for producing the outcome. Finally, the service coordinators recognized the primacy of the family in the life of their child and allowed the locus of decision making to remain with the family. They provided the family with choices and asked the family what they wanted to do. Once the family made a decision, they supported the family in its choice, even when it wasn't what they would have chosen.

The quantitative portion of this study indicated that an increased perception of empowerment is related to an increased perception of the ability to cope. The enabling attitudes and behaviors of the higher rated service coordinators resulted in more positive posthelping consequences for the families. As a result, the parents perceived themselves as more able to cope. This increased perception of ability may have caused the parents to reflect more positively on their relationships with their service coordinators. The parents viewed themselves in a more positive way and possibly, as a result, viewed those who worked with their families the most intimately, in the same positive light.

6. **The higher rated service coordinators were more willing to take "risks" than the lower rated service coordinators.** The higher rated service coordinators appeared to have increased risk-taking attitudes and behaviors which affected the manner in which they worked with families. For example, their attitudes seemed to allow them to be more open and flexible with families. They were more willing to ask the families what they felt or what they wanted and to be open to whatever the answer was. They did not feel they always had to know the answer or to always be "right". This allowed for a more balanced relationship between the service coordinator and the parents. If the service coordinator did not always have to be right, neither did the parent and as a result the two partners could explore new possibilities together. The higher rated service coordinators appeared more willing to try different ways when the first method of working with a family did not work. They seemed more willing to make mistakes and to try again. This could allow them to be more creative in their work with families.

7. **The higher rated service coordinators perceived themselves as more supported in their positions which allowed them to be more supportive of families.** Much like the families they served, the higher rated service coordinators perceived themselves as more supported and thus empowered to do their jobs. They emphasized the importance of their opportunities to interact frequently with colleagues in order to obtain support for what they had already done and to problem solve possible new solutions.

Their perceptions of support seemed to positively impact their perceptions of the programs within which they worked and ultimately of themselves as professionals. All of the higher rated service coordinators mentioned how pleased or proud they were of their programs. They felt they were really able to help families. They all liked what they were doing, regardless of how time consuming a job it was. It would seem that this was a result of their perceptions of support and their feelings that the programs within which they worked were effective in helping families. This has direct implications for administrators as they struggle to design family-centered early intervention services. Much has been written about the competencies that service coordinators need. However, little has been written regarding the support they require in order to carry out this demanding role effectively.

The Impact of Effective Service Coordination on Families

This section is designed to integrate the findings that resulted from employing both quantitative and qualitative methodologies. The benefits of combining the two methodologies is becoming increasingly recognized (Brewer & Hunter, 1989). This study demonstrates how using the two methodologies can offer a more comprehensive look at a phenomenon such as the relationship between service coordinator knowledge, beliefs, and behaviors and parental perceived empowerment and ability to cope.

In this study it was shown that the knowledge, beliefs, and behaviors of service coordinators can impact how empowered parents feel. These factors can also affect the parents' perception of their ability to cope. The parents' perception of coping is affected in two ways. One is by making them feel more empowered and thus that they have a greater sense of control over what happens to their child and their family. The second is by directly decreasing the stress they are experiencing (e.g., increasing resources, helping the parents to have a more positive view of themselves).

Interviewing the service coordinators that parents believe contribute to their sense of empowerment and ability to cope, revealed the knowledge, beliefs, and behaviors that contribute to an increased sense of well-being on the part of parents who have an infant or toddler with a disability. The findings from the two methodologies support each other. It is now possible to see what it is that service coordinators do differently that impacts family functioning and ultimately has the capacity to impact child outcomes.

For example, both the quantitative and qualitative analyses indicated that the higher rated service coordinators were better able to help families identify their needs and then connect families with the resources necessary to meet those needs. These resources included information the family wanted (e.g., information about the child's disability, possible medical treatments) and the actual services the family needed for itself and the child with a disability. The qualitative analysis revealed that this was because the service coordinators recognized how much families want such information and that they want to have the information explained to them in a manner that makes the information useful. In addition, the higher rated service coordinators emphasized their need to have access to current, accurate information at the local, state, and national level. The higher rated service coordinators also emphasized the importance of their connections in the community which allowed them to hook families up with what the family needed. In addition, the higher rated service coordinators may be better able to hook families up with the services they need because of their additional years of experience. The quantitative analysis revealed that those individuals who had been providing service coordination longer, were more positively rated by families. The higher rated service coordinators may be better able to assist families to access the services they need because the service coordinator has had longer to learn about the agencies that provide such services and to develop relationships with individuals in such agencies.

Another important resource that families want is to be connected with other families (Bailey et al., 1992; Gamel-McCormick, 1995; Thompson, 1995). The results of the two different analyses revealed discrepant findings in this area. The majority of the service coordinators interviewed mentioned this need on the part of families. They all discussed how they do this. However, reviewing the individual SCS items indicated that although families feel the higher rated service coordinators are doing this more than the lower rated ones, neither group is doing enough of this. This is interesting in that the literature relates that families identify their desire to meet other families like them as an important need. There are several possible reasons why service coordinators do not ensure that this always occurs. One possible reason for the service coordinators' hesitancy to introduce families to one another may be related to the fact that the majority of individuals who act as service coordinators for children eligible for services through *Early On* Michigan, are employees of an Intermediate School District (Lobb, 1996). They are delivering their services through Special Education systems. Families have a long history of advocacy within the Special Education system in their efforts to obtain the services they feel they need for their children. When families have met one another they have sometimes organized in some manner and worked together to cause change in the Special Education system. It has been the researcher's experience that the field of Special

Education has often viewed this advocacy in a negative light. This has seemed to lead to a feeling of distrust and concern about putting families in touch with one another. Special Education personnel are often not encouraged or not supported in their efforts to do so.

A second possible reason that families are not put in touch with one another is due to the need to protect the family's right to privacy. Professionals often use this as a reason for not doing so. However, if a professional believes it is important to put families in touch with one another, this obstacle is easily overcome by getting the permission of the family to release their name and phone number to another family. However, it does take time and a commitment on the part of the professional to do so.

A third possible reason that service coordinators do not emphasize putting families in touch with one another may be because Michigan is a birth mandate state in terms of providing Special Education services. This means that many of the developmental services an infant and toddler with a disability may need (e.g., physical therapy, occupational therapy) are available to the family, free of charge, through Special Education. Michigan has served infants and toddlers with disabilities who qualify, through Special Education for over twenty years. As a result of this tradition, when Part H of IDEA was implemented it became a predominantly formal service oriented early intervention system as opposed to a resource based early intervention system. Professionals working with families who have an infant or toddler with a disability immediately look to the Special Education system and other formal systems to meet the needs of the child and family. Professionals are not accustomed to beginning with the family and its community to identify and engage the informal support networks that already exist within that family or community. Both the quantitative and qualitative portions of this study support this conclusion. None of the service coordinators interviewed mentioned helping families to engage their own informal support networks. In addition, the SCS items indicated that families did not perceive their service coordinators as particularly strong in helping them identify friends and family members who could help them meet their needs. Promoting the family's use of natural support networks is an important component of an enabling and empowering model of helping (Dunst and Trivette, 1994).

The qualitative analysis also indicated that the higher rated service coordinators were more aware of what families want or need from professionals and that this awareness translated into more positive behaviors. During the interviews, the higher rated service coordinators gave more examples of their caring, empathic behavior toward families. The results of the quantitative analysis supported this finding. The families felt the service coordinators were more supportive, allowed the family to talk when they needed to, and helped the family view their child with a disability more positively. They were also more apt to go out of their way for the family. Overall, the families felt the higher rated service coordinators were helping them with their important task of redefining themselves as a family. They were helping them begin to see what was possible for them so they could envision their future as a family (Thompson, 1995). Once the families are able to envision their future, the task is then more manageable. They then perceive themselves as empowered and better able to cope with what the future holds.

Relating empowerment to coping is important because professionals are always told they should work with families in a family-centered, empowering manner. But they are rarely, if ever, told why this is true. In all the texts used as reference to this study, few if any related the concept of empowerment to coping and child outcomes. Carl Dunst and his colleagues are some of the few who have related empowerment to family functioning. However, even in these writings it is difficult to extract the connection between empowerment and family adaptation or coping. This study is one of the few to depict the complete chain. It is also one of the few to relate specific service coordinator behaviors to empowerment and ability to cope.

The results of this study show how important the role of service coordination is to families who have infants and toddlers with disabilities. Once professionals know the processes that families must go through and recognize the impact their attitudes and behaviors can ultimately have on the functioning of the family, it may be possible to better capture their attention during preservice and inservice learning opportunities. It will also assist in the development of content for effective preservice and inservice educational opportunities, as this study has highlighted specific knowledge, beliefs, and behaviors that are important in helping families to build a future.

The basis of the early intervention process is the interactive relationship between families and professionals. Families seek out early intervention services in the hope of acquiring what they need in order to shape a new future for themselves. The response of early intervention professionals can either help or hinder the family in this process (Dunst and Trivette, 1994; Thompson, 1995). It is important that the professional who is in the position to aid the family the most, the service coordinator, have the knowledge, beliefs, and skills necessary to effectively help families on this important journey.

Limitations of the Study

This study had several limitations. A discussion of each of them follows.

1. The sample of families who completed the Family Survey may not be representative of all families. The families sampled were predominantly European American. However, the sample closely resembled the population of Michigan (Lobb 1996). In addition, the respondents were predominantly female.

2. The service coordinators who completed the Service Coordinator Questionnaire were predominantly female. In addition, all ten of the service coordinators interviewed were female. This limits the generalizability of the findings. However, early intervention is a predominantly female dominated field, so the participants were representative of the majority of early intervention service providers.

3. The resources of the researcher limited the number of service coordinators that were interviewed. In addition, the researcher was required to utilize data that was the result of a single interview. This limited the breadth of information that could be obtained.

4. The researcher knew how families rated the ten service coordinators who were interviewed before analyzing the qualitative data. This could have led to bias on the part of the researcher. However, objective readers were employed to determine that it was possible to determine which service coordinators were rated more favorably as a result of simply reading the interviews.

5. The ten service coordinators who were interviewed were chosen as a result of the ratings of only three to five families. It would have been helpful to have a larger

number of families to rate each of the service coordinators in order to obtain a more complete picture of how well the service coordinators performed their duties.

6. Interviewing individuals is especially appropriate to the exploratory nature of this study (Marshall & Rossman, 1989). It is also an effective means for finding out those things that cannot be directly observed such as feelings, thoughts, and intentions (Patton, 1990). However, interviewing has it's limitations in that it may not be as effective as observation for determining how the service coordinators truly interact with families. What the service coordinators think they do may not actually be occurring.

7. This study did not include a measure of several variables which may impact empowerment and coping. Such variables include parental self-esteem, problem solving style, parental beliefs, social support (i.e., spousal support and social network), or additional family resources such as insurance and social services. Each of these variables may affect the relationship between the behaviors of the service coordinators and parental perceived empowerment and ability to cope.

Implications

This study established the important relationship between the knowledge, beliefs, and behaviors of service coordinators and the sense of empowerment and ability to cope that parents experience. The findings of this study have implications for practice, personnel development programs, and for future research. These implications are discussed in the following section.

Practice

Families who perceive themselves as more empowered and able to cope in this study, had service coordinators who emphasized being accessible to the families they served. This has implications for programs providing service coordination to families. Agency policies and operations must promote the parent-professional contact that needs to occur (Zipper et al. 1993). For example, traditionally, employees of most human service agencies, including education, work a pretty typical 8:00 a.m. to 5:00 p.m day, Monday through Friday. As many parents are working during these hours, it is unrealistic to expect them to meet with service coordinators during daytime hours, Monday through Friday, only. For single parent families, it is often impossible. Even in families in which there are two parents, and only one parent works outside the home, meeting with the family during the day often excludes the other parent from the process. Service coordinators will need to be allowed to have flexible work schedules if they are to meet the needs of their families. Program administrators are not always supportive of such scheduling. To do so may require an administrator to work during non-traditional hours or to have an employee working when no supervision is available. Administrators will need to be aware of the need for and support flexible scheduling for employees providing service coordination to families.

Families who perceived themselves as more empowered and able to cope also had service coordinators who viewed their role as service coordinator broadly. The higher rated service coordinator viewed their role as coordinating all services the family might need, not just education service. This finding has significant implications for practice in that the majority of service coordinators in Michigan are employees of educational institutions (Lobb, 1996). Many of these individuals are therapists (e.g. speech therapists, physical therapists) who also have large caseloads of children for whom they are responsible for providing therapy. In order to allow these individuals the time they need to truly provide service coordination, their administrators will have to be aware of the amount of time such a service entails and support them by keeping their caseloads at a reasonable size so they are able to work with children and families effectively.

Dunst and Trivette (1987) proposed the importance of engaging the family's informal support network. One way of doing so is to put families in touch with one another. Families have repeatedly stated how important it is that they be connected with other families who have a child like theirs (Bailey et al., 1992; Gamel-McCormick, 1995; Thompson, 1995). This study revealed that parents did not feel that their service coordinators were doing either to the extent the parent would like. This has significant implications for practice. Just making service coordinators aware of the fact that families want to be introduced to other families may encourage them to do so. They will also need to know that this is not simply forming a parent support group. Not all families want a support group. Support groups can carry a stigma for some families. Many just want to talk to another family, one-on-one. Opportunities must be provided for families to do so.

In contrast, service coordinators must begin to assist families to look to their own families and communities for sources of informal support such as grandparents, family friends, and churches. Professionals have not traditionally been trained to assist families to engage their informal support systems and will need to learn how to do so, which is an implication for the section that follows.

Training and Personnel Development

This study has shown how important it is that professionals recognize the impact their interactions with families can have on the families. Most early intervention personnel have had limited exposure to the concepts of family systems and human ecology. This leaves them to engage in an important relationship with families with little awareness of the importance of that interaction or what the consequences of their behavior may be (Thompson, 1995). In order to develop this awareness, it is important that professionals receive training in content areas not previously included in the curricula of the institutes of higher education.

Only in the past few years have the institutes of higher education begun to train students in family-centered practice (Niemeyer & Proctor, 1995). It is important that future service providers be educated to understand the dynamics of family systems so that they may better understand why family members often act as they do. This may help them develop the more positive view of families that this study has determined to be important. In the past, professionals have exhibited ambivalence about working with families. Such ambivalence may affect the professionals ability to assist families to feel empowered (Sokoly & Dokecki, 1992).

Much emphasis has been placed on the knowledge and expertise that early intervention professionals must acquire. However, there has been little mentioned about the need for professionals to develop their self-awareness. Increased self-awareness is needed in order for service providers to evaluate their own knowledge, beliefs, and behaviors to determine if what and how they are doing it, helps or impedes the growth of family members. They must know their own strengths and limitations. In addition, they must be able view the world as the family does (Sokoly & Dokecki, 1992). This concept was also captured by Singh (1995) when he stated that professionals “cannot facilitate growth in a family if we cannot see the world from their eyes” (p. 12). This should be an important component of curricula designed to help students and professionals develop the skills necessary to provide effective service coordination.

Increased self-awareness is also important for working as a member of a team. Part H of IDEA requires that service providers engage in interdisciplinary and interagency team processes. Bailey et al. (1990) found that the amount of time allotted for interdisciplinary team process, case management, or professional values and ethics was limited, especially in light of its significance in the field of early intervention.

Another area in which service coordinators must also develop skills is in assisting the family to engage its informal support network. Dunst and Trivette (1987) have found this to be an important aspect of an enabling and empowering model of help-giving. Thompson et al. (1996) reported that service coordinators in Michigan are still failing to do so. Traditionally, professionals have learned how to engage formal systems only. This often results in added problems of transportation and time spent away from home. The field of early intervention is just beginning to realize how important it is to utilize the family’s already existing supports rather than developing a network of formalized, professional support systems for families (Able-Boone et al., 1992). Service coordinators will need to be trained in this different philosophy and in procedures for helping families mobilize their informal support networks if this important change in focus, from a predominantly service based to a resource based system of early intervention is ever to occur.

The design of personnel preparation programs must also be reconsidered. For example, traditionally, preservice programs have been based predominantly on coursework and some limited practicums conducted by faculty. In order for future service providers to become more effective at working with families it is important that they have more opportunities to interact with families. Increased interaction with families increases the student's opportunities to become more sensitive to family issues and concerns. This study has shown that what makes a better service coordinator is doing service coordination. It would then make sense that what makes one better at working with families is having opportunities to interact and work with families.

The increased presence of family members in the training of future and present personnel could occur in many ways. One example is to provide students with field experiences with families (Niemeyer & Proctor, 1995; Thompson, 1995). Students could also be required to interview parents of children with disabilities or to view video tapes of families expressing their hopes and concerns (Thompson, 1995). Family members are also excellent additions to actual class sessions and should be employed as co-trainers in both preservice and inservice education programs. In this way, a family member is always present to add the family's perspective on topics and issues as they arise.

Early intervention personnel from all disciplines (e.g., nursing, physical therapy, special education) need to obtain expertise in working with families. In addition, they all need to learn how to work as members of a team. This advocates for cross-disciplinary coursework or inservice training opportunities that would allow individuals from the various disciplines to interact with each other on an on-going basis. Godfrey (1995) suggests that team process should be the basis for as many learning opportunities as possible. The author believes that in order to make the shift to a more holistic paradigm of family-centered early intervention, service providers must learn by experience that it is permissible to challenge each other's beliefs and practices. They must learn to question each other about terminology used and to learn to not be intimidated by another field that is different than their own.

Although the literature is beginning to reflect the need for future and present service providers from different disciplines to interact with one another so they will be able to work together as a team, an important component of the team that is often overlooked. It should be remembered, that the most important member of that team is the family of the child for whom planning is taking place. The family is the constant in the child's life. They know their child and family the best. This study has clearly indicated that families know what they want and need in order to be able to meet the needs of their child and their family. What better way for professionals to know what to do than to include the family in discussions from the very beginning? In order to do so, professionals and families must know how to communicate openly with one another (Jeppson & Thomas, 1997). Preservice and inservice training situations should provide for all prospective team members to learn how to interact effectively with one another.

Bailey et al. (1991) found that professionals who viewed themselves as less competent in working with families expressed greater concern about changing to family-centered practices. Preservice and inservice training activities must be tied to individual needs in order to assist early intervention personnel to perceive themselves as having the skills necessary to work in a family-centered manner. Such activities should include repeated opportunities to interact with families in order to remove the "fear of the unknown." By doing so, it will be possible to move toward a system of more family-centered early intervention services that will facilitate improved family functioning and ultimately improved child outcomes.

Future Research Activities

Although a review of the literature disclosed a number of studies regarding parent-professional partnership and parent empowerment, few of the studies have related the two concepts to one another. As a result, a number of areas for possible future research were generated. A few of those of most interest to this researcher will be discussed.

The samples used in this study were predominantly mothers of infants and toddlers with disabilities and female service coordinators. Therefore the results predominantly reflect the results of female to female interactions. An important area of future research would be to examine the relationships between fathers of infants and toddlers with disabilities and female service coordinators. Similarly, it would be important to examine the relationships between the parents of infants and toddlers with disabilities and male service coordinators. Does the fact that many males are frequently more instrumentally oriented, as opposed to relationship oriented affect parental perceived empowerment and ability to cope?

This study did not include measures of social support. It would be important to re-examine the relationship between the behaviors of service coordinators and parental perceived empowerment and coping when social support is included in the equation. Is the relationship between the parent and service coordinator actually a form of social support which contributes to parental perceived empowerment and coping? It is important to understand just how the behaviors of the service coordinator impact parental perceived empowerment and coping so that preservice and inservice training can more precisely address the development of skills necessary to impact parental perceived empowerment and coping.

The combination of research methodologies used in this study was a particular strength of the study. It allowed the researcher to obtain an objective parental rating of a specific group of service coordinators and then to examine more in-depth the attitudes, beliefs, and behaviors of that group of service coordinators. However, the in-depth look at the attitudes, beliefs, and behaviors of the service coordinators was obtained only through interviews with the service coordinators. This limited the researcher to only the service coordinator's perception of how they interact with families. An important area for future research would be to actually observe a group of service coordinators who were rated either high or low by parents to begin to more completely describe the differences in the interactions between the service coordinators and the families.

In the original analysis of the Family Survey data by Wayne State University CULMA, Thompson (1996) found that service providers were not assisting families to engage their informal support networks, but rather, were emphasizing connecting families with formal service delivery systems. The qualitative portion of this study also noted that none of the ten service coordinators mentioned promoting the development of the family's informal support network, other than introducing families to other families who had a child with a similar disability. An area for further research would be to study service coordinators to find out why they do not do this more often. Is this because they do not know the importance of informal supports to families? Are they unsure as to how to assist families to engage such supports? Is it just because Michigan has always emphasized the importance of coordinating formal service systems? All of these questions need to be answered and would have implications for future training and technical assistance efforts.

This study further elaborated on Thompson's (1995) theory regarding the family's need to persist in its efforts to obtain the information, support, and understanding necessary for them to shape a picture of the future for themselves. The higher rated service coordinators more often described their efforts to encourage the family to persist and to help them develop the skills necessary to do so. An area of additional research would be to determine why some service coordinators are more comfortable with and recognize the family's need to persist and actually support this task while others do not. What are the factors that separate the two groups of service coordinators?

The intent of all of these possible research activities would be to better understand the behaviors and perspectives of the service coordinators that help families to perceive themselves as more empowered and better able to cope. Through this improved understanding, effective training and technical assistance opportunities can be designed to meet the specific needs of the individuals in this very important role of service coordinator.

APPENDICES

Appendix A

Early On Eligibility Requirements

ESTABLISHED CONDITIONS

A. Definition.

This is a mandated eligibility category under Part H. Children with established conditions are those from birth through age two who have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

The categories of established conditions are:

1. Chromosomal anomaly/genetic disorder,
2. Neurological disorder,
3. Congenital malformation;
4. Inborn error of metabolism;
5. Sensory disorder,
6. Atypical developmental disorder,
7. Severe toxic exposure;
8. Chronic illness; and
9. Severe infectious disease.

B. Clarifying Information.

There are many examples of established conditions which have a high probability of resulting in developmental delay that fall under each of the respective categories outlined in the definition. Examples of these conditions are presented below.* These examples do not comprise an exhaustive list, nor are the categories mutually exclusive. The examples of listed disorders serve to represent the most well known conditions that can be subsumed under the general categories.

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*This list of established conditions was initially adapted from a NEC*TAS questionnaire sent out to developmental experts and revised by the State of Michigan Interagency Coordinating Council Identification Committee.

Services may be provided to families with children whose medical conditions are not listed below (e.g., rare or unusual conditions, etc.) but are known to have a high probability of causing a delay in development. New disorders which result in a high probability of delay in development may be described in the future and would render a child and his/her family eligible for services under this category.

1. CHROMOSOMAL ANOMALIES/GENETIC DISORDERS **INCLUDE, BUT ARE NOT LIMITED TO,** the following conditions:

Cri-du-Chat
Trisomy 21 (Down Syndrome)
Trisomy 18
Fragile X Syndrome
Oculo-Cerebro-Renal Syndrome
Cockayne Syndrome
Laurence-Moon-Beidl Syndrome
Waardenberg Syndrome
Cerebro-Hepato-Renal Syndrome

2. NEUROLOGICAL DISORDERS **INCLUDE, BUT ARE NOT LIMITED TO,** the following conditions:

- Neuromotor/Muscle Disorders
    - Cerebral Palsy
    - Dystonia Musculoram Deformans
    - Hereditary Progressive Muscular Dystrophy
    - Kernicterus
    - Myasthenia Congenita
    - Paralysis
    - Wilsons Disease
- Cerebrovascular Disease
    - Cerebral Arterial Thrombosis
    - Cerebral Embolus Thrombosis
    - Cerebral Venous Thrombosis
    - Intracranial Hemorrhage
- Degenerative Diseases (Myelination Disorders)
    - Acute Disementated Encephalomyelitis
    - Friedrich's Ataxia
    - Gangliosidoses
    - Kugelberg-Wehlander Syndrome
    - Leigh's Encephalomyelopathy
    - Leukodystrophies
    - Schilder's Disease
    - Werdnig-Hoffman Syndrome
- Neurocutaneous Disorders

- Bloch-Sulzberger Syndrome
- Neurofibromatosis
- Sturge-Weber Syndrome
- Tuberous Sclerosis

Malignancies
- Intracranial Tumors & Other Malignancies of the CNS

Head and Spinal Cord Trauma
- Fracture of vertebral column w/ or w/o spinal cord lesions

Seizure Disorders
- Nonrefractory and Intractable Type
- Refractory and Intractable Type (controllable)

3. <u>CONGENITAL MALFORMATIONS</u> **INCLUDE, BUT ARE NOT LIMITED TO,** the following conditions:

Cardiovascular
- Aortic Valve Atresia & Stenosis
- Coarctation of Aorta
- Patent Ductus Arterilsis
- Teratology of Fallot
- Transposition of Great Arteries

Orofacial
- Cleft Palate
- Hypoplastic Mandible (Pierre Robin)
- Noonan Syndrome
- Treacher Collins

Genitourinary
- Adrenal-Genital Syndrome
- Potter Syndrome
- Renal Agenesis and Hypoplasia

Musculoskeletal
- Arthrogryposis
- Reduction Deformity of Lower Limbs
- Reduction Deformity of Upper Limbs

Pulmonary/Respiratory
- Tracheomalacia

Central Nervous System
- Anencephalus
- Encephalocele
- Uncorrected Hydrocephalus
- Microcephaly
- Spina Bifida

4. <u>INBORN ERRORS IN METABOLISM</u> **INCLUDE, BUT ARE NOT LIMITED TO,** the following conditions:

- Mucopolysaccaridoses
    - Hunter Syndrome
    - Hurler-Schele Syndrome
    - Marqulo Syndrome
    - Martoteaux-Lamy Syndrome
    - Sanfilippo Syndrome
    - Schele Syndrome
    - Sly Syndrome
- Abnormalities of Amino Acid Metabolism
    - Maple Syrup Disease
    - Infant PKU
- Abnormalities of Carbohydrate Metabolism
    - Galactosemia
    - Glycogen Storage Disease
    - Infantile Gaucher Disease
- Abnormalities of Lipid Metabolism
    - Neiman-Pick Disease
    - Tay-Sachs Disease
- Abnormalities of Purine/Pyridlmine Metabolism
    - Lesch-Nyhan Syndrome
- Abnormalities of the Parathyroid
    - Hyperparathyroidism
    - Untreated Hypoparathyroidism
- Abnormalities of the Pituitary
    - Hyperpituitary
    - Hypopituitary
- Abnormalities of Adreno-Cortical Function
    - Hyperadrenocortical Function
    - Hypoadrenocortical Function.

5. <u>SENSORY DISORDERS</u> **INCLUDE, BUT ARE NOT LIMITED TO,** the following conditions:

- Eye
    - Amblyopia ex. anopsia
    - Anirldia
    - Anophthalmos/Microphthalmos
    - Visual Impairment/Blindness
    - Congenital Cataract
    - Retinopathy of Prematurity (ROP)
- Ear
    - Hearing Loss

6. ATYPICAL DEVELOPMENT DISORDERS **INCLUDE, BUT ARE NOT LIMITED TO**, the following conditions:

   Pervasive Developmental Disorder (PPD)
   Autistic Disorder
   Infantile Schizophrenia
   Reactive Attachment Disorder (e.g., nonorganic failure
   to thrive, child abuse/neglect etc.)
   Regulatory Disorders*

7. SEVERE TOXIC EXPOSURE **INCLUDES, BUT IS NOT LIMITED TO,** the following conditions:

   Prenatal
      Cocaine and Other Drugs Syndrome
      Fetal Alcohol Syndrome
      Maternal PKU
   Postnatal
      Lead
      Mercury

8. CHRONIC MEDICAL ILLNESS **INCLUDES, BUT IS NOT LIMITED TO**, the following conditions:

   Medically Fragile
      Children with complex health care needs
      Technology-Dependent (e.g., including those on apnea monitors, except for cases in which siblings died from SIDS)
      Central Hypoventilation
      Renal Insufficiency
   Medical Illness
      Bronchopulmonary Dysplasia (BPD)
      Cancer
      Chronic Hepatitis
      Cystic Fibrosis
      Diabetes
      Heart problems

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*A complete description of this disorder can be found in the Diagnostic Classification Manual of the National Center for Clinical Infant Programs (1990). This document also proposed several diagnostic classifications for disorders related to infancy, such as disorders of affect, mood, social relationships, and psychic trauma disorders, which may be considered under this category of atypical developmental disorders.

Renal Failure

9. SEVERE INFECTIOUS DISEASE **INCLUDES, BUT IS NOT LIMITED TO,** the following conditions:

- Congenital Infections
    - Cytomegalovirus
    - Herpes
    - HIV+
    - Rubella
    - Syphilis
    - Toxoplasmosis
- Acquired Infections
    - Bacterial Meningitis
    - Encephalitis
    - Poliomyelitis
    - Viral Meningitis

DEVELOPMENT DELAY

A. Definition.

This is a mandated eligibility category under Part H. Children who are developmentally delayed are those from birth through age two years whose development is delayed in one or more of the following areas:

> cognitive development; physical development, including vision and hearing; gross and fine motor development; language/speech development; psychosocial development; or self-help skills.
>
> Development delay will be determined by informed clinical judgment of a multidisciplinary assessment team which includes parent(s); multiple sources of information will serve as the basis for informed clinical opinion. Sources of information shall include, at a minimum:

1. a developmental history as currently reported by the parent(s) and/or the primary caregiver,
2. an observational assessment of the infant or toddler with parent(s) and/or primary caregiver,
3. a recent health status appraisal; and

4. an appropriate formal assessment measure (standardized developmental test or inventory or a behavioral checklist). This formal measure shall not be used as the sole criterion to determine the absence of delay.

B. Clarifying Information.

Four main sources of information (i.e., parent report of a developmental history, observation of the parent and child together, health status appraisal and formal assessment) are to be used to assist professionals and parents in their interpretation of a child's developmental status. The information derived from each of the assessment tools is essential for understanding the developmental abilities of the child and the child's growth within the individual and cultural context of his/her own family; together these sources contribute to the formation of a clinical judgment of developmental delay. Information communicated by the family in all areas of assessment is central to the understanding of the developing child.

1. A Parent Report of Developmental History

The purpose of a developmental history is to obtain information regarding the prenatal, perinatal, and family life experiences which may have influenced the child's current developmental functioning. First descriptive information related to the parent's perception and understanding of the child, the child's developmental capacities, patterns of development and accomplishment of significant milestones in all developmental areas (cognitive, socio-emotional, motor and health) needs to be obtained. Second, an account of the pregnancy, birth and perinatal history, daily care giving activities, experience of parenting the child, and significant and/or stressful family life events needs to be reported. Finally, information regarding the family's current and past health history, available resources, and networks of social support should be collected to enhance the professional's understanding of the child's growth within the individual and cultural context of the child's family.

2. Observation of Parent and Child Together

The purpose of the observational assessment is to understand the development of the young child within the context of his/her care giving environment. Observation of the child's behavior and parent-child interaction during caretaking or play activities, as well as during other naturalistic interactions (e.g., during the course of the informal conversation with assessment team members, etc.), should be used to achieve this goal. The observational assessment provides the professional with a method for identification of (1) the developmental capabilities of the child under optimal conditions-in his home or with his parents; (2) the child's style of interaction with parents and play things; and (3) the unique capacities that the parents demonstrate in taking care of their child.

3. Health Status Appraisal

The purpose of the health appraisal is to obtain information regarding the child's past and current physical development and health status. The health appraisal needs to consist of a comprehensive physical health examination which addresses the developmental status of the child and is conducted by a certified nurse, certified nurse practitioner or physician. If a comprehensive physical health examination has been conducted within the past three months for a child under 18 months, or within. the past six months for a child over 18 months by the appropriately designated professional, a current health status appraisal need not be repeated. The standards for a comprehensive physical examination set by the American Academy of Pediatrics should be followed.

4. Formal Assessment

The purpose of a formal assessment is (1) to enable professionals and parents to systematically observe the specific behaviors and capabilities of the child under standard test conditions; (2) to provide data about the area(s) of developmental concern in comparison to the general population; and (3) to identify areas of strengths and special needs so that possible strategies for intervention can be proposed. Any tests, procedures or standardized measures which are used must be appropriate to the area(s) of developmental concern. Together, the quantitative scores obtained from the assessment measure and the behaviors that the child exhibits in relation to the test materials, the evaluator and the parents, yield valuable information on the child's developmental status.

Formal assessment must be conducted by a multidisciplinary team which is defined in Section 303.17 of the Federal Regulations for this program as "the involvement of two or more disciplines or professions in the provision of integrated and coordinated services, including evaluation and assessment activities."

AT RISK OF DEVELOPMENTAL DELAY

A. Definition.

This is an optional eligibility category under Part H. At present Michigan has opted to not include at risk within its definition of eligible infants and toddlers.

Children at risk for substantial developmental delay are those from birth through age two who are at biological and/or environmental risk if early intervention services are not provided. These children may not currently display developmental delays.

Children will be considered at risk for substantial developmental delay based on parental and/or professional judgment and the presence of four (4) or more of the following risk factors:

1. Serious concern expressed by a parent or primary caregiver, or professional regarding child's development, parenting style or parent-child interaction

   This risk factor refers to any serious developmental concern that is raised in relation to the child's development (e.g., child's physical health status, emotional well being, atypical development etc.) by a parent, primary caregiver, or professional. The concern may be specifically child focused, related directly to the child's developmental status or parent-child focused, related to the nature of parent-child interaction. If the concern raises considerable anxiety on the part of the parent, primary caregiver, or professional, the presence of this concern should be interpreted as a risk factor.

2. Parent or Primary caregiver with chronic or acute mental illness/developmental disability/mental retardation

   This risk factor refers to parents or primary caregivers, with a formal diagnosis of mental illness, developmental disability or mental retardation.

3. Parent or Primary caregiver with drug or alcohol dependence

   This risk factor refers to a parent or primary caregiver who is known or observed to regularly abuse drugs (e.g., barbiturates, marijuana, cocaine, heroin, etc.) or alcohol (e.g., more than three drinks per day). The risk factor is to be differentiated from the category found under established conditions which refers to infant toxic exposure resulting from drug or alcohol ingestion.

4. Parent or primary caregiver with a developmental history of loss and/or abuse

   This risk factor refers to either the history of perinatal loss, miscarriages, or history of sexual or physical abuse that a parent or primary caregiver has experienced, or, to the death of a parent, spouse, or child as reported by a parent or primary caregiver.

5. Family medical/genetic history characteristics

   This risk factor refers to characteristics in the medical history of the biological parents which may directly relate to the developmental status of the child. A family history of sensory impairment, a previous birth of a handicapped child, or a death of a baby due to SIDS, are examples of medical factors which would be considered by this risk factor.

6. Parent or primary caregiver with severe chronic illness

   This risk factor refers to a parent or primary caregiver who has a terminal or severe chronic illness (e.g., cancer, multiple sclerosis, etc.) and has experienced the debilitating effects (emotional or physical) related to medical treatments (e.g., drug therapies, etc.) or progression of the disease.

7. Acute family crisis

   This risk factor refers to any sudden and extremely stressful family event which substantially disrupts the equilibrium of the family and impacts on the care giving of the child. A death of a spouse or a child, a sudden hospitalization of a family member, or an eviction from the home are examples of acute family crisis which may impact on the stability of the family and resulting care and/or development of a child.

8. Chronically disturbed family interaction

   This risk factor refers to a chaotic and disorganized family patterns of interaction and/or disturbed family interaction characterized by domestic violence of threats of violence.

9. Parent-child or Primary caregiver-child separation

   This risk factor refers to significant extended or recurrent separations of the parent or primary caregiver from the child. Examples of such events might include parent (or primary caregiver) and child hospitalizations, divorce, parental separations, parental incarceration, parental military duty, or foster care placements.

10. Adolescent mother

    This risk factor refers to any mother who is under the age of twenty years at the time of the birth of her child.

11. Parent has four or more preschool age children

    This risk factor refers to families with four or more children under the age of six, or families where the mother is pregnant and has three children under the age of six.

12. Family income up to 185% of federal poverty guide lines or eligible for family assistant programs

    This risk factor refers to families who are eligible for federal assistance programs, such as AFDC, Medicaid, or WIC. The poverty line, which varies by family size, is the income level that agencies within the federal government set to approximate the amount of money that will allow a frugal family to pay for its most essential needs which include food, shelter, and clothing (Edelman, 1987; Sidel, 1986). In 1989, the poverty line was $12,675 for a family of four and $9,890 for a family of three.

13. The presence of one or more of the following demographic characteristics:

Parent education is less than ninth grade
Neither parent is employed
Single parent

This risk factor refers to one or more of three specific demographic indices which are typically found to be highly interrelated. The demographic indices subsumed under this risk factor are: families where either parent has less than a ninth grade education, families where neither parent is currently employed, or families where there is only a single (i.e., separated,, widowed, divorced, never married) parent.

14. Physical or social isolation and/or lack of adequate social support

This risk factor refers to families who are geographically or emotionally isolated such that there is a very limited connection to personal or community networks. This risk factor also refers to the isolation that may occur when families are non-English speaking.

15. Lack of stable residence, homelessness, or dangerous living conditions

This risk factor refers to the absence of permanent housing resulting in the need to be housed in temporary shelters, or welfare hotels; transient living situations due to frequent shifts in residence; or dangerous living conditions which include housing situations characterized by a high level of crime and violence or housing situations which are physically unsafe and/or have been condemned.

16. Family has inadequate health care or no health insurance

This risk factor refers to relies who have no regular health care maintenance for their child or the family has no private medical care. In some cases, this risk factor may include families who are Medicaid eligible or covered by Medicaid.

17. Limited prenatal care

This risk factor refers to pregnant mothers who have had four or fewer obstetrical visits prior to the 34th week of pregnancy or whose prenatal care was initiated in the third trimester.

18. Maternal prenatal substance abuse/use

This risk factor refers to regular maternal use of tobacco, alcohol (more than one drink per day), or illicit and prescription drugs known to affect the developing fetus during pregnancy. Information on drug use may be obtained through self-report or results from urine analysis procedures.

19. Severe prenatal complications

This risk factor refers to complications during pregnancy known to potentially compromise neonatal outcomes. Examples of such complications include moderate to severe toxemia, placenta previa, abruptio placentae, more than one infant in a single pregnancy (i.e, twins, etc.), or such maternal illness as diabetes, rubella, etc.

20. Severe Perinatal complications

This risk factor refers to severe complications in the birth and postpartum period, such as prematurity, respiratory distress syndrome, etc. This risk factor should not be used in conjunction with another risk factor, very low birth rate, unless there are severe perinatal complications other than prematurity or respiratory distress which describe this infant.

21. Asphyxia

This risk factor refers to particular cluster of clinical signs which indicate that a reduction in the oxygen level below the physiological requirements of the neonate has occurred (Amiel-Tison & Ellison, 1986; Blackman, 1989; Brann, 1986; Broman, 1979). The clinical signs of asphyxia include fetal distress (i.e., fetal heart rate during the first stage of labor is lower than 120 or above 160, abnormal heartbeat patterns, and/or the passage of meconium) and neonatal distress (e.g., poor color, poor muscle tone, failure to breathe spontaneously as typically assessed by the Apgar scores used to designate the occurrence of asphyxia). To interpret a low Apgar (i.e., at least 5) as indicative of asphyxia, other signs known to occur during intrapartum asphyxia must also be present (e.g., fetal distress, passage of meconium, etc.). Symptoms in the neonate that indicate that asphyxia occurred are: lethargy (abnormal state of consciousness), seizures, abnormal muscle tone, poor feeding, and abnormal reflexes. Thus, the most accurate assessment that an infant has been asphyxiated is based on an indication of fetal distress in conjunction with evidence of immediate neonatal distress and signs of CNS abnormality.

22. Very low birthweight

This risk factor refers to premature infants whose birth weight is less than 1500 grams or 3.3 lbs.

23. Small for gestational age (SGA)

Small for gestational age (SGA) refers to infants whose birth weights are abnormally small for their gestational age. Researchers have been very consistent in defining abnormally small as having a birth weight below the 10th percentile for gestational age on one of several sets of sex-specific norms for that population (Klebanoff, Meirik & Berenedes, 1989; Neligan, Kolvin, Scott & Garside, 1976; Parkinson, Scrivener, Graves, Bunton & Harvey, 1986). This term can refer to premature or full-term infants.

24. Excessive irritability, crying, or tremulousness on the part of the infant

This risk factor refers to specific behavioral characteristics of the neonate and infant-excessive irritability, crying, or tremulousness, which are not responsive to usual comforting measures. These characteristics may be related to the infant's inability to self-regulate transitional behavioral states, physiological immaturity, and/or temperament. The presence of this risk factor should be differentiated from Regulatory Disorders (under established conditions) which may be characterized by these same behavioral symptoms. Regulatory disorders are defined by distinct behavioral patterns coupled with sensory, sensory-motor, or organizational processing difficulties which affect daily adaptation and interaction/relationships (NCCIP, 1990).

25. Atypical or recurrent accidents involving the child

This risk factor refers either to unusual accidents of the type not commonly experienced by the child's developmental age (e.g., broken leg) and to recurrent accidents which could imply the existence of physical disease, environmental neglect, or child abuse.

26. Chronic Otitis Media

Otitis media refers to the infection of the middle ear and resulting effusion (development of fluid) in the middle ear cleft behind the tympanic membrane (Feagans, Sanyal, Henderson, Collier & Applebaum, 1987). The greater the build up of fluid, the more likely it is that a mechanical blockage will result. Chronic otitis media refers to blockages/infections that do not drain in a timely fashion and are resistant to typical drug treatment procedures. A history of recurrent bouts of acute otitis media (i.e., at least six times in a year's period) often implies a condition of chronic otitis media.

Appendix B

Definition of Service Coordination from Code of Federal Regulations (CFR)

CFR 303.22 Service coordination (case management)

(a) *General.* (1) As used in this part, except in 303.12(d)(11), *service coordination* means the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program.
(2) Each child eligible child under this part and the child's family must be provided with one service coordinator who is responsible for-
(i)Coordinating all services across agency lines; and (ii) Serving as the single point of contact in helping parents to obtain the services and assistance they need.
(3)Service coordination is an active, ongoing process that involves-
(i) Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan;
(ii) Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided;
(iii) Facilitating the timely delivery of available services; and
(iv) Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility.

(b) *Specific service coordination activities.* Service coordination activities include-
(1) Coordinating the performance of evaluations and assessments;
(2) Facilitating and participating in the development, review, and evaluation of individualized family service plans;
(3) Assisting families in identifying available service providers;
(4) Coordinating and monitoring the delivery of available services;
(5) Informing families of the availability of advocacy services;
(6) Coordinating with medical and health providers; and
(7) Facilitating the development of a transition plan to preschool services, if appropriate (p. 40964).

Appendix C

Service Coordinator Questionnaire

Please respond to each of the following items by checking the appropriate space or filling in the appropriate answer.

1. Name:____ID#_______

2. Sex: ___Female ___Male

3. Number of years working directly with families (as opposed to children): _____years

4. Number of years providing service coordination or case management to ***Early On*** **eligible families**: _____years

5. Area(s) in which you received your training and degrees held: Check all that apply.

___Social Work ___BA/BS ___MSW ___Ph.D.
___Other, please specify_______________________________________.

___Special Education ___BA/BS ___MA/MS ___Ph.D.
___Other, please specify_______________________________________.

___Public Health Nursing ___BA/BS ___MA/MS ___Ph.D.
___Other, please specify_______________________________________.

___Physical Therapy ___BA/BS ___MA/MS ___Other, please specify_______________________________________.

___Occupational Therapy ___BA/BS ___MA/MS ___Other, please specify_______________________________________.

___Speech and Language Therapy ___BA/BS ___MA/MS ___Ph.D.
___Other, please specify_______________________________________.

___Psychology ___BA/BS ___MA/MS ___Ph.D.

___Other, please specify____.

___Other, please specify discipline (e.g., nutrition, counseling, nursing) and degree held: ____.

6. In which of the following have you received inservice training? Please **estimate** the number of hours of inservice received.

____typical infant development
____atypical infant development
____infant assessment
____infant intervention
____infant/parent relationships
____family assessment
____family-centered practices
____family intervention
____case management/service coordination
____interdisciplinary team process/collaboration
____advocacy
____adult learning styles

7. In which of the following have you had college/university coursework? **Please estimate the number of credits and if they were semester or term credits.**

	Term	Semester
a. typical infant development	____	____
b. family intervention	____	____
c. atypical infant development	____	____
d. case management/ service coordination	____	____
e. infant assessment	____	____
f. infant intervention	____	____
g. family assessment	____	____
h. family systems	____	____
i. interdisciplinary team process	____	____

8. How many different roles (e.g., service coordinator, direct service provider, administrator) are you required to fulfill in your present position? Please indicate number and specify those roles:

___1 ___2 ___3 ___4 or more roles

____
____
____

9. For how many families do you coordinate services? _____families

10. How many hours are you contracted to work per week (i.e, are you full-time or part-time)? ______hours

11. Based on a 40 hour week, indicate the number of hours for which you are contracted to provide service coordination to families (e.g., 10 hours per week, 20 hours per week)? _____hours

Appendix D

Family Empowerment Scale

Below are a number of statements that describe how a parent or caregiver of a child with a disability may feel about his or her situation. For each statement, please CIRCLE the response that best describes how the statement applies to you.

	Not True At All	Mostly Not True	Some-what True	Mostly True	Very True
1. I feel that I have a right to choose all services that my child receives..	1	2	3	4	5
2. When problems arise with my child I handle them pretty well..	1	2	3	4	5
3. I feel I can have a part in improving services for children in my community...	1	2	3	4	5
4. I feel confident in my ability to help my child grow and develop..	1	2	3	4	5
5. I know the steps to take when I am concerned my child is receiving poor services..................................	1	2	3	4	5
6. I make sure that service providers understand my opinions about what services my child needs..............	1	2	3	4	5
7. I know what to do when problems arise with my child...	1	2	3	4	5
8. I get in touch with my legislators when important bills or issues concerning children are pending...........	1	2	3	4	5
9. I feel my family life is under control.......................	1	2	3	4	5
10. I understand how the service system for children is organized...	1	2	3	4	5
11. I am able to make good decisions about what services my child needs...	1	2	3	4	5

	Not True At All	Mostly Not True	Some-what True	Mostly True	Very True
12. I am able to work with agencies and professionals to decide what my child needs	1	2	3	4	5
13. I make sure I stay in regular contact with the people who are providing services to my child	1	2	3	4	5
14. I have ideas about the ideal service system for children	1	2	3	4	5
15. I help other families get the services they need	1	2	3	4	5
16. I am able to get information to help me better understand my child	1	2	3	4	5
17. I believe that other parents and I can have an influence on services for children	1	2	3	4	5
18. My opinion is just as important as professionals' opinions in deciding what my child needs	1	2	3	4	5
19. I tell professionals what I think about services being provided to my child	1	2	3	4	5
20. I tell people in agencies and government how services for children can be improved	1	2	3	4	5
21. I believe I can solve problems with my child when they happen	1	2	3	4	5
22. I know how to get agency administrators or legislators to listen to me	1	2	3	4	5
23. I know what services my child needs	1	2	3	4	5
24. I know what the rights of parents and children are under the special educational laws	1	2	3	4	5
25. I feel that my knowledge and experience as a parent can be used to improve services for children and families	1	2	3	4	5
26. When I need help with problems in my family, I am able to ask for help from others	1	2	3	4	5
27. I make efforts to learn new ways to help my child grow and develop	1	2	3	4	5
28. When necessary, I take the initiative in looking for services for my child and family	1	2	3	4	5
29. When dealing with my child, I focus upon the good things as well as the problems	1	2	3	4	5

	Not True At All	Mostly Not True	Some-what True	Mostly True	Very True
30. I have a good understanding of the service system my child is involved in...	1	2	3	4	5
31. When faced with a problem involving my child, I decide what to do and then do it..................................	1	2	3	4	5
32. Professionals should ask me what services I want for my child..	1	2	3	4	5
33. I have a good understanding of my child's disorder...	1	2	3	4	5
34. I feel I am a good parent.......................................	1	2	3	4	5

Appendix E

Selected Items from Questionnaire on Resources and Stress-Short Form Adapted

3. T F If my son/daughter were more pleasant to be with, it would be easier to care for him/her.

4. T F Our family agrees on important matters.

5. T F The constant demands for care of my daughter/son limit growth and development of someone else in our family.

6. T F I worry about what will happen to my son/daughter when I can no longer take care of him/her.

7. T F There is no way we can possibly keep my daughter/son in our house.

8. T F We can afford to pay for the care of my son/daughter needs.

11. T F My daughter/son is easy to live with.

13. T F We enjoy my son/daughter more and more as a person.

15. T F Having to care for my daughter/son has enriched our family life.

16. T F My son/daughter doesn't do as much as he/she should be able to do.

17. T F Our family has received public assistance.

20. T F Our family income is more than average.

21. T F Caring for my daughter/son gives one a feeling of worth.

22. T F One of us has had to pass up a chance for a job because my son/daughter could not be left without someone to watch him/her.

24. T F I worry about what will be done with my son/daughter when he/she gets

older.

25. T F There is a lot of anger and resentment in our family.

26. T F Our family has managed to save money or make investments.

30. T F It is easy to keep my daughter/son entertained.

31. T F In the future my son/daughter will be more able to help himself/herself.

34. T F We can hardly make ends meet.

35. T F Members of my family are able to discuss personal problems.

36. T F My daughter/son is very irritable.

37. T F It is easy for me to relax.

38. T F I rarely feel blue.

39. T F Because my son/daughter uses special equipment and facilities, it is difficult to take him/her out.

Appendix F

Service Coordination Scale

	Much less than needed	Some-what less than needed	Just about right	Some-what more than needed	Much more than needed
21. Would you say the amount of contact with your service coordinator was...	1	2	3	4	5

22. <u>My Service Coordinator</u>:	Strongly Agree	Some-what Disagree	Neither Agree nor Disagree	Some-what Agree	Strongly Agree
a. helped us only when we were ready.........	1	2	3	4	5
b. helped us to get the information we needed...	1	2	3	4	5
c. made decisions for my family.................	1	2	3	4	5
d. put my family in touch with other families who had been through what we are going through..	1	2	3	4	5
e. let us know that our feelings were OK.....	1	2	3	4	5
f. supported us in making decisions and solving problems for our child and family...	1	2	3	4	5
g. helped us see the "good" things about our child with a special need.......................	1	2	3	4	5
h. helped us get the services we needed.......	1	2	3	4	5
i. helped us identify our child's and family's needs...	1	2	3	4	5
j. helped us to see that our child's condition is not our fault..	1	2	3	4	5

22. <u>My Service Coordinator</u>:	Strongly Agree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree
k. encouraged us to talk when we needed to	1	2	3	4	5
l. respected our family's beliefs	1	2	3	4	5
m. respected our family's privacy	1	2	3	4	5
n. helped us identify friends and family members who could help us meet our needs	1	2	3	4	5

	Very Unwilling	Somewhat Unwilling	Neither Willing Nor Unwilling	Somewhat Willing	Very Willing
23. How willing or unwilling was your service coordinator to meet and work with you as a partner?	1	2	3	4	5
24. How willing or unwilling was your service coordinator to meet and work with other people important to your family?	1	2	3	4	5
25. How willing or unwilling was your service coordinator to go out of his/her way to help your family?	1	2	3	4	5

26. <u>How would you rate</u>:	Terrible	Poor	Fair	Good	Excellent
a. the quality of help from your service coordinator in getting the services you family needed?	1	2	3	4	5
b. your service coordinator in helping you plan for the future?	1	2	3	4	5

	Very Dis-Satisfied	Somewhat Dis-Satisfied	Neutral	Somewhat Satisfied	Very Satisfied
27. How satisfied or dissatisfied are you with the service coordination your family has received?	1	2	3	4	5

Appendix G

Service Coordinator Interview Guide

1. Tell me about what it's like to be a service coordinator.

<u>Probes</u>:

-How do you feel about your job.
-What do you like and dislike.

2. Tell me about how you see the role of the service coordinator in working with families?

<u>Probes</u>:

-What do they do?
-What should they do?
-What do you believe are important responsibilities of a service coordinator?

3. Describe one of your typical days. We all have time crunches--how do you decide what has to get done in a day?

<u>Probes</u>:

-What do you think about when deciding what to do first?
-What think are the most important things you do?

4. What do you think families want/need from professionals?

<u>Probes</u>:

-What do you think families say they need/want?
-What helps families?
-Who helps families?
-How do you find this out?

5. Tell me about your relationships with the families with whom you work.

<u>Probes</u>:

-What do they feel like?
-How do you work with them?
-Where do you work with them?
-Who does what? How is this decided?

6. Are there situations that make you feel uncomfortable or uneasy?

<u>Probes:</u>

-Are there specific things that make it difficult to develop a relationship with a family? If so, can you describe these?
-Do you feel you have the skills you need to work with a particular family? If not, describe a time when you felt like you needed more or different skills.

7. What would increase your level of comfort?

<u>Probes:</u>

-Would additional skills help? What types, if any?
-Do you have support in place?
-What types of supports might be helpful?

8. What do you think a service coordinator can do to make a positive contribution to the lives of families who have an infant or toddler with a disability?

<u>Probes</u>:

-What will help a family the most?
-What is the most important thing for them to learn.

9. What do you think helps families feel empowered and able to cope?

<u>Probes</u>:

-What makes families feel empowered?
-What helps families cope?
-What do you think you do that helps families feel empowered and able to cope?
-What is it about how you do your job that helps families feel empowered and able to cope.

Appendix H

Observation Form

Name of Interviewee______________________________ID#_____Date_______

Begin Time_______End Time_______Location____________________________

Objective Observation	Subjective Interpretation

Appendix I

Table 7 - Zero-Order Correlations for Fathers on Variables of Interest

	Service Coordinator Scale	Parental Perceived Empowerment	Parental Perceived Coping
Service Coordinator Scale	1	.11	.65*
Parental Perceived Empowerment	.11	1	.37
Parental Perceived Coping	.65*	.37	1

*p < .05

Appendix J

Questions From Interviews and That Emerged From Initial Coding Of Interviews

1. Who do they think is in charge (them vs. family)?

2. What is their view of their role?

3. What is their view of families?

4. What is their approach to families?

5. How broad is the scope of the service coordination provided by the service coordinator?

6. How do they feel about their jobs?

7. Do they mention risk-taking or engage in risk-taking behaviors?

8. What is their point of focus (child vs. family)?

9. How available are they to families (different times, emotionally).

10. How is information gained from families?

11 What is their predominant style of communication (direct vs. indirect, honesty)?

12. Who decides who is the service coordinator (families, system)?

13. What is their desired outcome for families?

14. Who decides when the visits with the family are scheduled (family vs. service coordinator).

15. What is their awareness of what families say they want or need?

16. What do they think are important responsibilities for service coordinators?

17. What do they think empowers families?

18. What skills do they think families should learn?

19. What is their awareness of the outcome of different styles of help-giving?

20. Do they recognize the need for parent-to-parent connections?

21. How do they describe their relationships with families?

22. What is their understanding/view of the IFSP?

23. What is their level of support?

24. What is their level of professional-to-professional connections?

25. What interagency structure exists to support them?

26. What is their knowledge of families (e.g., functioning, dynamics?

27. What is their knowledge base for the profession?

28. Are their examples of empathy?

29. What do they prioritize?

30. What is the frequency and duration of visits with the family?

31. What do they say makes them uncomfortable or uneasy?

32. Do they work with the child in the context of the family?

33. What is their view of the future for the child and family? Are they preparing them for the future?

34. What do they think they do that makes a positive contribution to the lives of the families with whom they work?

Appendix K

Matrix Sample

Service Coordinator	P1 Low Rated	P2 Low Rated	P3 Low Rated	P5 Low Rated	P6 Low Rated	P4 High Rated	P7 High Rated	P8 High Rated	P9 High Rated	P10 High Rated
Who's In Charge										
View of Role										
View of Families										
Approach to Families										
Scope of Service Coordination										
Feel About Job										
Risk-Taking										
Point of Focus										
Availability										
How information Gained										

Appendix L

Table 8 - Mean Scores for Individual Service Coordination Scale (SCS) Items

SCS Item	Higher Rated Service Coordinators	Lower Rated Service Coordinators	Difference Between Mean Scores
#21 Amount of contact with service coordinator	4.66	3.54	1.12
#22a Helped only when ready	4.12	3.12	1.00
#22b Helped get information	4.94	3.28	1.6
#22c Made decisions for family	2.58	3.12	-.54
#22d Put in touch with other families with similar experience	3.30	2.42	.88
#22e Let know feelings ok	4.92	3.36	1.56
#22f Supported in decision-making	5.00	3.20	1.80
#22g Helped see "good" things about child	5.00	3.26	1.74
#22h Helped get services	4.74	2.86	1.88
#22i Helped identify needs	4.84	2.86	1.98
#22j Helped see not our fault	4.62	3.44	1.18
#22k Encouraged us to talk	4.92	3.06	1.86
#22l Respected family beliefs	5.00	3.38	1.62
#22m Respected family privacy	5.00	3.60	1.40
#22n Helped to identify friends and family to meet needs	4.34	3.00	1.34
#23 Willingness to work as partner	4.94	3.58	1.36
#24 Willingness to work with other people	5.00	3.26	1.74
#25 Willingness to go out of way to help	4.94	3.26	1.68
#26a Quality of help in getting services	4.96	3.60	1.36
#26b Helping to plan for future	4.86	3.00	1.86
#27 Satisfaction with service coordinator	5.00	3.30	1.70

Appendix M

Letter Accompanying Service Coordinator Questionnaire

Date

Dear Service Coordinator,

My name is Roberta Purcell and I am a doctoral student at Michigan State University in the Department of Family and Child Ecology. I am writing to ask you to participate in a study I am conducting regarding the very important helping relationship that exists between service coordinators and the families who have infants and toddlers with disabilities with whom the service coordinator works. Thomas Luster, Ph.D. is assisting me with this research. I am particularly interested in the relationship between the characteristics of service coordinators (e.g., educational background, areas of training, number of families on caseload) and how empowered and able to cope families perceive themselves to be.

I would really appreciate your assistance with this project. If you choose to participate in this study, please complete the enclosed questionnaire and return it in the self-addressed, stamped envelop provided for your convenience. It will take approximately 15 minutes to complete the questionnaire. Participation in this study is strictly voluntary. Your completing and returning this questionnaire indicates your voluntary agreement to participate.

Your responses to the survey will be kept in strict confidence. All subjects will remain anonymous in any report of research findings. If requested, overall results will be shared. If you have any questions or concerns, I can be reached at 517-347-7066. I hope you will decide to become a part of this important research by completing and returning the enclosed questionnaire by (Date). Thank you so much for you time. I look forward to hearing from you.

Sincerely,

Roberta L. Purcell
Doctoral Candidate
Michigan State University

Appendix N

Series of Letters to Interview Participants

Letter One
Date

Dear (Person's Name):

I am a doctoral student at Michigan State University in the Department of Family and Child Ecology. I am conducting research about the relationship between service coordination and how empowered and able to cope parents of infants and toddlers with disabilities perceive themselves. I am interested in knowing more about how service coordinators view their roles and their relationships with families. In order to better understand this relationship I will be having service coordinators complete a questionnaire and will be interviewing a few service coordinators in depth. You may have already received the questionnaire.

I have identified you as a person who provides service coordination to infants and toddlers from the data base maintained for the Michigan Department of Education on children eligible to receive services under Part H of the Individuals with Disabilities Education Act (*Early On*® Michigan). If you would be willing to do so, I would like you to be a participant in the interview portion of my study. The interview would take approximately one hour and I would come to your office. My goal is to determine what supports service coordinators may need in order to help them provide the type of service coordination that families say they need.

I will be calling in a week or two to see if you would be willing to participate in this study. Of course, I completely understand if you do not feel you can participate in this study. I look forward to talking with you in the near future and can answer any additional questions at that time.

Sincerely,

Roberta L. Purcell
Doctoral Candidate
Michigan State University

Letter Two
Date

Dear (Person's Name):

I really enjoyed having the opportunity to speak with you on the phone today. Thank you so much for agreeing to participate in my study. I hope you now know what to expect during the interview. Please complete the enclosed consent form. You can give it to me when I arrive for the interview on (Date and Time). Thank you again for your willingness to participate in this study. Ultimately your participation will help us to know what service coordinators need in order to help the families with whom they work. I look forward to meeting you in person.

Sincerely,

Roberta L. Purcell
Doctoral Candidate
Michigan State University

Letter Three
Date

Dear (Person's Name),

Thank you so much for being a participant in my research project. I really enjoyed the time I spent talking with you and I learned a great deal. I hope it was an enjoyable experience for you also. It isn't often that we actually get the opportunity to stop and reflect on how we carry out our professional roles.

Once again, thank you for your assistance. If you have any further questions about my study do not hesitate to contact me.

Sincerely

Roberta L. Purcell
Doctoral Candidate
Michigan State University

Appendix O

Interview Consent Form

1. I have freely consented to take part in a study conducted by Roberta L. Purcell, a doctoral student at Michigan State University under the supervision of Thomas Luster, Ph.D., a Professor in the Department of Family and Child Ecology at Michigan State University. This research requires me to participate in an interview in which I will be asked questions about my role as a service coordinator to families who have infants and toddlers with disabilities. I understand that the interview will take approximately 60 to 90 minutes.

2. This study has been explained to me and I understand the intent of the study and what my participation will involve.

3. I understand that I may refuse participation in the study, and may discontinue participation at any time. In addition, I understand that I may refuse to answer any of the questions during the interview.

4. I have given my permission to have this interview audio-taped, with the understanding that my identity will be kept confidential and that the interview will be erased as soon as it is transcribed. I understand that the transcriptions will be identified by a code number rather than by my name.

5. I understand that when the results of the study are reported, the interviews will be grouped together and that my responses will remain anonymous. Results of this study will be available to me upon my request.

6. I know that if I have any questions or concerns about my participation in this study I can contact Roberta Purcell at 517-347-7066.

Signed:____

Date:____________________________

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