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FAMILIES OF YOUNG CHILDREN WITH DISABILITIES IN MICHIGAN: USING GROUNDED THEORY TO UNDERSTAND THEIR EXPERIENCES WITH FORMAL EARLY INTERVENTION SYSTEMS

By

Jacquelyn J. Thompson

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ABSTRACT

FAMILIES OF YOUNG CHILDREN WITH DISABILITIES IN MICHIGAN: USING GROUNDED THEORY TO UNDERSTAND THEIR EXPERIENCES WITH FORMAL EARLY INTERVENTION SYSTEMS

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Jacquelyn J. Thompson

To meet the needs of families of young children with disabilities and to become more family centered in practice, formal early intervention systems must understand what families need and expect from the system, and how families would like to work with the professionals in the system. This study examined the perceptions of families relative to their experiences with early intervention systems in Michigan; attention was focused on family needs, family expectations, and family processes relative to such interactions.

The framework for this study was an ecological model of the family as a social system which interacts with and is interdependent on other systems for exchanges of information, goods, and services. Embedded in this framework are theories of family systems and symbolic interaction which provided the constructs for the analysis of the social interactions between families and professionals in early intervention systems.

Using a grounded theory process of qualitative research, the written responses of 45 mothers of children under the age of 6 with disabilities were analyzed. Emergent in the analysis of these data were the processes of goal-seeking and self-regulation, constructs of family systems, which shaped interactions between families and professionals. Using coding paradigms, constant comparison, and theoretical sampling, conceptual categories of actions and interactions between family and early intervention systems were discovered. The central phenomenon was the need that families have to understand how to be a family of a child with a disability in order to shape a future for the child and family.

The data revealed family attention to early intervention as a process of gaining knowledge and understanding, a process of family development, a process based on relationships between the family and the early intervention providers. Respondents emphasized family goal attainment as a measure of satisfaction with early intervention services. The emergent theory suggests that a component of effectiveness in early intervention is the extent to which professionals actively and sensitively engage in these goal-seeking processes with families.

DEDICATION

The findings of this study, which enhance our understanding of family processes, are dedicated to those mothers and children who have informed much of my professional practice and accomplishments. Without their generosity in sharing their experiences and their commitment to improving the delivery of early intervention services in Michigan, this study would have less potential to impact the early intervention system. In addition, without their involvement, my own theoretical sensitivity, a significant part of the grounded theory research process, would have been lessened.

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Personal and professional goals are not attained without support, encouragement, and guidance from those who share space in one's human environment. My earliest memories of my mother match the reality of today; I have benefited from her lifelong belief in my abilities and my potential. My husband Don, a partner for more than twenty years, has without fail supported and encouraged my academic and professional aspirations. Megan and Andy, our legacies in human development, have grown up during the course of my academic passages and have cheered for me at every milestone. Without family, this accomplishment would be diminished. My life's journey has been shaped and enriched by each of them.

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numerous dissertations which line her bookshelves. Her attention to detail and her knowledge of university process and protocol are held in high esteem by all of us whose complex personal ecologies leave little time for errors in this domain. My gratitude to her for the support and guidance she has provided is immeasurable.

My other committee members, both old and new, have been most appreciated. Dr. Barrie Thorne, now at the University of Southern California, taught me about gender issues; Dr. Brian Rowan, now at the University of Michigan, taught me about the complexities of organizations; and Dr. Tom Luster supported me through both the comprehensive examination and a search for a research area and methodology which fit my interests and talents. Drs. Anne Soderman, June Youatt, and Lou Alonso have been most supportive of my research and share responsibility for the fine tuning of this product. To all of these exceptional people I offer my thanks and appreciation.

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CHAPTER I

A CHALLENGE TO PROVIDERS OF EARLY INTERVENTION SERVICES

If families of young children with disabilities are to be effectively served and supported through the delivery of early intervention services, it is imperative that families have the opportunity to provide input regarding the impact of such services upon their child and family, and to share with the early intervention providers their perspectives regarding family needs and their expectations of the early intervention service system. Families have valuable insight regarding the quality of such services, the level to which such services may or may not be sensitive to family issues, and are best able to inform early intervention providers regarding family needs for support and assistance at a most vulnerable time in the life of the of family, i.e. when a disability is identified in a young child (Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992).

Professionals who provide early intervention services to families with young children with disabilities enter the life of a family at a time when families are searching for answers, for understanding, and for help in learning how to meet the needs of their child. Families want to believe that perhaps, after all, their child can be helped and that everything will be all right (Healy, Keesee, & Smith, 1985).

A Michigan mother of a child with a disability speaks eloquently of her reactions to the diagnosis, when it finally was determined, and shares her thoughts, in part (Appendix A), in the following manner (Fialka, 1993):

> I want my son back. That's all.
> I want him back now. Then I'll get on with my life
> If you could feel the depth of this wrenching pain.

If you could see the depth of our sadness
then you would be moved to return
our almost five year old son
who sparkles in the sunlight
despite
faulty neurons.

Please give me back my son
undamaged and
untouched by your labels, test results,
descriptions and categories.

If you can't,
If you truly cannot give us back our son

Then just be with us quietly,
gently
and compassionately as we feel.

Families who face such experiences as the one shared above find themselves thrust into a world of professionals, jargon and labels, intense emotions, and uncertain outcomes. For the professionals who are there to work with these families, the skill necessary to successfully assist families through this difficult period is of critical importance and is in addition to their disciplinary expertise. This is recognized and has been underscored by a major policy commitment in the United States through the passage of Public Law 99-457, the 1986 Amendments to the Education of the Handicapped Act (Hanson & Lynch, 1989).

The Challenge in Michigan

Part H of this act, the Handicapped Infants and Toddlers section, required significant changes to the delivery model for early intervention services as previously practiced in Michigan. A pioneer birth-mandate state, i.e. a state entitling special education and related services to children with disabilities from birth, Michigan had been providing free appropriate public education to infants and toddlers with disabilities since 1973, using a mildly modified Kindergarten through Grade Twelve model of service delivery. Such services were child-centered, specialized, and were delivered through the public education system.

This new legislation provided planning and development monies to states to implement a statewide, interagency, multidisciplinary, comprehensive system of early intervention services to infants and toddlers with disabilities and their families. The advocacy leading to this legislation sought to eliminate fragmentation of services and to direct attention to the family as the most important context for developmental and therapeutic services for this birth to three special population, rather than to the child alone. Further, the planning and development process was regulated to be interagency by design and to include parents as partners in the development of state policy and in the design of individual service plans for their child and family.

The concepts of family involvement, parents as partners with professionals, and family-centered services have brought new parameters to the field of early intervention for children with disabilities. Duwa, Wells, and Lalinde (1993) contend the heart and soul of this dramatic change is the reconceptualization from a child-centered to a family-centered service delivery system. These major changes are accompanied by a multitude of known and unknown challenges (Bailey, Buysse, Edmondson, & Smith, 1992; Bailey, Palsha, & Simeonsson, 1991; Dunst, Johanson, Trivette, & Hamby, 1991). Such challenges include changes in systems design, organizational structure, professional attitudes and behaviors, and training programs for future professionals, among others.

Of all of the challenges, however, those of creating a family-based system where families are indeed the focus of the intervention, where families participate at the level of their choice in service planning, and where professionals are comfortable as the facilitator rather than the leader, are of utmost concern to families. This expanded emphasis on family is based on the ecological and family systems philosophy that the child's needs are connected to those who are central in his or her care and nurturance (Richmond & Ayoub, 1993). Such a perspective recognizes the complexity of the interactions of family systems as well as the importance of such interactions on developmental outcomes for children. An ecological perspective also recognizes the variability and uniqueness of each family system both in its adaptation to stressors, such as the birth of a child with a disability, and in its response to the necessary exchanges with other systems, such as formal early intervention service systems.

An additional component is the expectation enforced by the current legislation that parents will participate as equal partners in planning for the early intervention services needed by their child and family. This aspect of family involvement is also new to the early intervention system and presents both opportunities and high expectations for and among families who are stakeholders in this system. Harnessing the talents and diversity of the programs and people, including parents, involved in early intervention programs is one of the major challenges in the realization of the promise of the Infant and Toddler Program (Meisels, 1993). Participation by parents and service systems personnel in mutual planning for individual family services stretches the historical boundaries of interaction between and among families and formal systems.

Background of the Problem

An ideological shift over the past two decades has resulted in the recognition of the importance of developing programs for children within the context of the family (Beckman & Bailey, 1990). Part H presents a unique opportunity for families and professionals to create partnerships that can redefine, reshape, and redirect early intervention for infants and toddlers with special needs and their families (McGonigel, Kaufmann, & Johnson, 1991).

The law requires that multidisciplinary team members collaborate with families to develop and implement an Individualized Family Service Plan, known as the IFSP. Family members may, if they wish, become full team members; federal regulations make it clear that the ultimate decision-making authority on whether to accept early intervention services rests with the family (Nash, 1990). Assessment, service planning, and interventions must be done "with the full participation and agreement of the parents of the child" (Federal Register, 1989, p. 26306). McGonigel and Garland (1988) have argued that, in implementing P.L. 99-457, professionals should be less concerned with making a place for the family on the early intervention team than with developing strategies that will enable professionals to become members of the family's team. The desired outcome of increased family involvement is for early intervention to become a collaborative process where the multidisciplinary team is, to the extent that the family desires, a family driven system (Nash).

However, prior to this landmark legislation, family participation on multidisciplinary teams working to develop the Individualized Education Program, or IEP, as required by the original Education of the Handicapped Act, has been limited by professional perspectives that place relatively little value on the input of parents (Day, 1985; Gilliam & Coleman, 1981; Pfeiffer, 1980; Shelby, 1985). Team participation has been limited to those with specific expertise based on formal training and hard data (Nash, 1990). Typically, only the professionals involved in the evaluation and assessment of the child's disability were involved in creating intervention plans; families were informed after the fact and asked to approve the plans. Therefore, family members have been limited to passive roles such as listening to professional input and being informed of decisions professionals have made (e.g., Crisler, 1979).

Prior to the enactment of Part H, program effectiveness has not been determined to be improved by family participation on multidisciplinary teams working with young children with handicapping conditions and their families (Castro & Lewis, 1984; Winton, Turnbull, & Blacher, 1985). In fact, parents have been seen as at risk of being perceived as inferior by professional team members (Bailey, 1984; Gilliam & Coleman, 1981; Shelby, 1985; Turnbull & Winton, 1984). By virtue of their specialized clinical knowledge, professionals become the experts, entitled to play a dominant role in their interactions with parents. If they recognized the parents' perspectives as valid, professionals would have to yield some of their dominance (Darling, 1989). As parents realized their positions on teams, they generally withdrew from active participation, depriving the team of their input (Bailey, 1984). With this history of limited membership on the interdisciplinary team, parents are encouraged by Part H to seek their place, while professionals may be challenged to reexamine their perceptions regarding the role of parents as team members.

Generally, as families have entered the service system due to the special needs of their young children, their situation has been professionally defined from a clinical perspective; the operating definition of the situation that is used may or may not be the same that is used by the family (Darling, 1989). Such clinical definition usually places the child and family in a diagnostic category which results in the loss of the uniqueness of the family and eliminates the consideration of any social system or other external cause as relevant to the issues facing the child and family (Darling). Consideration of all the systems with which the family interacts complicates the intervention process and is thus easily dismissed by the service providers. Moving toward a family-centered system of service provision presents many challenges to professional service providers, to those who train and educate them, and to families whose role in the early intervention system is expected to be enhanced.

Statement of the Problem

In order to meet the needs of families of young children with disabilities and to become more family centered in practice, the formal early intervention service delivery system must understand what families need, what families expect from the system, and how families would like to work with the professional providers of the service delivery system. What must receive attention is how individual professionals within each discipline can respond to families as unique systems having needs, concerns, and goals of their own. The formal early intervention service delivery system has not asked families what they need or expect from the system. These questions must be asked, and the answers must impact the nature of the delivery of early intervention services provided, if the delivery system expects to work successfully with families as well as their children, i.e. to become a family-based system.

Therefore, this study will focus specifically on family responses to questions about family needs relative to early intervention services and about family expectations of the formal early intervention system.

Purpose

This study is the analysis of the qualitative comments made by families of young children with disabilities, as part of their participation in a previous study conducted by Merrill Palmer Institute at Wayne State University. Using the grounded theory approach, the comments of family participants in this project are analyzed for themes and concepts which can be described and discussed to enhance our understanding of this group of families, to improve the system of early intervention services, to identify additional research questions, and to advance our knowledge of the unique worlds of families who have young children with disabilities.

The goals of this study are to: (a) gain insight into perceptions of early intervention service systems held by families who unexpectedly find themselves in need of early intervention services due to the birth of a child with special needs, (b) gain insight into families' perceptions of needs as they begin the task of meeting the developmental challenges of a child with a disability, (c) enhance the understanding of policy-makers, administrators, and service providers who create systems of early intervention services regarding families' needs, and (d) develop an understanding of what professionals must know and therefore how they should be trained for a family-based service delivery model.

Research Questions

1. What do families believe is most important for early intervention service providers to know about working with families?

2. What do families need most when they first learn that their infant or toddler has a disability?

3. What would families tell other families who are looking for help for their infant or toddler?

4. What do families consider to be the best feature of the early intervention service system?

5. What do families consider to the the weakest feature of the early intervention service system?

6. What would families say to administrators of service systems about: (a) their services and agencies; and (b), the families they serve?

Conceptual Background

Families as social systems which interact with other formal and informal systems constitute the overarching framework for this study. This framework is an ecological model which draws attention to the various components of family functioning, both inside and outside the family system. Embedded in this framework are theories of family systems and symbolic interaction. As systems, families exhibit constructs of goal-seeking and self-regulating mechanisms (Broderick, 1993) which impact interactions with formal systems outside the family. Further, both within the family system and in interactions with other systems, communication constitutes the mechanism of interaction. Such communications can be direct, indirect, concrete, abstract, subtle, and are regulated by articulated and unarticulated family and systems rules (Burr, Hill, Nye, & Reiss, 1979; Kantor & Lehr, 1975; Olson et al., 1983). As used in this project, a systems framework provides a view of families and their perceptions as they interact with other systems which can be described and interpreted for meaning, within the context prescribed by this study. Symbolic interaction theory is the basis for the interpretation of such meaning; it allows the researcher to learn about the families' worlds, to interpret and translate the meaning to the language of the research discipline (Chenitz & Swanson, 1986).

An approach to deeper understanding and finding meaning, grounded theory is a qualitative process of research which was developed from symbolic interaction theory. It is an approach to data analysis which is drawn from the analytic methodology and procedures of inductive quantitative analysis developed in the Department of Sociology and the Bureau of Applied Social Research at Columbia University (Glaser, 1993). It is well suited to the study of families, a very specialized area of study; family phenomena are complex, subjective, private, and require methods which are tailored to this complexity and subjectivity (Gilgun, Daly, & Handel, 1992).

Assumptions

The following assumptions are made for the purposes of this study:

1. Families of young children with disabilities have unusual challenges in maintaining equilibrium in the family system.
2 Families of young children with disabilities, in seeking resources and supports to meet this challenge, typically interact with formal systems of services designed to support the needs of the child.
3. Families of young children with disabilities frequently interact with formal systems of services which may not always successfully respond to the variability of the family as a holistic unit, i.e. a unit which may be in need of

supports and which has resources and strengths of its own.

4. Families of young children with disabilities have perceptions of the nature and quality of these services and formal systems which can be used to enhance and improve such services and systems.

Definitions

Clarification of terms used in this study is necessary in order to assure an understanding of the concepts used and concepts which may emerge in the process of data analysis. Grounded theory, which will be the methodology employed in this study, generates conceptual categories from the evidence at hand and such categories may be used to illustrate the concepts which are discovered (Glaser & Strauss, 1967). In order to gain theoretical sensitivity in the process of using grounded theory methods, it is important to use as few predetermined concepts or ideas as possible; therefore, only basic terms will be defined at this time.

Agencies are those public and private entities which have as part of their mission the provision of specialized services for populations with special needs, such as education agencies, social service agencies, health agencies, mental health agencies, and others.

Disability refers to the handicapping condition, as referenced in the Individuals with Disabilities Education Act, and can mean developmental delay, specific sensory conditions such as visual or hearing impairments, specific diagnostic conditions such as cerebral palsy, Down syndrome, autism, physical or health impairments, general developmental delay of unknown origin, and other handicapping conditions; the list is not exhaustive.

Early intervention services are those services which are available to support the development of a child with special needs, as referenced in Part H of the Individuals with Disabilities Education Act. These may include: assistive technology, audiology, certain medical and health services, counseling and home visits, family training, nursing, occupational therapy, physical therapy, psychological services, screening, assessment and evaluation, service planning and coordination, speech therapy, special instruction, transportation, vision services, and other services identified as necessary to meet the needs of the child and family (Federal Register, 1993).

Family is defined as those persons who are identified as family members by the respondents in the study .

Part H is the early intervention program for infants and toddlers and their families as enacted by the U.S. Congress in 1986 as part of the Amendments to the Education of the Handicapped Act (now known as the Individuals with Disabilities Education Act).

Service Providers refers to those professional disciplines trained to provide specialized evaluation, assessment, intervention and therapeutic services to persons with disabilities, such as teachers, therapists, nurses, counselors, psychologists, and other specialists.

Significance of the Study

The 1992-93 date for the collection of the data analyzed in this study represents a baseline of information pertinent to the delivery of early intervention services for families with young children with disabilities in Michigan. Since the collection of these data, the state has adopted policy which requires that all components of Part H of the Individuals with Disabilities Education Act be implemented (Michigan State Board of Education, 1993). Inherent in the implementation of this legislation is a changing paradigm in service delivery from one which was child-centered to one which is attempting to become family-centered. The perceptions of the families who chose to provide information in the 1992-93 survey are valuable information for evaluation of the system of early intervention services in Michigan. The data are also valuable as information which can be used to enhance and improve the emergence of a family-based system of services through better understanding the needs and realities of families who have already experienced interaction with such systems. Further, this will be the first study using qualitative methods of analysis of existing family data relevant to Part H in Michigan.

The qualitative methodology employed in this study, grounded theory, will further an ecological understanding of families who face the challenges of raising children with disabilities and who must learn to interact with formal systems of services and resources. Use of this qualitative approach to understanding the meaning of some families' experiences and expectations will further the field of early intervention. Such qualitative methodology has been identified by Johnson and LaMontagne (1993) as an important and valuable resource for successfully distilling data generated from written or verbal communication from parents and other stakeholders in early intervention systems.

CHAPTER II

PRELIMINARY LITERATURE REVIEW

A preliminary literature review is provided to create a context for this study. A detailed literature review, pertinent to the conceptual categories which emerge as a result of the grounded theory process, will be incorporated into the study concurrent with the data analysis. This current review will include a brief history of early intervention, a review of parent and professional relationships prior to the implementation of Part H of the Individuals with Disabilities Education Act, an overview of the family systems perspective, and a review of some recent studies of families of young children with disabilities.

History of Early Intervention

The field of early intervention for children with disabilities has grown rapidly with the recognition that early support and intervention can make an important difference in the lives of infants and toddlers and their families. A broad array of services representing a variety of disciplines have emerged as necessary components in the delivery of early intervention services. The demand for early support and intervention has increased as a result of improved neonatal medical technology as well as ever increasing rates of neonatal exposure to toxic substances. Low birth weight babies as well as those with multiple and severe anomalies are surviving in increasing numbers as a result of dramatic improvements in neonatal intensive care (Eisenberg, Sutkin, & Jansen, 1984).

In addition, the rapidly increasing number of babies born with fetal alcohol syndrome or prenatal exposure to crack cocaine, as well as HIV infection, significantly increases the necessity for expanding early intervention services. These risk factors, in addition to what is referred to as the new morbidities of the 1990s (Vanderpool & Richmond, 1990), i.e. health issues which are intrinsically linked to environmental and sociodemographic factors such as poverty, homelessness, lack of health care and related services, and the emergence of violence and drug abuse as major social problems, point inevitably to an ever expanding need for early intervention and support. Lack of prenatal care, particularly evident in impoverished, young, and poorly educated groups, creates a continuing need for early intervention (Schorr, 1988).

Increased emphasis on early intervention is also related to contemporary social attitudes regarding disability. The stigma of the late 19th and early 20th centuries which forced institutionalization has given way to more humane practices (Haring, 1990). With appropriate support services, individuals with disabilities are seen as being able to live relatively normal lives, within the context of their disabling conditions (Moroney, 1986). Current attitudes regarding community-based treatment, education, and living are showcased in PL 101-336, the Americans with Disabilities Act of 1990, which assures the full civil rights of those with disabilities.

After World War I the role of the federal government emerged in education and social services. It was also during this period that universal compulsory education for children was established. The federal role in education and in services for individuals with disabilities has expanded through much of the century. Federal legislation has created a wide array of services for people with disabilities across the life span (Zipper, Hinton, Weil, & Rounds, 1993).

Advocacy organizations made up of parents, individuals with disabilities, and professionals were first established in the 1930s. These organizations have continued to grow and have been a driving force in creating services for individuals with disabilities, and in making these services community-based (Turnbull & Winton, 1984). The civil rights movement of the 1950s and the 1960s provided a catalyst for more community-based services for children with disabilities (Haring, 1990). In Brown vs Board of Education in 1954, the Supreme Court affirmed the right of all Americans to an education, a right of which they could not be deprived except by due process of law (Zipper et al., 1993). Advocacy groups used this decision to argue successfully that public school systems must provide a free and appropriate education to all children, regardless of their disability (Haring). Active parent involvement in decision making has been a feature of much of the resulting legislation (Zipper et al.).

In 1960 legislation was enacted to fund model demonstration projects in early childhood special education; these projects have continued to provide guidelines for best practice (Hebbeler, Smith, & Black, 1991). In 1975, Congress enacted the mandate for the provision of a free and appropriate education for all children with disabling conditions. Prior to the federal mandate, Michigan had enacted its own Mandatory Special Education Act, entitling children from birth through age 25 to a free and appropriate education (PA 198, 1971). Michigan was the second state to enact such legislation, becoming a pioneer in the provision of special education for children beginning at birth. The federal legislation was a landmark in ensuring educational rights as well as requirements for specific procedural safeguards and an individualized education plan, or IEP, for all eligible children.

However, the federal legislation at that time had minimal impact on children below school age (Hebbeler et al.).

In 1986, P.L. 99-457 was signed into law as an amendment to the Education of the Handicapped Act. Among other requirements, it added Part H to the act, the Handicapped Infants and Toddlers Program. This part provided financial assistance to states to develop comprehensive, multidisciplinary, interagency systems of early intervention services for infants and toddlers from birth to 36 months who exhibited developmental delay, had established conditions with a high risk of developing delay, or who, at states' discretion, were deemed to be at risk for delay due to a variety of factors. Of great significance, the legislation added to this description of eligible infants and toddlers the inclusion of families as recipients of early intervention services.

Part H brought a strong emphasis on the family, providing the strongest legislative direction to date for family-centered services (Zipper et al., 1993). It mandated that parents, and other family members as necessary, be full members of the multidisciplinary team that develops and implements the Individualized Family Service Plan or IFSP. The law provides parents with the right to make all final decisions about assessments and about accepting services. According to the federal regulations:

> The secretary recognizes that parents (1) must be actively involved in making sure that their eligible children and other family members receive all of the services and protections that they are entitled to under this part, and (2) are major decision makers in deciding the extent to which they will participate in, and receive services under, this program (Federal Register, 1989).

In 1991, P.L.102-119 reauthorized the Education of the Handicapped Act, renaming it the Individuals with Disabilities Education Act, or IDEA, and further enhanced the importance of the family role in the early intervention process; states were encouraged to establish parent training centers which would provide activities to enhance parents' understanding of their rights under Part H, and provide parents with the skills they need to facilitate their child's development .

Relationships Between Parents and Professionals

One of the most significant legacies of the recent history of early intervention policy is the need for a more collaborative, less hierarchical relationship between service providers and service recipients (Meisels, 1993). The family-professional partnership is replacing the child-focused model of early intervention (Richmond & Ayoub, 1993). This increased emphasis on families is based upon a number of factors. First, Part H is based upon the assumption that the developmental needs of young children with disabilities can best be met by enhancing the families' effectiveness at caring for these children (Mahoney, O'Sullivan, & Dennebaum, 1990). Second, since families will be the primary recipients of a family-focused approach to services, it is logical that they should have input into those services (Bailey, McWilliam, Winton, & Simeonsson, 1992). Additionally, parents are becoming more sophisticated consumers of early intervention services and recognize their own need for support as parents (Simeonsson & Bailey, 1990). Finally, an ecological systems approach to early intervention services sets the family system within the context of the community and its service systems; the family itself develops within this context (Bronfenbrenner, 1979). Families with young children with disabilities, within this ecological context, develop reciprocal interactions with other systems; in the case of early intervention service systems, the families' primary interaction is with the professional service provider(s).

The traditional socialization and orientation of some professional disciplines involved in early intervention may create barriers to effective collaboration with parents. Training in some disciplines emphasizes the professional as expert and may not recognize the parent as an expert in knowledge of the child; other professionals may assume the role of expert instead of openly acknowledging the limits of their expertise and ability (Gliedman & Roth, 1980; Zipper et al., 1993). One outcome of this perspective toward expertise is that some professionals may discount parents' observations regarding their children's development; professionals may also have difficulty communicating with families without the use of professional jargon (Zipper et al.).

Past models of early intervention practice have been child-centered; the professionals have determined the goals of the intervention process for the child, and many times for the family as well, whether or not this was expected or requested. Many authors have documented the differences between the priorities and insights of families and those of professionals (Bailey, 1987; Blackard & Barsh, 1982; Cadman, Goldsmith, & Bashim, 1984; McGonigel & Garland, 1988; Turnbull & Turnbull, 1985). Past practice has not prioritized the involvement of the family on the early intervention team. In a study by Garshelis and McConnell (1993), parents reported they were not sure if they felt part of the early intervention team; the investigators speculated that parents may not even know if they are part of a team.

Further barriers to the development of positive relationships between parents and professionals include socioeconomic, cultural, ethnic, and racial differences. Anderson and Fenichel (1989) identified such factors as influencing beliefs about parenting and child-rearing, disabilities, ways of coping, how and from whom individuals seek help, and life dreams. When the culture, race, ethnicity, and socioeconomic status of the parent and professional differ sharply, parents may encounter difficulty in obtaining the understanding, information, and assistance they desire from the service providers.

Another barrier to effective relationships can be institutionalized in the design of formal early intervention systems and policies. Agency policies and operations sometimes interfere with family-centered service delivery. Hours of operation, restrictions on location of service delivery, lack of the provision of transportation and child care, and limited funding may all interfere with the development of effective relationships and family-centered or sensitive early intervention service delivery (Flynn & Harbin, 1987; Gallagher & Vietze, 1986; Harbin, 1987; Healy, Keesee, & Smith, 1985; Turnbull & Turnbull, 1985).

Family Systems

A social systems perspective views a family as a social unit embedded within other formal and informal social units. Such units are interdependent; events in one have effects on other units, either directly or indirectly. A social system perspective of the interdependence of these various units must consider events both within and between such units in any analysis of function. Using this perspective in the study of families who have children with disabilities, and the units to which they turn for support and assistance, is reflected by Bronfenbrenner (1979) suggesting parents' performance in their child-rearing roles within the family depends on the role demands, stresses, and supports emanating from other settings. Considering the family, and not the child, as the unit of intervention recognizes that the family system is comprised of interdependent members and that both child development as well as family development outcomes are dependent upon events within the family and events between the family and other units. How such events impact families is dependent on the various attributes of the family system. Family systems conceptual frameworks identify families as goal-seeking, self-regulating, and dependent on an internal hierarchical rule structure (Broderick, 1993; Bronfenbrenner, 1979; Burr et al., 1979). Broderick is careful to underscore the complexity of the goal-seeking attribute of family systems; like system rules, family goals are hierarchically structured and are impacted as well by the self-regulation of the family system. Such self-regulation is a process of feedback which allows the family system to monitor events and effects and to seek equilibrium. In the case of the family with a child with a disability, each of these attributes functions to determine how the family seeks help and support, when they seek it, and how they deal with it when they find it.

Recent Research with Families of Young Children with Disabilities

Mahoney, O'Sullivan and Dennebaum (1990) conducted a study to determine the extent to which programs for birth to 6-year-old children with disabilities were providing family-focused intervention services prior to the implementation of Part H of the Individuals with Disabilities Education Act. Using the Family-Focused Intervention Scale, developed by the investigators, a national sample of 503 mothers whose children were enrolled in early intervention programs participated in the study. The findings indicated a gap between the level of family services offered at the time and the kinds of family intervention services referenced in the legislation; almost 20% of the mothers from this sample reported receiving extremely limited family services, including such basic services as information about their children. Further, the data indicated that the commitment of intervention programs to addressing the personal and social support concerns of families that are not directly related to children's intervention needs was minimal.

The family-focused orientation was substantially greater in programs for children birth to 3 than for children 3 to 6 years of age. The investigators attributed these differences at least in part to the emphasis of federal legislation for infant/toddler intervention. The findings also indicated that intervention programs with home based components had a substantially greater family orientation than programs that were primarily center based. One interpretation offered was that decisions by intervention programs to provide family level activities may be influenced substantially by the intervention setting; i.e. center based settings may afford greater opportunities for child instructional activities, while home based settings may afford greater opportunities for family level services.

Most importantly, the findings indicated discrepancies between the types of services that mothers would like to receive and the services they were currently receiving. The greatest discrepancies between the types of services that mothers would like to receive and the services they were receiving was for services related to utilizing the early intervention system and identifying other community resources to assist them in the care of their children. Where mothers reported having Individual Family Service Plans, or IFSPs, as required by the legislation, a substantial relationship was found to increased family focused services being received. The results further indicated that there was a significant relationship between the quantity of family focused activities the mothers received and the extent to which both their families and their children benefited from intervention. It also appeared the fathers were more involved in their children's intervention programs when services had some sort of family focused orientation.

A study of family goals in infant intervention (Bailey, Winton, Rouse, & Turnbull, 1990), as specified in IFSPs (Individualized Family Service Plans), found that of the total 37 IFSPs analyzed, five had no family goals at all; the majority of the goals coded as family goals were closely related to infant needs while the others were more related to family needs such as respite, support, counseling, basic needs, and family enrichment. The issue of role boundaries and program responsibilities, identified by infant interventionists as an area of concern in the development of family focused services, was discussed. The complexity of family needs, and the need to assist families in the identification of their strengths and needs, were seen as requiring a review of staffing patterns and qualifications of early intervention staff.

Family goals in IFSPs should also reflect family strengths, according to the legislation. Bailey and colleagues (1990), in their discussion of family goals analyzed in this study, speculated that the strengths identified in the IFSPs may have reflected the professionals' definition of family strengths. Without a theoretical understanding of family strengths that takes into account unique cultural, ethnic, and value differences, professionals may define strengths from a strictly personal perspective that reflects their own background. The concept of family functioning style, rather than a continuum of strengths and weaknesses, as described by Dunst, Trivette, and Deal

(1988) was suggested as an appropriate way to approach the development of family goals. This concept is based on research and theory of those such as Hill (1949) and McCubbin and Patterson (1983). This theory base emphasizes the interaction of family perceptions and resources as major determinants of how families respond to crisis. An understanding of this theoretical perspective, according to the investigators, would encourage interventionists to facilitate the family's discussion of perceptions of events and resources rather than making global judgments about family strengths.

A final issue raised by the analysis of the family goals in IFSPs was whether programs should consider including family goals which are complex. Nearly half of the goals specified in the IFSPs analyzed could be accomplished with a single action, and more than half were classified as simply providing families with basic knowledge or information. The researchers suggested that goals limited to simplistic actions do not necessarily facilitate family independence in decision making or empowerment.

Garshelis and McConnell (1993) compared family needs assessed by mothers, individual professionals, and interdisciplinary teams. The results of the study demonstrated that interdisciplinary teams of early intervention professionals agreed more with maternal perceptions of family needs than did individual professionals. However, the teams agreed with maternal reports on less than 60% of the items assessed. The extent to which individual professionals or teams agreed with mothers was unrelated to the disciplines represented, the time individual professionals had worked in their field, or the amount of time an interdisciplinary team had worked together.

The needs most frequently cited by mothers in this study were identified as frequent needs in previous studies and included the need for information on available services, the need for information on services which might be needed as the child grew, the need for more time for themselves, and the need for reading material about how other parents coped with similar situations.

Mothers in this study who indicated more than the average number of needs felt less involved in team decisions than those with fewer needs. This is similar to other studies which have observed that emotional needs, time and stress management needs, and economic needs are ignored by professionals because they are not traditional targets for intervention (Dunst, 1984; Schultz, 1982; Turnbull, Summers, & Brotherson, 1983).

Garshelis and McConnell (1993) concluded that while teams did a better job of matching mothers than did individual professionals, they still did not do well in assessing family needs. As a result, some families may receive information about services they do not need or want, and some families may never have their needs met. They suggested that individual professionals and teams should allow families to identify their needs before services are initiated; family responses to needs surveys or checklists may be helpful as a method of identifying needs. In addition, the findings would strongly indicate that parents should always be invited to participate in team meetings. Part H of the Individuals with Disabilities Education Act requires that parents be invited to team meetings, and further requires that family needs, priorities, and resources be identified and incorporated into the individualized family service plan.

Summary

The field of early intervention services for young children with disabilities has changed significantly over the past several decades. From institutionalization to community-based services and from deficit models of limitations to contemporary models of family driven expectations, services and supports for these young children and their families have developed rapidly in response to entitlements enacted by the United State Congress. As formal systems of early intervention services have developed in response to these changes, professionals in the various disciplines which deliver such services have also had to respond to a changing framework of roles and skills. The newest legislation, Part H of the Individuals with Disabilities Education Act, demands the greatest changes; professional early intervention service providers now must learn how to become partners with families in the evaluation of child and family needs and in the planning for appropriate services and supports. Recent studies indicate that there is much room for improvement in this area.

An ecological framework appears to be the most appropriate for this new approach to the delivery of early intervention services. Current literature supports a family systems model as the most functional in the analysis, planning, and practice of building working relationships between families of young children with disabilities and formal systems of early intervention services.

CHAPTER III

QUALITATIVE METHODOLOGY

Gilgun (1992) cautions that defining qualitative family research is not for the faint of heart. A simple explanation of qualitative research is to define it as processes which are used to make sense of data which are represented by words or pictures and not by numbers. Such processes include ways of conceptualizing, collecting, analyzing, and interpreting data. There is a basic fit between families as a focus of study and qualitative research, as qualitative methods are suited to understanding the meanings, interpretations, and subjective experiences of family members (Daly, 1992). Qualitative methods focus on the processes by which families create, sustain, and discuss their own family realities.

Qualitative family research does not seek to count the number of families with particular sets of characteristics, but rather to provide insight into the meaning of their experiences. In general, qualitative methods permit the researcher to study selected issues in depth and in detail, without the constraints of predetermined categories of analysis; this contributes to the depth, openness, and detail of qualitative inquiry (Patton, 1990). Qualitative family research has a focus on experiences within families as well as between families and outside systems (Gilgun, 1992). The use of the grounded theory methodology exemplifies this thoroughly.

Selected Methodology: Grounded Theory

Grounded theory is a style of qualitative research which uses coding paradigms, constant comparison, and theoretical sampling to ensure conceptual development and density (Strauss, 1987). It is a process of theory development which is fundamentally based on the pragmatism of Dewey, Mead, and Pierce as well as the field techniques used extensively at the University of Chicago from the 1920s through the 1950s in the study of the sociology of work (Strauss). It allows the complexity of sociological phenomenon to be recognized within the research process. The process itself is a cycle of induction, deduction, and verification which utilizes complex analysis of data and the development of conceptual categories which lead to patterned or grounded theory, that is, theory which is empirically and conceptually tied to data (Strauss; Gilgun, 1992). As in qualitative evaluation research, analytic processes are particularly oriented toward exploration, discovery, and inductive logic, i.e. the researcher attempts to make sense of the situation without imposing preexisting expectations on the phenomenon or setting under study (Patton, 1990).

The goal of grounded theory is to generate theory that accounts for a pattern which is both relevant and problematic for those involved (Glaser, 1978). This occurs around a core category, i.e. one to which other categories and patterns are related. At this point theory is integrated and rendered dense and saturated, according to Glaser. As the theory emerges, sampling of the literature for verification begins; thus the literature review happens as the data are analyzed, not before. It is important to understand that proving a hypothesis is not the outcome of grounded theory. Rather, the theory emerges from the data and might later be studied for possible verification. It is also important to note that a search for linear causality is not regarded as a focus of qualitative research. Inherent in qualitative research is the assumption of complex social processes which transcend the boundaries of unit analysis.

Grounded theory differs from other qualitative research methods in its emphasis upon theory development. There is an extensive interrelated data and theoretical analysis which, throughout the analytic process, strives for verification of the core conceptual framework (Strauss & Corbin, 1994).

Grounded Theory Process

The first step in the analysis of the data is coding. Coding is the process in which data are broken down, conceptualized, and reorganized. In grounded theory development the process of coding is intended to result in theory which is grounded in the data and which is rich in explanatory power.

Preliminary and Axial Coding: Categorical Development

In the case of analyzing written responses to a set of dated and finite open ended questions, where additional probes are not possible and which is the case with the data available for analysis in this study, the focus on coding discrete observations is imperative. Typical line by line or sentence by sentence analysis must give way to phrase by phrase and word by word analysis. This level of concept analysis provides an opportunity for a more detailed analysis and coding process than would occur using a broader format.

As the researcher codes, a constant questioning is applied to avoid overlooking concepts and to avoid the easy application of common labels which provide little specificity and risk being differentially interpreted by the researcher or others at a later time. While numerous and diverse, and therefore difficult to document while actually pursuing the analysis, the kinds of questions relative to stages of coding are generative in nature and function to make the process robust. Strauss and Corbin (1990) list the ongoing basic questions as Who? When? Where? What? How? How much? and Why?

The initial level of coding begins with the use of conceptual labels applied to each discrete observation. Once this level has been completed, a subsequent level of axial coding is used; this process puts the data together in new ways by making connections between a category and its subcategories (Strauss & Corbin, 1990). This focus is on specifying as to particular conditions, i.e. the context in which it is embedded, the interactional strategies by which it is actualized, and the outcomes. This articulates the development of subcategories. In practice, the researcher moves between initial coding and axial coding, alternating continuously and eventually, automatically.

Memos, Notations, and Diagrams

Written records of the coding and analysis related to the coding are developed throughout the research process. Memos containing the actual products of the coding such as conceptual labels, paradigm features, and operational notes are maintained. Diagrams and models of the emergent theory are drafted to visually sort the categories and identify how the categories might be related. Standard practice (Strauss & Corbin, 1990) is to do initial coding on the documents, but to do memoing and diagraming separately. This provides a freedom for the researcher to analyze and compare without destroying the recorded data. It also provides a bank of analytic ideas which can be sorted, ordered, and reordered according to the organizing scheme (Strauss & Corbin, 1990). Memos and diagrams are usually dated or numbered sequentially; theoretical notes make a reference back to the code note that stimulated it. Memos which list emergent codes and categories are maintained for undertaking constant comparison of the categories and concepts.

Constant Comparison

As the initial and axial codes are developed, Strauss (1987) suggests that the questions to be asked regarding the properties of the observations include what category or property of a category does the incident indicate? As incidents are compared one to another, concepts emerge. As the concepts emerge, additional incidents or observations are compared to the concepts to generate properties of concepts. Similar incidents expand the relevance and density of the concept. In essence, concepts are the basic units of analysis in grounded theory.

Generating Categories

As incidents are compared and concepts emerge, patterns are identified. A pattern of many similar incidents can be given a conceptual name as a category; incidents which vary somewhat can be named as properties of categories, and the compared incidents can be seen as interchangeable incidents for the same concept. When many interchangeable incidents are collected which indicate the same pattern and no new properties are discovered, saturation is reached. The task is to work toward conceptual density as well as specificity, with enough variation to provide applicability to many different instances of any given phenomenon.

Theoretical Sampling

The process of data analysis is controlled by theoretical sampling according to the emerging theory. This sampling occurs when the emergent pattern or theory is compared to additional incidents to see if the pattern or theory still holds.

Since the researcher does not begin with a preconceived theoretical framework, she cannot anticipate the categories or concepts which will be evident in the data. As such categories and concepts emerge they are compared with other observations or incidents to control the theoretical relevance of the data. Comparing as many differences and similarities in the data as possible forces the researcher to generate categories, their properties, and their interactions (Glaser & Strauss, 1967).

In the case of a finite data set, when additional data cannot be collected, the literature is reviewed for concepts which would support the emergent pattern. When secondary analysis of existing data is the case, Glaser (1978, 1993) recommends that the researcher theoretically sample the data which are presented, and appreciate what is available.

Data Source

The data analyzed in this study were collected as part of a larger study in 1992-93, funded by the United States Department of Education, Office of Special Education and Rehabilitative Services, Award # H 159.A 1000; it was the first federally-funded evaluation of Part H in the nation awarded under the State Agencies Federal Evaluation Studies (SAFES) category. The project , A Utilization-Focused Evaluation of the Resources and Barriers to Implementation of P.L. 99-547, Part H in Michigan (Benn, 1993), was conducted by research faculty at the Merrill Palmer Institute at Wayne State University.

Original Project Design

The project was a 24 month evaluation of the resources and barriers to the implementation of Part H in Michigan, using a variety of utilization-focused evaluation activities (Patton, 1986) designed to recommend alternative strategies for overcoming the identified barriers. An innovative multimethod approach was used which incorporated personnel at all levels of state and local government, including local service providers, and parents of children with disabilities. The utilization-focused design concentrated on involving those who would actually use the results, or who would be impacted by the results of the evaluation, i.e.stakeholders, in the actual evaluation process.

The focus on evaluation in this project is best defined by Patton (1990) as any effort to increase human effectiveness through systematic data-based inquiry. This includes an emphasis on gathering information and generating findings that are useful. As such, evaluation is applied research, utilized to inform action, enhance decision making, and apply knowledge to solve human problems.

Three central questions were addressed:

1. What are the barriers to the implementation of an optimal system of early intervention services in Michigan?
2. What options or alternatives exist for overcoming these barriers?
3. Which strategies would be most effective for implementing these options or alternatives?

The study consisted of three phases of activity that correspond to these questions. The first phase included planning and instrument development, and the convening of a core advisory group. Phase two consisted of the distribution of a questionnaire to parents and professionals with concerns for infants and toddlers with disabilities. The questionnaire was designed in collaboration with members of the core advisory group in a manner to elicit the respondents' perceptions of resources and barriers to optimal services in the state. In the third phase several different and smaller stakeholder groups met to focus on specific barriers identified in the questionnaire responses and to identify possible solutions. Finally, the core advisory group met with state policy-makers to attempt to devise methods for overcoming these barriers and making maximal use of resources.

Purpose of Utilization-Focused Evaluation

Utlilization-focused evaluation has as its purpose the improvement of programs and the increase of the quality of decisions that are made relative to programs. Patton (1986) contends that the hallmark for judging evaluations is their utility, and useful evaluations should give decision-makers, information users, and stakeholders the data they need to make programs more effective. Stakeholders are the personal factor, according to Patton, which carry the commitment to the evaluation and the information it generates. Studies (Ayers, 1987; Greene, 1987; Mark & Shotland, 1985; Miller, 1987) have shown that stakeholder participation in evaluation design is worth the considerable effort involved in its design. In keeping with this focus, the family section of the survey provided for the gathering of information from stakeholders who had experienced personal involvement in the system being evaluated, i.e. families who had been involved with formal systems of early intervention services.

Family Participants in Original Project

Families with children with disabilities were included, as key stakeholders, in each phase of this project. Family members sat as members of the core advisory group, assisted in the design of the family section of the questionnaire, and of course families were part of the sample for the response to the questionnaire. This was in keeping with the landmark legislation's focus on family-centered services and family-led planning activities for early intervention services. The project traced those elements of the service delivery system and the policy environment which facilitate or impede family effects on young children with disabilities.

Data Collection

In phase two, the questionnaires were sent to the 57 Intermediate School Districts in Michigan, as the local lead agencies for the planning and development of Part H, and as the historical primary service providers to the target population. The sample was one of convenience and reflected the intent of the project to include key stakeholders in the evaluation process.

The total sample for the questionnaire included 500 individuals and consisted of administrators, service providers, and members of local interagency coordinating councils, including parents. Two parents from each intermediate service area were selected by the local Part H coordinator to respond to the questionnaire, for a total of 114 anticipated family respondents. At least one parent selected was to be a member of the local interagency coordinating council. It was anticipated that the parent representation of this sample would reflect the diverse populations of the particular counties or service areas of the intermediate school districts in Michigan.

The family questionnaire included not only categories of closed-end responses, but also included an open-ended qualitative response section. This section attempted to provide participating families the opportunity to respond individually, in their own words, and was to provide the evaluators with a rich set of data which would provide additional and valuable information regarding families' perceptions of the early intervention services system as well as their recommendations regarding family concerns and needs which should receive attention from the formal early intervention systems.

The open-ended response section of the family questionnaire included six distinct questions, one of which had two parts. They were designed to elicit information regarding parents' perceptions about the existing early intervention service system and about the needs of families who have very young children with disabilities in relation to early intervention services. The questions 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. What advice would you give to other families who are looking for help for their infant or toddler?
4. What, in your opinion, is the best feature of the early intervention service system in your county?
5. What, in your opinion, is the weakest feature of the early intervention service system in your county?

6. If you could talk to the administrators of the service systems 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?

A total of 76 families responded to the questionnaire and their responses constituted the family section of the project. The closed-end questions in the survey have been analyzed by the research staff at Merrill Palmer Institute; the open-ended responses, which constitute the qualitative component of the survey instrument, have not previously been analyzed and are the data upon which this current study is based.

Respondents

The respondents are described in the federally-funded proposal as a sample of convenience. Families were selected by local Part H Coordinators for their involvement with and understanding of the early intervention services system. The respondents were perceived to reflect families who self-identified as key stakeholders in the evaluation of the service delivery system. This approach to respondent selection was part of the stakeholder based evaluation design.

The original survey response included 76 families representing a range of family variables. Each had a child with a disability; 65 respondents were mothers, 6 were fathers, 3 were foster parents, 1 survey was completed by a mother and father jointly, and 1 was completed by a grandmother. The children discussed in the family surveys ranged in age from 5 months to 9 years of age; in addition, one parent reported about her experiences with her child who was 20 years of age at the time of the survey.

For the purpose of this study, the analysis was limited to the responses made by mothers of children under 6 years of age. This age range represents a developmentally and culturally distinct grouping. Developmentally, the children are highly dependent upon family members for meeting their physical and emotional needs and cognitively vary from sensorimotor through preoperational stages (Piaget, 1954), depending upon the nature of their disability. Culturally, these children have not yet reached the age of compulsory school attendance, when time away from the family typically increases and family involvement in daily activities of children is reduced. Further, the ages of birth through 5 years old include both the target range for early intervention services, i.e. infants and toddlers ranging from birth through 2 years old, as well as the preschool years immediately following the infant and toddler stages. Perceptions of needs for early intervention services and actual experiences with early intervention service systems were therefore current or recent for those respondents with children in this age range.

Since mothers were the most frequent respondents in the original project, the study limited analysis to mothers' responses, thereby providing a dimension of commonality for analysis, i.e. mothers' perceptions of family needs relative to the delivery of early intervention services. Further, a reasonable number of respondents (N=48) was achieved. As the data were analyzed, 3 of the 48 respondents selected were found to have provided incomplete survey responses and were deleted from the total, resulting in 45 total respondents (see Appendix B for demographic data) being selected for analyses (N=45).

Gaining Permission to Use the Data

Access to the data was requested through the director of the original project, Dr. Rita Benn at the Merrill Palmer Institute at Wayne State University (Appendix C). As the family data from the open ended response section of the surveys had not been analyzed, and the funding for the project had ended, Dr. Benn was willing to release the data for analysis. As part of the agreement to release the data, all personally identifying information was deleted from photocopies of the original responses which were forwarded to the researcher. The data were to be kept secure to further protect the family participants. The use of these data was approved (IRB # 94-532) by the University Committee on Research Involving Human Subjects (UCRIHS), Office of Research and Graduate Studies, at Michigan State University.

Preparing to Analyze the Data

The written survey responses were photocopied from the original survey booklets, deleting any personally identifying information, and forwarded to the researcher by the director of the original project at Merrill Palmer Institute. The written response section of the survey included a half page of demographic information relative to typical sample variables, and two full pages accommodating the six primary research questions and responses.

The photocopied pages were standard 81/2 by 11 inches in size. As grounded theory methodology requires various levels of written coding of the data, it was necessary to create a second photocopy for the actual working copy, which expanded the pages to 81/2 by 17 inches, providing the original page on the left side of the working copy and a blank 81/2 by 11 inches space on the right side to allow coding and notations. Separate pages (8 1/2 by 11 inches) were used for the creation of memos and model development. Memos were created throughout the coding process and labeled both sequentially and categorically; as models of interaction were tested relative to the discovery of conceptual categories, these too were labeled as part of the memo series.

Inevitably, the research process yielded a continuous cycle of induction, categorization, and interpretive model testing. The cycle was not limited to the time and physical space dedicated to the research project, but occurred at all times and in all settings. Therefore, the memo series was drafted in a variety of formats on differing occasions, using whatever notation instruments were available. This resulted in an eclectic collection of memos, notes, and models, all of which were used in the constant comparison process and which constitute a colorful and well worn archival testament to the grounded theory process.

Role of the Researcher

The researcher brings to the qualitative process a combination of knowledge, experience, creativity, understanding of theories and theory development, and sensitivity to the data. The researcher herself is a source of theoretical sensitivity and a tool in the discovery and development of grounded theory. For example, previous experience as a provider of early intervention services, as an administrator of early intervention programs, and as a member of early intervention policy-making bodies, allows this researcher to better understand the data; these experiences yield sensitivity to conditions, events, and actions which facilitates the research process (Strauss & Corbin, 1990).

An additional source of theoretical sensitivity is found in literature relative to the subject of study. The researcher's familiarity with a body of literature adds to her understanding of the phenomena uncovered in the study. However, her understanding of the appropriate use of this information in the qualitative process is a very important variable in the quality of the research outcome. The researcher must therefore continually ask herself if preconceived assumptions, concepts developed by others, or an inherent affinity for a particular theory base are interfering with the discovery of concepts and relationships which result in grounded theory.

Limitations of This Study

The use of existing data limits the study to the contents of such data; this subsequently limits the level of theoretical sampling, an important component in grounded theory process. Additional cases or observations cannot be added without replicating the original study and expanding the data collection to additional participants.

The sample in the original study was one of convenience. While the criteria for selection of participants, i.e. stakeholders involved in and knowledgeable about early intervention systems, were important, the sampling process relied upon regional implementation by a variety of persons; consistency in the sample selection could not be assured. The sample which resulted was not representative of the population of families who have been involved in formal systems of early intervention services in Michigan.

The use of open ended questions in a written survey format presents limits on the quantity of the data generated and cannot capture individual nuances available in an interactive exchange format such as an interview.

Overview of the Analysis

The presentation of the analysis of the data in this study includes frequent use of respondents' comments; such presentation is in bold face to distinguish the data. The data are presented exactly as written by the participants; grammatical or spelling corrections have not been made (see Appendix D for examples). No respondent is specifically identified through the use of a number or pseudonym as all responses are important and the emerging theory is tied to all data, not that of specific respondents.

Chapter IV explains the initial and axial coding process and presents the initial conceptual categories which resulted. Chapter V explains the substantive coding process and the emergence of the core and subsidiary conceptual categories. In Chapter VI the grounded theory paradigm is presented which provides the integration of the conceptual categories, their properties and conditions; at this point all components of the theory are analytically presented. In Chapter VII the grounded theory is presented and discussed. A summary and discussion of the implications of the findings bring the reporting of this study to conclusion in Chapter VIII.

Throughout the analysis, the reader is asked to remember the role of the researcher in the grounded theory process; theoretical sensitivity is gained, in part, by the knowledge, understanding, and experiences which the researcher brings to the data. Decisions regarding coding, labeling, and integration of data elements have been based on this sensitivity. The researcher has made a conscious decision to avoid the use of labels and terminology which have become the jargon of early intervention at this time; this is an attempt to reduce the risk of differential meaning or assumed meaning which would misinterpret or misrepresent the analysis of these data.

CHAPTER IV

DISCOVERING THE CATEGORIES

The initial analytic step in the grounded theory process is the coding of phenomena through careful examination of the data. Data are broken into discrete parts and subjected to comparisons and questioning. This chapter describes this process as it was used to examine the responses of the families in this study.

Initial and Axial Codes: The Data Come to Life

Examples of the data, in bold face, and exactly as written by the participants, are used to demonstrate and clarify the analytical process. Grammatical, punctuation, or spelling corrections have not been made in the data as the actual language of the respondents is a more accurate representation of the families who participated in this study. Subheadings are used to identify the initial conceptual categories, which follow.

Emotions, Affect, Feeling

The initial coding was easily prompted by the responses of the mothers in the data set selected for this study. Such responses were highlighted, coded initially with the words of the respondents, and through axial coding grouped under the heading of emotions, affect, feeling. Many of the responses included words which had immediate impact on the researcher, i.e. words which stimulated both emotion and reflection upon similar comments made by the many mothers of young children with disabilities with whom the researcher has had extended contact in the past several years. Labeling of emotions expressed was a starting point in coding responses to the survey question (#1) which asked what families consider most important for early intervention service providers to know about working with families. Responses included:

> **I feel the most important thing to know is that for most parents, this experience they are involved in is new to them and scarey** [sic] **- threatening almost.**

Another mother responded specifically about family feelings:

> **Compassion. By this I mean that families are very aware that they have a child with special needs and helping them to better understand that all is not lost with this child the better the family feels about themselves and the child.**

In the first example, the codes of **scarey** [sic] and **threatening** were simply noted by highlighting the phrases in which they occurred. Subsequent axial coding placed them under emotions, affect, feeling and memos were developed which grouped the codes and which noted the dimensions of time and place relevant to the expressed emotions. In the second example, **all is not lost** was coded as hopelessness, and then grouped and memoed similarly.

The second survey question, which asked what families need most when they discover that their infant or toddler has special needs, also elicited responses which described emotions and which initially were labeled in a similar manner. For example:

> **...the acceptance of their anger, grief, and frustration.**
>
> **... families are in a state of crisis at this time.**

Another example,

> **... listen to their fears and confusion. The first year or two a**

> **parent needs to know that it isn't their fault and that they aren't alone in their feelings and emotions.**

In the first example, the words **anger, grief,** and **frustration** were highlighted, listed in a memo, and later coded under emotions, affect, feeling with memo notations as to relative time and place dimensions. In the second example, the phrase **state of crisis** was similarly coded and memoed. In the third example, the words **fears and confusion** were similarly coded. The phrase **isn't their fault** was coded as guilt with subsequent axial coding of emotions, affect, feeling and then similarly memoed. The phrase **aren't alone** was initially coded as isolation and subsequently handled as were the other responses described above.

Even survey questions which were more directed toward evaluation of the nature of the formal service systems elicited responses describing emotions and the emotional status of families. For example, in the survey question #5, which asked for an opinion regarding the weakest feature of the early intervention service system in the respondent's county, this category is demonstrated:

> **I'm scared about what the future holds.**

A sample list of respondent language coded initially and then grouped under emotion, affect, feeling included: **angry, embarrassed, fear, denial, pain, grief, degrading, strong, positive, lonely, shock, powerless, confidence, depressed,** and **sad**. The memoing related to emotions, affect, feeling included notations regarding dimensions of time and place. For example, some of the codes were tied to the time of the initial diagnosis of disability, others were tied to the time of accessing early intervention services, and yet others were tied to the time of meeting other families with similar experiences. Place or location notations included such settings as hospital, school, community, and home. This level of analysis is important to the eventual theory development, as such dimensions are constructs for the interactions and patterns which emerge as the qualitative analysis progresses. This level of analysis is generated with the never ending questions of When? Where? What? and Why?

Planning, Finding, Knowing Future

Another immediate impression which directed the initial coding process was the stated need for assistance with future related issues; mothers made reference to such concerns as they responded to many of the survey questions. Responses which indicated a concern with future issues were highlighted, coded initially with the words of the respondents, and through axial coding grouped generally under a future heading. The initial coding stages clearly revealed this general category; however, moving toward a conceptual label seemed problematic at the time.

While labels such as planning, finding, and knowing were reflective of respondent language, as categorical concepts they seemed too typical and did not reflect the intensity with which the concept was emerging from the data. Relying on the theory development process, the researcher continued coding, noting, and memoing, ever hopeful that the power of the conceptual category itself would yield more appropriate labels.

In response to the first question in the survey, which asks what is most important for early intervention service providers to know about working with families, one mother requested **help with future planning.** When asked what families need most when they discover that their infant or toddler has special needs (survey question #2) a respondent wrote:

> **...a plan for their future, so you don't feel like you're living from day to day and never getting anywhere.**

Another mother responded that the best feature of the system in her county (survey question #4) was:

> **Being in touch with other families and teachers and aides who can give me some insight of some sort - to the future with my child.**

And another mother replied, in response to question #6, which asked what she would tell the administrators of the service systems in her county about their agencies and services:

> **...and greatly helped us to get on with our life.**

As these examples of the respondents' comments indicate, whether questioning about families or about the early intervention service systems, responses frequently referred to future issues.

In the first example, future planning was used as the code; similarly, this code was also used for the response **a plan for their future**. For the response ..**insight of some sort - to the future with my child**, future was the initial code; in coding the response to question #6, above, **get on with our life** was coded as having a future. These are examples of the breadth of the category as it emerged, a continuous thread conceptually, regardless of which survey question was asked.

Constant comparison with additional cases or observations added to the initial and axial coding, resulting in an ever increasing list; a sample of the respondent language which stimulated this category includes: **wishes, hopes, dreams, chances, life, goals, desires**, and **achieve**. Memos and notations were continuously created to compare the responses to the various survey questions as the category grew with additional observations or cases. As with the emerging category of emotions, affect, feeling, this category was clearly distinct and relative to dimensions of time and events. Responses which created this category referred to family futures, child futures, lack of futures, and futures dependent upon decisions regarding services, events such as surgeries, placements, or treatments, and events such as the inevitable death of a parent.

As the category emerged, it also was in need of meaningful theoretical or substantive coding (Strauss & Corbin, 1990) as continuing cases were observed and coded. The researcher was constantly developing notations for potential theoretical coding which would convey the significance of the category; the labels initially applied once again appeared too common, i.e. had properties which were too broad and subject to varying interpretation, thus increasing the likelihood of poor representation of the phenomenon. The ongoing basic questions (Who? What? Where? When?) were therefore imperative as this category grew.

Helping, Supporting, Listening

Helping, supporting, and **listening** were frequent requests from mothers as they wrote their replies to the various survey questions. The researcher, ever mindful of the intent of the study, was challenged to search the data for proximal observations which would lend meaning to these responses. Using these responses for labels or codes, although sufficient for the initial coding, represented common terminology which could be expected as a response from a variety individuals when asked, What do families of young children with disabilities need? If improved early intervention services, improved training of future early intervention professionals, and improved policy making is an intended outcome of better understanding these families' needs and experiences, these initial labels and codes were insufficient to lead to improved understanding. The researcher had to continually ask, What kind of support? Support when? What kind of help? Help when? Listen how? Listen when?

Some of the additional responses, coded initially with the language of the respondent, included: **talk, understand, confide, trust, respect, care, concern, accept, honest,** and **feel.** All of these were initially categorized under the heading of helping, supporting, listening. Examples of respondent comments which created this fledgling category follow.

In response to question #1 regarding what is important for service providers to know about working with families, mothers responded:

> **To be empathetic and to allow parents an opportunity to talk about their concerns and hopes.**
>
> **...shows a lot of concern for our family.**

Each of these responses referred to helping, supporting, and listening, and were coded as such. The important step for the researcher at this point was the constant comparison of additional observations and attention to the dimension of context. Notations made during this process would later assist in the conceptual development of the emergent theory.

When asked what the families would tell the administrators of the service systems in their counties about their agencies and services (question #6), responses included:

> **I like that fact that...the're** [sic] **there for us parents to help us**

out when we need it.

The response to this question provides contextual information, especially when compared to similar and differing observations. The context implies that timing and availability of early intervention services are a property of this category. That is, in order to support and help families, the early intervention provider must be accessible at a time when families have need for the services. It could also mean that the early intervention provider presents herself as having time for the family. Notations regarding these possible meanings were included in memos relative to this stage of coding. It was apparent to the researcher that the development of this category, at this stage, was not yet refined.

The examples of responses to survey question #1, regarding what families believe is important for early intervention service providers to know about working with families, illustrate a focus on valuing both the need of the family to talk (**allow parents an opportunity to talk**) and acknowledgment of their feelings (**to be empathetic; shows a lot of concern)**. Notations regarding these comparisons and contextual dimension, at this stage of the analysis, serve to further interpret the meaning of the respondents' comments. It appears at this stage that an additional quality or property of this category is in fact a particular kind of listening, one that provides validation of the families' feelings and concerns.

Family responses also indicated a particular property of the category related to the dimension of timing, i.e. when to help, support, or listen; this property was noted as the data were compared and notations were made as to timing being a variable of family rules regarding boundaries; an example follows:

> **It has to be approached very carefully for the family and child's sake. Be considerate of the families** [sic] **privacy.**

This response to the question regarding what families want providers to know has a more precise message: **be considerate of the families** [sic] **privacy**. This provides a caution to the delivery of early intervention services regarding individual family rules about boundaries between the family and the formal early intervention system. The compared meaning is relatively clear; helping, supporting, listening is a category of family needs which is variable among families and which must be recognized and acknowledged by the service provider.

Notation regarding variation in this category was made with initial thoughts added regarding the skill needed for interpreting a family's readiness for early intervention services, i.e. their willingness to modify family boundaries to allow exchange with a formal system. Issues of trust and confidence were noted as possible variables to explore in the comparison of observations and events in the data; which families were eager for the exchange with formal systems and which families would rather wait or not participate?

While remaining dissatisfied with labeling (helping, supporting, listening) for this conceptual category, there were sufficient observations which fit the paradigm to realize that it was an important part of the emergent theory, i.e. that it played a role in the interactive process between families and early intervention service providers.

Asking, Demanding, Advocating

Survey question #3, which asked what advice families would give to other families, generated many responses which began to fit together. These responses frequently used the words **get, find, ask, demand, insist, persist**, and such phrases as **fight for, don't give up, keep looking, keep asking.** The following responses demonstrate the pattern that emerged even with initial coding:

Ask questions!

Don't be afraid to ask questions!

Explore all possible avenues...

Be persistent...

Talk to other parents...

Keep asking questions...

Interview, ask questions...

Keep looking for more...

Ask about <u>all</u> services available...

Keep asking for what they want...

Always be a squeaky wheel...

Don't give up...keep asking til [sic] **you get what you want.**

All of these incidents were coded initially in a general category of asking, demanding, advocating, with constant comparison yielding a very strong property relative to a sense of urgency in these responses as parents indicated the importance of seeking answers to questions, of not giving up, of learning all there was to learn, and of becoming assertive in gaining information. This is further represented by the following data:

Don't be intimidated by professionals ...

...and don't be intimidated by anyone's degrees or big words.

If you don't like what you're told, fight it.

Don't accept any doctor's word as "the law."

This group of respondents, having been involved with a variety of agencies and professionals, even for only a few years or less, had apparently developed a strong sense of what it takes to get information and services. The notations and memos made while coding these responses included those related to the dimensions of place, i.e. doctor's offices, hospitals, schools, and other agencies, as well as dimensions of frequency.

As the researcher anticipated the development of substantive or theoretical coding, these notations became very important. The questions of How to ask? When to ask? Who to ask? would need to be answered to develop and explain an interactive pattern regarding this role or behavior experienced by parents. Once again, the final label or categorical nomenclature for this conceptual category would have to capture the essence of this spirit and task.

Information, Learning, Finding

Families indicated a broad need to find information, specialized resources, and others to talk to who had similar experiences. In response to question #2, which asked what families need most when they discover their infant or toddler has special needs, the responses included many similar to the following:

> **...to get information re: subsidies, respite care, specialists. etc.**
>
> **...information, literature to read about their special need...**
>
> **...they need the resources available to them to learn more about their child's disease or disability.**

Families need to have their questions answered...

Initial coding for responses similar to these included labels such as information, learning, finding, and getting. The general conceptual category initially appeared to be learning or finding or knowing. Additional phrases which were coded collectively and in axial coding moved into a general related category included:

...support from other families of similar circumstances
...other families with similar needs...
...support groups with experience sharing and problem solving sessions.

The need which was indicated in these responses related to finding other families similar to one's own family, i.e. with a child with similar needs. This appeared to be related to gaining information and understanding of the particular disability and to learn how other families had managed to deal with it. Memos were made with notations regarding why families wanted to meet other families and what information they were seeking. Comparisons across observations in this subcategory began to reveal a common theme relative to finding other families with similar characteristics, families like themselves.

As with other emerging conceptual categories, the labels seemed insufficient to convey the image of interaction or level of need which was becoming apparent through the words of the respondents. The researcher was eager at this time to move to substantive coding, to incorporate the many notations in the memo series which had accumulated and to begin to tease out the patterns which seemed just under the surface of the codes and memos.

Patterns in Memos: The Need for Substantive Coding

As the initial and axial coding resulted in numerous memos and notations and as these were compared, the emergent conceptual categories began to become more concrete. Attributes or properties of each category were articulated through the comparison of discrete events observed within the categories and noted in memos. A variety of dimensions were also evident in the memos; as comparison of these dimensions and attributes both within and among categories was intensified, a sense of dynamic interaction between families and early intervention service providers emerged.

The language of the respondents was evocative. The researcher found herself with never-ending memos of potential model development, but to capture the reality of the interactions, the meaning of the data, became the next challenge and task. Strauss and Corbin (1990) describe the next step in the analytical process as integration; in essence, telling a story analytically. This becomes the point in the research process where the researcher must also select a core category around which other categories will be subsidiary. The central or core category is described as the heart of the integration process. This subsequent stage of the research and the theory development process is the focus of the next chapter.

CHAPTER V

REFINING THE CATEGORIES

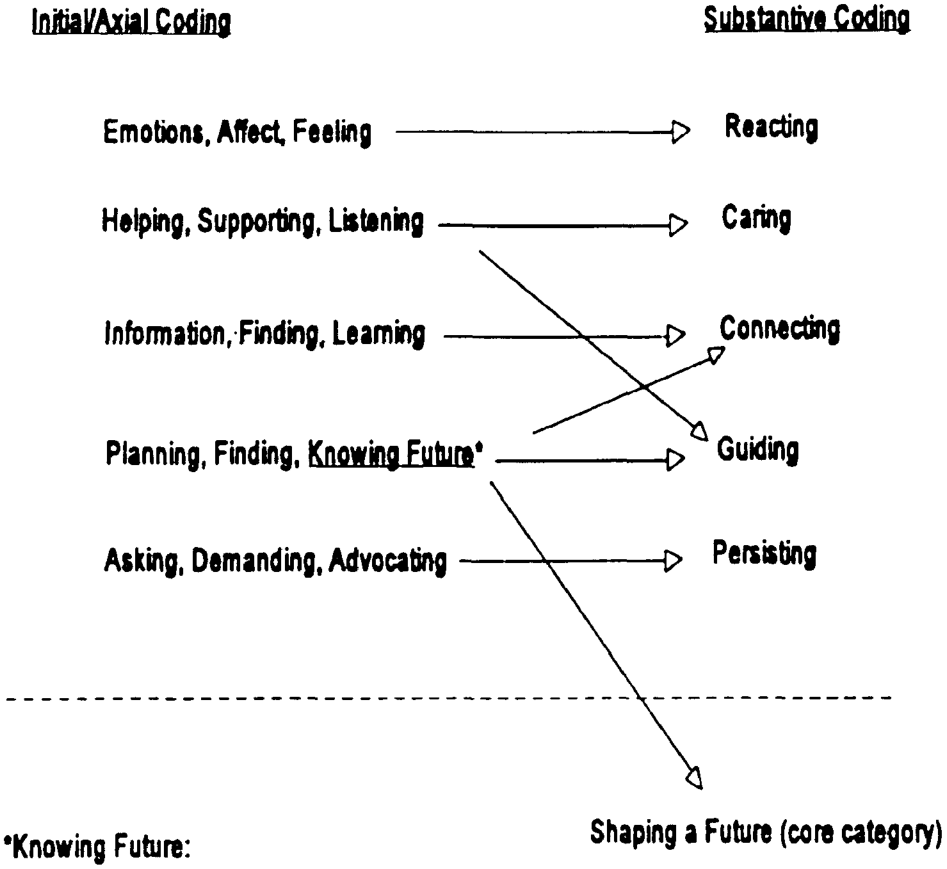
The result of initial and axial coding, memoing, and diagraming is the compilation of detailed data analyses. Conceptual categories have been outlined, compared, and studied. At this point in the grounded theory process substantive coding provides the opportunity to adjust and refine the categories, so they more accurately reflect the meaning of the data. The use of dimensional constructs and comparison of various properties of categories, which should be emerging in memos, allow an integration of all components of the analytical process. Theoretical sampling is further developed through the comparison of data with findings from relevant literature.

Substantive Coding: The Data Tell A Story

As the initial categories were analyzed and as memos were studied, it became apparent that further comparisons were necessary to determine if the categories really fit the data. The previous chapter revealed the concern of the researcher with the labels of each category and the utility of those labels to carefully and specifically represent the meaning of the phenomena to which they were attached. The following conceptual categories represent the results of the analytical process and are the refined categories (Figure 1); their meaning is explained using examples of respondents' comments.

Reacting

The initial code of emotions, affect, feeling reflected data which revealed families' responses under a variety of conditions. The initial



*Knowing Future:
reference to future permeated all categories, but initially placed in this grouping.

Figure 1. Refining the categories.

diagnosis, for example, can have a profound impact on the family:

> **They should realize how devastating it is to have a child like this. Also how hopeless the rest of your life looks when they** [sic] **have a lifelong disability.**
>
> **...how overwhelming everything seems when a special problem is first diagnosed.**
>
> **...most of the families are very sad and angry when they find out about their child's disability.**
>
> **...first of all parents go through shock...**

These comments represent responses or reactions to the initial discovery or diagnosis of disability. The birth of a child with a disability is broadly identified by investigators as a critical event, a crisis, a period of transition for families (Beckman, 1983; Friedrich & Friedrich, 1981; Friedrich, Wilturner, & Cohen, 1985; McKinney & Peterson, 1987; Wikler, Wasow, & Hatfield, 1981). The process of reacting to the diagnosis constitutes a condition under which family systems frequently enter formal early intervention service systems. The analytical process of grounded theory seeks to identify just such conditions under which the patterns of interactions between social agents occur, providing an element of the integrative detail which is the hallmark of grounded theory (Strauss & Corbin, 1990).

The nature and quality of interactions between families and formal intervention systems, particularly at the point of entry into the formal systems, has been a focus of historical and personal reports, such as Turnbull and Turnbull (1985). Establishing a new relationship, a pattern of interaction, under a condition in which families are experiencing strong emotional reactions, and seeking support and understanding, sets the stage for sensitive responses. The respondents provided further information regarding the need for consideration and understanding of their reactions to events as a condition under which providers will meet them:

> **The families I've seen are stressed and they do need help & understanding from the places they obtain help.**
>
> **...this is probably the most stressful time the family has ever had to deal with.**
>
> **You may be meeting us at a very emotional time.**
>
> **...families are wrapped up in a world of their own...it takes time and effort to let down defenses and trust that they will be taken care of...**

Reacting is a phenomenon which will vary from family to family and from condition to condition under which the reaction occurs; the reactions may be to diagnostic information and procedures, to learning more about the diagnosis and its implications, or to the style with which the response to the family is made. As respondents indicate:

> [families] **...are deeply affected by the way you speak to them and refer to them. Don't stereotype them!**
>
> [don't say] **..."we understand" when they haven't experienced that situation...it has to be approached very carefully for the family & child's sake.**

One of the respondents indicated a sensitivity to the challenge which faces providers of early intervention services as they begin interacting with families who are experiencing significant reactions:

> **First of all the parents go through shock and denial. Practically, then, it helps the parents if the child is spoken of**

> **in terms of being a normal person (with problems). Terms like "special needs" and "handicapped" are very hard to deal with. Leave out the labels as much as possible...Parents feel all at once an urgency to "fix" their child, and at the same time want to think that the baby will grow out of it by themselves. So the service providers have a tough balancing act.**

Such awareness and advice from families is important to service providers as the nature of interactions between families and providers is evaluated. Families indicated a need to seek providers who respond in particular ways which, from their perspective, would enhance the interactions and the relationships between the two systems. This need constitutes the next conceptual category.

Caring

Responding to families, as they react to the new reality of their lives, is described in various ways by the respondents. Such responses on the part of the formal systems with which the families may interact are those which were initially coded as helping, supporting, listening. These are labels which convey general meaning, but do not provide interpretation of specific behaviors which could be practiced by early intervention providers to better respond to families. In order to refine this conceptual category, the data were subjected to continued comparison. Respondent language was analyzed and compared to search for properties and contextual conditions which could clarify the meaning embedded in this category. Collectively, the data which fit this category emerged as a condition of responding, best labeled as caring.

Caring has broad meaning, i.e. to care for, to care about, to be careful, to take care; all have meaning which reflected the response families were seeking. Some of the data which explain this are illustrated below.

> (families need)...**someone who will listen and help the family sort out feelings and identify needs of the child and family.**
>
> **...someone to listen to them.**
>
> **Someone to turn to who can listen to their fears and confusion. The first year or two a parent needs to know that it isn't their fault and that they aren't alone...**

Listening was a frequent response to survey questions which asked families what they needed or what they would like providers to know; this appeared to constitute a subcategory of caring. The quality of the listening, as a response to family reactions, was frequently framed within a context of the need for family reactions to be acknowledged as valid. Families want providers to accept them as they are; to accept their vulnerability, their fears, their uncertainty, and their personal variations in taking time to accept what this diagnosis means in terms of the family dynamic and adjustments. As one respondent explained:

> **They need a short time to let it sink in themselves. It took me a few days before I could talk about it at all (even with my family let alone a stranger). When the parent is ready it is great to have someone to talk to that understands and can help explain what your** [sic] **dealing with.**

Kalmanson and Seligman (1992) caution early intervention providers to be extremely sensitive to parents' intense emotions about their children. Families in this study provide evidence of this need.

Another respondent articulated the time it takes to accept the diagnosis in terms of denial:

> ...[professionals need] **to realize the parents are in denial in the beginning so they don't want the help that is needed.**

The interactions between the family and provider systems, as implied in these data, must be based in the providers' recognition of systemic variations across families in the time needed for acceptance, the readiness to receive assistance, and most importantly in the understanding of the need families have to find someone to listen to them. The need for listening to families' concerns and fears was embedded in the data; a frequent response was that families needed someone to talk to who could understand them, who could cry with them and acknowledge their grief. Several examples illustrate these needs.

> ...[families need] **the acceptance of their anger and grief, the chance to cry...**
>
> **...also, a shoulder to lean on...**
>
> **Let the parent talk, there are a lot of feelings that parents go through.**

Further, the data revealed the needs that families may have to lift a sense of guilt, to move on from blaming:

> **They need to know that blame is not important, but working together to better support the child is...sometimes helping the child will need to begin with helping parents.**
>
> **...a parent needs to know it isn't their** [sic] **fault.**

Related to these needs are those for tangible acknowledgment of the families' reactions, of validation of their emotions. Thurman (1991) also emphasizes the importance of attending to the emotional and psychological needs of families. This is implied in the respondents' requests for **someone to listen, someone to talk to**, as well as in requests for physical evidence, such as: [we need] **positive hugs and comments. Encouragement!!**

In addition, respondents indicated a need for confidence and trust from the providers, as well as being there for them when they need it. The data contributing to this property of caring include:

> **...and confide in about their feelings.**
>
> **...non judgmental support...**
>
> **...to feel that they are not outcasts because of their child...**

The data indicated another subcategory of caring which is listening for the purpose of answering questions, in a manner which fits all of the properties of caring, i.e. with regard to the individual needs and characteristics of families, with respect to their ability to understand, and with respect for their hopes and expectations at a particular point in time. Examples from the data include the following:

> **...that each one is unique in its needs and to treat these families as such.**
>
> **...with professional back-up for any question.**
>
> **...to speek** [sic] **at there** [sic] **level.**
>
> **...provide answers so that they can understand them.**
>
> **...don't preach to families about what they should do. Goal setting should be on the family's terms.**
>
> ...[listen to] **the family's goals for this child.**

Families further expect that answers to their questions will be honest, that the caring will respect their ability and their right to truthful answers, as indicated by the respondent who articulated this property of caring providers:

...acceptance, sensitivity, honesty...believe in the families. Another property of caring, of responding to families as unique in their needs and perspectives, is recognizing the importance of including members of the family in the intervention process. As one mother requested, **...encourage fathers' participation when possible.** This was not specifically articulated by other respondents, but rather implied with the varied references to including the whole family in the intervention process, to consider the family as well as the child, and to remember that **they are working with a whole family, not just a child.**

Related to the category of caring is a level of responding which, as the data were analyzed and compared, emerged as a conceptual category in and of itself. This is a significant category which had implications for both systems in its interpretation. It is described next.

Connecting

Connecting is a conceptual category which accommodates the meanings and examples of interactions between family and early intervention systems which were initially coded as information, learning, finding. This category involves action and behaviors on the part of both social agents in this study. It includes the concepts of connecting families to information, to resources, to services, to opportunities to learn, and to other families in similar circumstances.

Families expressed a continuing need to be provided with information; they want to know more about their child, more about the diagnosis, more about resources and assistance which are available, more about services and what they can do and learn to help their child, and especially more about how other families have dealt with the complexities of disabilities of very young children. Respondents also expressed a heartfelt recommendation that other families should be told how important their own role is in accessing and using information gained from various sources.

Information about their child's developmental needs, about services and resources, and about programs was evident in the data as an important need. Families expect providers within the early intervention system to connect them with all of this kind of information, as indicated by the following responses:

> **..need the resources available to them to learn more about their child's disease or disability.**
>
> **...make them aware of all the programs available.**
>
> **...knowledge of what is available and how to get the assistance they need.**
>
> **...should know about available resources.**
>
> **...need to get information out to all new mothers... Information.**
>
> **Information on where and who to get in touch with for help.**
>
> **...use other agencies to help families.**

Families expect early intervention service providers to know not only about how to assist their child, but where and how to connect families with additional information and resources. Families expect the early intervention system to provide them or connect them with additional information and materials about the disability they are facing, how they can assist their child's development, and where they can get material, information, and personal support and assistance. Dunst (1985) confirms the need for intervention programs to provide connections between needs and resources, between information gaps and information sources, to improve the ability of the family to take action.

In effect, families have a need for and expect much more than just disciplinary expertise from the early intervention service provider. They find it logical that information, resources, and services should be organized in such a way that their involvement with an early intervention provider will be the access point for these connections. When such connections are made, the families judge the service system to be responsive and caring. When such connections are not made, they judge the system to be less effective.

The data provide evidence of an additional need for connection with other families in similar circumstances. Respondents indicated in a variety of ways that getting connected with other families serves many important purposes. Families want to learn from other families; they want to see how other families have adapted to having a young child with a disability and they want to see how they can adapt, i.e. they want to meet other families who are like them.

This need is articulated in various ways throughout the data. Some examples include:

> **...to meet with other parents that have speacil** [sic] **needs children so they do not feel that there** [sic] **the only one's** [sic] **and can understand better...**
>
> **...other families with similar needs to support each other. Support is important to know they are not completely alone,**

> **to get support from parents who have been through the same thing.**
>
> **They need encouragement, to meet with parents with the same problems.**

There is expressed in these comments the reality of how alone families perceive themselves to be when they are beginning the search for information and understanding of their child's disability and what it means to their family. There is a yearning to see other families who are like them, now that they are different from what they were before the birth of their child. The new reality of their family creates dissonance from what they have known and from what they expected, from the image they had before the birth of this child. Finding others like them is a task with which families seek assistance from the early intervention provider and they expect an understanding of why this is important to them.

Guiding

Two potential categories, labeled as planning, finding, knowing future, and helping, supporting, listening in the initial coding phase, were analyzed with discrete incidents within each category compared to each other once again. Memos were compared and contextual conditions noted; the questions of when and how were key to this constant comparison. Respondents' language was closely examined for meaning. This resulted in a reorganization of some of the incidents or events previously placed in the initial categories to better reflect an improved understanding of the meaning of the data. This new category was labeled guiding, reflecting the primary property of this conceptual category as well as the interactive process which was central to the interface of family and early intervention systems.

Guiding suggests both the responsive nature and the locus of expertise which are primary to the role of the early intervention professional. It reflects the families' perceptions of a preferred relationship with the provider and of their own sense of family ability and potential. It also reflects an expectation for guidance which may be antithetical to practice in some early intervention programs, where a distancing from families has been the acknowledged model (Sokoly & Dokecki, 1992).

One respondent summed her comments regarding this process with the phrase **gentle guidance** which captured the essence of the category and which created its label. Examples from the data which illustrate the components of this category follow:

> **...someone who can provide information and answer questions.**
>
> **...they need to help preants** [sic] **throw** [sic] **this priad** [sic] **in time...so they can understand better.**
>
> **They need cheerful, complete guidance from program to program. Also, the average clientelle** [sic] **isn't highly educated, so paperwork is really intimidating.**
>
> **They need to know what to do, how to achieve success...**

Families of young children with disabilities find themselves in a world of specialists, multiple agencies, and programs which may or may not be appropriate to meet their needs, with frequently confusing information and suggestions. They have an expressed need to find an early intervention provider who can explain, clarify, interpret, and help them evaluate the incoming information in order to make sense of it all. Families are concerned about their decision making . They want to be sure that they are making decisions which are in the best interest of both the child and the family. As one mother responded, **Our baby is our life & we only want what is best.**

A property of guiding is that it be responsive to the variations of family systems, that it respond to the level of assistance preferred by an individual family. While some families may want detailed information all at once, others will want only what they can handle at a specific point in time. Respondents were clear about this; they expressed a need for guidance, for responsiveness to their questions, for assistance in their search, but at their level:

> **Help us when we're ready to get information...**
>
> **...may not be ready to absorb all the new information at once.**
>
> **...to help us out when we need it.**
>
> **I would make sure that everything is explained in terms that the families would understand.**

The timing of the information and advice, the manner in which it is explained, and the quantity of information provided are properties of this category which are contingent upon conditions or context relative to the family system which is requesting and receiving this guidance.

Families may need encouragement to access guidance, they may need assistance in knowing which questions to ask, or they may need suggestions relative to resource acquisition. Data indicated these subcategories of guiding were important to the respondents:

> **..making families feel at ease about asking or receiving help.**
>
> **Parents may not know what to ask for. More concrete**

> **direction is needed.**
>
> **...knowledge on what is available and how to get the assistance they need.**

Guiding is specific to the role of the early intervention provider and is not necessarily dependent upon the disciplinary field in which the provider is trained; a physical therapist will provide guidance relative to the physical development and therapeutic interventions prescribed for the individual child. However, if this therapist is also the principal early intervention provider working with the child and family, and if another early interventionist has not been identified as the primary resource for the family, the physical therapist will be placed in the role of principal guide by the family whether or not this has been a formal designation. This occurs because of the therapist's place in relation to the family system; she becomes an important or even singular link between the family and the information, resources, and understanding which the family seeks.

Persisting

Coding and memos from the original category of asking, demanding, advocating, were compared; the data were reviewed for contextual conditions and respondent language was examined for meaning. A sense of urgency and a recommendation to **keep asking** were pervasive in responses to question #3 which asked about advice the respondents would give to other families seeking help for their infants or toddlers. A comparison of these data with a focused analysis as to their meaning resulted in the label of persisting. This need to persist, to continue seeking, a sense of an unrelenting search, may be related to the lack of influence families sometimes experience in interacting with professionals (Fiorelli, 1988); if their needs are not met, if their perspective is not understood, if they are not listened to, they may persist in seeking outcomes.

Families perceived the quest for information, understanding, and obtaining appropriate services as never ending. They expressed a strong belief in the need for families to learn everything they can about their child's disability, about services, and about other resources. They expressed a controlled skepticism about advice and information which has not been corroborated or substantiated by other sources. Families in essence described the need to become investigators and consumer experts, and to learn how to be the primary member of any team which had decision making responsibility in areas relative to child or family well being. Several examples of such properties of this category follow, beginning with the persistent question asking:

Ask questions.

Don't be afraid to ask questions.

Ask as many questions as you have!

Ask questions because not much information is volunteered.

Don't be afraid to ask for help and don't give up.

Respondents indicated the need to seek and gain the appropriate services by a constant and persistent searching which includes continued questioning and evaluating:

> **Please persist in obtaining help allowing yourself to be angry, sad, and frustrated. Don't believe all you are told** [and] **become educated so you are able to make good decisions.**

> **...interview, ask questions, don't accept what is given as opinion without obtaining more information. Keep looking for more. Always keep looking for more.**
>
> **I would advise them to keep asking...**

Families have to learn to persist, ask, evaluate, and judge; they must learn even to demand if necessary. Some of the respondents shared their personal experiences as a way to provide advice:

> **There are many wonderful people who really want to help you. I know it can be hard to ask for help but it has been good for our son and our family.**
>
> (I was)...**initially dissatisfied with the transportation program and I made noise about it. Changes were made to my satisfaction, & I was very pleased.**

Persisting, as a process, may require families to extend interactions to additional formal systems far beyond those typically found in the immediate environment. Families may have to leave their community to find the information and advice which satisfies their sense of thoroughness in the persisting process:

> **I took my daughter to Children's Hospital in Boston for a special clinic & was told she was not getting anywhere near the services she needs. The** [local agency] **made me believe it was enough. I'm learning. I had to practically beg for summer services! I persisted and it paid off.**

The data also suggested that persistence is a necessary attribute of families' involvement in early intervention programs, once the services are in place. Respondents indicated that passivity is not a feature of successful interactions with formal early interventions systems, once families are connected to formal services and programs:

> **Take control - be actively involved in all your child's programs as possible. Keep talking and don't stop communicating.**
>
> **...be as involved as possible with school and any decisions.**
>
> **...their input is not only appreciated, but required.**
>
> **...don't sit back and wait for agencies to do the work...**

One observation in the data yielded a subcategory of persisting which could be called anticipatory persistence; a respondent indicated that persistence includes being prepared for any service need that might arise, preparing for any contingency:

> **Ask about all services available for your child and sign up for them right away, even if you don't know if the service will be used it** [because it] **saves the agravation** [sic] **of trying to get services when needed.**

Based on the data, it appears that families of young children with disabilities cannot expect formal early intervention systems to meet their needs if they do not persist in articulating those needs. As one respondent stated, **keep asking for what you want until you are satisfied**; another concurred with:

> **When you are the parent of a special needs child you have to be their advocate. Don't give up, you have to really work for the rights they deserve. Don't be afraid to ask for help or information, it is for your child's benefit!**

Learning to be an advocate, persisting in gaining access to services and supports, questioning professionals and others about their recommendations, and challenging decisions which do not meet family needs may not fit the types of interactions which families have previously experienced or with which they are comfortable. This new behavior may pose challenges to existing rules of family systems relative to behavior in the community and interactions with professionals or others outside the family system. A change in the identity of the family, in the image the family has of itself, as well as internal systemic rules, may be required before the persistence of being their child's advocate can become successful.

Core Category: Shaping a Future

The integration of data at this point in the research process is focused on the identification of a core category and its properties and the subsequent relationships of the other substantive or subsidiary categories. The core category then becomes the central phenomenon around which the other substantive or subsidiary categories are related. As grounded theory is an action oriented model, it illustrates action or change, or the reasons for minimal change (Strauss & Corbin, 1990); the core category then is the central action or change phenomenon, in effect becoming the story line which is woven throughout the data.

An initial category, labeled planning, finding, knowing future, was analyzed with observations within the category compared to each other as well as incidents coded to other categories. As memos were studied in this process, the task of delineating a future for the child and family was evident, not only in this initial category but throughout the data. Secondary to this task of delineating a future was the identification of who the family was and how the family fit into a greater framework once the attributes of disability were added to the family system. This task was very evident in the families' needs to connect to other families with similar characteristics and experiences. The need to find others like themselves was part of understanding who they were, who they were becoming as a family, and how they could define a future, given the unknown and unexpected challenges brought to the family system as a result of the birth of a child with a disability.

Interrelationships: Properties of the Core Category

Data which revealed this task orientation to shaping a future were interrelated with each of the refined categories: reacting, caring, connecting, guiding, and persisting (Figure 2). Additional data from relevant literature provided support for these findings. Examples of these interrelationships follow.

Reacting to the Future

Families indicated early concern regarding the impact of disability on family and child futures. For example, stated clearly by one respondent, **I'm scared about what the future holds**, the immediate focus on future indicates the probability that this will be an overarching concern as the family begins to learn more about the disability and its effect on the child. Reacting to the place of the family in a larger ecological context was also interrelated with initial reactions to the diagnosis; stating that the family...**needs to feel they are not outcasts**, this respondent shares a sense of anomie resulting from the realization that the family is no longer typical, that its place in the social context has changed. This sense of being an outcast indicates that the family

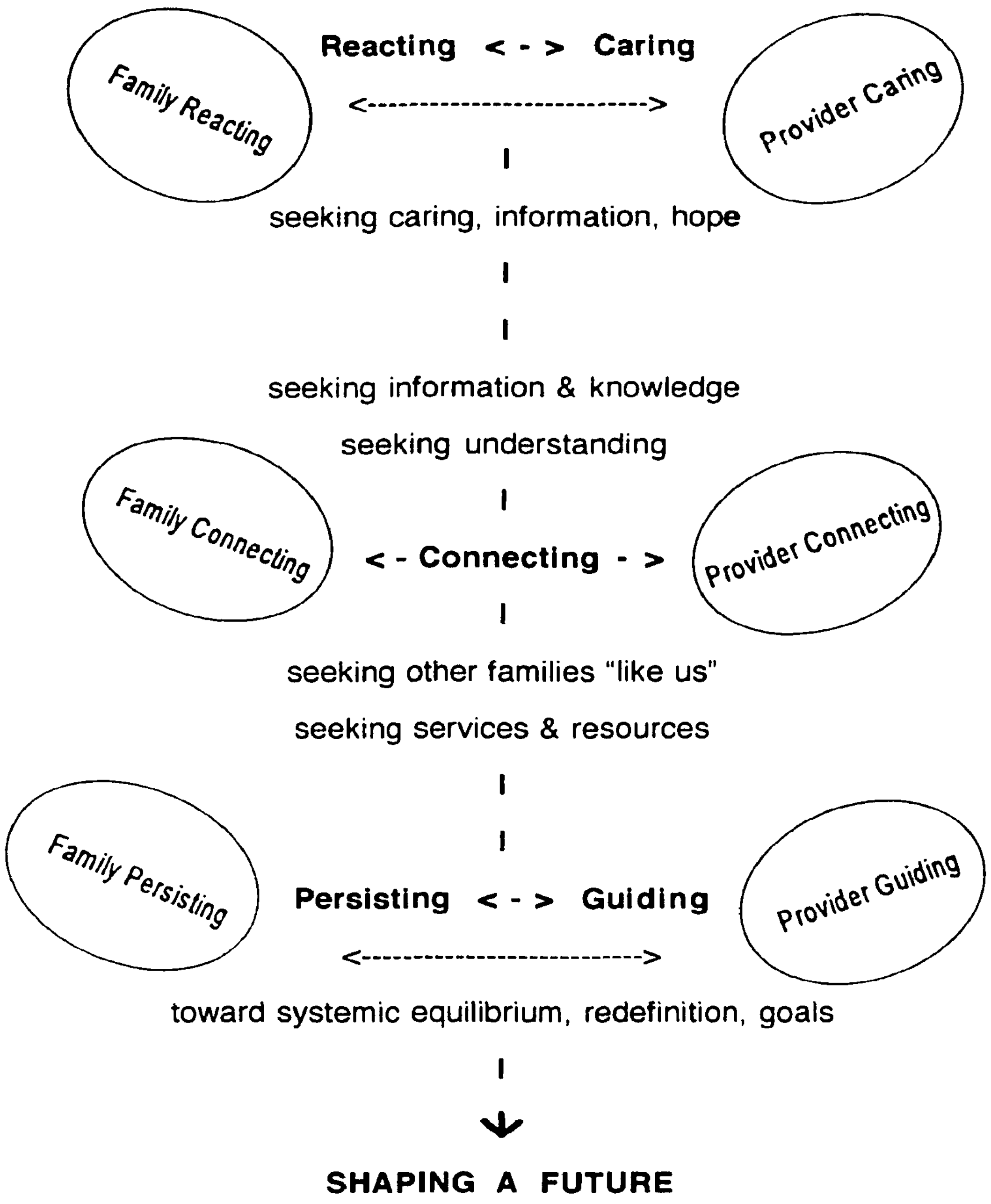


Figure 2. Conceptual categories in shaping a future.

identity is not clear, that the family has a sense that they no longer fit into a larger category of families who have not experienced disability, but where they do fit now is unknown. Thus, the category of reacting interrelates with the core category of shaping a future; families have a need to articulate a new identity as a prerequisite to focusing on the future.

Darling (1988) concurs that parents, at the point at which diagnosis is occurring, have a sense of anomie; McHugh (1968) has shown that anomie consists of both meaninglessness and powerlessness. Parents' initial reactions include a sense of powerlessness because of what they do not know or understand, and because they cannot see the future.

Caring about the Future

Respondents expect that a caring response will support their reactions and uncertainties about future outcomes. One respondent included expectations that families would have...**the chance to cry and laugh and begin to build a different life than they anticipated**. Another mother included the expectation that a caring response would ...**help them understand that all is not lost**. This implies that they will find hope for the future as part of the caring and support that are provided by the professional in the early intervention system.

Caring is a task of the interactive process which provides evidence to families that resources, support, and hope exist for them and their children. A caring response will include attention to listening for family concerns about the future. Van Riper and Selder (1989) cite data from their qualitative study of parents responding to the birth of a child with a disability; parents of infants with disabilities expressed a sense of urgency about knowing something about the future for them and their children, and expressed a belief that if the disability did not exist, the urgency regarding knowing the future would not exist.

Connecting to the Future

Connections to information, resources, and other families are interrelated to shaping a future for the child and family. One of the primary reasons for the need to connect to other families in similar situations is the chance this provides to learn how other families have adapted and to see what families can become. As one respondent indicated, meeting with other families provides the opportunity to **...see possible avenues or alternatives to make the road smoother**. The image of making the road smoother vividly implies the family expects to be going someplace in the future; it is how to get there that creates the challenge.

Another mother clarified the need to connect to other families because **...to see other families getting on with life lets you know you can too**. Learning how others are getting on with life provides information regarding adaptations that families could consider as they redefine identities and plan for futures. Other families also provide connections for mutual support; the expectation that early intervention systems will facilitate such connections was indicated by one respondent as ...(we need to meet) **other families with similar needs to support each other**.

Van Riper and Selder (1989) engaged in a qualitative analysis of parental response to the birth of a child with Down syndrome; in the process of seeking information, the parents in this study also sought connections with other families who had children with Down syndrome. Van Riper and Selder identified this process as cohort comparative testing, a process which provided information, validation of feelings and concerns, and a comparative basis for measuring family progress through this transition. These findings are compatible with the meaning of the data as it emerged in this study.

Guiding for the Future

Guiding is the process of explaining, clarifying, and interpreting options and alternatives, of suggesting and offering directions and strategies, of informing, and of acknowledging family decisions. This provider task is very much related to assisting the family determine a course of action for the future. It includes encouraging families to connect with other families like themselves, as indicated by one mother who said that families may **...need encouragement to meet with parents with the same problems**. Guiding is also a task which supports family progress toward goals ...(which families) **may have set**, as well as helping families identify needs, supports, and goals through questioning. As indicated in the data, families cannot ask for what they do not know about. When this task is undertaken successfully, the respondents indicated that early intervention was effective:

> **...our service coordinator is great. She shows a lot of concern for our family and helps us with future planning.**

Embedded in this comment are properties of shaping a future related to caring and guiding, or guiding in a caring manner. This facilitates the family task of identifying goals and building toward a future; as Darling (1989) suggests, this exchange between the family and early intervention systems is directed toward helping the family move from the initial crisis to adjustment to the child's disability. A family systems analysis would identify this as a self-regulating function toward equilibrium.

Persisting toward the Future

Family systems are goal-seeking systems (Broderick, 1993); as such they function to move forward, to make progress toward goals. Families of young children with disabilities press toward the development of goals which reflect the adaptations they are making to having a child with a disability. Persisting is the task identified in the data which families indicate is of significant importance to moving forward. Families will persist whether or not the early intervention system supports this task. As one mother recommended to other families:

> **...you have to advocate for your own child. Rely on them** (providers) **for information and advice but remember this is your child and you must get the help you both need.**

Future directed and committed, respondents stress the importance of goals which have been determined by the family: **...work with families to meet goals they have set.**

Without a future orientation, without the development of goals, family experiences with early intervention systems will be less than satisfactory. As Nash (1990) has pointed out, families and early intervention providers become a team and teams must have goals to be successful. If a future orientation is not shared by families and early intervention providers, conflict may result. For families, persisting is a task which supports family goals; whether or not it creates conflict with the providers with whom they are interacting is dependent upon the providers, their perspective taking, their attitudes, and their responses (Dunst et al., 1988).

Summary

Substantive coding, memoing, and diagraming have resulted in the refinement of conceptual categories which are key to the interactive social process which occurs between families of young children with disabilities and formal systems of early intervention services. Grounded in the data, these categories constitute the actions or interactions between the principal social agents in this process and have been identified as reacting, caring, connecting, guiding and persisting.

Central to this process is the core category, shaping a future, which is linked to the function of families as goal-seeking and self-regulating systems. Inextricably related to shaping a future for a family of a young child with a disability is the task of redefining the family, or understanding their new identity and what it means to the family system and its future. This primary task is the central theme of the story which is embedded in the data.

CHAPTER VI

GROUNDED THEORY PARADIGM

During coding certain patterns, i.e. repeated relationships between properties and dimensions of categories, were identified; data were grouped accordingly. This is when the emergent theory began to gain specificity. Constant comparison, in effect a combination of inductive and deductive activity in which questions were asked and comparisons made, resulted in refined categories which fit together in various patterns. The data, at this point in the grounded theory process, were related not only at the broad conceptual level, but also at the property and dimensional levels for each major category; the basic components of theory were now in place. The patterns of interactions between the family and formal early intervention systems which are grounded in the data and which tell the analytical story are the focus of this chapter. Components of the paradigm are explained which create the outline of the emergent theory.

Once the core category has been selected, the remaining, or subsidiary categories, are analytically connected or related to it by means of a paradigm. This paradigm is essentially the conditions, context, strategies, and consequences of the interactive process under study. Simplified, the paradigmatic relationship is: conditions are related to phenomenon, which is related to context, which is related to action, interaction, and strategies, which are related to consequences. The actual relating of categories is more complex due to intervening sets of conditions; it is such sets of conditions which will determine variations in outcomes. Thus, the conditions must be discussed in relation to the subsidiary categories (Strauss & Corbin, 1990).

In the emergent theory, the interaction between the family and the early intervention system constitutes the condition of the phenomenon under study; the variability of the primary systems involved create intervening conditions which account for variations in outcomes. The identified conceptual categories are the actions or interactions which are related to the consequences; these are viewed within the contextual dimension of effectiveness of early intervention. The consequences are the child and family outcomes (Figure 3).

In this study, the crystallizing data were those which either directly or indirectly implied that shaping a future and the related task of defining a family identity were the driving forces for each task, for each step in the reciprocal processes of reacting, caring, connecting, guiding, and persisting in which the family and early intervention systems engaged. Thus the interrelated tasks of shaping a future and family redefinition emerged as the core conceptual category.

Paradigm Components

This chapter explains the grounded theory paradigm using the conceptual categories, their properties, and their interrelationships as found in the data. Illustrations from the data are used as are data from relevant literature, in the continued process of developing theoretical sensitivity.

Condition

As a component of the grounded theory paradigm, the condition is that aspect of the process being analyzed which identifies the relevant environment in which the process is being studied. In this study that

Paradigm Components	**Categories & Data Elements**
Condition:	Interactions between family and formal early intervention systems.
Intervening Conditions:	Variability of family and early intervention systems.
Central Phenomenon:	Shaping a future for child and family; subsidiary: redefining family.
Contextual Dimension:	Effectiveness of early intervention.
Actions, Interactions, & Strategies:	Reacting < - > Caring < - Connecting - > Persisting < - > Guiding
Consequences:	Child and family outcomes; identity and future.

Figure 3. Grounded theory paradigm: Shaping a future.

This illustrates how the core category, subsidiary categories, and ecological elements of the social phenomenon identified in this research fit the grounded theory paradigm proposed by Strauss and Corbin (1990).

environment is generally defined as the mesosystem, described by Bronfenbrenner (1979) as the ecological level which comprises interrelations between two or more microsystems, such as the developing person (or family) and community settings such as school (or early intervention programs). The condition for the process analyzed in this study then is the point at which two systems interface. Bronfenbrenner argues that every mesosystemic event is in fact an ecological transition and as such is both consequence and instigator of developmental processes. In the case of family and child interactions with early intervention programs such ecological transition is intended, by design, to instigate or facilitate human development. As professionals in early intervention programs assess an infant's development, evaluate strengths and deficits, and plan programs of stimulation, habilitation, and interactive learning, human development is the anticipated outcome.

At systemic interface, families are also beneficiaries of early intervention program practice. As a direct and intended outcome, parents are usually provided with information on child development and usually provided opportunities to participate in some kind of parent group or activity which may indirectly result in peer coaching or learning. However, the concept of family development as a parallel to child development is not a stated function of most early intervention programs (Dunst et al., 1988).

Simeonsson and Bailey (1990) outlined a progression of family involvement in early intervention programs which traced evolution from a child centered model to a family involvement model, where families may be seen as legitimate recipients of services. While several models for family involvement have been suggested (Bailey et al., 1986; Barrera & Rosenbaum, 1986; Dunst et al., 1988; Halpern, 1986), most early intervention programs do not identify family development as an intended outcome. Further, there exist no well established models for relationships between parents and interventionists (Halpern). How parents and interventionists relate, interact, or otherwise communicate and subsequent outcomes for both child and family development have had little attention. Generally, this component of early intervention programs is left to chance. These are the conditions, then, that set the stage for the story of families of young children with disabilities and their experiences with formal early intervention systems.

Intervening Conditions

The primary sociological agents of this study, namely family systems and early intervention systems, are equally complex. Both vary as to structure, rules, access to and control of information, and in feedback mechanisms which allow adjustments to be made to fit the ecology of their respective environments.

Early intervention systems.

Early intervention systems are impacted by external regulatory control which is imposed on the system from interrelated sectors or systemic levels, such as government, via legislation and funding power, and individuals within the systems who collectively negotiate many of the internal rules of the system, such as unions. Early intervention systems are open systems, with similarities in types of inputs and outputs, but among systems they vary as to structure, complexity, size, history, culture, and organization set (Thompson, 1967). The organization set refers to the network of organizations within the focal organization's environment. This is the network with which an early intervention system or program may have to interact to fulfill its responsibilities in the delivery of early intervention services. If the organization set is complex, for example, or if there is a history of conflict among agencies, then effective interagency cooperation or coordination for early intervention services may be problematic.

Other ecological factors which impact early intervention agencies include geography and physical size; population density; economic conditions of the area; county, state, and international boundaries; and population diversity. For example, in Michigan's Upper Peninsula and the Northern Lower Peninsula, it may be necessary to provide early intervention services to a family which lives on an island accessible only by ferry; to refer a family to another state or country for specialized medical services; or to drive three hours round trip to provide a home based therapy session. On the other hand, in a major metropolitan area, early intervention programs may have to develop ready access to interpreters of Asian, Middle Eastern, and Latin American languages, among others; to negotiate across a complex network of peripheral agencies and programs with especially problematic political histories; or to be expected to deliver early intervention services to a population whose needs far exceed the collective resources of the providing agencies.

Internal variability also creates intervening conditions in the delivery of early intervention services. The organizational structure of an early intervention program can be tightly or loosely coupled (Weick, 1976); that is, some will have flexibility in responding to family needs and requests while others will have little or no flexibility. The loosely coupled organization generally is more able to create novel solutions and diversity in responding to changes in its environment, such as changing expectations of consumers.

Family systems. Family systems vary in structure, rules, use of information, adaptation to inputs from within and outside the system, and the cybernetic or feedback mechanism which allows the system to make adjustments to fit the ecology of its environment (Broderick, 1993; Burr et al., 1979; Kantor & Lehr, 1975; Melson, 1980; Scanzoni & Szinovacz, 1980; Wilden, 1972).

Family systems are open systems, meaning that energy, information, and matter flow back and forth across a permeable boundary. Such a description implies change and prescribes change as something which occurs only in relationship to time; thus, a family system has a past, present and future (Broderick, 1993). Each family system varies as to this past, as to its present ecology, and as to future goals and plans.

Family systems are goal-seeking; this implies that families select goals and determine methods to achieve such goals. To do so, the system monitors progress toward goals and makes accommodations or corrections when deviations from intended goals are identified. Families vary, however, as to goals selected and methods of seeking goal attainment. Families also vary as to investment of energy or attention on the achievement of certain goals; some will be highly committed to goal attainment while others will seem more passive in this regard (Broderick, 1993).

Self-regulation is another aspect of family systems which is variable. Self-regulation is visible as family decision making. To be effective, such regulation must have information from three sources: the world outside the family system, information from the system's past, and information about the system itself (Buckley, 1967). As this information will vary from family to family, so too will the decision making style as well as the decisions. This variability is evident in interactions with early intervention systems and impacts the nature and outcomes of such interactive processes.

Of particular relevance to this study is the function of family systems in regard to goal-seeking and self-regulation when discrepancies in the status of the family system are experienced. Family systems function toward equilibrium, a balance of inputs and outputs which are in tune with family rules and goals. When this balance is disrupted, when the equilibrium is lost, the goal-seeking and self-regulating mechanisms are put into action. Thus, when a child is born with a disability, these attributes of family systems determine how the family will respond, the timing of the response, and the magnitude of the response. The variability across families is broad and the interface with formal early intervention systems will reflect this variability.

Family rules are also variable and impact interactions with other systems. For example, some families value the immediate input from formal systems which can offer assistance and support in times of crisis; other families are less trusting, have more rigid rules regarding family boundaries, and are slower to engage in exchanges with other systems. Such variations as these will color and shape the interactive processes between family and early intervention systems.

Central Phenomenon

To determine one conceptual category as the core, and others as subsidiary, Strauss and Corbin (1990) suggest that a central phenomenon, one that in fact is the story line, be chosen from all of the categories discovered. This core category is one which is abstract enough to encompass all that is included in the story of the basic pattern of interactions that has been observed.

The birth of a child with a disability is an event which impacts not only the structure of a family system, but also every other systemic feature. Images of the family, or family identity, must adapt not simply to how many members are now in the family, not only to the temperament and personality of the infant, but to the meaning of being a family of a child with a disability.

The image and meaning of this new identity, this new classification, is not focused or understood initially. There is a cognitive dissonance which must be reconciled; at this stage, families do not know how to be a family of a child with a disability. Adaptations are required in roles, rules, goals, and relationships both within and outside the family system. As a goal-seeking system (Broderick, 1993) the family must now focus attention on redefining goals, on finding a direction to follow to attain such goals, and articulate who and what the family is becoming. This challenge of systemic adaptation, of goal definition, of shaping a future for the child and family, constitutes the core conceptual category of the emergent theory, and is aptly phrased by one respondent: **I need a plan for my child's future so I could have a plan for mine.**

Contextual Dimension

The research questions which generated the data analyzed for this study were designed to obtain consumer responses regarding perceptions of resources and barriers to a model of family centered services. Essentially, the questions asked families what they needed, what was important to them, and what the strengths and weaknesses of the current system were. Collectively, the families' responses provided information about perceptions of the level of satisfaction with assistance received, or effectiveness, of early intervention services.

The data revealed information about structural components of early intervention systems, such as time, location, and quantity of services; about disciplinary expertise, i.e. the competencies of teachers and other interventionists; and about the nature of interactions between professionals and parents. This interactive domain is the location for the central phenomenon of the study and is the focus of the contextual dimension.

The data revealed more consumer attention to early intervention as a process based on interactions and relationships with providers than to structural or disciplinary components of the system. Families emphasized progress in getting on with their lives, in family goal attainment, as measures of satisfaction or positive evaluation of the early intervention system. Frequently, their praise of the system, i.e. a judgment that it had been effective, was based on the quality of interactions which led to family development or progress. For example, when asked what the best feature of the system in their county was, a respondent said:

> **They were very caring and eager to be of help and greatly helped us to get on with our life.**

The properties of this interactive relationship, caring, providing help (connecting), and guidance for family progress, have been identified as conceptual categories in the grounded theory process. Further indicators of the importance of a caring relationship include:

> **The therapists are easy to talk to.**
>
> **...they were helpful and not intimidating.**
>
> **...that the're** [sic] **there for us parents to help us out when we**

> **need it.**
>
> **...the staff is excellent, they are good listeners.**

These data focus on judging the quality of the services received by the relationship established between the providers and the parents. Focusing on the relationships between the professionals and families has not been a common area of concern or investigation in early intervention. This is supported by Vincent (1992) who reviewed the professional journals in the field of early intervention to identify the primary topics of concern to professionals. Disciplinary expertise, teaming models, service setting, curricular models, assessment and diagnosis, and efficacy of early intervention as measured by child development gains were the primary topics; not a single article or study dealt with relationships between parents and providers. Vincent suggested that the vision of Part H, i.e. family centered care, would only be reached by developing relationships with families. Respondents in this study underscore this perspective, as further indicated by their comments to the question which asked what they would like to tell the administrators of the systems in their counties:

> **I would tell them how much I appreciate their care and everything they have accomplished for us and the information that they obtained.**

The emphasis on **us** rather than only on the child and the focus on accomplishment and information as outcomes, rather than only on child development outcomes, describes the sense of process that is of concern to families. This is articulately emphasized by the following respondent comment:

> **...the growth of a family is a process and most needs cannot**

> **be solved, but rather need to be worked out and supported.**

As an indicator of quality and effectiveness, the statement of another mother is specific:

> **Our service coordinator is great. She shows a lot of concern for our family and helps us with future planning.**

Since interactions with others are part of what professionals do, thought must be focused on the nature of relationships between providers and families and how this influences the effectiveness of professionals' work (Provence, 1990). In the analytical process of grounded theory, the data in this study have focused attention on the interactive relationships between families and professionals and therefore have indicated effectiveness of early intervention systems as the contextual dimension..

Actions/Interactions/Strategies

Action or interactional strategies are those events which are implemented to maintain, obtain, or achieve some desired end in relation to the phenomenon under study (Strauss & Corbin, 1990). Such events imply the passage of time and the changing conditions which occur over time. The data in this study have indicated key actions, interactions, and strategies which are initiated or sought by families as they attempt to make progress toward a definition of the family following the birth of a child with a disability and the larger and related goal of shaping a future for the child and family. These actions or interactional strategies include reacting, and seeking a caring response; searching for connections to information, resources, and other families who have had similar experiences; a search for gentle guidance from others who have expertise and knowledge; and persisting in each action until the necessary information, support, and understanding have been gathered to satisfy the need to define the family at a given point in time and to shape a sense of the future, and its possibilities, for the child and family. These actions and interactional strategies can take place in any context, under any condition, and may vary accordingly. In this study, such actions and strategies have been analyzed under the condition of family interaction with professionals in early intervention systems and within the context of the effectiveness of the response of the early intervention systems; provider tasks (Figure 4) have been identified in the data.

Families necessarily react in some manner to the birth of a child with a disability. The search for understanding of the meaning of this event to the child and the family begins immediately. The family seeks information about the disability to better understand its implications. The family seeks consolation as the many emotional reactions seep through and affect the family system. They seek hope and safe places to confide their fears and confusion. Some of this seeking is done interactively with professionals in early intervention systems. Professionals in the early intervention system, if they respond effectively, provide caring responses to the family. Such responses meet the needs of the families and assist them in moving toward the meaning and understanding they seek.

Responses include listening empathically and for understanding, being physically available and providing physical comfort as appropriate to family indicators or cues, and acknowledging emotional reactions. Effective responses provide information relevant to immediate needs of the family and child. Providers wait for family responses and invitations to continue the interaction. An additional component of responsive caring is providing hope

Reacting < - > Caring

listening
being there
giving physical comfort
acknowledging reactions
informing
providing hope
waiting
respecting

< - Connecting - >

to specific services in the early intervention system
to disciplinary expertise
to services outside the early intervention system
to material supports and resources
to information
to other families
to informal support systems

Persisting < - > Guiding

explaining
clarifying
interpreting
identifying options
identifying questions
evaluating
encouraging

Figure 4: Provider tasks for actions, interactions, strategies.

This illustrates the responsive behaviors identified in the research which constitute provider tasks in the early intervention process.

through information about assistance and potential outcomes, and above all respecting systemic family rules regarding distance and boundaries.

The caring provided by the early intervention system is a responsive task and can help or hinder family progress and development. Successful interactions can promote additional exchange between the two systems which have the potential to continue to support family progress and development.

Additional strategies which families seek to initiate are connections to information, resources, and other families like them. These connections enhance the understanding of the disability, provide assistance and therapeutic interventions for the child and family, and allow the family opportunities to identify options and alternatives which will facilitate both child and family development. Such connections may result in additional services, material resources, and the chance to learn from other families. Both the family and the professional in the early intervention system may initiate such connections.

Effective early intervention services facilitate the connections which meet the needs identified by the family and subsequently support the family's continued progress toward shaping a future. Early intervention providers are expected by families to be able to facilitate connections to child specific services which have been identified through assessing the child's developmental needs. In addition, families expect early intervention providers to facilitate connections to services for parents which allow them to extend and enhance the child focused interventions. Families also expect connections to services outside the resources of the immediate early intervention system, including those which might be found in other agencies or systems, such as material and instrumental resources which promote family capacity.

Respondents in this study also indicated the importance of connections with informal support systems, such as other families, support groups, and other community organizations.

Throughout responsive actions the early intervention professional has the opportunity to provide guidance to families, to assist them in ways that facilitate movement toward redefinition and potential for future outcomes. Such guidance is based on the needs of the child and family and pertains to decisions which may be related to options within the early intervention system, options external to the early intervention system, and options specific to the family system. In providing such guidance, professionals engage in explaining, clarifying, and interpreting, especially when information from other systems has been obtained or provided in clinical or disciplinary language. The identification of options, assistance with questions which should be asked, and the evaluation of incoming information, as well as decisions, are also guidance tasks of the early intervention professional. The data also revealed that families may need encouragement to engage in decision making and judge early intervention services effective when such encouragement is provided.

If the connections and guidance provided by the early intervention system are not sufficient to meet family needs, families implement a strategy identified in the data analysis as persisting. Persisting is behavior which results in the desired outcomes; it can be asking, demanding, advocating, insisting, or enforcing kinds of behavior. It can be unrelenting in its application until goals are met; families in this study expect to persist in seeking what they identify as child and family needs without regard to formal systemic barriers or professional behaviors. Professionals have the opportunity, if it is recognized, to contribute to this persistence in ways which promote competence and independence in both the child and family.

Consequences

Consequences are the outcomes of actions, interactions, or strategies which may or may not be predictable or intended. They may be subsequent actions, interactions, or strategies; they may create new conditions for other consequences. Consequences may be potential or actual; they may occur in the present or in the future. Consequences are those aspects of the grounded theory paradigm which are also conceptual categories or subcategories resulting from the analysis of the data. In this study, the consequences are the child and family outcomes relevant to levels of success in the secondary task of redefining family identity and the primary task of shaping a future for the child and family. The outcomes, in this study, are dependent on the effectiveness of the early intervention services as measured by the families' interactions with such service systems.

Data in this study identified a variety of outcomes which are related to interactions between family and early intervention systems. Child growth and development, mediated by specific or multiple disabilities, is generally the primary focus of early intervention services; however, the data revealed that families also have systemic tasks and goals which can be facilitated through effective early intervention. Thus, the consequences which are of interest in this grounded theory paradigm are those pertaining to the systemic tasks and goals of families of young children with disabilities, i.e. redefining an identity as a family of a child with a disability and shaping a future for the child and family.

CHAPTER VII

SHAPING A FUTURE

When a child is born with a disability the family experiences a crisis: their image of the family, of who they are or thought they were becoming, of what they thought their future might be, is blurred. The family is faced with the task of redefining their identity as a family of a child with a disability. This requires new information and an understanding of the nature of the disability and its implications for the child and family. This is a prerequisite task to recreating a vision of the future. In their reaction to this crisis, in their attempt to redefine family identity and vision of the future, they typically turn to various support systems, one of which may be a formal system of early intervention services.

The provision of early intervention services to young children with disabilities and their families is not an exclusive task; it is inclusive of the child, the family, and the professional early intervention providers(s). When the professional assesses, evaluates, or otherwise treats the child, the provider joins the family team. It is an interactive relationship which is dependent on tasks and functions which must be accomplished by all members of the team: child, family, and provider. The tasks and functions are reciprocal and, within the context of the interaction, determine the duration, the quality, and the relative success of the outcomes.

The process itself is forever dynamic with each member making contributions to the unfolding development of relationships, growth, and progress toward goals. Parents react and need caring. Professionals care and connect the family with information, resources, and services. Parents learn and grow through these connections. They ask questions; providers explain, clarify, and gently guide. Parents react; they make decisions and they persist. Professionals acknowledge and validate such decisions as well as family persistence. Throughout this process both the family and the provider care for and treat the child; they listen and respond to one another. Families seek to gain a clearer vision of who they are and what they can become. Together they begin to shape a future which fits family values and goals and which gives purpose to the challenge of everyday living.

Interactive Process of Shaping a Future

From a family perspective, formal systems of early intervention services should be able to provide access to information and services which are pertinent to the child's disability. From a family perspective, systems of early intervention services are potential resources which may be able to provide the support and information which families need to assist their children who are challenged by disabilities. From a family perspective, early intervention services are only one source of support and information which the families may use to gain the competencies they need to care for their children. How effective the early intervention systems are in providing what families want and need is dependent upon many factors. Of great importance, however, is the nature of the interactive process in which families and professionals participate when families choose to seek assistance from systems of early intervention services. Early intervention systems have the potential to provide effective responses and services to families. The success of these services will be measured according to the level of effectiveness they attain as judged by families who participate in these services.

Reacting < - > Caring

Reacting to the birth of a child with a disability is the beginning point in the process of redefining an image of a family. Immediately upon the identification or diagnosis of disability, the family identity is altered. Families are no longer the same; now they are different from typical families, from what they once were. The family has a need to understand this new identity, what it means in terms of daily living, in terms of relationships, in terms of personal and family goals and future plans. Confusion and shock are typical reactions at this time; families feel as if they are without hope, without power, and sense they have little or no control over their lives or their children's lives.

Early intervention providers who meet the family at this point in time are challenged to respond in a caring manner, to effectively meet some of the family's needs, if the redefinition of identity and shaping of a future is to begin with potential for successful family and child outcomes. Given the vulnerability of the families at this time, the emotional and psychological needs of the families must be given consideration while the infants' needs are interpreted within the family context (O'Brien & Dale, 1994). Early intervention providers must respond to both developing units, i.e. the infant and the infant's family, in order to initiate an effective intervention strategy.

Family members will be experiencing different stages of shock, grief, and adjustment to having a child who has a disability; family members may move along a continuum of possible levels of readiness for involvement with early intervention providers (Nash, 1990). According to Dunst (1985), the more that intervention providers focus on family needs and resources, rather than simply child centered needs, the more children and families are expected to benefit from intervention services.

Families in this study indicated that they want professionals to consider the whole family, the needs of the family, and they expect a caring response to their situation at this critical time in the development of the infant and family. Caring responses to varying family reactions can be identified by families. They have suggested that they need to understand the nature of the disability and its implications; a caring response is provided in such a way that they can see some hope in the situation, so that they can be assured that **all is not lost** . Professionals who interact with families must be sensitive to this need for hope and must know how to convey such information in a way that supports a sense of hope within the framework of careful and honest information about the disability. When done effectively, families **feel better about themselves and the child**.

Families have indicated that, for some, the physical presence and comfort from **someone who understands** is very important; **a hug, a shoulder to lean on** can communicate empathy and validation of the emotional status of the family. In some cases, the most responsive approach to caring is to wait; families have indicated that for some of them, **it takes time to know what they feel and what they need.** Professionals must be able to interpret family needs, to quickly assess individual and family rules such as those of boundaries and distancing described in family systems theories (Broderick, 1993; Burr et al., 1979) if they are to be tactful and successful in responding in this manner.

Families indicated that there is an overwhelming need to find someone who will listen to them, **someone who will let them talk because there are lots of feelings that parents go through**. Listening and responding meaningfully is another category of behavior which families have requested in this study. A. Turnbull, in Turnbull and Turnbull (1985) shares that one of the most compassionate and meaningful interactions she had with a professional, when persisting in the search for help for her son, was with a psychologist who, while listening to her, had tears running down her own cheeks, thus validating Turnbull's own sense of desperation. Another parent recalled that, while in the hospital following the birth of her child, she could not stop crying as a result of the diagnosis of disability; she feared that the medical and health care staff would judge her as not coping well. When she attempted to apologize to a nurse for her crying, the nurse responded by telling her that it was okay, that she was crying because she loved her child, thus responding in a caring manner because she had listened to the meaning in the mother's words. This helped the mother to move on with the postnatal process (Turnbull & Turnbull). This level of compassion is respected by parents who indicated, in this study, that they do not appreciate professionals saying, **I understand**, when they really do not.

Generally, many professionals do not feel comfortable with this level of responding to families, as their clinical training has not included any skill building in this area. Many professionals, however, need to improve the strategies they use when counseling parents following the birth of a child with a disability (Pueschel, 1985; Van Riper, Pridham, & Ryff, 1992). In some agencies, the administrative philosophy does not regard interpersonal exchanges of this nature as appropriate; distancing from the families is perceived as more professional. Conditions such as these, i.e. training deficits and organizational bias, impact the nature of the exchange between family and early intervention systems. Kalmanson and Seligman (1992) observed that working with infants and their families, especially where children have special needs, can be emotionally provocative and challenge long standing defenses and coping strategies for professionals as well as for parents. The challenge to professionals in early intervention practice, in responding in a caring manner that helps families move through the process of reacting to disability, is significant. It is one, however, that must be met if interactions with families are to be effective and successful in helping families with the process of understanding the possibilities for themselves and their children.

Families have a need for information, **for getting questions answered**, and they want it **all explained in terms families understand.** Sometimes professionals get involved in the clinical environment and ignore the need to eliminate jargon and clinical terms in their communication with families. Using terms that families understand, and providing information as needed, are important components of responsive caring when interacting with families who are reacting to the birth of a child with a disability.

In all components of responding to families' needs, i.e. listening, informing, providing physical and emotional support, acknowledging reactions and validating concerns, providing hope, and waiting, professionals demonstrate respect for families when they respond appropriately. This is a beginning of a relationship that can provide significant input to a family system over the course of the early years of a child's life; it is a relationship that can impact the future of both the child and family.

< - Connecting - >

Families in this study expressed the priority of a need for information; information about the disability, about programs and services, and about learning how to adapt, cope, and build a future. A chorus of respondents asked for **resources available to them to learn more about their child's disease or disability.** This ongoing need for information cannot be underestimated as a potential source of stress (Berger & Foster, 1976). Families have indicated that gaining information is a never ending task. They seek information wherever they can get it, from formal systems, from families, and even from strangers, as one mother reported that **most leads we got were from average people I only met once, but I quizzed them**.

It would seem that of all the tasks that providers are challenged to meet, connecting families with information would be a relatively easy one. However, that apparently is not the case. A combination of factors can intervene which sometimes limit the amount of information which is provided to families. For example, the clinical training of some early intervention professionals results in an attitude which assumes the ability to determine what information families should have and what they should not have. They tend to view themselves as experts and pay less attention to the input of the parent (Garshelis & McConnell, 1993). When this happens, the delivery of early intervention services is less than effective; families' needs for information are not met.

Other factors which can intervene in the connecting process include lack of information held by the provider, and lack of knowledge about where or how to obtain such information. Professional training is sometimes responsible for this because it is limited to a specific discipline without providing awareness of the interrelated nature of one discipline to another, or about the need to be responsive to family concerns in addition to child concerns (Bricker and Slentz, 1988; McCollum, 1987).

Parents also want information about normal child development

(D'Amato & Yoshida, 1992) and how their child is expected to vary in meeting developmental milestones because of the disability; and, they want specific information on what they can do to stimulate and support their child's progress (Gowen, Christy, & Sparling, 1993). As one mother said, (we) **need to know what to do, how to achieve success in working with the teachers and our child.** Their concerns are not unlike those encountered by most parents (Duvall, 1971). Connecting families with this kind of information is specific to the early intervention system and service providers; such information should be available and easily provided. It is in this area that professionals and parents can develop a sense of partnership that has the potential to enhance their interaction in other areas.

The most direct connection between the family and early intervention systems is in the delivery of and participation in specific disciplinary services. Early intervention services, such as special education, physical therapy, or speech therapy, are typically the primary interventions provided to young children with disabilities. These are areas of expertise where the professional providers generally are perceived by families as very skilled and effective.

Parents frequently request assistance in identifying resources and services which they need and which may be outside the primary intervention system, such as **personal help and financial help**, or **clear and concise medical information**; they expect that their primary provider will be able to make these connections for them. Effective delivery of early intervention services should result in appropriate referrals and contacts for assistance from other agencies and systems; families are not experts in managing the sometimes complex maze of service agencies and private providers. In addition, families have significant challenges in meeting family and infant needs, and are better able to focus on these needs if they can rely on the early intervention system to provide assistance in making such connections. Dunst, and colleagues (1988) concur that families would benefit from **a liaison to offer contacts, resources, or appropriate referrals that can help the family cope with their crisis**.

Families have been very articulate about their need to be connected with other families, both for support and to learn how other families have adapted and coped. They are eager to meet other families like them to gain a sense of identity, to learn how to be a family of a child with a disability, and to see how the future might look. Connecting with other families provides a sense **that they are not alone** and they can **see other families getting on with life**. This need was a prominent one in this study and is related to the central task of gaining enough information to begin to shape a future for the child and family. Providers have to be sensitive to this need and take an active role in facilitating such connections. Studies have shown that such connections are very important for families of children with severe disabilities (Krauss, Upshur, Shonkoff, & Hauser-Cram, 1993). Generally, parent support groups or parent to parent support networks are not routinely accessed through formal systems of early intervention services. Such access tends to be an afterthought or dependent on the individual provider's personal knowledge of the existence of such groups. Formal connections are not part of the regular menu of services available in many early intervention agencies. In fact, many of these connections are made outside of the formal systems. If early intervention services are to meet the needs of families, to be effective in assisting families in the process of redefining the family and shaping a future, then such connections should be readily available through the professional contacts.

Persisting < - > Guiding

Families have indicated that early intervention is a process of gaining knowledge and wisdom, not merely a list of services they or their children might receive; it is a process which is based on relationships between the early intervention providers and the family (Vincent, 1992). In order to facilitate this process, providers must learn to gain the family perspective, to understand needs, concerns, and goals through the eyes of the families. This is an important part of strengthening the interactive process by which early intervention providers help guide families toward an understanding of being a family of a child with a disability and gaining a vision regarding goals and potential for the future.

In the continuing quest for information and understanding, families have the need for someone to facilitate this process of gaining wisdom; someone to help explain or clarify a new diagnosis and its implications or to interpret new assessment findings. This **professional back up** is in fact an input to the family system which enhances the capacity of that system for self-regulation or decision making. Not only do families want and expect **someone who can provide information and answer questions**, they also **need encouragement and guidance**. They expect **support to enable them to accomplish some of what is being asked of them**. This may include helping the family identify questions which should be asked as **parents may not know what to ask; more concrete direction is needed**.

As options are identified for programs and services, such as what preschool setting might be most appropriate when the child is ready for transition out of the early intervention program at age 3, parents want an interactive relationship which provides **advice and guidance**. This helps them evaluate options so they can **know what to do...know what is available...** and become **aware of all the programs available**. Throughout this process of guidance, families also want **everything explained in terms they understand** and want the information provided **when they need it.**

All of these various elements of guiding are part of a caring response to family needs. Families who participated in this study clearly indicated that such guidance is necessary if early intervention systems are to be effective for them; families will persist in seeking such help whether or not it is available through their interactions with formal systems of early intervention services.

This persistence in seeking information, support, and services can be a problematic property of effective family and early intervention system interactions. Families will **keep asking for what they want until they are satisfied** and do not expect **to sit back and wait for agencies to do the work**. This persistence can create conflict. Such conflict may be the result of role ambiguity, differences in goals, resource limitations, or as a result of poor communication or understanding between the two systems (Nash, 1990). If the early intervention professional is able to understand the family perspective, it is possible that such conflict can be avoided or minimized. All too frequently, however, professionals have not been trained to understand the systemic nature of family behavior and actions or to interact effectively when such conflict arises. As a result, the potential effectiveness of early intervention services can be minimized and family progress toward shaping a future can be compromised.

A Grounded Theory

Families of young children with disabilities who engage in interactions with formal systems of early intervention services judge such systems to be effective when, through caring responses to family needs and gentle guidance for family development, appropriate connections are made for the information, services, and supportive learning which families actively seek; collectively these interactions assist families as they persist in redefining who they are as a family of a child with a disability, assist the family in discovering who they can become, and enhance the family system in its persistence toward shaping a future for both the child and the family.

CHAPTER VIII

SUMMARY AND IMPLICATIONS

The purpose of this study was to gain insights into perceptions held by families of young children with disabilities regarding their needs and their expectations of systems of early intervention services relative to meeting these needs; to enhance the understanding of professionals, administrators, and policy makers regarding such needs and expectations; and, to develop an understanding of what professionals must know and therefore how they should be trained for a model of early intervention services which is family based. Using a grounded theory process of qualitative research, the written responses of 45 Michigan mothers of children under the age of 6 with disabilities were analyzed. These data were made available for this study by the Merrill Palmer Institute at Wayne State University, having been previously collected in 1992-93 as part of a larger study supported by a grant from the United State Department of Education, Office of Special Education Programs .

This particular qualitative research process utilizes the researcher as a source of theoretical sensitivity in the discovery and development of grounded theory. Relevant literature is used as needed for theoretical sampling once the analysis has proceeded to a substantive stage. The researcher does not begin with a hypothesis nor is linear causality a focus of the research. Rather, a purposeful sequence of coding paradigms, constant comparison, and theoretical sampling is used to discover theory grounded in the data; such methods are particularly oriented toward exploration and inductive logic. Inherent in this methodology is the assumption of complex social processes which transcend the boundaries of unit analysis. Such an approach to family research allows the processes by which families create, sustain, and discuss their own realities to bring meaning and rich description to an improved understanding of social phenomena. In this study the focus was on the interactions between family systems and formal systems of early intervention services.

An ecological model of the family as a social system which interacts with and is interdependent on other systems for exchanges of information, goods, and services provided the overarching framework for this study. Embedded in this framework are theories of family systems and symbolic interaction. As systems, families exhibit constructs of goal-seeking and self-regulating mechanisms which impact interactions with formal systems outside the family. Using a symbolic interaction theoretical approach, such interactions have been described and interpreted for meaning to gain a better understanding of such social processes.

The grounded theory process yields a core conceptual category around which other conceptual categories are integrated by means of a paradigm to tell a story analytically. The paradigm includes the primary and intervening conditions, the central phenomenon, the context, the interactions, and the consequences, all of which are interrelated. In the emergent theory, the interaction between the family and the early intervention systems constitutes the condition of the phenomenon under study; the variability of the primary systems involved creates intervening conditions which account for variations in outcomes. The identified conceptual categories are actions or interactions which are related to the consequences. These are viewed within the contextual dimension of effectiveness of early intervention systems. The consequences are the child and family outcomes.

The central phenomenon which was identified was the need families have to redefine who they are and what they can become before they can begin to shape a future for the child and the family. Adaptations are required in roles, rules, goals, and relationships both within and outside the family system. This challenge of systemic adaptation, of goal definition, of shaping a future for the child and family, constitutes the core conceptual category of the emergent theory, and was aptly phrased by one respondent: **I need a plan for my child's future so I could have a plan for mine**.

A subsidiary phenomenon which was identified as a result of the grounded theory process was the need that families have, upon the birth of a child with a disability, to understand what it means to be a family of a child with a disability. Families necessarily react in some manner to the birth of a child with a disability. The search for understanding of the meaning of this event to the child and family begins immediately. The family seeks information about the disability to better understand its implications. The family seeks consolation as the many emotional reactions seep through and affect the family system. They seek hope and safe places to confide their fears and confusion.

The data revealed more family attention to early intervention as a process based on interactions and relationships with providers than to structural or disciplinary components of the system. Families emphasized progress in getting on with their lives, in family goal attainment, as measures of satisfaction or effectiveness of the early intervention system. Frequently, their praise of the system, i.e. a judgment that it had been effective, was based on the quality of interactions which led to family development or progress.

The grounded theory process resulted in conceptualizing the interactions of family and early intervention exchanges as reacting, and seeking a caring response; searching for connections to information, resources, and other families who have had similar experiences; a search for gentle guidance from others who have expertise and knowledge; and persisting in each action until the necessary information, support, and understanding have been gathered to satisfy the need to define the family at a given point in time and to shape a sense of the future and its possibilities for the child and family. These actions and interactional strategies can take place in any context, under any condition, and may vary accordingly.

Data in this study identified a variety of outcomes which are related to interactions between family and early intervention systems. Child growth and development, mediated by specific or multiple disabilities, is generally the primary focus of early intervention services; however, the data revealed that families also have systemic tasks and goals which can be facilitated through effective early intervention. Thus, the consequences which are of interest in this grounded theory paradigm are those pertaining to these tasks and goals, i.e. redefining an identity as a family of a child with a disability as a prerequisite task to shaping a future.

Families indicated that early intervention is a process of gaining knowledge and wisdom, not merely a list of services they or their children might receive; it is a process based on relationships between the family and the early intervention provider(s). In order to facilitate this process, providers must learn to gain the family's perspective, to understand needs, worries, and goals through the eyes of families.

Families will persist in seeking the information and resources they need; this can create an environment for conflict if the professionals do not understand this goal orientation which is a construct of systemic family organization. The potential effectiveness of early intervention services can be minimized and family outcomes compromised if early intervention providers are not sufficiently skilled in working with families toward facilitating their progress and development.

The grounded theory which emerged from the analysis undertaken in this study can be succinctly stated as follows: families of young children with disabilities who engage in interactions with formal systems of early intervention services judge such systems to be effective when, through seeking caring responses to family needs and gentle guidance for family development, appropriate connections are made for information, services, and supportive learning; collectively these interactions assist the family in redefining who they are as a family of a child with a disability, assist the family in discovering who they can become, and enhance the family system in shaping a future for both the child and the family.

Implications

Both the findings of this study and the methodology applied yield a discussion of broader implications. These implications include further evolution and application of the grounded theory process to survey research, additional research activities, implications for preservice training and professional development, and implications for policy and administration relative to early intervention practice and the continued implementation of Part H of the Individuals with Disabilities Education Act. These implications are discussed in the following section.

Grounded Theory

The use of grounded theory as a qualitative method has been gaining in popularity since its introduction by Glaser and Strauss in 1967 (Strauss & Corbin, 1994). Since that introduction, the methodology has evolved and expanded to a diverse application across many disciplines. Its unique feature is that it connects research with theory; it goes beyond reporting quantities of characteristics or possible causal relationships. Instead it focuses on the complex phenomena of social interaction through an inductive development of theory grounded in the research data. As such, it is a complex process and therefore runs a risk of incomplete application or misapplication. However, its potential contribution to enhancing the understanding of particular sociological events is its greatest asset.

In this study, two significant points regarding the application of grounded theory methodology must be made. First, the researcher has not been able to locate any other study where grounded theory methodology has been applied to data generated through the use of open ended survey questions. However, where open ended survey questions are well designed to generate broad and very personalized responses, as they were in the original study which generated the data analyzed, the potential for further use of grounded theory in the analysis of survey data seems rich. Typically, the grounded theory process is applied to fieldwork such as observation and interviews, and in some cases to archival documents. Since a key element of the process is theoretical sampling, the ability to continue to generate data is important; thus the typical use is in settings where that is possible. In this study, at least for the analysis which has been reported, the theoretical sampling was limited to the existing data and the existing literature.

However, Glaser (1978, 1992) and Strauss and Corbin (1990, 1994) now have an ongoing debate over theoretical sampling techniques and coding paradigms. This indicated to the researcher that the method is continuing to evolve and provided a sense of scholarly challenge to participating in its evolution. In fact, the application of the methodology in this study represented a modification of both the earlier (Glaser & Strauss, 1967) and the more recent (Glaser; Strauss & Corbin) descriptions of the methods. Thus, the second point is that researchers should continue to apply and refine this method, as the results of its application in this study have been exciting, descriptive, and informative, and will lead to further understanding and improvements of the process of early intervention.

Research Activities

The grounded theory which resulted from this study is a middle range theory, i.e. one which uses a coherent set of assumptions and terminology, is logically interrelated, is sufficiently modest in scope so that it can be grasped as a whole, and is sufficiently abstract to make it possible to deduce a number of testable hypotheses that can corroborate or argue against the validity of the ideas (Burr et al., 1979). The possible research activities which could follow from this study are many; those in which this researcher is most interested include those which would provide further understanding of the elements which need improvement in the training of early intervention professionals and the indicators of quality practices in early intervention.

Such activities which are of interest to this researcher include an investigation into the variations of family attributes relevant to goal-seeking behaviors, i.e. why do some families persist in seeking information and services in a manner which is more intense than do other families? And, what behaviors or responses from professionals in the early intervention field best support family goal-seeking and persisting toward positive outcomes?

One of these activities would include the use of focus groups to generate additional data regarding the need families have to seek knowledge and understanding which allows them to make decisions relevant to future outcomes for their children and families. This would begin with a family systems ecological framework and would include a more in depth analytical application to the systemic constructs of self-regulation and goal-seeking which appear to have important conceptual foundations for explanatory properties of the action identified in this study as persisting.

Further research activities would include interviews with early intervention providers to better understand their perceptions of persisting and how they subsequently respond to actions which fit this description. Such understanding would then be used to develop improved instruction and training for future and current early intervention professionals.

The ultimate goal of these activities is to better understand the perspective of each of the primary agents in the interactive process of early intervention as it pertains to persisting, as described in this study. This area of interaction can be most problematic and is a phenomenon which can seriously compromise the possible positive outcomes of the early intervention process. Improved understanding would hopefully lead to improved practice and better support for child and family development.

Training and Professional Development

The practice of early intervention is a multidisciplinary undertaking with each professional entering her respective field well trained by discipline. What is missing, however, is the knowledge and skills necessary to work successfully with families who are stressed, confused, and sometimes angry when they begin their relationship with those in the field. In addition, most professionals have not been exposed to, or have only minimal awareness of, concepts of family systems and human ecology, thus participating in a dynamic interaction with families and having little awareness of the nature of that interaction or the consequences of their own behavior.

What is needed at the preservice and graduate levels is an interdisciplinary course, and perhaps even a practicum, which will better prepare early intervention professionals. Such preparation would include objectives relating to knowledge of family systems, understanding of the process of familial adaptation to disability, an awareness of the varied literature which is available for those in this interdisciplinary practice, and opportunities to be exposed to the realities of families of young children with disabilities, either through field experience, interviews with families, video presentations, class presentations, or some combination of these. This same course or a variation of it could be made available for off campus instruction for professional development opportunities for those already practicing in the field.

There are other approaches, no doubt, to improving practice; this is one which has been emerging in concept as a result of the experience of this researcher throughout the course of the data analysis. It is further reinforced by personal experience as a speech pathologist, as an administrator of early childhood programs, and as a participant in policy development in the field of early intervention in Michigan. Other states are already pursuing such training models, and recent pilot projects in inservice training have indicated positive outcomes for practitioners (Bailey, Buysse et al., 1992; Bennett, Smith, White, Moon, & Davenport-Ersoff, 1992).

Policy and Administration

Part H of the Individuals with Disabilities Education Act has challenged state policy makers, administrators, and professionals to improve and enhance early intervention services to young children and their families, to make them more family based. This study has indicated that issues of practice and organizational bias may be factors in the successful delivery of family based early intervention services. Support for professional development which will provide professionals with the knowledge and skills necessary to effectively facilitate child and family development within the context of individual family goals and values is an area where the commitment to Part H can be operationalized.

Families have much to tell us about early intervention services and how those services can be of assistance to them and their young children. It is in the best interest of effective service delivery for policy makers and administrators to support methods of gaining that information from families. Research, including focus groups, interviews, and surveys which target families as the key participants should be supported to further the practice of effective early intervention services. Policy and administrative guidelines should be modified to reflect the findings of such research, thus allowing formal systems of early intervention services to respond to and support families and their children.

Conclusion

The process of early intervention is an interactive relationship between families and professionals. Families come to early intervention providers seeking comfort, information, hope, and guidance in order to learn how to be a family of a child with a disability, how to care for their child and each other, and to gain some perspective on how to shape a new future for themselves. How professionals in the early intervention system respond can either help or hinder this family process. The dynamic interplay of the systemic constructs of families and those they encounter in their quest to shape a future is beautifully described in the following poem, written by a Michigan mother of a child with a disability for another Michigan mother, like her. Together, they shared with one another intimate stories of their experiences with professionals upon the birth of their children. This is presented with permission of the poet.

Rural mother
        snatched out of
                quiet country.

        Plopped rudely into
                dense city traffic
                        and heat.

Soft, silky skin
        paled.

Darkness crept into eyes and soul.

Too much noise.
Too many rushing faces,
Too many tubes
        hooking her new born baby
        to something
            they called "life."

Waiting, waiting.
Walking down sterile corridors
Looking in
                the eyes of doctors
                for answers.

Not knowing the questions.
Only knowing
        the lump in throat.

More surgery.
More unknowns,
        unknowns
        unknowns
        un   knowns.

Un knowing the world
        that once was.

Then the doctor
        raises his pitchfork of predictions
        plunges the sharp point
        into the mother's heart
        and says:

        "NOTHING LEFT, BUT TO PUT THE BABY IN AN INSTITUTION."

Years later,
this baby, Andy,
Learns to pick dandelions
with his new friend.
They giggle as their tiny fingers
pull each strand of yellow sunshine.

Mother smiles.

Oddly,
she remembers the doctor
and the pitchfork
that maimed her heart.

She whispers to the doctor:

"You could have told me with your heart.
You did not need to use your weapon."

She vows never to let another
pitchfork plunge
deep into the heart
of a grieving mother.

She thinks that she will
send a yellow dandelion
to this doctor.

She'll tell him that
Andy
picked it for him.

Janice Fialka
June 1994

APPENDIX A

Advice to Professionals who must Conference Cases

Advice to Professionals who must Conference Cases

Original poem by Janice Fialka (1993), a mother of a child with a disability.

Before the case conference
I would look at my almost five year old son
And see a golden hair boy
Who giggled at his new baby sister's attempt to clap her hands,
Who charmed adults by his spontaneous hugs and hello's,
Who captured his parents with his rapture with music and
his care for white haired people who walked a walk
a bit slower than younger folks,
Who often became a legend in places visited because of his
exquisite ability to befriend a few special souls,
Who often wanted to play "peace marches,"
And who, at the age of four,
went to the Detroit Public Library
requesting a book on Martin Luther King.

After the case conference,
I looked at my almost five year old son.
He seemed to have lost his golden hair.
I saw only words plastered on this face.
Words that drowned us in fear and revolting nausea.

Words like: Primary expressive speech and language disorder
severe visual motor delay
sensory integration dysfunction
fine and gross motor delay
developmental dyspraxia and
RITALIN now.

I want my son back. That's all.
I want him back now. Then I'll get on with my life.
If you could feel the depth of this wrenching pain.
If you could see the depth of our sadness
then you would be moved to return
our almost five year old son
who sparkles in the sunlight
despite
faulty neurons.

Please give me back my son
undamaged and
untouched by your labels, test results,
descriptions and categories.

If you can't,
If you truly cannot give us back our son

Then just be with us quietly,
gently
and compassionately as we feel.

Just sit patiently
and attentively as
we grieve and
feel powerless.

Sit with us and create a stillness known only in small, empty
chapels at sundown.
Be there
With us
As our witness and
as our friend.

Please do not give us
advice,
suggestions,
comparisons or
another appointment. (That's for later.)

We want only a quiet shoulder
upon which to rest our too-heavy heads.

If you can't give us back our sweet dream
then
comfort us through this nightmare.

Hold us
rock us
until morning light creeps in.

Then we will rise
and begin the work of a new day.

APPENDIX B

Demographic Information from Respondents

Demographic Information from Respondents

Table 1

Diagnostic categories of children (N = 45)

Diagnosis	Children
Cerebral Palsy	11
Down Syndrome	9
Multiply Impaired	7
Mentally Impaired	3
Health Impaired	2
Hearing or Vision Impaired	2
Autistic	2
Other	6
No diagnosis	1
Missing data	2

Table 2

Ages of children (N = 45)

Ages	Children
Less than 12 months	3
12 - 23 months	8
24 - 35 months	16
36 - 47 months	7
48 - 59 months	7
60 - 72 months	4

Table 3

Number of agencies providing services to families (N = 45)

Agencies	Families
Education only	14
Education & 1 agency	12
Education & 2 agencies	5
Education & 3 agencies	4
Education & 4 or more agencies	3
Single agency, not education	3
Two agencies, not education	2
Three agencies, not education	1
Four or more agencies, not education	1

Table 4

Education level of mothers (N = 45)

Education	Mothers
Less than high school	1
High school	11
Some college	21
Bachelors degree	7
Masters degree	2
Beyond Masters degree	3

Table 5

Marital and employment status of mothers (N = 45)

Status	Mothers
Married	
Employed	18
Not employed	23
Single, never married	
Employed	1
Not employed	0
Single, divorced	
Employed	0
Not employed	2
Other	
Employed	0
Not employed	1

Table 6

Household income levels of families (N = 45)

Annual Income	Families
Less than $10,000	5
$10,001 - $20,000	5
$20,001 - $30,000	7
$30,001 - $40,000	7
$40,001 - $50,000	8
More than $50,000	11
Missing data	2

APPENDIX C

Gaining Permission to Use the Data

Gaining Permission to Use the Data

Wayne State University

The Merrill-Palmer Institute
for family and human development

Eli Saltz. Ph.D Director

Rita Benn
Merrill Palmer Institute
Wayne State University
Detroit, MI. 48202

Jacquelyn Thompson
1110 Dillon Circle
Lansing, MI. 48917

September 15, 1994.

Dear Jacquelyn,

I am very excited that you are planning to analyze the parent data from our Barriers and Utilization project for your dissertation. I am sending you copies of the 76 questionnaires from parents with identifying information deleted from them. As additional protection, please make sure that you keep them locked in a file.

I would be interested in hearing about your results as they become available. Good Luck.

Sincerely.

Rita

Rita Benn, PhD
Project Director

71-A East Ferry Avenue • Detroit. Michigan 48202 • (313) 872-1790
FAX No 577-0995

APPENDIX D

Examples of Data

Examples of Data

B. Responses to the following questions will greatly assist the improvement of early intervention services for families and their children.

1. What is most important for early intervention service providers to know about working with families?

To speek at there level.

2. What do families need most when they discover that their infant or toddler has special needs?

One person that is very understanding of all funtion of all agencies and direct them as far to which ones would be - [illegible] for them
appropriate

3. What advice would you give to other families who are looking for help for their infant or toddler?

be persistant Know your rights. Talk to other parents.

4. What, in your opinion, is the best feature of the early intervention service system in your county?

The teacher are great very interested in our child and future

B. Responses to the following questions will greatly assist the improvement of early intervention services for families and their children. We would appreciate your thoughts to these questions.

1. What is most important for early intervention service providers to know about working with families?

Parents with special needs kids have different outlooks + feelings about their Child's disability + their family life. It has to be approached very carefully for the family + child's sake. Be considerate of the families privacy.

2. What do families need most when they discover that their infant or toddler has special needs?

Somebody that has experienced a similar situation, not someone saying "we understand" when they haven't experienced that situation. Let the parent talk, there are alot of feelings that parents go through.

3. What advice would you give to other families who are looking for help for their infant or toddler?

When you are the parent of a special needs child you have to be their advocate. Don't give up, you have to really work for the rights they deserve. Don't be afraid to ask for help or info, it is for your Childs benefit!

4. What, in your opinion, is the best feature of the early intervention service system in your county?

The follow up. The initial evaluation is good, but then you get the follow-up to see if things are different or changing.

B. Responses to the following questions will greatly assist the improvement of early intervention services for families and their children.

1. What is most important for early intervention service providers to know about working with families?

That sometimes helping the child will need to begin with helping parents. Some parents don't put a lot of emphasis on sending child to school because they may look at school as a very negative experience.

2. What do families need most when they discover that their infant or toddler has special needs?

They need to know that there is nothing to big to overcome. They need to know that blame is not important but working together to better the support for the child is.

* No-one knows it all & Parents are needed by teachers & staff & teachers are needed by Parents - Team WORK!

3. What advice would you give to other families who are looking for help for their infant or toddler?

Don't be embaressed, Don't be afraid to ask Questions, Don't be ashamed. The only thing to be ashamed of is if you & your child need help & you don't ask for it! And don't be intimidated by anyone's degrees or big words you are just as important & valuable

4. What, in your opinion, is the best feature of the early intervention service system in your county?

The way they do use other agencies to help families and they are much more available for family support.

B. Responses to the following questions will greatly assist the improvement of early intervention services for families and their children.

1. What is most important for early intervention service providers to know about working with families?

To be empathetic and to allow parents an opportunity to talk about their concerns and hopes. To encourage fathers participation when possible

2. What do families need most when they discover that their infant or toddler has special needs?

Helps us when we're ready to get the information re: subsidies, respite care, specialists, etc.

3. What advice would you give to other families who are looking for help for their infant or toddler?

Ask questions! Expect the school districts to provide what services are needed and attend all meetings with husbands)

4. What, in your opinion, is the best feature of the early intervention service system in your county?

The personal contact with professionals and sharing between other mothers. I feel that the professional truly care for my son.

5. What, in your opinion, is the weakest feature of the early intervention service system in your county?

There isn't any publicity or Community
knowledge that there is a program out there for
Children with special needs. Families that
aren't aware that there are programs for
Special Children are only hurting themselves and their

6. If you could talk to the administrators of the service systems in your county: Child.

a) What would you tell them about their agencies and services?

To spread the word that they are there to
help. Much more public awareness is needed

b) What should they know about the families which receive services from these agencies?

That each one is unique in its needs and
to treat these families as such. Families that
have a special needs child needs to feel that
they are not outcasts because of their child; that
they are the same as any other family.

THANK YOU FOR COMPLETING THIS SURVEY

Please fold this packet so that the Merrill-Palmer Institute address faces up, staple or tape the open end of the questionnaire and place it in the mail by June 10, 1992. Postage is pre-paid.

MAKING FAMILIES FEEL AT EASE ABOUT ASKING OR RECEIVING HELP. WE ALL GRIEVE DIFFERENTLY, THEREFORE, NO ONE METHOD WILL WORK FOR ALL FAMILIES.

5. What, in your opinion, is the weakest feature of the early intervention service system in your county?

ONCE WE MADE CONTACT MIPPS HELPED US ALONG.
DIRECT REFERRAL FROM NICU'S MAKES IT EASY FOR PARENTS WHO ARE TRYING TO COME TO TERMS WITH HAVING A SPECIAL NEEDS CHILD. PARENTS MUST PASS THE DENIAL STAGE BEFORE THEY CAN BEGIN TO HEAL AND HELP THEIR CHILD.

6. If you could talk to the administrators of the service systems in your county:

a) What would you tell them about their agencies and services?

OUR FAMILY HAS ONLY WORKED WITH THE SCHOOL SYSTEM. AND CHILDREN'S SPECIAL HEALTH CARE SERVICES. THEY WERE VERY CARING AND EAGER TO BE OF HELP AND GREATLY HELPED US TO GET ON WITH LIFE

b) What should they know about the families who receive services from these agencies?

YOU MAY BE MEETING US AT A VERY EMOTIONAL TIME. EACH FAMILY NEEDS TO BE HELPED IN DIFFERENT WAYS. THE MORE INPUT YOU RECEIVE FROM FAMILIES THE BETTER YOU CAN MEET THEIR NEEDS. AND THE NEEDS OF THEIR SPECIAL CHILD.
WE TRULY APPRECIATE YOUR HELP

THANK YOU FOR COMPLETING THIS SURVEY

Please fold this packet so that the Merrill-Palmer Institute address faces up, staple or tape the open end of the questionnaire and place it in the mail by [illegible], 1992. Postage is pre-paid.

ASAP

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