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Understanding Families' Definitions and Perspectives of Family-Centered Early Intervention Programs.

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UNDERSTANDING FAMILIES' DEFINITIONS AND PERSPECTIVES
OF FAMILY-CENTERED EARLY INTERVENTION PROGRAMS

A Dissertation

Submitted to the Graduate Faculty of the
Louisiana State University and
Agriculture and Mechanical College
in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

in

The Department of Curriculum and Instruction

by

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# TABLE OF CONTENTS

ACKNOWLEDGEMENTS .............................................. ii

LIST OF TABLES .................................................. vi

LIST OF FIGURES ............................................. viii

ABSTRACT ........................................................ ix

CHAPTER 1  INTRODUCTION ........................................ 1
  Background and Justification of Study ........... 1
  Statement of the Problem ............................... 6
  Purpose of Study ........................................... 7
  Objectives of the Study ................................. 7
  Rationale and Theoretical Framework ............... 8
  Transactional Theory of Early Development ....... 9
  Family Systems Theory ................................... 9
  Ecological Theory of Human Development .......... 12
  Limitations of Study ..................................... 15
  Significance of the Study .............................. 18
  Definition of Terms ..................................... 18
  Summary .................................................... 24

CHAPTER 2  REVIEW OF LITERATURE ............................... 26
  Evolution of Family Involvement ..................... 26
  Implications of the Theoretical Framework ........ 31
  Transactional Theory of Development .............. 31
  Family Systems Theory .................................. 33
  Ecological Theory of Human Development .......... 36
  Family-Centered Practices ............................ 39
  Diversity .................................................. 43
  Summary .................................................... 52

CHAPTER 3  METHODOLOGY ....................................... 54
  Rationale for Methodology and Design Choice ...... 54
  Description of Methodology and Data Analysis ... 56
    Participant Observation ............................... 56
    Interviews of Participants ........................... 58
    Document Analysis ..................................... 59
  Site and Participant Selection ..................... 60
  Description of Families .............................. 65
    The Cook Family ......................................... 65
    The Brown Family ....................................... 69
    The Gordon Family ..................................... 72
    The White Family ....................................... 76
    The Smith Family ....................................... 80
    The Cramer Family ..................................... 82
# Table of Contents

**The Regan/Johnson Family** ........................................ 88
**The Lotto Family** .................................................. 91
**Description of Interventionists** ............................... 95
**Triangulation** ..................................................... 98
**Summary** ............................................................ 99

4 **RESULTS** ..................................................................101
**Research Questions** ..................................................101
**Domain Analysis of Participant Observation** .............. 102
**Domain Analysis of Participant Observations**
and Interviews ..........................................................110
**Domain Analysis of Interviews** ..................................119
**Taxonomic Analysis of Participant Observations and Interviews** ..................................130
**Componential Analysis of Participant Observations and Interviews** ..............................147
**Triangulation of Data** ................................................161
**Summary** ...............................................................162

5 **SUMMARY, DISCUSSION, REFLECTIONS, AND IMPLICATIONS** ..................................... 165
**Summary** ...............................................................166
**Discussion** ............................................................168
**Reflections and Implications** .....................................181
**Suggestions for Future Research** ...............................185

**REFERENCES** ..........................................................187

**APPENDIXES**

| A | Louisiana ChildNet Access Flow Chart .................................. 194 |
| B | Louisiana Individualized Family Service Plan ..................... 196 |
| C | Louisiana Multidisciplinary Evaluation Form ...................... 201 |
| D | Question Guide for Study ............................................... 204 |
| E | Sample Progress Notes, Progress Reports, and Individualized Family Service Plans ............. 209 |
| F | Special Education Directors Letters of Consent .................. 222 |
| G | Letters of Inquiry to Special Education Directors .............. 225 |
| H | Early Interventionists Journal Excerpts ........................... 228 |
| I | Family Interview Transcript Excerpts .............................. 239 |
| J | LSU Consent Form ....................................................... 262 |
| K | Participant Consent Form .............................................. 264 |

**VITA** ..........................................................................266
<table>
<thead>
<tr>
<th>Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Selected Family Participants</td>
<td>64</td>
</tr>
<tr>
<td>4.1</td>
<td>Where does early intervention occur?</td>
<td>103</td>
</tr>
<tr>
<td>4.2</td>
<td>What services to these families receive from Part H?</td>
<td>104</td>
</tr>
<tr>
<td>4.3</td>
<td>What activities occur during early intervention?</td>
<td>106</td>
</tr>
<tr>
<td>4.4</td>
<td>What is the typical sequence of events in an early intervention session?</td>
<td>107</td>
</tr>
<tr>
<td>4.5</td>
<td>Who participates in early intervention?</td>
<td>108</td>
</tr>
<tr>
<td>4.6</td>
<td>What equipment is used in early intervention?</td>
<td>109</td>
</tr>
<tr>
<td>4.7</td>
<td>What is the frequency and duration of an early intervention session?</td>
<td>110</td>
</tr>
<tr>
<td>4.8</td>
<td>What are parents' roles in early intervention?</td>
<td>112</td>
</tr>
<tr>
<td>4.9</td>
<td>What does the family service coordinator do for the family?</td>
<td>115</td>
</tr>
<tr>
<td>4.10</td>
<td>How does your early interventionist present new ideas to you and your child?</td>
<td>116</td>
</tr>
<tr>
<td>4.11</td>
<td>How do early interventionists communicate with families?</td>
<td>119</td>
</tr>
<tr>
<td>4.12</td>
<td>What is the focus of individual early intervention programs?</td>
<td>119</td>
</tr>
<tr>
<td>4.13</td>
<td>How is the location for early intervention determined?</td>
<td>121</td>
</tr>
<tr>
<td>4.14</td>
<td>What happened when you enrolled your child in early intervention?</td>
<td>123</td>
</tr>
<tr>
<td>4.15</td>
<td>Since your child has been enrolled in early intervention what have been your experiences (good and bad)?</td>
<td>125</td>
</tr>
<tr>
<td>4.16</td>
<td>If you could change your experiences with early intervention, what would you like to be different?</td>
<td>126</td>
</tr>
<tr>
<td>4.17</td>
<td>How have you and your child been prepared for the transition from Part H services to preschool?</td>
<td>127</td>
</tr>
<tr>
<td>4.18</td>
<td>What is your family service coordinator like?</td>
<td>128</td>
</tr>
</tbody>
</table>
4.19 What is your early interventionist like? ......... 130
4.20 Taxonomy of family perceptions of FSC. ......... 133
4.21 Taxonomy of Family Perceptions of Early Interventionists ................. 134
4.22 Taxonomy of parental roles in early intervention .. 138
4.23 Taxonomy of communication styles with families .. 141
4.24 Taxonomy of initial frustrations with early intervention ................. 144
4.25 Taxonomy of ongoing frustrations with professionals 145
4.26 Taxonomy of changes desired for early intervention 147
4.27 Dimensions of contrast in family perceptions of FSC 150
4.28 Dimensions of contrast in family perceptions of early interventionist ................. 155
4.29 Dimensions of Contrast in Communication Styles of Early Interventionists ................. 161
LIST OF FIGURES

3.1 Cook Family Home .........................68
3.2 Brown Family Home .........................71
3.3 Gordon Family Home .........................75
3.4 White Family Home .........................79
3.5 Smith Family Home .........................83
3.6 Early Interventionist's Parents' Pool ....86
3.7 Rehabilitation Center Pool ................87
3.8 Regan/Johnson Family Home ...............92
3.9 Lotto Family Home .........................96
ABSTRACT

While both the federal and Louisiana state infant/toddler legislation and early childhood special education best practices literature of the late eighties and nineties provided impetus for family-centered early intervention, neither provided specific guidelines on how professionals were to implement the same. In order for early interventionists to provide effective services to individual families they must be able to evaluate and understand how each family they served defined an individualized family service plan as being family centered.

This qualitative study extended the knowledge and constructed an understanding of how select families in the Acadiana area, whose children were Part H eligible, defined family-centered early intervention services, based on their experiences and interactions with family members and systems outside the family. Family diversities, such as socioeconomic status, gender, geographic location, and ethnic background, generated both similarities and differences in the definitions.

Specifically, participant observation of early intervention sessions, individual interviews with families, and document analysis (Spradley, 1979, 1980) were used over the four month period of this study. Eight families participated in the study including three of African American and five of European American ethnic backgrounds. Four of the five European American families were of Acadiana
heritage. The other demographics of the families were evenly divided between rural and urban residents and low and middle socioeconomic status. Two fathers and six mothers were a part of the group.

All of these eight families wanted in some way to define the framework of their child's early intervention program including what services were needed, the intensity of the services, and their own level of involvement. The desire for control crossed gender, locale, socioeconomic status, and ethnic lines. These selected families wanted professionals to listen to them, to provide them choices, and respond to their concerns. The family service coordination system was not working for these families. They needed an early intervention program sensitive to their unique preferences. Family-centered intervention required an understanding of their preferences as they had developed from the interaction of their diversities and experiences.
CHAPTER 1
INTRODUCTION

Family-centered early intervention refers to a combination of beliefs and practices that define particular ways of working with families that are consumer-driven and competency-enhancing (Sexton, Aldridge, & Snyder, 1994). In this chapter the background and justification of this study of family-centered intervention are examined through the historical events of the parent involvement movement and related legislation. The specific problem and purpose of the study are then delineated. This is followed by a brief discussion of the theoretical framework used. Finally, the significance of the study and definitions of terms to be used are included.

Background and Justification of Study

Parents' involvement in the treatment and education of their children with disabilities increased to new heights with the passage of PL 99-457 (Hallahan & Kauffman, 1994). In the past, early intervention for children with disabilities was child-centered with a professional expert determining the needs of the child and giving little or no attention to the family's perspective. PL 99-457 placed an emphasis on family-centered or family-focused intervention and encouraged professionals to promote family decision making capabilities and competencies (Westby & Ford, 1993). Professionals no longer viewed parents as passive recipients of their advice, but as partners in the child's education.
The United States Congress found, in a study of the needs of infants and toddlers with disabilities, that in order to enhance their development and minimize their potential for developmental delay, programs were needed to increase the families' capacity to meet their children's special needs (Maloney & Drenning, 1993). The laws passed by Congress gave states the mandate to develop a comprehensive, coordinated, multidisciplinary, interagency early intervention program for infants, toddlers, and their families. The same congressional studies found that minority, low income, and rural families of infants and toddlers with disabilities were the most underserved. The mandate to early intervention programs was to give special attention to these target groups (U.S. Department of Education, Federal Register, 57(85), 303.128).

The major impetus for a family-centered approach came from PL 99-457 legislation, with additional motivation provided by changes in the conceptualization of early intervention best practices (Bailey, Buysse, Edmonson, & Smith, 1992). The Individualized Family Service Plan (IFSP), mandated initially in PL 99-457, was the most obvious reflection of the shift in views toward family-centered early intervention. Through the IFSP early intervention personnel were to provide the family support to enable them toward independence (Bailey et al., 1992).

The Individuals with Disabilities Education Act of 1990 (IDEA), §1477, required the assessment process in the IFSP
to be family directed (Maloney & Drenning, 1993). The IFSP process assessed the resources, priorities, and concerns of the family and also identified supports (internal and external) available and services necessary to enhance the family's capacity to meet the developmental needs of their child (Department of Education, Federal Register, 57(85), 303.322).

The IFSP included a description of family strengths and needs, specified major family outcomes, and described services to be provided to the family, including coordination of services. The parent or guardian was to be included in the development process of the IFSP, and parental consent was required to implement the IFSP. IDEA also called for the establishment of a federal interagency coordinating council and state interagency coordinating council each of which included at least three parents of children with disabilities (Maloney & Drenning, 1993).

Louisiana Bulletin 1928--Childnet (1994) was Louisiana's plan for implementing PL 99-457 and subsequent revisions in IDEA. Louisiana Bulletin 1928 (1994) specified that the "IFSP must be developed jointly by the family and appropriate qualified personnel" (p. 40). The IFSP requirements included services that would enhance not only the development of the child, but also the capacity of the family to meet the special needs of the child. The scheduling of the IFSP meeting was to be convenient to the family, the meeting was to be conducted in the family's
native language, and the family was to be encouraged to participate in all steps of the development of the IFSP.

Best practices in early intervention included recommendations for modification of techniques and materials, arrangement of learning environment, and means to maximize a child's development. Early intervention best practices had shifted from child-centered to family-centered.

The family support movement was another aspect of the paradigm shift from a child-centered focus to a family-centered focus. The movement was also called "parent empowerment" by Dunst, Trivette, and Deal (1988); "family-focused" intervention by Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, and Helm (1986); and "family-centered" intervention by Shelton, Jeppson, and Johnson (1987).

Each of the above models within the family support movement was different and somewhat unique, but they shared these basic assumptions: children and family were intertwined, intervention with a child affected the family, and family intervention affected the child. Involving and supporting families was likely to be a more powerful intervention than mere child-focused intervention. The level of involvement in an early intervention program was decided by the individual family members (Bailey, McWilliam & Winton, 1992). The decisions about the appropriate program and scheduling of services for the child and family were
made by the parent. The professional's role was enabling and supportive. While each family defined family-centered differently, family-centered early intervention was considered best practice for all families (Stepanek, 1994).

While both the legislation and best practices literature provided impetus for family-centered early intervention, neither provided specific guidelines on how professionals were to implement the same. Through survey instruments, such as Brass Tacks by McWilliam and Winton (1991) and Family Orientation of Community and Agency Services (FOCAS), by Bailey (1990) and through other quantitative studies, professionals have delineated possible policies and practices viewed as family-centered. However, the quantitative nature and boundaries of these instruments have not provided an in-depth understanding of how families structured their world and their individualized early intervention services (Rank, 1992).

The reauthorization hearings for IDEA in June 1994 cited problems with family-centered service delivery. Specifically, the hearings indicated that "improved responsiveness to the needs of families" was necessary; and there was a "need to fully practice the spirit of family-focused legislation" (Part H Testimony: Problems with family-centered service delivery, 1994, p. 1). Brenda Hantzes, a parent from northern Virginia, testified that

This family-centered law is a great concept, but the reality of implementation of Part H is a different story. Public agencies still seem to hold onto the
medical model idea, where the child must be fixed and the family must do as they are told" (Part H Testimony: Problems with family-centered service delivery, 1994, p. 3).

The IDEA reauthorization hearings also cited the need to continue to educate both families and professionals about the nature of family-centered care and early intervention. According to Stepanek (1994) "family-centered care is not when the family gets whatever they want" (p. 2); this would be irresponsible behavior on the part of the professional.

Statement of the Problem

In order for early interventionists to provide effective services to families, they must be able to evaluate and understand how each family defined an IFSP as being family-centered. However, there were no prepackaged tools designed to elicit this information from a family. An early interventionist was expected to subscribe to the philosophical base of the current legislation and early childhood special education best practices of providing family-centered early intervention. The early interventionist typically fostered the family's growth as the ultimate decision makers in planning and implementing of a program for their child with special needs. The interventionist was required also to understand the ways in which family characteristics and experiences influenced families in constructing their conceptualization of family-centered early intervention (McWilliam & Bailey, 1993).

The researcher chose to study the problem of understanding and interpreting how selected families in
Acadiana defined early intervention services as family-centered. The family's definition was based on their experiences with early intervention providers' policies, procedures, practices, services, and interactions. The participant family members' demographic characteristics such as their locale, socioeconomic status, gender, and cultural background was considered along with the observation field notes and interview responses. Similarities and differences in the information provided were compared along these demographic dimensions.

Purpose of Study

The purpose of this study was to extend the knowledge and construct an understanding of how select families (consumers), whose children are Part H eligible, defined family-centered early intervention services, based on their experiences with early intervention service providers.

Objectives of the Study

Specifically, this study examined in depth how select families in the Acadiana region formed their definitions of family-centered early intervention in their interactions between family members and systems outside the family. Family diversities such as socioeconomic status, gender, locale, and ethnic background may have generated similarities and differences. Both low and high socioeconomic status families, male and female, rural and urban, and African American and European American families were observed and interviewed.
Rationale and Theoretical Framework

The research on parent-child interactions, the transactional theory of early child development, the family systems theory, and the ecological theory of human development provided the rationale and theoretical framework for family-oriented intervention.

Building family and professional partnerships was consistent with several child and family development theories. Early development of the child was embedded within the social context of the caretaker's environment. The social context included the quality of early attachment, relationships with caregivers, and parent-child interactions. These early family relationships seemed to have implications for later development (Baumrind, 1983; Belsky, 1984; Silber, 1989).

Studies of infants in adverse caregiving environments have shown a negative impact on the child's physical growth, and delayed and deviant development (Zeanah, Mammen, & Lieberman, 1993). The child's interactions with caretakers and the immediate physical environment helped to formulate the internal working model or mental imagery and "lens" through which all of the rest of life's experiences are viewed (Belsky & Penske, 1988). Some of the earliest studies on the importance of early relationships became the forerunners of concepts developed in the transactional theory of early development, ecological theory of human development, and family systems theory.
**Transactional Theory of Early Development.** Behavior seldom developed in only one direction or in response to only one influence. Sameroff (1975) suggested that while biological factors occurring during reproduction may have an initial role in a child's development, the care taking environment (effects of social, familial, and environmental factors) determined the ultimate outcome.

In the transactional theory of early development a child's outcomes were not the result of the child in isolation or the experiential context alone. A child's development was a combination of both these entities. The family and the social context provided the experiences that continuously interacted over time and fostered each individual's development. Sameroff and Fiese (1990) also suggested the importance of remembering that subsequent interactions for both the child and the family would be based on the given history of their interactions. McCollum and Maude (1993) suggested that the transactional theory of early development lent further support to the inclusion of a family-oriented theme in early intervention.

**Family Systems Theory.** The family systems theory was another construct which has provided support and a rationale for family-centered early intervention. This theory emphasized the importance of the interactions of family members and central components of the family system on a child's development. A family's interaction patterns were characterized by their adaptability, cohesion, and style of
communication. Adaptability was apparent when the family encountered situational or developmental stress and was able to change its power structure, role relationships, and relationship rules to respond to the crisis. Cohesion has to do with the emotional bonding and degree of individual autonomy that existed within a given family system. The communication component of the family system enables its members to move or change their patterns of adaptability and cohesion.

The central components of the family systems theory included basic functions, family structure and characteristics, family cycle stages, support networks, and values. All parts of the family were interrelated—events that affected one family member affected other family members, too (Turnbull & Turnbull, 1990). Families also performed many functions for their children, including nurturing, providing security, and educating.

The structure of the family referred to its size and membership characteristics. The chronological age of the youngest child was used to identify a family life cycle stage. The stage a family was currently in would impact their needs, priorities, and concerns. The four major life cycles were early childhood (0-5 years), childhood (6-12 years), adolescence (12-21 years), and adulthood (21 years and up). Families also had support networks which might be internal, such as religion and self-esteem, or external, such as friends and extended family members.
The family system theory suggested four constructs which seemed to contribute directly to the rationale and theoretical framework for family-centered early intervention. These were circular causality, nonsummativity, equifinity, and homeostasis.

Circular causality has been one of the strongest arguments for family-oriented early intervention. This construct stated that changes in one member of a family affected other family members and affected the family system as a whole (Krauss & Jacobs, 1990). The construct of nonsummativity stated that the family system as a whole was more than just the sum of its parts. A family's behavior therefore represented an interlocking system which must be acknowledged within early intervention.

Equifinity, as a part of the family systems theory, stated that similar stimuli (like intervention strategies) may lead to different results (Krauss & Jacobs, 1990). The converse was also true, that similar outcomes could be achieved from different stimuli. The family's effort to maintain its stability was described as homeostasis. The family maintained homeostasis through its normalization activities, interactions, and mutually reinforcing feedback loops.

From the principles and constructs of family system theory it was apparent that early intervention could not separate itself from a family-centered approach. All parts
of the family structure, characteristics, interactions, and functions were interrelated.

Ecological Theory of Human Development. The family also existed within a larger ecological context of human development, as described by Bronfenbrenner (1977, 1979, & 1986). The ecological theory of human development embedded an individual or the family within a broader number of important systems. In his ecological model of human development, Bronfenbrenner (1979) stressed the influence of the family on the behavior of an individual. The complex, interconnected system was composed of the child, nuclear family, extended family, friends, neighbors, and the larger community. According to the theory, all systems within the system incorporated basic value assumptions about what was desirable for children and families.

According to ecological theory, changes at any level were likely to have direct or indirect effect on the other levels. In order to understand the behavior of a family and a child with special needs, it was important to understand the influence of other social systems on the child and family (Bronfenbrenner, 1979). The interactions between the individual or the family and these systems helped to explain human development as learning and socialization. The interactions were both direct and indirect. In the circular causality construct of the family systems theory, interactions with a system change individuals, and those changes in the individual could have reciprocally changed a
system. The development of a child cannot be fostered or assessed in isolation from the influence of the various systems.

The ecological theory of human development has four major systems. They are the microsystem, the mesosystem, the exosystem, and the macrosystem. The child has spent the most significant amount of time within the microsystem. The microsystem was defined as "the complex of relations occurring between the developing person and the environment in an immediate setting containing that person" (Bronfenbrenner, 1977, p. 514). Microsystems included the members of a family or early intervention professionals. Bronfenbrenner (1979) said in his description of the microsystem that when someone looked at the developing person's environment, they could not examine just the concrete/relevant properties or features. They must also look at the way these properties were perceived by the developing person. The implications of the theory were in order to understand, an individual required more than looking at just the obvious characteristics. That person's unique perceptions of experiences or events in their lives would also need to be understood.

The mesosystem was composed of "the interrelations among the major settings containing the developing person at a particular point in his or her life" (Bronfenbrenner, 1977, p. 515). The interactions of microsystems or the major settings containing the developing person at any given time
composed the mesosystem. An example of the mesosystem was
the relationship between the parents or caregivers and the
professionals in an early intervention program.

The exosystem was "an extension of the mesosystem
embracing other specific social structures, both formal and
informal, that do not themselves contain the developing
person but impinge upon or encompass the immediate settings
in which that person is found, and thereby influence,
delimit, or even determine what goes on there"
(Bronfenbrenner, 1977, p. 515). The components of the
exosystem were those settings that had bearing on the
development of a person, but the person did not have a
direct relationship to the situation.

For example, the parents' place of employment might
have had an impact on the child's development. The exosystem
included both formal and informal social structures, the
major institutions of the society, local and state agencies,
religious organizations, advocacy groups, and early
intervention programs.

The macrosystem referred to the information and
ideology that institutions imparted to the other systems.
Specifically, Bronfenbrenner (1977) describes "a macrosystem
as the overarching institutional patterns of the culture or
subculture, such as the economic, social, educational,
legal, and political systems, of which micro-, meso-, and
exosystems are the concrete manifestations" (p. 515).
The macrosystem shared beliefs about how things should be done. Some of this information actually existed in explicit form, such as recorded laws, regulations, and rules, but usually it was informal (Bronfenbrenner, 1977, 1979, 1986). The macrosystem included the cultural and legislative/judicial context. PL 99-457 and IDEA were a part of the macrosystem.

Bronfenbrenner's (1977, 1979, 1986) theory and model provided clarification for the hierarchical relationship among multiple levels of a system. It was apparent from the brief description of each of these systems and their impact on one another that critical components existed for effective early intervention. They were an acknowledgment and understanding of the ecological context of human development, along with adoption of a family-centered approach.

An additional influence or impact on the adoption of family-centered early intervention approach was the early interventionist and those who have trained the interventionist. These factors were taken into consideration as this study was planned and discussed in the limitations of the study.

**Limitations of Study**

This qualitative study of select families participating in early intervention programs in the Acadiana region could, at the most, provided an increased understanding of the issues involved in defining an early intervention program as
family-centered, but did not give generalizations for the total population.

Two Acadiana early intervention programs were used for data collection. The availability and willingness of families to participate determined the extent that cultural diversity, socioeconomic status, gender, and locale criteria were studied. Information considered a part of the families' private sphere was not always accessible, but an awareness of the ways these boundaries were defined, provided additional insight (Daly, 1992).

The urban population was 10,000 or more, based on the 1990 census. This would be considered small for some urban studies.

In qualitative research it is appropriate to inform the reader of the researcher's relationship to the field of study and specific biases and foreshadowing for the study. First, the researcher has supervised preservice teachers placed by the University of Southwestern Louisiana in the early intervention programs of Acadiana for field experiences. For this reason the researcher was a familiar face to most of the early intervention program administrators and interventionists. This familiarity facilitated access to participant observation during home visits and helped establish rapport for individual interviews with the families.

Second, the researcher has taught three of the required courses for early intervention certification at the
University during the past three years. Some of the interventionists have been students in these classes. Since evaluation or observation of the early interventionists' performance was not the goal of this study, but rather trying to better understand how the families they work with define family-centered early intervention, the researcher believed this would diminish the possibility of a problem.

Third, the researcher worked as an early interventionist for nine years prior to the passage of PL 99-457. During that time the focus of early intervention was child-centered. This study was not being conducted in early intervention programs where these experiences occurred. These prior experiences seemed to be an asset in the goal of understanding how families assigned meaning to realities of the intervention experience. As suggested by Miles and Huberman (1994), familiarity with the phenomenon and setting under study encouraged an in-depth analysis, rather than superficial data collection and interpretation.

In order to avoid unnecessary influence of the researcher's perspective and training, it was important for the researcher to stay within the role of researcher and participant observer, and maintain a nonhierarchical relationship with the families and interventionists participating in the study. The researcher needed to set boundaries on requests for information, advice, or actions as an "expert helper" (Daly, 1992) prior to the observations and interviews. For example, the
researcher asked early interventionists to introduce her as another early interventionist, not as a university professor or supervisor. During observations the researcher interacted with participants or interventionists only when invited.

Significance of the Study

The significance of this study lies in its potential contribution to the understanding and training of preservice and inservice early interventionists who serve families with Part H eligible children. The review of the literature supported the fact that legislation seldom gave enough detail to facilitate full implementation in standard fashion.

For example, McWilliam and Bailey (1993) cited the responsibility of the early interventionist to "generate statements of family concerns, priorities and resources" (p. 6). Their research showed that to be an effective family-centered early interventionist required reconceptualization of the interventionist's role, increased training in the ability to work with adults, and a better understanding of the families worked with and how they constructed their meanings (Bailey et al., 1992). A general understanding of the terminology used within the new legislated early intervention programs was also needed.

Definition of Terms

ChildNet is Louisiana's statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention for children aged birth through two years
(Advocacy & Prompt, 1994). A flow chart of the basic ChildNet process is included in Appendix A.

Child search coordinator is the person designated by the local school system to receive all referrals of children suspected of having developmental delays and in need of special services. This person is the single point of entry into the Louisiana ChildNet System. The referral of a child to the Child Search Coordinator begins the multidisciplinary evaluation process. Since the child search coordinator is parents' initial contact with the early intervention system, the child search coordinator must provide them with both an oral and a written explanation of their rights. It is also the responsibility of the child search coordinator to provide families with information on their rights and choices in selection of a family service coordinator.

Diversity refers to cultural, racial, spiritual, educational, economic, and geographic differences within and across families that contribute to strengths, needs, values, concerns, and priorities of families.

Family, according to Louisiana Bulletin 1928 (1994), is a unit defined by itself. Therefore, the family will determine who makes up its membership and who is eligible to participate in the multidisciplinary evaluation and IFSP processes.

Family-allied intervention calls for family members to carry out interventions planned and developed by the professional (Dunst, Johanson, Trivette, & Hamby, 1991).
Family-centered intervention is consumer driven. The professional works for the family and looks for ways to increase parental decision-making power. Family-centered intervention recognizes the complex relationship among family members and between the family and the community (Dunst et al., 1991). The central role that the family plays in the development of the child is recognized in family-centered intervention (McWilliam & Bailey, 1993).

Family-directed assessment allows the family to identify their concerns, priorities, and resources, including the supports and services necessary for the family to enhance the development of their child with the assistance of the professionals.

Family-focused intervention shows appreciation for parents' capabilities, and the family and professional develop intervention together (Dunst et al., 1991).

Family service coordinator is the person who advocates for the child and family and assists the family in the assessment process, program planning, writing of the IFSP, and accessing services. In Louisiana, this person has a college degree in a human resource-related area of study, such as sociology, psychology, education, or human ecology, and has completed the state-approved sixty-contact-hour family service coordination training course. They must also be employed by an agency licensed to provide service coordination through Part H and Medicaid.
The parents select their family service coordinator from a list of approved family service coordinators provided by the child search coordinator. The family is given the right to employ or dismiss their family service coordinator at any point in time. If the family decides to dismiss a family service coordinator, they would then contact the child search coordinator about obtaining a new person. At the time of this study, the early interventionist and the family service coordinator could not be the same person.

**Individualized Family Service Plan** (IFSP) is a written plan for providing early intervention services for Part H eligible children and their families. The initial IFSP is written with the family, participants in the multidisciplinary evaluation, the family service coordinator, and other service providers who will provide services to the child and family. The IFSP is updated every six months, or more often if the family requests it.

The required components of the IFSP are: a statement of the child's present level of functioning in physical, cognitive, communicative, social, and adaptive areas; with the family's consent, a statement of their concerns, priorities and resources as they relate to enhancing the development of their child; a statement of the major outcomes expected to be achieved for the child and family; a statement of specific early intervention necessary to meet the unique needs and expected outcomes of the child and family; a statement of assurance that to the maximum extent
possible the services will be provided in natural environments typical for those without special needs; a statement of projected dates for initiation of services; the name of the family service coordinator; and the steps to be taken supporting the transition of the child at age three if necessary. An example of a Louisiana IFSP is in Appendix B.

**IDEA.** Individuals with Disabilities Education Act of 1990 replaced (PL 94-142).

**Low socioeconomic status.** According to the U.S. Bureau of the Census standards the poverty threshold for a family of four is an annual income of $13,924. The poverty definition is based on pre-tax money income only, and does not include such noncash benefits, such as food stamps or Medicaid (Information Please Almanac, 1994).

**Multidisciplinary Evaluation** (MDE) is a process to verify or determine Part H eligibility for services and to collect initial planning information for the development of the IFSP. Referrals for a MDE may come from a variety of public and private sources. These may include, but are not limited to, families, service agencies, health providers, day care centers, early intervention programs, school systems, or anyone else who may suspect that a child is eligible for services. The single point of entry into the multidisciplinary evaluation process is through the Child Search Coordinator in the local school system.

The parent or legal guardian must give their written consent to the evaluation process. Some of the required
components of the MDE are a concise review of the child's health status and medical history, a Kid-Med screening, the child's developmental functioning levels, the child's strengths and needs, and, if desired by the family, their concerns, priorities, and resources. The multidisciplinary evaluation is to be completed within 45 days of the referral. In Appendix C is a copy of the Louisiana MDE.

Part H Eligible infants and toddlers are birth to three years old. A licensed medical doctor has diagnosed the child with an established medical condition, physical or mental, with a high probability of developmental delay, including genetic disorders, contracted congenital infections, sensory impairments, chronic or degenerative orthopedic and/or neurologic conditions. Alternatively, the child has been identified as having a developmental delay in cognitive, physical (including vision and hearing), communication, social or emotional, or adaptive skills areas by a multidisciplinary team consisting of at least two disciplines. (Louisiana Bulletin 1928, 1994)

PL 99-457 was passed in 1986, and extended the requirements of PL 94-142 to children aged three to five, with special incentives to states for instituting programs for ages birth to three years.

Professional-centered early intervention is provided and directed by the professional. The paradigm is based on the premise that professionals have the expertise, and
families are in need of this skill in order to function effectively with their child (Dunst et al., 1991).

Rural families reside in communities with less than 10,000 population.

Urban families reside in communities with more than 10,000 population.

Summary

The major impetus for family-centered early intervention has come from the reconceptualization of best or ideal practices in early intervention and the legislation of PL 99-457 and IDEA. The research on parent and child interactions, transactional development, ecological theory of human development, and family systems all emphasized the need to integrate the family and the contextual environment to better understand a child's development. The contributions of these theories and the family support movement have changed the focus of best practices in early intervention. Unfortunately, the research on how to implement this reconceptualization of best practices in early intervention has not received as much attention.

The legislative mandates for developing an IFSP have made it impossible to avoid family involvement and partnerships. Congressional findings relative to the infants and toddlers with special needs legislation reinforced the family's need for support, particularly minority, low income, and rural populations. The reauthorization hearing
of IDEA documented the need for enhanced family-centered early intervention services.

Quantitative instruments developed to measure family-centered early intervention program policies and practices have not provided the necessary in-depth understanding of how individual families define family-centered early intervention. The scope and format of the family-centered survey instruments do not provide professionals the in-depth information and understanding needed to assist families and their children with special needs.
CHAPTER 2
REVIEW OF LITERATURE

The central role of the family in early intervention has emerged as a critical component in the professionals' service to young children and their families. This selected review of the literature has included the evolution of family involvement in early intervention and the related terminology. The implications for early intervention from the rationale and theoretical framework for family involvement in early intervention, recommended practices of family-centered early intervention from research, and suggestions for intervention with culturally diverse families have been included.

Evolution of Family Involvement

Family involvement as a required component of early intervention was not a new concept. The Handicapped Children's Early Education Program (HCEEP) in 1968 required the inclusion of families. Family roles in early intervention were simply as bystanders and receivers of information, as determined by the professional. The primary program focus, whether home based or center based, was on the child (Simeonsson & Bailey, 1990).

The passage of PL 94-142 in 1976 guaranteed parents the right to be active participants in their child's educational program planning (McCollum & Maude, 1993). Parents were essentially to cooperate in writing their child's individualized education plan, share ideas for targeted
goals and objectives, and give consent to evaluation and placement. The professional's role was to explain the child's needs and services to the family, then develop and implement the appropriate educational program. In some situations the family involvement was increased by providing parents teaching activities and therapies to do in the home. But even in early intervention, the professional maintained the role of expert in the relationship with families (Simeonsson & Bailey, 1990; Turnbull & Turnbull, 1990).

Research conducted since the passage of PL 94-142 indicated that families' participation in their children's education tended to be either passive or adversarial (Turnbull & Turnbull, 1990). Neither the passive nor the adversarial involvement roles reflected the desired parent-interventionist collaborative relationship. Research also indicated that participation was low in occurrence, suggesting that the current approaches were not meeting the needs of families (Winton, 1986). Professionals frequently viewed families who did not follow through on the home teaching activities as resistant and uncooperative (Dunst, Leet, & Trivette, 1988). According to Michael, Arnold, Magliocca, and Miller (1992), the special education field did not have a long tradition of positive working relationships with parents and teachers.

In 1986, Congress passed PL 99-457 as an extension of the coverage under the Education for All Handicapped Children Act (PL 94-142). The new legislation went beyond
the original legislation in the infant/toddler component (Part H). The federal government gave states incentives to develop infant/toddler (birth through two years) early intervention programs, and to design the programs to be family-centered and family driven. The critical and unique role of the family in the child's development was very evident, with 29 references to the family in Part H of the legislation.

In contrast to the past, there were no longer prescribed patterns of service for families. The family was a voluntary consumer of early intervention services and they decided on the level and type of involvement they wanted the intervention to play in their lives (McCollum & Maude, 1993). The rules and regulations of the law clearly stated "that Congress intended for families to play an active collaborative role in the planning and provision of early intervention services" (Maloney & Drenning, 1993).

The new legislation also provided professionals an opportunity to redefine parent and early interventionist collaboration to reflect a family-centered orientation. Families were to be involved in the decision making process from policy development to individualized service delivery (Turnbull & Turnbull, 1990). Early interventionists were to modify common practices to strengthen families and enhance family resources (Dunst, Trivette, & Deal, 1988).

Legislators and early interventionists described the central role of the family as family-focused, family-
centered, and family driven. The appropriate philosophical attitude for the early interventionist was enablement and empowerment (Dunst, Trivette, & Deal, 1988).

The terms family-centered and family driven shared similarity in their emphasis on the theme of early intervention efforts to be family oriented within the total system. Family focused was a dramatic departure from the former child-focus, separatist approach. Family-centered early intervention programs were family driven. Specifically, they allowed the family to be the primary decision maker, to determine the course of their child's intervention and the services to be used, and to evaluate the quality of services provided (McCollum & Maude, 1993).

A study by Dunst, Johanson, Trivette, and Hamby (1991) defined family-oriented program paradigms along a continuum of family-centered, family-focused, family-allied, and professional-centered. The "family-centered paradigm" was based on the family's concerns and needs. These factors drove the assessment process. The family decided what was written on the individualized family service plan (IFSP). The role of the service coordinator and services to be used were determined by the family's needs and lifestyle. The family-centered early intervention program was consumer driven and competency driven.

In slight contrast, the "family-focused paradigm" included assessment of family needs primarily related to the child's development. Families and early interventionists
developed and selected goals and objectives for the IFSP. Service coordination primarily promoted the use of professional services available. The family-allied paradigm emphasis was similar to the old model of enlisting parents as teachers and therapists, but the professional prescribed the intervention. With the professional-centered paradigm, the interventionist not only did all of the assessment and decision making, but the implementation, too.

The philosophy of enablement and empowerment has also received considerable attention (Dunst, Trivette, & Deal, 1988). The family of a child with a disability was more capable of the decision maker role as the result of enablement. Enablement was providing parents with skills and knowledge to successfully manage their child. Empowerment also provided families the opportunity to have control and make decisions about their child's early intervention. The interventionist was responsible for preparing and assisting the family toward independence and competence in caring for their child with a disability. The interventionist's goal was helping families help themselves.

The philosophy of enablement and empowerment focused on informal rather than formal sources of support. The early interventionist encouraged the family to accept responsibility for setting and achieving their needed goals (Hallahan & Kauffman, 1994). The form, focus, and complexity of the early intervention program, whichever term it subscribed to, varied depending on the interactions of the
child, family, and program variables (Simeonsson & Bailey, 1990).

Current literature on best practices has shown a trend toward a family-centered approach, with emphasis on the family as the driving force in planning interventions. Families and early interventionists have the responsibility within each individual case to decide the roles each take, and in some situations the family as the driving force have decided to be family focused, family allied, or professional centered rather than family-centered.

**Implications of the Theoretical Framework**

Chapter 1 described the support for family-centered early intervention within the research on early parent-child interactions, and the contributions of this research to the development of the transactional, ecological, and family systems theories of development. Each of the theories seemed to build from the other, and yet expanded in new directions.

Early intervention for the child with special needs has not ignored the quality of parent-child interactions and provided effective treatment in isolation from this significant influence on early development. The child with special needs sometimes required modification of their environment and supportive actions by their caretaker to maximize potential development and facilitate opportunities for interaction.

**Transactional Theory of Development.** Within the transactional theory of early development the individual and
the environment were interdependent and constantly interacting. Specifically, for early intervention, this suggested that biological problems might be modified by environmental factors. It also meant that social and environmental factors could be the etiology of difficulties. A child's outcome became the cumulative product of a series of interactions and transactions (Bailey & Wolery, 1992).

Children and caregivers interdependently influenced each other. For example, a child who was difficult to comfort and soothe might foster feelings of incompetence in the caregiver. Over time, the feelings of incompetence altered the interactions and relationship between parent and child. Interactions and transactions shaped and influenced skills, values, and choices of families in complex ways (Bailey & Wolery, 1992).

Early interventionists following transaction theory suggested that problems faced by families of children with disabilities were viewed as a product of a "series of experiences and perceptions of the participants regarding those experiences" (Bailey & Wolery, 1992, p. 67). Another implication of the transactional theory for early intervention was that every family situation required a unique analysis of the risk factors, followed by the development of a unique set of intervention strategies.

In addition to the support from this model directly were the documented differing needs of families of special children. Early interventionists had to consider the
multiple effects and perspectives, along with application of strategies at multiple levels within the system (Bailey & Wolery, 1992).

Sameroff and Fiese (1990) suggested three goals within the transactional theory of development for working with caregivers: remediation, redefinition, and reeducation. Remediation took the form of assisting parents in helping their child acquire a given developmental skill, such as communication. The enhancement of communication skills and improved ability to recognize the child's interaction efforts would likely increase the interactions between the child and the caregiver. The increased number of interactions could, in turn, normalize some transactions.

Redefinition in early intervention focused on assisting the caregivers in reconstructing their perceptions of their child's strengths, abilities, weaknesses, and needs. Reeducation involved direct instruction to the caregiver on child raising and development. Caregivers of children with special needs required specific services or training in the form of information, resources, or therapies to foster the development of their child (Mahoney, O'Sullivan, & Dennebaum, 1990).

Family Systems Theory. The family systems theory advocated focusing intervention on four interrelated components of the family: characteristics, interactions, functions, and life cycle stage (Hallahan & Kauffman, 1994). It specifically provided early intervention professionals a
better understanding of families' goals for their children and for themselves, their functions and priorities beyond parenting a child with special needs, and how they chose to participate within a given program. Hallahan and Kauffman (1994) cite increased success in early intervention with education and treatment programs that acknowledged the influence of relationship and interactions among family members.

Families served the basic functions for the child of nurturing, security, sustenance, socialization, and education. All of these functions had dynamic relationships with each other and on the development of the individual child (Gallagher, 1990). There were many factors that affected the family's ability to perform their functions, including its structure and characteristics, stages, support, resources, and values.

Families tended to function at their best when their adaptability, cohesion, and communication skills were in the middle of the continuum. Extreme reaction, such as in cohesion, manifested itself as an enmeshed family (members incapable of functioning independently), and resulted in rigidity as opposed to flexibility. Irrational communication created chaos (Krauss and Jacobs, 1990). Structure referred to family membership—its size and composition. Characteristics included the style of decision making within the family, the severity or type of the child's disability,
the family's socioeconomic status, the educational level of
parents, and the family's cultural background.

The impact of the disability also changed over time. The life cycle stage the family was currently in impacted their needs, priorities, and concerns. The transitions between life cycle stages has been particularly stressful for families of children with special needs, due to the uncertainty related to the upcoming stage (Hallahan & Kauffman, 1994).

A family's ability to perform basic functions was also dependent on the available support systems—both the informal network, such as friends, neighbors, and extended family, and the formal network, including professionals and social agencies. Family-centered early intervention called for cognizance of these networks and methods of access. Each family has its own value system, based on ideological beliefs, culture, and ethnic background. An awareness of and respect for these aspects was critical to the success of early intervention.

The four constructs of the family systems theory—circular causality, nonsummativity, equifinity, and homeostasis—each influenced early intervention toward family-centeredness. Intervention practices that did not acknowledge circular causality and nonsummativity, and were directed solely at the child, might have a positive or negative impact on other members of the family and the family as a whole. The interventionist needed to understand
the family, be sensitive to their needs, and discuss with them the possible impact of specific intervention activities before recommending implementation.

The importance of IFSPs and intervention programs was apparent within the construct of equifinity. Early intervention programs should not have developed and implemented a set of specific guidelines for ALL services with ALL families and expected success because of equifinity. The family-centered early interventionist also needed to recognize that the family's efforts to maintain homeostasis took many different forms and respected its efforts. The family systems perspective provided early interventionists an understanding of families that facilitated better program development and collaborative efforts between professionals and families (Krauss & Jacobs, 1990).

Ecological Theory of Human Development. The ecological theory of human development suggested that early intervention services must be congruent with the family's expressed goals and their unique environment (Bailey & Wolery, 1992). The microsystem included homes, friends, neighbors, relatives, or staff of a day care center. The early interventionist needed to be aware of and familiar with each child's multiple microsystems. Particularly, an interventionist understood how a child participates in the system, assessed its degree of influence on development,
identified critical aspects, and helped facilitate change as needed (Bailey & Wolery, 1992).

Bailey and Wolery (1992) suggested that two aspects of Bronfenbrenner's mesosystem were critical to family-centered early intervention. They were the intersetting connections and the ecological transition. The intersetting connections were described as the links between and within microsystems that would influence a young child with a disability and his/her family. This might take the form of parent and professional, as suggested earlier, or professionals within a given child care program (Bronfenbrenner, 1979). At the mesosystem level, family-centered early intervention needed to recognize the importance of collaboration, open communication, and team work.

The ecological transition was the movement from one setting to another. The ease of transition within a microsystem, or from one microsystem to another, would be the result of the quality of intersetting connections. An understanding of the significance of transitions within families and children with disabilities was of paramount importance, too (Bailey & Wolery, 1992; Bronfenbrenner, 1977).

Family-centered early intervention at the exosystem level called for an awareness of programs and services available in an area. It called for the provision of case management or service coordination that is family-centered. The intervention program staff needed to recognize and help
families use informal support systems, and to involve families in the decision making process at all levels (Bailey & Wolery, 1992).

Bailey and Wolery (1992) suggested four implications for family-centered early intervention from the macrosystem. They were the importance of knowledge and understanding of the relevant laws, appreciation for the value of early intervention, capability to cope with ethical issues that involved the well-being of a given family, and willingness to serve as an advocate for appropriate and high quality services to a child and family.

Early intervention was effective only if there was a match between the value framework and the individual ecological makeup of the family. Bronfenbrenner's (1977, 1979, 1986) theory and model provided clarification for the hierarchical relationship among multiple levels of a system. It was apparent from the brief description of each of these systems and their impact on one another that effective early intervention for a child with special needs required acknowledgment and understanding of the ecological context of human development, along with the adoption of a family-centered approach.

A child's problem was not to be treated in isolation without understanding the system factors that contributed to the problem. These other systems lent support or worked against a given change. The interventionist had to consider the potential impact of a change on other systems that were
related to the child before implementation (Bronfenbrenner, 1977).

Family-Centered Practices

Family-centered practices, as defined earlier, took many different forms. There were no definite rules or models. Family-centered early intervention practices reflected a recognition that the family has its own individual structure, roles, values, beliefs, and coping styles. Early intervention that was family-centered was further complicated by the timing and purpose of the intervention, along with the diagnosis of the child (Simeonsson & Bailey, 1990). Showing respect for these diversities laid the foundation for effective family-centered early intervention programs (Dunst et al., 1991; McGonigel, Kaufmann, & Johnson, 1991).

In the provision of their services, interventionists needed to recognize the child as part of a family system; to recognize and respect the family's priorities, concerns, and needs; and to permit the parents to participate in early intervention at the level they desired (Bailey, McWilliam, & Winton, 1992; McGonigel, Kaufmann, & Johnson, 1991). This meant that early intervention programs that were previously child focused must now have the flexibility, expertise, and resources to meet the needs of all family members as they related to the child's development.

A family-centered early intervention philosophy reflected the belief that the family was the constant in a
child's life, and therefore, the family was central to all decisions regarding the child's care (Stepanek, 1994). The decisions made by the family may be simple or complex. Research has shown that parents make decisions best when they have been provided with an unbiased information base and experiences in care for their child (Stepanek, 1994). Family-centered early interventionists needed to listen actively, avoid preconceived judgements, and use an honest and open communication style.

Researchers also cited the need to make family-centered intervention a reality, rather than merely an idealized philosophy. The testimonies in the reauthorization hearings for IDEA described in Chapter 1 reflected this same concern. Stepanek (1994) presented two additional challenges to the field. First, early interventionists were to learn how to serve children within the context of their families, and families within the context of the community.

Second, there was a need to document the benefits of family-centered intervention through research and other empirical data. This helped reinforce to policy makers and service providers the benefits of best practices, and improved medical and psychosocial outcomes for children and their families.

A study by Eck, of IFSPs, summarized in the Early Childhood Reporter, reflected little congruence between recommendations of early intervention professionals and the goals selected by families. The research pinpointed the lack
of effective communication between the family and the professional as the primary reason for the absence of agreement. According to Eck, "It is up to professionals to figure out what puts families at ease, because what we envisioned is not working" (Are IFSPs leaving families in the dust?, 1994, p. 8).

The Council for Exceptional Children's Division for Early Childhood (DEC) developed a handbook for early interventionists. Specifically, as suggested in the DEC Recommended Practices (McWilliam & Strain, 1993), early intervention programs that were family-centered provided families choices in the nature of services, matched the intensity of an intervention to the family's desired level, and both encouraged and supported family participation even in clinic-based intervention.

Dunst et al. (1991) suggested looking to the family support movement for guidelines to developing family-centered practices. Suggestions included focusing on building of interdependencies between the family unit and the community, and emphasis on the common needs and supports of all people to develop intervention programs. Early intervention programs needed to strive to mobilize resources and supports, like building and strengthening the informal support network and providing flexibility in services within formal support networks.

The family-centered early intervention program ideally shared responsibility and fostered egalitarian collaborative
relationships between parents and professionals, rather than hierarchical relationships. Families' capabilities and competencies should be developed through enabling and empowering early intervention, rather than through the use of corrective deficit approaches.

Finally, Dunst et al. (1991) recommended that early intervention programs needed to be proactive. The resources and support to be provided were to be consumer driven. They were not merely prescribed by a professional or simply a reflection of the services available within a given program.

Sexton, Aldridge, and Snyder (1994) outlined similar family-centered indicators to those of Dunst et al. (1991). In addition to those guidelines discussed above, they recommended that early interventionists be aware of and sensitive to the multiple variables influencing all aspects of the individual, family, and community systems. Interventions needed to occur within natural family and program routines and be inclusive. A team approach, where the family was given the opportunity for equal membership status was to be used for assessment, program planning and related decisions.

Data collection sources included the family, the home environment, and other sources knowledgeable about the child and family. Family-centered early interventions were "initiated, planned, and monitored by the family with assistance from the early intervention team" (Sexton, Aldridge & Snyder, 1994, p. 15). The data that was gathered
needed to stress strengths, resources, concerns, and priorities, but not deficits.

The early interventionist with an empowerment perspective encouraged partnerships, effective communication, and problem-solving strategies supportive of families (Swick, 1994). Bailey (1987) stressed the importance of the interventionist to incorporate his/her knowledge of parent and family cultural values as much as possible into the individualized program. With this awareness the family-centered professional avoided conflicts and established collaborative relationships in goal setting.

Research has also shown that successful programs in family involvement and interaction emphasized communication that is frequent and systematic (Williams & Chavkin, 1989). Positive interaction between families and early interventionists was most likely to occur when not only multiple opportunities were provided, but consideration was also given to parental background and preferences. Information was to be shared in a manner sensitive to the adult learner, too. For example, parents were to be given the opportunity to scaffold (use, build, or create with) information and relate it to their life experiences and existing knowledge (Stamp & Groves, 1994).

Diversity

Diversity in this study included socioeconomic status, gender, ethnicity, and geographic location. In a study by Hodgkinson (1992), students of color within the school
population were projected to reach 33% by the year 2000. Another study estimated the corresponding proportion of teachers of color to be near 5% in the year 2000 (Haselkorn & Calkins, 1993). This type of predicted mismatch called for early interventionists in family-centered programs to be cross-culturally effective (Lynch & Hanson, 1992). Cross-cultural effectiveness needed to be demonstrated by positive attitudes about other cultures, openness to knowledge of new beliefs and practices, and willingness to try new perspectives of viewing the world and interacting (Lynch & Hanson, 1992).

The early interventionist must begin with an understanding of his/her own beliefs, values, attitudes, and practices, and how each of these was influenced by culture. The interventionist also needed to learn specific cultural information about families and individuals different from his/her own. Cross-cultural effectiveness should be demonstrated to families through recognizing communication style differences and matching of the early interventionist's communication style to that of the family. Good listening skills and respect for the other culture's perspective were also critical (Lynch & Hanson, 1992).

Bronfenbrenner (1986) emphasized the influence of the ecological context (different cultures) on child development. Cultural diversity was also apparent in the interrelations among various settings and systems. Sameroff and Fiese (1990) included in their transactional theory
model the idea of "cultural code." Cultural code was reflected in the complex design characteristics of socialization and education that establish a society's child-rearing practices. The developmental outcome of a child in the transactional model was the combination of cultural, family, and individual codes.

Adults naturally tried to impose on young children cognitive, linguistic, motivational, and social competencies that their culture considered important (Coll & Meyer, 1993). Parents emulated child-rearing techniques and patterns they felt would be of the most benefit to their child. Within different cultures, aspects of child development varied in timing, content, or expression. For example, cultures set different appropriate ages for when a child should be weaned from the bottle, toilet trained, or participate in adult conversations.

Interactions with boys and girls showed different responses and socialization patterns from birth in numerous cultures. The more important factor noted in gender studies was the caregiver's interpretation of an infant's behavior and needs. The adult caretaker with stronger sex stereotypes was more likely to practice gender-different child rearing practices (Coll & Meyer, 1993).

The Carolina Institute for Research on Infant Personnel Preparation (CIRIPP) defined culturally sensitive as recognizing "families come from different cultures and ethnic groups. Families reflect their diversity in their
views and expectations of themselves, of their children, and of professionals. Early intervention services should be provided in ways that are sensitive to these variations and consistent with family values and beliefs" (Crais, 1991, p. 4). Results from studies of human services utilization patterns showed that ethnicity (minorities), income (low socioeconomic status), geographic location (rural), and functionality (having a disability) placed that person at risk for using the resources at lower levels than their potential and availability (Sontag & Schacht, 1993).

Hanson (1992) described several characteristics of families with European American cultural backgrounds that should be addressed by early interventionists. One of these was language and communication styles. Most families in this category preferred speaking directly and honestly about issues. They expected their child's service providers to interact with them in the same manner, particularly on diagnosis and treatment issues. Preferred conversation style included eye-to-eye contact, social distance of arm's length, and deliberate turn taking.

The European American family expected to have a role in their child's education. They anticipated working as partners with professionals in establishing goals for their children's educational program, and expected to be kept informed (Hanson, 1992). As a group, European American nuclear families did not seem to have a dominant decision maker with respect to their children's raising. Often the
responsibilities of decisions were made collectively. Early interventionists often heard from a family member the need to discuss an issue with an absent partner before finalizing a decision.

European American families' bonds seemed to be closest to the nuclear families. Extended family members were viewed as "relatives" and would not actively participate in the decision making process, as was often seen in the African American families (Hanson, 1992).

The European American family, according to Hanson (1992), seemed to expect both appointments and meetings to be regular and punctual. In many families both parents worked, and flexibility in the scheduling of times and place was also desired.

For both European American and African American families poverty and low socioeconomic status impacted infant development both in material hardships and within a variety of social dimensions. Poverty may cause families to relocate in geographically and socially isolated communities (Halpern, 1993). "The constant difficulties and social depredation associated with being poor in U.S. society undermine the physical energy and psychological well-being of caregivers, and thus the capacity of those caregivers to provide attentive and nurturant care" (Halpern, 1993, p. 3). This included obtaining affordable housing, providing food, and keeping children healthy.
Among some African American families, it would be important to develop early intervention strategies that respected cross-generational and cross-familial bonds. Within the African American culture the ties of family and the strong kinship network should be viewed by early interventionists as a resource on which to build. In many areas of the country the African American kinship network is viewed as collectively responsible for raising the children.

Despite the cultural, ethnic, racial, and socioeconomic differences, the early interventionist needed to continue to assist each family to establish some control over their lives (Willis, 1992). For the African American culture, family was a source of strength, resilience, and survival. Group effort for a common goal was a higher priority than individual effort. Despite this emphasis on collective efforts, independence (being able to make it on one's own) was valued within the family context and was an extension of the group ethic (Willis, 1992).

The African American family's interaction patterns also reflected a characteristic of reinterpreting eloquent language from speeches to what they might call plain talk. The reinterpretation often provided humor and new meaning. This process involved a stripping away of excess verbage, usage of metaphors and descriptors, along with body language and motion for illustration. Willis described this as a way of releasing feelings and concerns, and said it should not be interpreted as the family not taking a situation
seriously. At the same time the interventionist should be attuned to the messages given with body language and motion.

Some African American families used Black English rather than Standard English. Some of the differences were the omission of the verb "to be," use of multiple negatives, omission of consonants and suffixes at the ends of words, and omission of the verbs when contractions were used (Willis, 1992).

Within the European American and African American families included in this study were families who also were of Acadian descent. The Acadians immigrated to Southwest Louisiana from around Nova Scotia in Canada during the latter part of the eighteenth century (Ancelet, Edwards, & Pitre, 1991). The Acadians' native language was French. While the Acadian family was not unique in its basic organization, some of their feelings, traditions, and values may have had a direct impact on early intervention.

The mother in an Acadian family typically was the person who transmitted the culture's traditions and values to the children, and the father was the head, with responsibility for the family's economic and social destiny. Acadians placed a great deal of emphasis on the family. The larger membership size of a family was more desirable. Acadian culture stressed the importance of social interactions among all members of the extended family. Food, drink, and repartee were characteristic of these informal social gatherings (Ancelet, Edwards, & Pitre, 1991). Among
both rural and urban families, common social events included the boucherie (butchering of an animal), the afternoon veillee (vigil), the fais do-do (dance), the cock fight, the bouree (card) game, or the soiree (evening party).

The gregariousness of the Acadians was also often reflected in family decision making. For example, numerous adult extended family members might be consulted for approval of a marriage. A strong principle of leaving no one out prevailed. For this reason even small babies were brought to a fais do-do and young children might be seen dancing with elderly adults. This traditional close relationship to the extended family through numerous social gatherings also encouraged marriages between cousins of varying degrees. Ancelet, Edwards, and Pitre, (1991) stated that cousin marriage was often encouraged by parents for the advantage of keeping property within family groups. In the rural areas Acadian children tended to marry young and settled close to their families.

The Catholic religion has also had considerable influence on the Acadian family. The church's beliefs supported the strong emphasis on the family organization. The Acadians had folk religion traditions, too, which were beliefs and practices not always sanctioned by the church, but that had become an integral part of their everyday religious lives. Activities such as the king cake, associated with Epiphany, Mardi Gras revelry, egg pacquing at Easter, and other festivals have developed from Acadian
folk religion (Ancelet, Edwards, & Pitre, 1991). Acadian families, for example, seemed to place a great amount of emphasis on godparents—the parrains and marraines. These people were not only spiritual guides and guardians of children when parents were lost, but were an integral part of the family—someone with whom children had regular interactions.

Another person of particular importance to Acadian families was the folk curer—the traiteur. These people were believed to have a divine gift for healing. Traiteurs were viewed by Acadians as exceptionally good people, and considerable faith was placed in these persons' "gifts" (Ancelet, Edwards, & Pitre, 1991).

Other cultures may view professionals as "outsiders," and hesitate to reach out for help. The family, parenting, and membership in a community can take many different forms. "The diverse values that underlie ethnic minorities' approaches to family, parenting, and community have equal claim to validity, and, in fact, have often existed many centuries longer than the majority Anglo Culture" (Vincent, Salisbury, Strain, McCormick, & Tessier, 1990, p. 186).

Early interventionists must be more cognizant of the child's and family's ecological context in order to provide family-centered early intervention. Regardless of socioeconomic status, caregivers vary greatly in their ability to foster their child's development and buffer that child from the effects of their environment. Early
interventionists must be sensitive to the perspective of each low socioeconomic status family and define with them the specific types and ways help is desired and needed.

As with all families, early interventionists must be cautious in ascribing certain practices and characteristics typical of family-centered early intervention programs to culturally diverse families. There were also other mitigating factors that may have had a profound influence on a family's cultural identity, such as education level, proximity to other members of their ethnic community, age, gender, and language proficiency (Lynch & Hanson, 1992).

In working with culturally diverse families early interventionists needed to first observe and listen to gain an understanding of the diverse environments in which these young children function. Then, with the family, they must analyze the information gathered and determine what the content, strategies, and services needed to be for the early intervention. The interventionist and the family needed to interact in order to integrate the family's beliefs about child development and child-rearing practices and basic generalizable skills. In this way, the family-centered paradigm can be accommodated with a behavioral-ecological approach (Vincent et al., 1990).

Summary

The research question that remained after review of this selected literature was, how do families themselves define a family-centered early intervention program? Do the
practices outlined in this paper, as suggested by numerous authors, but supported by limited research, actually reflect family values and beliefs? Of particular concern for this study were the differences that geographical location, cultural and ethnic background, and socioeconomic status of parents or caregivers made on how a family participating in an early intervention program defined family-centered.

Family-centered early intervention programs needed to provide opportunities for culturally diverse families to tell their stories. Early intervention programs were to provide families with opportunities that fostered their self-respect and self-direction. Early intervention services needed to be culturally, linguistically, and experientially sensitive in order to be family-centered. Families did not need case management, but service coordination. The practices of family-centered early intervention must be for all families, a process of building a relationship of trust and equality, and not just the provision of services (Vincent, 1992).
CHAPTER 3
METHODOLOGY

In Chapter 3, I explain the rationale for the methodology and design choice used in this study. This is followed by a description of the process including the three levels of observation, interviews, and document analysis. The remainder of the chapter describes the site and participant selection process, the actual sites, and the participants.

Rationale for Methodology and Design Choice

I selected a qualitative research design for this study because I believed this methodology would provide the best opportunity for understanding in depth the meaning families attach to the term family-centered early intervention. This type of research, which focused on experiences within individual families as well as between families and the outside systems, provided me with data in the form of words and pictures, rather than numbers (Gilgun, 1992). In order to answer the question of how families actually defined early intervention as family-centered, I needed to "catch the details of actual occurrences" of families living together and working with their interventionists (Lightburn, 1992). Sacks (1984) suggested that a detailed study of phenomena within families led to a more complex understanding of what people were doing.

The in-depth knowledge of how families constructed their understandings through experience with early intervention service providers was best gained through a
more qualitative or inductive approach to research (Handel, 1992). Qualitative approaches permitted the families (consumers) of early intervention services to structure the world as they saw it, rather than as a researcher might construct it, and provided a unique understanding of issues that might be missed through quantitative methods (Rank, 1992). Qualitative data is needed to inductively generate new theories or inform and expand existing theories (Jarrett, 1992). I agreed with Daly (1992), that qualitative research with families was strongly associated with Weber's (1947) verstehen tradition or "the meanings, interpretations, and subjective experiences of family members" (pp. 3-4) needed for this study.

The diversity of the families, and the need to substantiate the data collected as trustworthy and reflective of the families studied, necessitated the use of diverse methodologies. Specifically, participant observation, individual interviews, and document analysis were used. These qualitative methods provided a holistic look at the family as a unit of analysis. I was able to look at their interactions, dynamics of relationships, and the contexts, rather than isolated parts, from a survey instrument (Daly, 1992). My goal in observing and talking to families and examining their individualized family service plans (IFSPs) was to better understand how some families with unique characteristics defined early intervention as family-centered.
Description of Methodology and Data Analysis

Participant Observation. Participant observation was used to gather information on the people (family members and interventionists), activities, and situations in my study. According to Spradley (1980) a participant observer has two purposes: to participate in activities that are appropriate to the situation and to observe that same situation including the activities, people, and physical aspects. I used three levels of observation as suggested by Spradley (1980): descriptive, focused, and selective. Throughout the observation process I took field notes, made diagrams of sites, and kept a journal of my reflections.

The descriptive observation answered "grand tour" questions as to the place, actors, activities, objects, events, feelings, goals, time, and acts that occurred within families enrolled in early intervention programs. One example of a grand tour question during my descriptive observations was, Where do family-centered intervention activities occur? I reviewed, categorized, and looked for patterns or domains within my field notes. This procedure was important in developing a domain analysis and developing structural questions for my focused observations. Domains were defined as categories of cultural meaning that included other smaller categories (Spradley, 1980).

The review of data collected and domain analysis involved my looking for cover terms and included terms and determining the semantic relationship between the two. Using
the example given previously, the cover term included places where family-centered early intervention occurred. The included terms were the living room of a home, the kitchen, a school classroom, a therapy room in a center, and a swimming pool. The semantic relationship was the location for action: X is a place for doing Y (Spradley, 1980). With the domains identified, discussed and illustrated in detail previously, the structural question took the form, What were all the places for family-centered early intervention?

I followed the focused observations with a taxonomic analysis to examine the individual domains identified earlier for patterns and relationships. Taxonomy was defined as a set of categories all based on a single semantic relationship. Taxonomies show more of the relationship of items within a domain. They reveal subsets and the ways they are related to the whole (Spradley, 1980). For example the domain locations for early intervention could be divided into smaller categories by the type of service provided in a location. For example early intervention within this study provided by occupational and physical therapists usually occurred in therapy rooms while speech therapists and early childhood teachers were typically in the family's home.

My third level of observations was selected and asked contrast questions. In some cases my selected observations contrasted two members of a domain or at times two members of a domain were contrasted with another member. At this level of observations I began informal interviewing due to
familiarity with the participants, which Spradley (1980) suggested as typical. A specific example of this occurred when I was called upon by a mother to assist with emergency care of her child. The early interventionist had stepped outside of the house to get something from her vehicle. The established familiarity I had with the family combined with this brief collaborative effort initiated the beginning of the interview process within the selected observations step.

I looked at the domains and taxonomies that had been established for differences, rather than similarities. The types of questions asked were contrast questions: dyadic, comparing two members of a domain; triadic, and in some cases comparing two members of a domain to a third; looking at differences among all members of a domain. The differences I discovered became dimensions of contrast and theme analysis as a part of the componential analysis. With the completion of the participant observation I began collecting data through interviews.

Interviews of Participants. The interviews with individual families followed a combined format of continuation of the descriptive, structural, and contrasting questions developed during the participant observation and analyses (Spradley, 1980), along with an open-ended interview guide approach (Patton, 1990), using selected topics from FOCAS (Bailey, 1990) and The Family Report (McWilliam, 1991). The Carolina Institute for Research on
Infant Personnel Preparation developed both of these instruments, and permitted their use for research and evaluation as long as the source was recognized.

FOCAS was designed to assess the dimensions of parent involvement in the decisions about assessment, the assessment process, team planning, and the provision of services (Bailey et al., 1992). The Family Report looked at entrance into the program, the assessment process, developing and writing the intervention plan, and services provided (McWilliam, 1991). Specific examples of the questions used as a guide in this study are included in Appendix D. The interview question guide also helped to target early interventionists' philosophies, practices, and services as they impacted the family.

I recorded the interviews on audio tapes, and transcripts were made of all interviews (Appendix I). I also continued to keep a journal of personal reflections regarding the interviews. Each family participated in at least three 60-minute interviews beyond the informal conversations held during early intervention sessions toward the end of the participant observations. I also requested the interventionists to write reflections on the early intervention session visits (Appendix H).

Document Analysis. With each family participating in the study, I used document analysis. I secured permission to examine their IFSP, progress reports, and progress notes. The progress notes related to the IFSP and were made by the
interventionist and the family after each visit. Samples of these documents are included in Appendix E.

Document analysis provided another window on current understanding of family strengths, needs, and priorities. Its contents were compared to data collected during participant observations, and to family perceptions provided during the interview process (Harbert, Vinick, & Ekerdt, 1992).

I synthesized, interpreted, and placed data collected throughout the observations, interviews, and document review within the framework suggested by Spradley (1979, 1980) of domain, taxonomic, and componential analyses.

Site and Participant Selection

Site and participant selection followed the guidelines of criterion sampling in Patton (1990) and purposeful selection of Lightburn (1992). Targeted areas of interest in answering the question of how families define an early intervention program as family-centered were whether where the family resides, their socioeconomic status, ethnic background, and gender presented different perspectives. I believed these characteristics addressed some of the specific questions raised in the reauthorization hearings and the review of the literature.

I sent letters of inquiry and the necessary consent forms regarding the possible study to two directors of special education in parishes with early intervention programs that were less than 25 miles from Lafayette
(Appendix F). I selected programs in Acadia and Vermilion parishes. The directors of special education in Acadia and Vermilion parishes were willing to participate in the study (Appendix G).

The Director of Special Education in Acadia Parish readily agreed, and the next step of contacting the two early interventionists within the program was implemented. In September I contacted the interventionists in Acadia Parish regarding their willingness to participate and had them sign the necessary consent forms (Appendix K). I believed it was important to limit the number of interventionists observed in order to decrease the impact varying styles of intervention might have on family perspectives. Actual home visits were begun the third week in September in Acadia Parish.

In Vermilion Parish the study was delayed in implementation by almost two months, due to the hospitalization of the Director of Special Education and the departure of one of the two early interventionists. After the approval was received, the remaining interventionist was contacted. Actual home visits with only one early interventionist began in the third week of November in Vermilion Parish.

I asked each of the early interventionists to identify at least three families who had participated in an early intervention program for at least one year. Spradley (1979) suggests the use of informants who have been enculturated
within a field for a minimum of one year. The following criteria were used in the selection process:

1. Family resided in a rural community (R)—population less than 10,000
2. Family resided in an urban community (U)—population more than 10,000
3. Family has low socioeconomic status (LSES)—recipient of food stamps or welfare
4. Family has middle or high socioeconomic status, (MSES or HSES) does not receive financial assistance in the form of food stamps or welfare, but child may qualify for Supplemental Security Income (SSI)
5. Family's ethnic background is African American (A/A)
6. Family's ethnic background is European American (E/A)
7. Primary caretaker is male
8. Primary caretaker is female

The three early interventionists contacted each of the families by phone, a home visit, or both, whichever they deemed most appropriate regarding their willingness to participate in the study. The early interventionists told the families that their participation included permitting me to observe approximately four early intervention sessions, reviewing their IFSP, and their participating in at least three interview sessions with me.

I had anticipated this process would identify four to six families willing to participate, but instead ten agreed
to participate. The two families who participated from Vermilion Parish were unable to complete the participant observations and interviews, due to the delayed beginning of the study in that parish, repeated scheduling problems, and illnesses. This study was therefore based on eight families in Acadia Parish. Two of these eight remaining families in Acadia Parish (the Regan/Johnson and Lotto families) were unable to complete the entire study, but were included as far as their participation permitted.

The obstacles for these two families that prevented completion included for the Regan/Johnson family a combination of the maternal grandmother's unpredictable cooperation and the mother's and grandmother's limited intellectual functioning level, and for the Lotto family, significant marital problems and hospitalization of their child prevented completion. Since the remaining six families in Acadia Parish addressed all of the criterion sampling characteristics outlined in the proposal, information gathered from these will serve as the core of the study and the two other families will be included as appropriate.

The study was limited to the two early interventionists in Acadia Parish. Specific descriptions of each family are included later in the chapter. The demographic characteristics of the family participants are reflected in Table 3.1. There were two fathers, seven mothers, and one grandmother who participated in the study. Three of the eight families were African American and five of the
families were European-American. Among this group of five families, four of them had at least one parent of Acadian heritage; the remaining family was Italian.

Table 3.1

Selected Family Participants

<table>
<thead>
<tr>
<th>Name (pseudonym)</th>
<th>Caretaker</th>
<th>Ethnicity</th>
<th>Marital</th>
<th>SES</th>
<th>Locale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brown</td>
<td>Mother</td>
<td>A/A</td>
<td>Single</td>
<td>LSES</td>
<td>R</td>
</tr>
<tr>
<td>Cook</td>
<td>Mother</td>
<td>E/A</td>
<td>Married</td>
<td>MSES</td>
<td>R</td>
</tr>
<tr>
<td>Gordon</td>
<td>Mother and Father</td>
<td>A/A</td>
<td>Married</td>
<td>MSES</td>
<td>R</td>
</tr>
<tr>
<td>Cramer</td>
<td>Father</td>
<td>E/A</td>
<td>Divorced</td>
<td>LSES</td>
<td>R</td>
</tr>
<tr>
<td>Smith</td>
<td>Mother</td>
<td>E/A</td>
<td>Married</td>
<td>MSES</td>
<td>U</td>
</tr>
<tr>
<td>White</td>
<td>Mother</td>
<td>E/A</td>
<td>Single</td>
<td>LSES</td>
<td>U</td>
</tr>
<tr>
<td>Regan/Johnson</td>
<td>Mother and Maternal grandmother</td>
<td>A/A</td>
<td>Single</td>
<td>LSES</td>
<td>R</td>
</tr>
<tr>
<td>Lotto</td>
<td>Mother</td>
<td>E/A</td>
<td>Married</td>
<td>MSES</td>
<td>U</td>
</tr>
</tbody>
</table>

The participant observations were made in locations previously agreed upon by the families and their interventionists. These locations included living rooms, kitchens, swimming pools, therapy rooms in rehabilitation centers, and school classrooms. I went on the day and time of the families' regularly scheduled visits with the early interventionists.

The interventionists' schedules for visits varied from once per week to once every other week, and from 30 to 60 minutes in length. The specific schedule for each family is included in their description.

All but one of the families' interviews were conducted in the family home. In the Cramer family, the father preferred to have the interviews at the same locations as he usually brought his child for intervention, which were the
swimming pool, classroom, or therapy room in a rehabilitation center.

I had anticipated in my original time lines that it might take longer to establish rapport and sound relationships in order to gather trustworthy data, but I was surprised that with the six core families it came very quickly. From September through December, each of the six families who completed the interviews were visited at least seven times. Glesne and Peshkin (1992) and Matocha (1992) suggest that research should continue until no new information is forthcoming. I followed this procedure with these families.

The interviews with each of the families began at the end of the participant observations. I recorded the interviews on audio tape and made transcripts of all interview sessions. The interventionist provided child care at a location other than the interview site for the Cramer and Smith families; the rest of the families arranged for the care of their child. The interview process took three sessions. After each interview I also made field notes.

Descriptions of Families

The Cook Family. Mr. and Mrs. Cook were a middle class European American family with two children. Both Mr. and Mrs. Cook were of Acadian heritage. Mr. and Mrs. Cook were in their late twenties. Their oldest son, Jerry, was 11 years old. Jerry was in a resource room at school. Mrs. Cook described him as having a great deal of difficulty with his
school work, having been diagnosed by the family physician with attention deficit disorder, and currently taking ritalin, which helped some. Jerry was very fond of his little sister and tried to help with her care. Mr. and Mrs. Cook had a second child who lived only a few days.

The youngest child, Lisa, was 15 months old. She was a very pretty child, who was slightly chubby, with fair white skin and curly brown hair. Lisa was a full-term baby who had a very traumatic birth. She has severe neurological involvement, little or no head control, cortical blindness, and hypotonic muscle tone. She has both petit and grand mal seizures that were not consistently controlled by medication. Lisa was fed by a gastrostomy tube and button. She did not take anything by mouth.

According to her mother, Lisa communicated only by crying, and the crying was usually associated with discomfort or pain. She did not communicate when she was hungry. However, both her mother and the early interventionist reported that she seemed to be aware of the presence of immediate family members, particularly her father. I did not observe this during any of my visits. During my home visits she was observed to make a few guttural and humming sounds.

Mr. Cook, the father, was a high school graduate and a car mechanic in a local garage. Mrs. Cook was a student at Louisiana State University at Eunice. She planned to major in special education. In the fall semester she was taking
remedial courses in English and math, along with a study skills course. The maternal grandmother and Mrs. Cook's sister lived in the same community. According to Mrs. Cook, her sister cares for Lisa one day of Mrs. Cook's classes, but her sister does not feel comfortable caring for Lisa. The paternal grandparents had lent some emotional and physical support, but were some distance (250 miles) from the family.

Lisa was referred to early intervention from the hospital. She received the services of occupational therapy, physical therapy, speech therapy, early intervention, and home health. The latter two were provided in the home. All of the services were weekly 30-minute sessions. The same family service coordinator has worked with Mrs. Cook since Lisa's birth until mid-October of this past year.

Mr. and Mrs. Cook lived in a white frame house with a pier foundation in a small rural community. The home was always neat and clean. The living room had a carpeted floor with an early American sofa, one easy chair, one rocker, one end table with a lamp, and a large console color television. On the walls, pictures of both children were hung. The walls were paneled in a fairly dark wood. The room always seemed somewhat dark. See Figure 3.1 for a diagram of the Cook home.

The early interventionist always worked with Lisa on the living room floor, but occasionally discussions between the interventionist and the mother would occur after the
Figure 3.1. Cook Family Home

LEGEND:
- = movement
C = child
E.I. = early interventionist
P = parent
R = researcher
S = stranger
session across the breakfast bar, which separated the living room from the kitchen, or they would go into the kitchen and sit at the table.

The Brown Family. Ms. Brown was a single African American mother with some Acadian heritage, who was in her late twenties. She has four sons who were in fifth grade, first grade, kindergarten, and the youngest, Albert, who was enrolled in early intervention. According to the early interventionist there was a man who also lived in the trailer with Ms. Brown and her four sons. The interventionist had no additional knowledge of the man's relationship to family members. During my many visits and contacts with Ms. Brown and her family, no mention was ever made of him in conversation, nor did I see him.

Albert was premature at birth, weighing only 3.2 pounds. He has continued to be very small for his age, but active. He usually spoke to his mother or the early interventionist in one word phrases. His eyes sparkled with enthusiasm as he played. He loved imaginary play. He was first referred to the early intervention program in Lafayette. The family participated in that program for several months before they were transferred to the program in Acadia Parish. Albert was 31 months old at the beginning of this study. His primary developmental delay at the time I made my observations was in expressive language skills.

Ms. Brown was enrolled in Project Independence and was working on her GED. She has completed through the seventh
grade level. Project Independence provided childcare for Albert when she was in class and one day per week for studying. Ms. Brown was highly motivated about attending school and getting her GED. Her oldest son had difficulty in school last year, and she felt very frustrated when she could not help him. It was at that point in time she decided to re-enter school and complete her high school education.

Ms. Brown's mother lived in the same community and provided support to the family through transportation and some child care. Ms. Brown also had friends who provided assistance with the care of her children.

Albert received only physical therapy at the early intervention program in Lafayette. The Browns have had at least two family service coordinators, although Ms. Brown was not certain, and described no understanding of the duties or purpose of this person. Since referral to the Acadia Parish early intervention program, Albert has received primarily language development activities in intervention sessions for 30 minutes, twice per month.

Ms. Brown and her family lived in a small trailer park at the edge of a small rural town. There were eight trailers on her street. The trailer was quite old. It had an attached wooden porch with two concrete steps. The trailer was sparsely furnished, but very clean. Early intervention visits took place in a large room with a tile floor that served as living room, kitchen, and dining room. (See Figure 3.2 for a diagram of the Brown trailer.) The kitchen
Figure 3.2. Brown Family Home

LEGEND:
C = child
E.I. = early interventionist
P = parent
R = researcher
S = stranger
cabinets were wood and painted a soft pink. There were a small wooden dinette set, two couches, and a color TV in the large room. The TV was usually turned on when we arrived but without sound and picture was very fuzzy.

The trailer had three bedrooms. The trailer was always well lighted from either daylight or artificial light. Depending on the temperature, there was a window fan or space heater on the floor in the living room for comfort. The front door was usually left open slightly primarily because Ms. Brown did not have a telephone and was dependent on her neighbor next door to get messages to her.

The Gordon Family. Mr. and Mrs. Gordon were a young African American couple in their mid-twenties. They had three sons: Lance, Jr., who was five years old; Robert, who was two years and five months old; and Carl, who was one year old. They lived in an extremely rural area of Acadia Parish.

Robert was an extremely petite boy, occasionally shy, but very clever. He was almost three months premature. He weighed 1 lb, 10 oz at birth. He remained in the hospital for almost six months after his birth. When Robert was released from the hospital, he was referred to the early intervention program in Lafayette. This program was serving Acadia Parish at the time. Mr. and Mrs. Gordon reported that his most obvious delays at the time were motor and language. At the time of my study, language was the only area of
delay. Robert has had a history of respiratory and ear infections and asthma, too.

Mr. and Mrs. Gordon were a highly motivated young couple who wanted to be financially independent. Mrs. Gordon was a high school graduate. She was studying for the ACT test this fall and hoped to start at Louisiana State University at Eunice in January. Her sister was a respiratory therapist and she hoped to enter the same program. Mr. Gordon had recently quit his job at a local service station. He had obtained a job at a plant in a nearby community as a machinist. The job was part of "Project Independence," and also required him to attend classes one day a week toward his GED. He was very proud of this accomplishment and progress.

Both Mr. and Mrs. Gordon had numerous extended family members living in the area. Primary support for care of the boys came from the maternal and paternal grandmothers. When Mrs. Gordon had worked part time after Robert's birth, the two grandmothers had taken turns caring for the boys.

Initially Robert received only physical therapy at the early intervention program in Lafayette. The family drove there one or two times per month. When he was about one year old, services were changed to the Acadia Parish School Board. At this time early intervention services were changed to the home and physical therapy was discontinued, as Robert was then walking. The early interventionist came to the home every other week for approximately 30 minutes. This was the
Gordons’ second early interventionist since switching to Acadia Parish. The Gordon’s have had four family service coordinators since Robert was born and have had little or no contact with any of them.

Mr. and Mrs. Gordon lived in a three bedroom trailer at the edge of a sugar cane field about one-half mile from the settlement of Branch. The outside of the trailer had rust spots and was in need of paint. There were four wooden steps and a porch on the trailer. The front windows of the trailer were covered with aluminum foil on the inside. There were usually two vehicles parked in the yard. The older one was a Pontiac coupe and the other a Suzuki four-wheel-drive vehicle. Only the latter was apparently ever driven, as the grass was dead under the Pontiac.

Inside, the trailer decor was very warm and cheerful. (See Figure 3.3 for a diagram of Gordon family home). The living room was carpeted and had a medium brown paneling on the walls. There were two windows, but the drapes were always pulled closed. Pictures of their three boys, their parents, and extended family members were on the walls. There was a dark blue upholstered early American style sofa and love seat in the room at right angles to each other, along with two oak end tables with lamps, and a coffee table. There were also a large console color TV and a stereo in the room. The kitchen was adjacent to the living room, with a partial wall separating the two rooms. The kitchen had what appeared to be fairly new appliances, a small
Figure 3.3. Gordon Family Home

LEGEND:
B = booster
C = child
D = Dad
El = early interventionist
HC = high chair
M = Mom
R = researcher
dinette set, a booster chair, and a high chair. The floor in the kitchen was covered with 12-in. square linoleum tiles. Early intervention activities frequently occurred at the coffee table in the living room, or in the kitchen.

The White Family. Ms. White and David lived in government housing with the maternal grandmother and Ms. White's stepbrother. Ms. White had just turned 18 years old. She was a single, European American mother who dropped out of high school at about the age of 14. David was her only child. Although Ms. White's real name was not Acadian either, she described herself as being part Cajun. She and her son received food stamps and were on welfare. Ms. White was also diabetic and had numerous allergies.

David was two years and six-months old, with developmental delays in all areas, but primarily cognitive, language, and fine motor skills. He was a pale, little boy with blonde hair. He was at times very active and was easily distracted. David seemed to have significant expressive language delays. His mother reported he was using two- and three-word phrases, but I did not observe this. David usually only imitated single words during my visits.

Ms. White always seemed overwhelmed by her own and David's health problems. She was also always very anxious about finding a place of her own. She was very pleasant and polite throughout the visits. She usually watched the early intervention activities while smoking a cigarette, and responded to questions when directed to her. Ms. White's
answers were sometimes inconsistent, but frequently she would catch the inconsistencies herself. She attributed her confusion to her sugar level and the diabetes.

David's father and paternal grandmother had occasional contact with the family, but provided no financial support or care. The maternal grandmother was absent from the home during the first half of my study. She was convalescing in a nursing home from a recent surgery. She was a very obese woman with limited mobility, but she seemed genuinely concerned about her daughter's and grandson's well being. She seemed to provide some emotional stability for Ms. White and David.

The maternal grandmother was always present during intervention visits after she was discharged from the nursing home. She was usually talking on the telephone and listening to her portable stereo (country music) during the interventionist's visits. At the same time she periodically made comments about David's activities with the interventionist. The interventionist reported that mother and daughter have had some bitter conflicts in the past, and on those occasions she would find Ms. White and David living with Ms. White's sister Charlotte and her children (also in the same housing project).

David was referred to the Acadia Parish Early Intervention Program at about age 10 months by the KidMed Clinic for the Health Unit because of his overall developmental delays. He had also had a history of chronic
ear infections. The family service coordinator had been trying to get David to an appointment with an otologist for some time with little success. On the day of the last interview visit the FSC had just come by the home and told Ms. White David had an appointment in Lafayette that afternoon. The FSC was coming back later to take them.

Ms. White and David lived in a three bedroom apartment in a government housing project in an urban area. The front yard was cluttered with a stroller missing two wheels, a torn baby buggy, and large trash bags half full of unknown contents. There was a black Chow dog chained in the yard. Two panes of the windows were broken and covered with masking tape, cardboard, and aluminum foil. The front door had about 1-1/2 in. space underneath it.

Early intervention occurred in the living room. The floor in both rooms was a linoleum, which was cracked in places and did not appear clean. The living room had two sofas, an overstuffed chair, a television, book shelves, and a nonoscillating fan (See Figure 3.4 for a diagram of the White home.) The roaches were always numerous and, as the diagram indicates, all around. It was the interventionist's impression this housing project had been abandoned by HUD and that there were no real landlords now. The living room opened into the kitchen. There was a square table with two chairs (the backs were broken out of each), a small gas stove, a porcelain sink attached to the wall, an old refrigerator, a metal storage cabinet, and a water heater.
Figure 3.4. White Family Home
The Smith Family. Mr. and Mrs. Smith were a young European American (of Acadian heritage) couple in their late twenties, who lived in an urban area of Acadia Parish, and were middle socioeconomic status. They had two daughters: Kathleen was one year and ten months old, and Cheryl was two years and ten months old.

Kathleen and Cheryl were both enrolled in the early intervention program. They had both been diagnosed with mannosidosis, which was a hereditary, genetic disorder, characterized by a lysosomal enzyme deficiency (Alpha D-mannosidase). This deficiency manifested itself by progressive physical and mental deterioration. The disorder was considered terminal.

Kathleen was more severely affected by the disorder than Cheryl. Kathleen was able to sit independently and was trying to crawl, but her mobility was greatly hampered by arthritis in her arms and legs. Kathleen communicated through gestures, facial expressions and body language, and was beginning to use jargon. She had also been fitted with hearing aids, but did not tolerate them.

Cheryl was able to walk, although her gait was a bit unsteady. She had at least twenty words in her vocabulary, and put words together into phrases occasionally, but she preferred to use her own elaborate jargon system combined with body language. Cheryl had to take all of her food by a gastrostomy tube and button. She wore glasses and tolerated
them well. Both girls were frequently ill with colds, ear infections, and asthma attacks.

If not for the difference in size, Cheryl and Kathleen could have passed for twins. They both had blonde hair and very similar facial features. They both were very interested in dolls, tea parties, and other pretend activities. They also enjoyed watching themselves in family videos. They were very apprehensive of strangers; Kathleen moreso than Cheryl.

Despite the pessimistic prognosis for their children, Mr. and Mrs. Smith seemed determined to make the most of each day. Both parents had high school diplomas. Kim stayed at home full-time to care for the girls. Mr. Smith worked in a oilfield-related position. Both maternal and paternal grandparents lived in the area, and were very supportive through assistance with child care and accompanying Mrs. Smith and the girls to specialists in New Orleans. Mr. and Mrs. Smith also both had siblings in the area who helped with care of the girls. The maternal grandmother recently wrote an article about the impact of having two grandchildren with disabilities on the extended family. Mrs. Smith said she was surrounded by people who really cared about them. She also attributed a great deal of their strength in raising the girls to their religious faith.

Initially, Cheryl was serviced by the early intervention program in Lafayette, but because of her fragile health she was seen primarily in the home. After Kathleen was born and diagnosed with the same condition,
Acadia Parish early intervention program took over the services. The girls also received physical therapy in the home and speech therapy was scheduled to begin soon.

Mr. and Mrs. Smith lived in a brick ranch home in an urban subdivision. Early intervention sessions usually occurred in the living room. It was carpeted and there was a medium brown panelling on all the walls. The room was lighted primarily by the overhead light fixture. (See Figure 3.5 for a diagram of the Smith home.) There was one lamp in the corner of the room. The couch and chair were early American style in shades of brown and gold. Along one wall were shelves with the television, VCR, stereo system, books, and pictures set on them. The house was always very clean, organized, and cheerful.

The Cramer Family. Mr. Cramer was a 39-year-old, disabled European American father of Acadian heritage. He was divorced and had sole custody of Missy. Missy was two years and eight months old. Her mother abandoned her shortly after birth. Mr. Cramer and Missy lived in a very small rural community. Mr. Cramer completed high school, but was unable to work due to injuries received in a car wreck. The Cramers were of low socioeconomic status; Mr. Cramer received disability pay and Missy received monthly SSI checks. Mr. Cramer had three older children, aged 15, 12, and 10 years, by his first marriage, but did not have custody of them. He saw them about once a month.
Figure 3.5. Smith Family Home
Missy was 32 months old and had been diagnosed with cerebral palsy. The cerebral palsy had primarily affected the lower half of her body. Missy's most significant delays were in motor and language areas. She was able to sit independently, walked with a rollator walk, and propelled herself forward short distances in a specially designed wheelchair. She had been fitted with ankle/foot orthotic (AFOs) devices to facilitate her walking. She communicated primarily through jargon, gestures, and facial expressions, although she was beginning to imitate and spontaneously use some single words (e.g., Daddy, no, ball). She was beginning to learn some sign language, too. Missy was very independent in every activity. Her favorite activity was to watch "Barney" video tapes at her grandmother's house. Missy had bright red hair and was a very happy little girl.

Mr. Cramer was a very positive person who was constantly searching for ways to help Missy progress. Due to the injury mentioned above, he had some difficulty walking. He was open-minded and willing to try new activities. Missy's care and therapy had been the primary focus of his life since her mother's departure.

Missy began with an early intervention program in Lafayette, but at the time of this study she received only physical therapy and speech therapy, twice a week, at a rehabilitation center in Lafayette. She also received early intervention services one time per week from the Acadia Parish Early Intervention Program, which included swimming
therapy. She received occupational therapy initially, but had progressed beyond the need for it.

Mr. Cramer had a very strong support system from his extended family at the time of this study. His mother had only recently become involved in all of Missy's intervention services. Mr. Cramer's sister and cousins had also assisted him with her appointments and program.

All of Mr. Cramer's and Missy's early intervention visits were made outside of the home, by his choice. The first few visits were held at the home of the interventionist's parents, who had a pool in their back yard that was enclosed by a plastic shell. (See Figure 3.6 for a diagram of the interventionist's parents' swimming pool.) There were chairs along one side of the pool and a slide on the opposite side. The interventionist usually had a portable stereo there playing children's songs. There was also a bag of plastic water toys for the children to use.

In the second month of the study the swimming therapy was changed to a therapy center in Crowley. This pool was surrounded by white concrete walls. (See Figure 3.7 for a diagram of the therapy pool.) The acoustics in this room made it difficult to communicate unless you were right on top of the person. On either side of the pool there were ladders to enter the water. On one side there was also a hoist/chair lift for lowering patients into the water. The interventionist brought the same toys to the setting, but was unable to effectively use the children's song
LEGEND:
C = child
E.I. = early interventionist
G = grandparent
P = parent
R = researcher

Figure 3.6. Early Interventionist's Parents' Pool
Figure 3.7. Rehabilitation Center Pool

LEGEND:
C = child
EI = early interventionist
P = parent
R = researcher
recordings. The third place where Mr. Cramer and Missy came for intervention was an elementary school in Crowley, which I did not witness during this study.

The Regan/Johnson Family. The Regan family consisted of Ms. Regan, Ann, and Ursula. They were African American and lived in a small rural community. The family was of low socioeconomic status. They received assistance from SSI, food stamps, Medicaid, and welfare. They lived in a home with Ms. Regan's mother, Mrs. Johnson, and her stepfather, Mr. Johnson. Ms. Regan is 18 years old, her daughter Ann is 2 years and 11 months, and her daughter Ursula is two years. Ms. Regan attended a special education program in Acadia Parish. The interventionist indicated she believed the maternal grandmother, Mrs. Johnson, had also had difficulty in school and had not completed high school. The maternal great-grandmother had a severely retarded daughter whom both Ms. Regan and Mrs. Johnson helped care for, but they did not live in the same house.

Ann's physical development appeared to be normal for her age. She was always dressed in very cute clothes. According to her medical reports, she was normal at birth but, at six months of age she developed pneumonia. She was hospitalized locally, but when the condition worsened she was sent to New Orleans. She was placed on an ECO machine for 15 days as part of a life support system. She was unconscious or only semiconscious for over three months.
Since that time Ann's cognitive and language skills have been severely delayed. She was able to walk, run, and jump, but her balance was not steady. She was in almost constant motion. She did not regularly use words to communicate. The interventionist estimated she might have 5-10 words in her vocabulary. She still drank from a bottle and was not toilet trained. It was very difficult, if not impossible, to make eye contact with Ann.

Ms. Regan was a single mother and as indicated earlier had limited intellectual abilities. She seemed to enjoy playing with her younger daughter, but it was more or less child-to-child in nature. Frequently, her mother, Mrs. Johnson, corrected her for inappropriate interactions with the girls. The interventionist said that the grandmother had told her often she wanted Ms. Regan to take more responsibility for the girls. Ms. Regan did regularly attempt to control Ann's activity level and prevented such catastrophes as broken dishes. Ms. Regan spoke to me and the interventionist only when we asked her questions, and then her responses were usually one or two words. Ms. Regan typically deferred to Mrs. Johnson, the maternal grandmother, when a decision about the girls was to be made, but according to both the interventionist and the grandmother, Ms. Regan was their legal guardian. She also participated in their care by going with them to medical appointments, along with the grandmother. Ann and Ursula did
not have the same father. Ms. Regan was still involved with Ursula's father.

Ms. Regan was very dependent on her mother, Mrs. Johnson, and stepfather for the care of her two daughters. Mrs. Johnson usually made all of the appointments and she and the stepfather frequently took the girls to local doctor appointments. The interventionist indicated that the maternal grandmother had an alcohol problem and had not always been reliable in helping Ms. Regan keep appointments.

Ann was scheduled initially by the family service coordinator to receive services of occupational therapy, physical therapy, speech therapy, and regular visits by a home health nurse. All of these had been discontinued because of the family's failure to keep appointments. The only services they received at the time of the study were the early interventionist coming to the home every other week, if they were there.

The Regan/Johnson home was a shotgun-style house (one room behind another in a row) in poor repair. There were no knobs on the inside or outside of the front door. It was locked by the use of a hasp and padlock on the outside. Access to the house from the outside was possible by merely pushing the door open; but going outside from inside the house was more complicated. A small object, such as a table knife, was typically used in the crack between the door and the frame to open the door. There was what appeared to be an abandoned car in the side yard.
The living room and kitchen floors were covered with linoleum. The house was very clean. The living room was furnished in wooden early American furniture with brown tweed stuffed cushions. There was a couch, two chairs, a wicker coffee table, and two aquariums. (See Figure 3.8 for a diagram of the Regan/Johnson home.) One aquarium had fish in it, but the other had toys and handcuffs in it. The walls were uniquely decorated with 59 family pictures, religious sayings, and posters. The two posters that drew my attention were "The devil is a lawyer" and "Hooray for underachievement" by Bart Simpson.

The location of the early interventionist, child, parent, and grandmother were not fixed on this diagram. The reason for this was the constant motion of Ann during a visit. The early interventionist, Ms. Regan, and Mrs. Johnson were also constantly moving to prevent Ann from leaving the house, tearing up an object of value, or hurting herself. Sometimes the early interventionist was able to catch Ann and restrict her to sitting on the couch for one to two minutes, but usually the early interventionist had to follow the child around the room trying to engage her attention for a few seconds.

The Lotto Family. The Lotto family consisted of Mr. and Mrs. Lotto, Jessica, and Janie. Jessica was five years old and in kindergarten, and Janie was seventeen months old. They were European American of Italian heritage, living in
Figure 3.8. Regan/Johnson Family Home
an urban area as defined for this study, and were of middle socioeconomic status.

Janie was born with a webbed larynx, and at the time of the study she had a trach to facilitate her breathing. At birth and for almost a year after she had required a ventilator and numerous other machines for life support. Now she required only a machine to process the room air and increase its moisture level and occasional breathing treatments with a nebulizer. Janie had limited mobility, due to the required modification of the air she breathes. There was about a six-foot plastic hose attached at one end to the machine, and the other end fitted into a funnel-shaped cup suspended over her trach.

Due to her fragile health, Janie's life had been very sheltered. The interventionist reported that during the first few months she serviced the family, the parents restricted Janie's activities to either her crib or her playpen. Their reasons were concern for her safety. Janie apparently became very frustrated during this time period. Now Janie was in almost constant motion, and it was difficult to engage her in an activity for more than 30 seconds. She seemed to be a very bright child, quickly learning new tasks.

At the time of this study she had no verbal expressive language skills. She attempted to mouth "mama." She usually pointed to indicate her preferences or went after the object herself. The parents had refused to consider the use of
total communication or sign language as a means of increasing Janie's expressive language skills. Her receptive language skills seemed to be age appropriate. Janie was a very pretty, light brown haired, petite girl. According to her mother, Janie would have corrective surgery on the larynx. Then a plan for gradual transition off the trach would be implemented when Janie reaches a specified weight. She continued to have frequent illnesses and numerous hospitalizations.

Mr. and Mrs. Lotto were both in their early thirties. Mr. Lotto had a machine shop business on the family property. Mrs. Lotto was not employed outside of the home at this time. They were both high school graduates. The Lottos have had numerous marital problems, according to both Mrs. Lotto and the early interventionist. Some of the problems seemed to be related to the intense level of medical care Janie has required during the past seventeen months and the restrictions her health has placed on the family's mobility.

From my brief observations and the interventionist's journal notes, Mrs. Lotto's moods seemed to vacillate frequently both within a single visit and from visit to visit. Only three visits were made to the home. One of those three times only Mr. Lotto and a home health nurse were present. They reported on that occasion that Mrs. Lotto had needed to get away and was spending time with her sister.

The Lottos had some extended family in the same community, but they provided only limited support to them.
They received respite care services from a home health agency to give Mrs. Lotto time away from the care of Janie. The time allotted for respite service had recently been reduced to 12 hours per week. According to the interventionist and the home health nurse, Janie's older sister, Jessica, was very domineering and could be difficult for the parents to manage.

The only other services the family currently received was the early interventionist coming into the home twice a month for 30 minute sessions. Speech therapy was to be initiated if the family decided to consider some augmentative communication system or if the series of surgeries was started.

The Lottos' home was a trailer. The trailer was very well kept and nicely furnished, but it was always very dark. Intervention usually occurred in the living room area. (See Figure 3.9 for a diagram of the Lotto home.) There was blue carpeting on the floor in that room, along with a large console color television, an overstuffed couch and chair, and a lamp. There was also always a bag of toys on the floor and a compact toy kitchen set.

Description of Interventionists

Initially, three early interventionists were selected for the study. Each came from a different training background and work experiences. All three of the early interventionists' were in their thirties. The early interventionist from Vermilion Parish, whose families were
Figure 3.9. Lotto Family Home

LEGEND:
C = child
EI = early interventionist
P = parent
R = researcher
not included in the study, was the only one who began her career in early childhood and family studies.

The two early interventionists in Acadia Parish brought combinations of special education training backgrounds and human resources to their positions. Marsha had taught mentally handicapped students of varying ages for 15 years. She also taught kindergarten before becoming an early interventionist. Marsha had her master's degree plus 30. She continued to take graduate work to become certified in early intervention. She has been an early interventionist for the parish for two and a half years.

Marsha also worked part-time as a Part H Family Service Coordinator Supervisor in another parish. Although she was of Acadian heritage, she would describe herself as more typical of where she grew up--Texas. I would agree with this analysis; while she understood the Acadian culture, she was not typical of it in her speech, mannerisms, or practices. Marsha was divorced and had one child in college.

In her reflections on family-centered early intervention Marsha said

The goals and objectives must be child and family specific therefore requiring constantly changing needs and resources. As an interventionist, I have to be aware of the many resources available in addition to having flexibility and creativity in accessing and incorporating them into the family structure.

This philosophy was apparent in her interactions, program planning, and scheduling of appointments for families.
The second interventionist, Louise, received her initial training as a speech, hearing, and language specialist. She worked as a speech therapist for 12 years with early childhood and elementary school programs. Louise has her master's degree in child and family studies. She had worked as an early interventionist for almost two years.

Louise was of Acadian heritage and frequently interacted with her intervention families about local cultural events. She enjoyed and attended many of the local cultural events. She was married and had three children. Louise continued to provide speech therapy services one hour per day for the school system at a local parochial school. Louise stated in her reflections on family-centered early intervention that:

The family and myself have to establish a workable relationship that demonstrates respect for each individual....Due to many changes in each family flexibility in my teaching is a must. Flexibility, patience, adaptations to stressful environments are a large part of my philosophy of child/family centered philosophy. Many days I use this philosophy with one or more family members needing my attention instead of the child.

**Triangulation**

I used triangulation to strengthen this study through the use of four different data sources: participant observation, individual interviews, multiple observers—early interventionists, and document analysis. After each visit the interventionists made comments on their parish progress notes form (sample in Appendix E), which I reviewed each week. They also wrote a reflective summary of their
experiences with each family (included in Appendix H). Other
documents reviewed were the child's progress report and
their IFSP. Samples of these with identifying information
deleted were also included in Appendixes E.

I afforded participant families the opportunity to
review their personal transcripts and my analyses to
establish accuracy and trustworthiness of the data. Each
family was revisited, and their interview transcripts, field
notes, and analyses were shown to them. This also served to
clarify any areas of confusion.

A research team consisting of two university professors
and an early intervention service provider, who were
familiar with qualitative research, the Part H legislation,
and early intervention services, were asked to look at
random samples of the transcripts and documents in order to
analyze and compare my analyses for additional
triangulation, and to validate the trustworthiness of my
interpretations (Lincoln & Guba, 1985). The use of an early
intervention service provider was a change from the initial
prospectus proposal to use a state department program
manager. The latter was not available to complete the task.

Summary

The qualitative methodologies of participant
observation and interviews of participant families were used
in this study in order to provide the opportunity for each
family to tell their story and share their understanding of
family-centered early intervention with me. This information
was supplemented by the following documents: IFSPs, six weeks progress reports, the weekly session progress notes, and the interventionists' journal reflections.

Eight families and two early interventionists participated in the study from Acadia Parish. All of the families had participated in early intervention services for at least a year. There were three African American families (one of these three had some Acadian heritage), one family with Italian heritage, three families with strictly Acadian heritage, and one family with both European American (English) and Acadian heritage.

The family members participating included two fathers, seven mothers, and one grandmother. Five of the families came from rural areas, with population less than 10,000, and three of the families were from urban areas. The families were evenly divided among low and middle socioeconomic status.

Observation and interview data were the primary sources for the determination of each family's understanding of family-centered early intervention. The participating families and early interventionists were given an opportunity to read and comment on their respective observations and transcripts.
CHAPTER 4

RESULTS

This study investigated how select European American and African American families of both low and middle socioeconomic status, who lived in rural and urban areas and participated in Part H services, defined early intervention as family centered. This chapter was organized, first, with the research questions and a discussion of the method of analysis; second, with domains identified during descriptive participant observations, observations and interviews, and interviews alone; third, with a discussion of information gathered from focused observations and interviews within taxonomic analysis; fourth, a discussion of selected observations and interviews within componential analysis; and fifth, a discussion of the triangulation of the data.

Research Questions

Two main research questions were the focus of this study.

1. How do families themselves define a family-centered early intervention?
2. Do families from diverse locales, ethnic backgrounds, and socioeconomic status define family-centered early intervention differently?

Qualitative methods of analyzing the field notes and transcripts into domains, taxonomies, and dimensions of contrast were used to report the results of this study (Spradley, 1979, 1980).
Domain Analysis of Participant Observation

The study began with the answering of grand tour questions regarding the space, objects, acts, activities, events, time, actors, goals, and feelings observable during an early intervention session. I needed to be cognizant of the actual occurrences within each family's and child's early intervention programs before I could discuss with parents their perceptions and understandings.

The first domain (Table 4.1) identified the places where early intervention occurred. For the eight families studied, there were four basic locations identified that were used for early intervention services. They were a swimming pool, a room in the home, a therapy room at a rehabilitation center, and a classroom in a school. All of the families except the Whites had experienced early intervention in at least two locations—a room in their home and a therapy room at a school or center. The Whites had early intervention services only in their home. At the beginning of the study it was not clear how these locations had been determined, but it was an issue I clarified later with the parents. The focus of my question for later was whether the parents felt they had a part in the decision and if this was their preferred location. The ecological theory of human development as discussed in Chapter 2 suggested that early intervention services must be provided in settings that are congruent with the family's preferences and unique environment (Bailey & Wolery, 1992).
Table 4.1

Where does early intervention occur?

<table>
<thead>
<tr>
<th>Included Term</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living room</td>
<td>Location for Action</td>
<td>Site for Early Intervention</td>
</tr>
<tr>
<td>Kitchen</td>
<td>(is a place for)</td>
<td></td>
</tr>
<tr>
<td>Home pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy pool</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Therapy room</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary school (class/play room)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Related to this issue, were what kinds of services a family can receive from Part H (Table 4.2). Four of the families—the Browns, Gordons, Whites, and Regan/Johnson—were currently receiving only one type of Part H service—early intervention—and this was provided in their homes.

For the Cooks, Cramers, Smiths, and Lottos, the service location pattern was more complex. They received from two to five services, including a home health nurse, physical therapy, occupational therapy, speech therapy, and early intervention. A comparison of this short list to the Recommendations for Services in Section E of the Multidisciplinary Evaluation (Appendix C), indicated that this early intervention program had problems similar to those cited in the Reauthorization Hearings and by Dunst et al. (1991). The services provided for families were a reflection of what was available and not what families saw as their need.

Mrs. Cook's child received the most services—five—and at three different locations—home and two different rehabilitation centers. Mr. Cramer's and Mrs. Smith's
children received four kinds of Part H services each, but the former went to three locations—a swimming pool, a classroom, and a rehabilitation center—and the latter now receives services in only one place—the home.

Table 4.2

What services do these families receive from Part H?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>&gt;Semantic Relationship&gt;</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical therapy</td>
<td>&gt;Strict Inclusion&gt;</td>
<td>Part H Services</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td></td>
<td>(is a kind of)</td>
</tr>
<tr>
<td>Speech therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early Intervention</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The next descriptive question addressed what happened during an early intervention session (Table 4.3). For each family there was the usual infant stimulation activities in one or more of the developmental areas of language, motor, cognition, self-help, and social skills, which were individualized according to their child's need. For example, during one visit at the Browns' the early interventionist brought the game "Monkeys in a Barrel." Albert and the early interventionist counted the monkeys, named the colors, and attempted the fine motor task of hooking the monkeys' arms together.

Usually there was also an update on the child's health and recent accomplishments. The early interventionist might first ask if the child had any recent medical appointments or what had he or she done in therapy that week. Second, the early interventionist might ask if the child had succeeded on a particular skill or what new things he or she was
doing. Mrs. Cook commented once during an observation to the early interventionist she was tired of these "update" questions from all the therapists; that she would tell them if there was something important that changed. She said with Lisa's severe involvement, the therapists should know that she would tell them if there was something new.

The remaining activities included in Table 4.3 seemed to be unique to the early interventionist or the family. From assistance to a father in understanding how to solve mathematics problems for an upcoming job test to helping prepare a meal, there was great variety in what might occur during a visit. I saw the variety of activities within the early intervention session as related to what Bailey, McWilliam, and Winton (1992) had suggested as recognition of the family's priorities, concerns, and needs. This information was to be used to plan interventions. The early interventionists' focus on a variety of activities were also evidence that circular causality from the family systems theory was applicable, too. These occurrences were explored further in the taxonomic and componential analyses of this study.

The typical sequence of events was consistent when the focus of the early intervention session was primarily on the child, as shown in Table 4.4. However, there were an equal number of times when, after the initial informal adult interaction, all other routines were put aside to address a special task or concern. An example of a special concern
Table 4.3

What activities occur during early intervention?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infant stimulation</td>
<td>&gt;Strict Inclusion&gt;</td>
<td>Activities in Early Intervention</td>
</tr>
<tr>
<td>- cognitive, social,</td>
<td>(is a kind of)</td>
<td></td>
</tr>
<tr>
<td>- language, motor, social,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- and self-help skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Update on child's health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Update on skill progression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tutor Dad on math skills</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assist Mom in preparation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- for ACT Test, writing paper</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phone contact to home health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cooking activity with child and parent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tactile and kinesthetic stimulation of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relaxation exercises in water with music</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

that became the focus of the early intervention session was the adjustments on Lisa Cook’s wheelchair. The day prior to our visit Lisa had received her new wheelchair. The occupational therapist had made some modifications to the chair but mother was still not satisfied with how Lisa was positioned. She felt the shoulder and arm supports were not encouraging Lisa to bring her hands to midline. The early interventionist worked for over a half an hour attempting to modify these supports and achieve the desired effect. The families of both early interventionists expressed their appreciation for the many "extras" they did.

The actors in an early intervention session were numerous and varied, as Table 4.5 illustrates. The professionals who might participate included the early interventionist, the family service coordinator, physical,
Table 4.4

What is the typical sequence of events in an early intervention session?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informal adult interaction</td>
<td>&gt;Sequence&gt;</td>
<td>Routine of Early</td>
</tr>
<tr>
<td>Update on child</td>
<td>(is a step in)</td>
<td>Intervention</td>
</tr>
<tr>
<td>Establish rapport with child</td>
<td></td>
<td>Session</td>
</tr>
<tr>
<td>Inquiry/parental concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Response to concerns</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstrate or perform</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stimulation activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make program suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schedule next appointment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have parent sign progress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>notes for current session</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

occupational, and speech therapists, and the nurse. Among the families who participated, I observed one and both parents, the maternal and paternal grandmothers, the sibling of a child who was Part H eligible, and extended family members, such as aunts, uncles, and cousins participating in the session. The Gordon family was the only one I observed where both parents actively participated in the early interventionist's session with their child.

The next domain that was determined strictly from participant observations was the type of equipment used in the various early intervention sessions (Table 4.6). One of the more common included terms was demonstration toys/materials used by the early interventionist to encourage the development of a particular skill (e.g., using a bottle of bubbles to work on increasing breath support when speaking, or Play-Doh to improve fine motor skills).
Table 4.5

Who participates in early intervention?

<table>
<thead>
<tr>
<th>Included Term</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Interventionist</td>
<td>&gt;Strict Inclusion&gt;</td>
<td>Participants</td>
</tr>
<tr>
<td>Parent</td>
<td>(is a kind of)</td>
<td>in Early Intervention</td>
</tr>
<tr>
<td>Grandparent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Service Coordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Siblings of child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended family/aunts, uncles, cousins</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

These toys were used very effectively in both low and middle socioeconomic status homes. For the children in the lower socioeconomic status (LSES) homes the toys were sometimes a problem. The children never wanted the early interventionist to pack her bag and take the toys with her. On two occasions the early interventionist decided to leave at least one toy to pacify the child who was very upset.

Another difficult situation regarding the equipment occurred when the family service coordinator (FSC) for the Cook family resigned and picked up all the equipment he had loaned the family. The new FSC was from the same agency, but the old FSC said he had to return all the borrowed equipment to the center. Mrs. Cook was told she could request the equipment again for her use, and it would be brought back immediately. This action made Mrs. Cook quite angry, and she responded that she would rather be without it.
The Lotto family did not want their early interventionist to bring any toys into the home. Mrs. Lotto was afraid the early interventionist's toys would expose Janie to germs. (The toys were disinfected between home visits.) The early interventionist felt this family preference made her lessons more difficult to plan and implement. She never knew from one visit to the next what toys Mrs. Lotto would make available.

Table 4.6

What equipment is used in early intervention?

<table>
<thead>
<tr>
<th>Inclusion Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side lyer</td>
<td>Strict Inclusion</td>
<td>Equipment Used</td>
</tr>
<tr>
<td>Therapy ball</td>
<td>(is a kind of)</td>
<td>In Early Intervention</td>
</tr>
<tr>
<td>Therapy wedge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shape sorter</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Augmentative communication switch</td>
<td></td>
<td></td>
</tr>
<tr>
<td>toys</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rollator walker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lock and Key Busy Box</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tape recorder</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Water toys</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstration Toys/materials</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children's books</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The final domain identified in the participant observation period was the frequency and duration of early intervention sessions (Table 4.7). The most frequent was twice per week for 30 minutes each time, and the least frequent was twice per month for 30 minutes each time. Children with more severe disabilities were given the additional time and/or frequency.
The Cook, Smith, and Cramer families whose children had more severe disabilities, had more than one type of early intervention service every week. The Regan/Johnson family had been scheduled for more than one service and more frequent services in the IFSP, but their failure to keep appointments had terminated that option. In the interviews discussed later in this chapter the families of children with milder disabilities all expressed the desire for more frequent services (i.e., one time per week.) They also said they had little or no part in the decision regarding the frequency of services. They were told what was available.

Table 4.7

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 time per week</td>
<td>&gt;Attribution&gt;</td>
<td>Frequency and</td>
</tr>
<tr>
<td>2 times per week</td>
<td>(is characteristic of)</td>
<td>Duration of Services</td>
</tr>
<tr>
<td>2 times per month</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 minutes per session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60 minutes per session</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Domain Analysis of Participant Observation and Interviews

The next four domains were identified, first, within the participant observation period, and then expanded during the interviews. I looked at what parents might engage in for activity during a given early intervention session. A complete list of the responses observed and told to me are included in Table 4.8. With both early interventionists there was a wide range of parental responses to their role during the session. Mrs. Smith, Ms. Brown, and Mr. Cramer
were consistently actively involved in the session through assessment, observation, planning, asking questions, or participating in their child's activity.

Others, such as Mrs. Cook, Mrs. Gordon, and Mrs. Lotto, were actively involved some of the time, but they felt that it was also an opportunity for respite and to perform another task if needed. The third group—Ms. White and Ms. Regan, who were the youngest of the mothers—chose to consistently use the time for respite from their child by making personal phone calls, running errands, preparing meals or to play with their other child (i.e., Ms. Regan and Ursula).

These excerpts from Mrs. Smith and Ms. White illustrate the "need for respite" perspective. Ms. White said

I never get a break from David. He is constantly on the move. No one else will keep him for me, so I use the time Ms. Marsha is here to get caught up, to be by myself.

Mrs. Smith said

I want to see everything the girls do with Ms. Marsha, as they do so much better for her. It also gives me ideas of ways I can play with them and help. But sometimes I just need to get away. I am nearly always with them. I don't want to go very far, because, as my husband reminds me, their lives may be very short. I want to enjoy them while I can. It's just hard.

Bailey, McWilliam, and Winton (1992) and McGonigel, Kaufmann, and Johnson (1993) had all described the importance of permitting parents to participate at whatever
level they desired. The families observed seemed to be content with their roles. The issues involved in determining the family's role during an early intervention session will be discussed further in the taxonomic analysis.

Table 4.8

What are parents' roles in early intervention?

<table>
<thead>
<tr>
<th>Included Term</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assess</td>
<td>&gt;Strict Inclusion&gt;</td>
<td>Parent Roles</td>
</tr>
<tr>
<td>Observe</td>
<td>(is a kind of)</td>
<td>in Early Intervention</td>
</tr>
<tr>
<td>Plan activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ask questions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make program decisions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coordinate child's services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participate in activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practice teaching/learning a skill</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prepare noon or evening meal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make personal phone calls</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

According to the legislation (PL 99-457 and IDEA), as discussed in Chapters 1 and 2, the family service coordinator was to be an integral part of the early intervention program. During this study I met two families' FSC. I had anticipated that over the three and a half months' duration of this study I would have the opportunity to meet the FSCs for all eight families. This did not occur. Since I had observed that some of the families were having so few contacts with their FSC, and others had reported to the early interventionist recent confusing conversations with their FSC, I decided to try to ascertain what families thought the FSC was supposed to do (Table
4.9). I asked them to focus their answer on four different time periods as suggested in the quantitative instruments *Brass Tacks*, by McWilliam and Winton (1991), and the *Family Orientation of Community and Agency Services* (FOCAS), by Bailey (1990). These four time periods were their initiation into the program, the assessment process, the writing of the individualized family service plan (IFSP), and program implementation. For all the families it was difficult to separate the first three events in telling about their experiences with family service coordinators.

The Gordon family had the most family service coordinators and was the most adamant in their feelings. They had been technically (on paper) served by four different family service coordinators. Their FSCs had dropped their case due to attrition, moves, and financial collapse of agencies. At the beginning of this study they had just been notified that they would need to select a fifth FSC. They could recall only once that a FSC had made a home visit. Since they did not have a telephone, communication had been by mail or through the early interventionist. Mrs. Gordon said,

> At the beginning I wasn't sure what the FSC was supposed to do. Most of the therapy for Robert focused on his motor development. I never said anything because I thought that was all the FSC was allowed to schedule. I didn't want to hurt anybody's feelings by demanding more than they could give. Now, I know different, and I am more demanding.
Mr. Gordon said,

They collect paychecks for doing absolutely nothing. When that woman came to our house I didn't think she was listening to me at all. They didn't talk to me about what I wanted for my child. They just made appointments and demands.

For the Brown and White families there was absolutely no knowledge of what the FSC was supposed to do, or even who this person was. The Smith, Cook, Cramer, and Lotto families had more positive experiences and understandings of family service coordination. They knew the FSC was supposed to help them secure services, make transportation arrangements if needed, and plan their child's early intervention program. Mrs. Smith spoke very highly of both her FSCs, "They have become a friend who really cares about my family."

With the Regan/Johnson family, it was impossible to ascertain their understanding of the role of the FSC. This was due partially to the limited intellectual capabilities of Ms. Regan and the obvious hostility Mrs. Johnson, Ms. Regan's mother, had toward their current FSC. I observed this hostility during one of my early visits to the home. Later Mrs. Johnson said "He (FSC) thinks we should jump every time he makes a suggestion. He doesn't know how it is!"

All of the families expressed interest in knowing how to work effectively with their child in varying degrees. At this point in the study it seemed important to address how the families were presented information about teaching specific skills (Table 4.10) and how the early interventionist communicated with families (Table 4.11).
Observations made during the participant observations aspect of the study revealed that the early interventionists usually used modeling or modeling with verbal and/or physical prompts to teach a skill. If the child was more involved, such as Lisa Cook, the interventionist used direct instruction and physical guidance. The style of the early interventionist also played an important role. Marsha seemed to feel more comfortable asking parents to participate in the activity, but not requiring it. Louise would use a less direct approach, and then at the end of the lesson tell a parent what they needed to work on for homework.

Both of the early interventionists used verbal and preferred activities (Premack principle) as reinforcers for progress in mastering a skill. With the Premack principle and preferred activities an early interventionist required the child to perform a less desirable task before he or she was allowed to do the more desirable activity (Bailey & Wolery, 1992.) They also both occasionally allowed the child to play naturally and facilitated learning through the

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Secure services</td>
<td>&gt;Attribution&gt;</td>
<td>Perceived Role of Family Service Coordinator</td>
</tr>
<tr>
<td>Write IFSP</td>
<td>(characteristic of)</td>
<td></td>
</tr>
<tr>
<td>Arrange transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lend toys/equipment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Determine frequency of visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Solicit parent feedback</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do absolutely nothing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No idea of what they do</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
ongoing activity. This technique of using natural play was used with the Brown, Gordon, and Lotto families.

Typically, the early intervention sessions began with informal conversation, including the interventionist's asking what had happened recently with the child or family. These were almost always initiated with open-ended questions. Table 4.10

How does your early interventionist present new ideas to you and your child?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model for child</td>
<td></td>
<td>Teach new skills</td>
</tr>
<tr>
<td>Use of reinforcers</td>
<td>&gt;Means/End&gt;</td>
<td></td>
</tr>
<tr>
<td>Model with verbal</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and physical prompts</td>
<td>(is a way to)</td>
<td></td>
</tr>
<tr>
<td>Direct instruction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demonstrate and then</td>
<td></td>
<td></td>
</tr>
<tr>
<td>invite parent to participate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct instruction and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>give parents required homework</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use of natural play activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>to facilitate learning</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

or statements, such as to Mrs. Smith, "What have the girls been doing this week?", or to Mrs. Cook, "Tell me about your trip to Houston last week," or to Mr. Gordon "What did the doctor say?". As indicated in Table 4.11, the early interventionists used open and closed questions, open and closed statements, active listening, suggestions, recommendations, and commands in communicating with their families.

Closed questions frequently used by both early interventionists were whether a specific date would be
acceptable for the next appointment, or "Have you heard from your FSC recently?". The closed statement used frequently by both early interventionists was "I wouldn't worry about that." There were also times when the early interventionists asked questions to which it seemed they only desired limited responses. For example, Louise asked the parent if the physical therapist talked about modifying the head rest on the wheelchair at the last visit instead of inviting the parent to talk about any important topics that were discussed.

Both early interventionists attempted to use active listening within their sessions. The time given to active listening and the effectiveness with which it was used seemed to be partially dependent on the early interventionist's time schedule and agenda for the day. On some days the early interventionists were less rushed and took more time to listen to parental concerns and to clarify issues.

The responses to concerns expressed by the families typically came in the form of suggestions or recommendations. Suggestions were presented as options for parental choice. The early interventionists usually described both the positive and the negative attributes of the choices and then left the decision to the parent. For example, Mrs. Cook had to decide from numerous choices the portability features she wanted on Lisa's wheelchair.
With recommendations the family was told the options, but the early interventionist's preference was also very clear. Usually more time, explanation, and emphasis was given to what the early interventionist felt was the desired response or choice for the family.

At the end of the session, the progress notes written by the early interventionist were reviewed with the family. During this discussion, recommendations or commands for the child's continued program were frequently reiterated. If the early interventionist felt the family was not likely to follow through on the suggestion or recommendation, it became a command. For example, one of the early interventionists told a parent to be sure and call to get an appointment for home health before the next visit. The family in this case resented the early interventionist's communicative style.

Bailey and Wolery (1992) suggested that the intersetting connections of Bronfenbrenner's mesosystem are critical to a family-centered early intervention. These intersetting connections or links were most effective with open communication, collaboration, and team work.

In Chapters 1 and 2 of this study, the important role of the family in a child's development was discussed and supported through the literature review. The IDEA legislation and its predecessor, PL 99-457, called for the family to be the driving force of the assessment and planning processes. It also contained provisions for the
Table 4.11.

How do early interventionists communicate with families?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-ended statements and questions</td>
<td>Means/End</td>
<td>Communicate</td>
</tr>
<tr>
<td>Closed statements and questions</td>
<td>(is a way to)</td>
<td>with Families</td>
</tr>
<tr>
<td>Listening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommendations</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commands</td>
<td></td>
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</tr>
</tbody>
</table>

identification of family strengths and needs, including concerns, priorities, and resources, but only with the approval of the family. The next question addressed what families saw as the focus of early intervention (Table 4.12). The families were evenly divided on this issue. Ms. Brown, Ms. Regan, Mrs. Lotto, and Ms. White all saw early intervention as strictly a service for their child. Mr. and Mrs. Gordon, Mrs. Smith, Mr. Cramer, and Mrs. Cook viewed early intervention as a service for both child and family.

Table 4.12.

What is the focus of individual early intervention programs?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child</td>
<td>Means/End</td>
<td>Focus Early</td>
</tr>
<tr>
<td>Family/child</td>
<td>(is a way to)</td>
<td>Intervention</td>
</tr>
</tbody>
</table>

Domain Analysis of Interviews

The last seven domains were constructed from the multiple interviews with the six families (Cook, Cramer, Gordon, Brown, Smith, and White) and informal conversations with the other two families (Lotto and Regan/Johnson) during
and after early intervention sessions. The first issue I talked to the parents about was how the location for early intervention services had been decided. Table 4.13 illustrates the four ways the early intervention location was determined.

Mrs. Cook was told that only the early intervention and home health service could be provided in the home and that she would have to travel to Lafayette to find an approved occupational, physical, and speech therapy center. She felt that government regulations had determined where Lisa's services were provided, and not her health needs. Mr. Cramer indicated that he wanted the swimming therapy and preferred going to the interventionist's parents' pool, as it was closer to his home. He also wished that he had shorter distances to travel for Missy's speech, occupational, and physical therapies. It was his understanding that government regulations were preventing local rehabilitation centers from becoming Part H service providers.

Mr. Cramer also wanted the early interventionist to establish some play groups, but this was not possible due to parish school policy. The parish school board had denied a request for a special early intervention play room at one of the schools, citing the lack of space as the reason.

Both Marsha and Louise, the early interventionists, said they would prefer some of the times to have the children all come to one location and not have to travel as
much. One of the reasons the early interventionists established the swimming program was to have a central location for services. The only time all of the participating families had gone to one location in the past was for holiday activities.

When I asked parents to tell me about their experiences in getting their child enrolled into early intervention, I heard numerous frustrations (Table 4.14). The families

Table 4.13

How is the location for early intervention determined?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent preference</td>
<td>&gt;Means/End&gt;</td>
<td>Determine Location</td>
</tr>
<tr>
<td>Parish policy</td>
<td>[is a way to]</td>
<td></td>
</tr>
<tr>
<td>Early Interventionist preference</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government regulations</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

frequently combined their experiences of the referral, assessment, and writing of the IFSP processes into one large experience. Legally, these three steps must occur within 45 calendar days (IDEA) from beginning to end (Appendix A), and are separate steps. Mrs. Smith was perhaps the most vocal of the study families about early days in the program, as this aspect of her interview illustrated.

At first it was a lot of paper work, it's like to get past that and to get into the program, you know. After we got in, it was fine, but it was to get in, a lot of paper work. But, of course, I understand that. But it's like you have to go and answer so many questions--but, you, it's just--it was a lot of paper work. I just remember that. It was two years ago, but God, I remember that. I don't know. It's like we had to
go and go, and it was like a long time before they actually started coming to the house and working with us. It's like—I don't know how long.

Mrs. Johnson, Ann Regan's grandmother, said, "From the beginning enrollment and planning our FSC has been too pushy." Mr. and Mrs. Gordon were not exactly sure how they got referred; only that there was a lot of paper work and that everyone stressed how important it was to keep all their appointments. The Gordons, Ms. Brown, Mrs. Smith, Mr. Cramer, and Mrs. Cook all commented on the inconvenience of driving/riding into Lafayette to get services and that the professionals acted as if the parents didn't exist, ignored their questions, and didn't provide guidance for home activities. Mr. Cramer said his mother and sisters were very unsupportive, as this vignette from his interviews indicated.

It was bad enough all of the hassles I had to go through to get Missy in therapy and the FSC not really listening, but then my mother said Missy doesn't need to go to therapy. She wanted me to take her about once a month, and Missy's cerebral palsy is pretty bad.

The Gordons, Ms. Brown, Mrs. Cook, Mrs. Smith, and Mr. Cramer all described a sense of relief to finally get their child enrolled in early intervention.

In talking with parents about their current experiences within the early intervention system, there was a better balance between the positive and negative comments. For families without their own transportation (Whites, Regans, and Cramers), there were many vignettes of long trips,
Table 4.14

What happened when you enrolled your child in early intervention?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper work</td>
<td>&gt;Strict Inclusion</td>
<td>Initial Frustrations</td>
</tr>
<tr>
<td>Transportation</td>
<td>is a kind of</td>
<td>of Families</td>
</tr>
<tr>
<td>Unsatisfactory responses</td>
<td>from professionals</td>
<td></td>
</tr>
<tr>
<td>Slowness in initiation of services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extended family unsupportive</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

missed appointments, and inconvenience. There were also concerns expressed by those who had transportation. Mrs. Cook talked about the distance she had to drive to secure services for her medically fragile child. In contrast, Mrs. Smith, Mr. and Mrs. Gordon, and Ms. Brown currently had all of the services in their home and therefore were not experiencing transportation difficulties.

Two of the families talked about the additional services they wished were available for their children and families, including play groups and experiences with other parents. Other ongoing frustrations were related to the behavior of professionals. I heard statements from each of the families about at least one professional who had not given them any respect or who had not acknowledged they might know their own child’s needs best.

Mr. Cramer said,

Whether it is the FSC or a therapist, I can never be sure they are telling me the complete story. It is so frustrating. I think they figure I am just a dumb old Cajun, but I understand and I think I take good care of my daughter.
Families also frequently had to advocate for the continuation of the therapies when the services their child received were supported by government funds. Mrs. Cook found this particularly frustrating. She said, "It is a constant battle. It ought to be obvious to them Lisa needs help and that we cannot afford to pay for all of it."

The families also described positive experiences, which included the joy in seeing their child progress, the emotional support the whole family received from the interventionists and therapists, the technical assistance given with services and equipment, the information they learned, and the "extras." Mr. and Mrs. Gordon, Ms. Brown, and Mrs. Cook characterized the extras as helping with their own school work, a family problem, or with something around the house.

In the last session of the interviews I asked families, "What aspect, if any, of the early intervention program would you change to make it more family centered?" The issues targeted by the six families who completed the interview process (Cook, Gordon, Brown, Smith, White, and Cramer) were reflective of the frustrations expressed in Table 4.15. The three families who received services every other week wanted an increase in the frequency of the services provided.

All of the families expressed an interest in changing the location of the services and the types of services
Table 4.15

Since your child has been enrolled in early intervention what have been your experiences (good and bad)?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of services</td>
<td>Strict Inclusion</td>
<td>Early</td>
</tr>
<tr>
<td>Inconvenience of services</td>
<td>(is a kind of)</td>
<td>Intervention</td>
</tr>
<tr>
<td>Transportation availability</td>
<td></td>
<td>Experience</td>
</tr>
<tr>
<td>Inconvenient transportation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>schedules</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constant advocacy to obtain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>and maintain services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inappropriate professional</td>
<td></td>
<td></td>
</tr>
<tr>
<td>behavior</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child is progressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance with procuring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information about disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child enjoys play activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early interventionist and</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FSC listening/caring</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

offered. Mrs. Cook wanted all of the services in the home for her medically fragile child. Mr. Cramer would have been happy with services located closer to his home. Mr. and Mrs. Gordon talked about being able to get services that their child needed, rather than just what was available. Along the same theme, all the families wanted some changes in the structure of the services provided in order to get answers to their questions and have more control. These issues will be discussed in greater depth in the taxonomic analyses of this domain in Table 4.24.

According to IDEA a transition plan must be included in the IFSP as children exit the Part H program (at their third
Table 4.16

**If you could change your experiences with early intervention, what would you like to be different?**

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frequency of services</td>
<td>&gt;Attribution&gt;</td>
<td>Changes</td>
</tr>
<tr>
<td>Location of services</td>
<td>(is characteristic of)</td>
<td>Recommended</td>
</tr>
<tr>
<td>Types of services</td>
<td></td>
<td>by Families</td>
</tr>
<tr>
<td>Structure of services</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

birthday). This plan and decision process was also to be family centered. I asked the families who had children scheduled to leave early intervention at the end of this school year about their experiences with transition. Their responses are summarized in Table 4.17.

The Gordons, Browns, Regans, Cramers, and Smiths all had children involved in this process. Ms. Brown and Mr. and Mrs. Gordon were particularly confused about what might happen to their child next year. They had asked the early interventionist, and her response was described as vague. She had told both of them that her services would stop at the end of the school year, and if their child did not continue to qualify for special services in the school program maybe they could try Headstart or something similar.

Typically, according to IDEA the FSC was to assist families with the transition process but the absence of effective or family-centered FSC added to the families' frustrations. Neither of these families felt they had received specific advice as to how to proceed if their child went somewhere other than the public school special education program. Mrs. Gordon said "I'm not sure if I will
need a babysitter for Robert next year or what will happen. I don't think he has completely caught up and might need more help like he is getting from Ms. Louise."

Ms. Regan and Mrs. Johnson were anxious to get Ann started. Grandma was especially pleased when the early interventionist told her about the possible school program and placement. Mrs. Smith said she appreciated the early interventionist's supporting her in the placement decisions for her oldest daughter. Because of her daughter's fragile health the school system had decided to let her continue in a home program.

Mrs. Smith and Mr. Cramer had both been afforded the opportunity to visit the classroom where their child might be placed. They felt the school staff were most supportive and patient in answering all their questions.

Table 4.17

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>&gt;Semantic Relationship &gt;</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of field visits</td>
<td>&gt;Function &gt; (is used for)</td>
<td>Preparation for Transition</td>
</tr>
<tr>
<td>Explanation of process by early interventionist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Answering of questions by early interventionist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assurance of service continuity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assurance of continued parent involvement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No information</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the last two domains of the study (Table 4.18 and Table 4.19) I focused on the characteristics that each
family attributed to their FSC and early interventionist. Family service coordinators were described by the families in this study in many different ways. The families' perceptions of these people would seem to indicate large numbers of persons when in reality they were describing less than ten people.

The differences in the descriptions of FSC (Table 4.18) between families of similar ethnic, socioeconomic status Table 4.18

What is your family service coordinator like?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendly</td>
<td>&gt;Attribution&gt;</td>
<td>Family Perception</td>
</tr>
<tr>
<td>Respectful</td>
<td>(is characteristic of) of FSC</td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequent contacts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consistent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accessible</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wholistic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowledgeable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unpredictable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor listener</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unresponsive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostile</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useless</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insensitive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bossy/dictatorial</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Slow</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Critical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited knowledge of children, early intervention, and services available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonexistent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have no idea who FSC is</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Guess they are okay for help</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
and locale backgrounds seemed to reflect Bronfenbrenner's theory (1979) that a person's (family member) perception of someone or something (their family service coordinator or early interventionist) was based on the interaction and interdependence of the person's personality traits, experiences, and their contextual environment. This perception was also not static but changed over time. The perceptions of the family service coordinator ranged from supportive and friendly to unpredictable and bossy to a nonexistent person.

In Table 4.19 the families' perceptions of their early interventionists were listed. The Gordon and Brown families had been served by both early interventionists, Marsha and Louise. Initially, Acadia Parish had only one early interventionist, Marsha, serving the entire area. The Brown, Cook, Gordon, and Regan/Johnson families were served by Louise, and the Cramer, Lotto, Smith, and White families were served by Marsha during the four month period of this study. These family assignments were made by the central school board office and were based on the families' geographic location in the parish. While there was a range in the characteristics describing each early interventionist and between early interventionists, the diversity in the perceptions of the families was less extreme and the negative attributes were described with less intensity than those ascribed to the FSC.
Table 4.19

What is your early interventionist like?

<table>
<thead>
<tr>
<th>Included Terms</th>
<th>Semantic Relationship</th>
<th>Cover Term</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>&gt;Attribute&gt;</td>
<td>Family Perception</td>
</tr>
<tr>
<td>Encouraging</td>
<td>(is a characteristic of)</td>
<td>of Early Interventionist</td>
</tr>
<tr>
<td>Supportive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good listener</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cares about needs of whole family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpful with extras</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flexible about scheduling</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Makes me feel important</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respects me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reliable</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Willing to teach me and my child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not pushy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pushy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows what is best</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demanding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Controlled sharing of facts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not sure knows what to do</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nosey</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Socializes too much</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Taxonomic Analysis of Participant Observations and Interviews.

Based on participant responses, I followed up with questions as to whether they would label these characteristics as family centered or not. A taxonomy of the positive, negative, and neutral characteristics emerged for both family service coordinators and early interventionists (Tables 4.20 and 4.21).

The positive characteristics of the FSC (Table 4.20) were described by the families as attributes they liked and
designated as family-centered. The list of these positive characteristics of a FSC included supportive, helpful, knowledgeable, frequent contacts, consistent, accessible, respectful, wholistic, and caring. Mrs. Cook described her first year with her FSC as just what she needed. The FSC called at least every two weeks, had told her to call whenever she needed help, had listened carefully to what she wanted for Lisa, and always tried to address her concerns efficiently. Mrs. Smith described her daughters' family service coordinator as a real friend who was interested in the whole family and was as helpful as possible.

The negative characteristics attributed by the eight families to a FSC: were limited knowledge of child development, early intervention process, and services available; dictatorial style; insensitive; unresponsive; hostile; useless; unpredictable; does not listen; slow; and critical. The FSC for the Regan/Johnson family was the same person for the Cooks, but their perceptions of this person were the opposite. Mrs. Johnson said their FSC "had an attitude." He was described as hostile, bossy, and argumentative. The Gordons described all of their family service coordinators as useless and of no assistance.

The neutral category was particularly interesting. The comments received in this group were from the Brown and White families. According to the IFSP records, both families had a FSC. At the first interview I inquired about how Ms. Brown felt about Albert's FSC. Her almost
immediate response was "I don't think I have one of those." I suggested some of the things this person might have helped her get as services and write the IFSP. She said "Only Louise (the early interventionist) helped me with that." The records did not show that Louise had ever been this family's FSC. In the second interview I asked again about the FSC. Ms. Brown said "If I have one, I don't know who it is. I guess it would be helpful to have one. Cause if I had one, maybe they could help me with getting Albert in Headstart."

Ms. White had similar responses in the first two interviews and then during the third session determined the FSC was the negative person she had tried to avoid. In the componential analyses levels of this study these characteristics were examined further as to whether they were more typical of specific gender, ethnic, socioeconomic status, or locale diversities of these select families.

As I did with the FSC characteristics, I asked the families to tell me which of the attributes assigned to the respective early interventionists, Louise and Marsha, they would categorize as family-centered. In Table 4.21 the attributes were divided as positive and negative. The positive attributes were characterized by the families as family centered. The list of positive characteristics included both early interventionists. Both early interventionists were described as having characteristics that were family-centered by some of their families. They especially liked their caring attitude, good rapport with
Table 4.20

Taxonomy of Family Perceptions of FSC

<table>
<thead>
<tr>
<th>Positive</th>
<th>Neutral</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friendly</td>
<td>Do not have a FSC</td>
</tr>
<tr>
<td>Respectful</td>
<td>Have no idea who FSC is</td>
</tr>
<tr>
<td>Helpful</td>
<td>Person might be helpful</td>
</tr>
<tr>
<td>Supportive</td>
<td></td>
</tr>
<tr>
<td>Frequent Contacts</td>
<td></td>
</tr>
<tr>
<td>Consistent</td>
<td></td>
</tr>
<tr>
<td>Accessible</td>
<td></td>
</tr>
<tr>
<td>Knowledgeable</td>
<td></td>
</tr>
<tr>
<td>Holistic</td>
<td></td>
</tr>
<tr>
<td>Caring</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative</td>
<td></td>
</tr>
<tr>
<td>Unpredictable</td>
<td></td>
</tr>
<tr>
<td>Poor listener</td>
<td></td>
</tr>
<tr>
<td>Hostile</td>
<td></td>
</tr>
<tr>
<td>Useless</td>
<td></td>
</tr>
<tr>
<td>Insensitive</td>
<td></td>
</tr>
<tr>
<td>Bossy/dictatorial</td>
<td></td>
</tr>
<tr>
<td>Slow</td>
<td></td>
</tr>
<tr>
<td>Limited knowledge of children, intervention, and services</td>
<td></td>
</tr>
</tbody>
</table>

their child, and helpfulness with the "extras." Louise did receive some criticisms from her families for at times "being pushy," "unpredictable," "socializing too much," or being "too nosy."

The negative characteristics attributed to Marsha related to inadequate sharing of knowledge. Mrs. Lotto and Mr. Cramer both expressed concern that their early interventionist had not shared all the information they should have in the beginning. Mr. Cramer said "it was like she was trying to protect me from the facts." The componential analyses of these characteristics were also examined as to how they were distributed across the demographics of socioeconomic status, gender, ethnic, and locale attributes of the families participating.

Parental roles, communication styles, initial and ongoing frustrations with early intervention, and changes
Table 4.21

Taxonomy of Family Perceptions of Early Interventionists

<table>
<thead>
<tr>
<th>Positive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraging</td>
</tr>
<tr>
<td>Supportive</td>
</tr>
<tr>
<td>Good Listener</td>
</tr>
<tr>
<td>Cares about Needs of Whole Family</td>
</tr>
<tr>
<td>Helpful with Extras</td>
</tr>
<tr>
<td>Flexible about Scheduling</td>
</tr>
<tr>
<td>Makes Me Feel Important</td>
</tr>
<tr>
<td>Respects Me</td>
</tr>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Reliable</td>
</tr>
<tr>
<td>Willing to Teach Me and My Child</td>
</tr>
<tr>
<td>Not Pushy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Negative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pushy</td>
</tr>
<tr>
<td>Knows what is best</td>
</tr>
<tr>
<td>Demanding</td>
</tr>
<tr>
<td>Not sure knows what to do or how to help</td>
</tr>
<tr>
<td>Controlled sharing of facts</td>
</tr>
<tr>
<td>Nosey</td>
</tr>
<tr>
<td>Socializes too much</td>
</tr>
</tbody>
</table>

desired in early intervention were addressed in the taxonomic analysis in addition to the two preceding domains that were also analyzed at this level. In both the participant observations and interviews, parents took many different roles during the early intervention sessions from actively participating to completing tasks totally unrelated to the early intervention (Table 4.22). This variety reflected the changes in patterns of service and levels of family involvement discussed in Chapter 2 by McCollum and Maude (1993). The responses illustrated in Table 4.22 also were reflective of the enablement and empowerment philosophy advocated by Dunst, Trivette, and Deal (1988).

The early interventionists and families seemed to be comfortable with their chosen roles. In looking at what parents did during an early intervention session, for example, the assessment process included the parents' being requested to complete on their own a questionnaire on their
child's current level of functioning or answering questions while the interventionist filled in the answers. Acadia parish was starting to use a new curriculum for the early intervention program, and it had a child assessment profile to be completed by the parent as one of its components. Parents were also frequently asked, when a child attempted a task, whether this was a typical response. If the early interventionist was not sure whether the child had succeeded at a task, the early interventionist also asked the parent to get a second opinion.

Mr. Cramer and Mrs. Smith both commented in their interviews about the importance of being a good observer and assessor, because during the multidisciplinary evaluation process they were asked many questions about their children's skills by professionals. Mrs. Smith and Ms. Brown stated that they enjoyed watching their child work with the interventionist. Ms. Brown said "Sometimes Louise can get him to say or do something I have tried for weeks to do. It's exciting to see him succeed and frustrating, too." Mrs. Smith said that by watching she learned new ways to play with the girls to encourage their speaking and learning.

The role of planning future activities for parents included a wide variety of topics, from talking about how a walker might be incorporated into the entire program, to whether their child should be considered for the water therapy program. Some of the questions that were asked by parents during early intervention sessions focused on better
understanding their children's diagnoses and the terminology used by professionals. Parents had questions about their children's prognoses for progress in certain skill areas, and where their children might receive services after they turned three years old.

Other parent roles included making decisions about their child's program. For example, Mrs. Cook was struggling with the issue of whether to continue Lisa's physical therapy one time per week. She did not feel that Lisa was benefitting from the service, and the traveling time was three times the length of the therapy. However, Mrs. Cook was also concerned that if she gave up the service it would be difficult to get physical therapy again later when Lisa might need it more.

Each of the families had their own way of keeping track of their child's busy schedule of appointments. Some kept all the information on a central family calendar, while others had personal organizers or files to record the information. Still other families seemed to choose not to record or attempt to coordinate the services at all. For example, Ms. White had the FSC, health unit nurse, early interventionist, and me all come on the same day within a few short hours. When I asked her about it later, she said

Well I just can't remember it all so I don't even try to write it down. It is just too much! You and Ms. Marsha (early interventionist) always call before you come, but the rest of them are just unpredictable. So if I feel like seeing them, I let them come in, and if I don't, I don't let them in.
Only three of the families consistently physically participated in their children's activities during the early intervention session. They were Mrs. Smith (MSES and E/A), Ms. Brown (LSES and A/A), and Mr. Cramer (LSES and E/A). Mrs. Smith typically engaged in the pretend tea parties and doll play, Ms. Brown played the games, and Mr. Cramer participated in the swimming. There were two mothers and one father who chose to take the more active role in the sessions.

Mr. Gordon, on occasion, engaged in Robert's activity with Ms. Louise and encouraged his son's participation. All of the parents did participate to the extent that they applauded or cheered for their child's accomplishments. Mrs. Smith, Ms. Brown, and Mr. Cramer were also the only three parents who asked to be shown how to do particular activities and attempted them during the session, in order to work on them later with their children.

There were also some families who, on occasion, chose to engage in activities away from the early interventionist and their child. These activities included preparing a meal, cleaning up in the kitchen, and making personal phone calls. On one occasion Ms. Cook left Lisa in the care of the early interventionist while she completed an errand at the store in order to finish preparation for the noon meal. The last two categories in the taxonomy which were parent roles not directly related to the early intervention program might also have been an expression of the need for respite by some
families. In the case of Mrs. Cook leaving Lisa in Louise's care it also seemed to be an expression of her trust of Louise to care for her child.

Table 4.22

Taxonomy of parental roles in early intervention

<table>
<thead>
<tr>
<th>Assessment</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion of questionnaires</td>
<td>on child's</td>
</tr>
<tr>
<td></td>
<td>skills</td>
</tr>
<tr>
<td></td>
<td>Answered</td>
</tr>
<tr>
<td></td>
<td>questions</td>
</tr>
<tr>
<td></td>
<td>about</td>
</tr>
<tr>
<td></td>
<td>performance</td>
</tr>
<tr>
<td></td>
<td>Asked</td>
</tr>
<tr>
<td></td>
<td>questions</td>
</tr>
<tr>
<td></td>
<td>about</td>
</tr>
<tr>
<td></td>
<td>prognosis</td>
</tr>
<tr>
<td>Observe</td>
<td></td>
</tr>
<tr>
<td>Watch</td>
<td>to learn</td>
</tr>
<tr>
<td></td>
<td>new ways</td>
</tr>
<tr>
<td></td>
<td>to teach</td>
</tr>
<tr>
<td></td>
<td>child</td>
</tr>
<tr>
<td></td>
<td>Watch</td>
</tr>
<tr>
<td></td>
<td>child's</td>
</tr>
<tr>
<td></td>
<td>accomplishments</td>
</tr>
<tr>
<td>Plan Future Activities</td>
<td></td>
</tr>
<tr>
<td>Discussed</td>
<td>possible</td>
</tr>
<tr>
<td></td>
<td>future</td>
</tr>
<tr>
<td></td>
<td>objectives</td>
</tr>
<tr>
<td>Discussed</td>
<td>benefit of</td>
</tr>
<tr>
<td></td>
<td>participating</td>
</tr>
<tr>
<td></td>
<td>in water</td>
</tr>
<tr>
<td></td>
<td>therapy</td>
</tr>
<tr>
<td>Ask Questions</td>
<td></td>
</tr>
<tr>
<td>To better understand</td>
<td>diagnosis or</td>
</tr>
<tr>
<td></td>
<td>terminology</td>
</tr>
<tr>
<td>About future progress</td>
<td>of child on</td>
</tr>
<tr>
<td></td>
<td>a skill</td>
</tr>
<tr>
<td>About future placement</td>
<td>of child</td>
</tr>
<tr>
<td>Make Program Decisions</td>
<td></td>
</tr>
<tr>
<td>Determine value of a</td>
<td>particular</td>
</tr>
<tr>
<td></td>
<td>therapy or</td>
</tr>
<tr>
<td></td>
<td>service</td>
</tr>
<tr>
<td>Determine location of</td>
<td>services to</td>
</tr>
<tr>
<td></td>
<td>be provided</td>
</tr>
<tr>
<td>Determine frequency of</td>
<td>service to be</td>
</tr>
<tr>
<td></td>
<td>provided</td>
</tr>
<tr>
<td>Coordinate Child's Services</td>
<td></td>
</tr>
<tr>
<td>Schedule appointments</td>
<td>with</td>
</tr>
<tr>
<td></td>
<td>therapists,</td>
</tr>
<tr>
<td></td>
<td>doctors,</td>
</tr>
<tr>
<td></td>
<td>early</td>
</tr>
<tr>
<td></td>
<td>interventionists</td>
</tr>
<tr>
<td>Ignore responsibility and</td>
<td>just let</td>
</tr>
<tr>
<td></td>
<td>services</td>
</tr>
<tr>
<td></td>
<td>happen</td>
</tr>
<tr>
<td>Participate in an Activity</td>
<td></td>
</tr>
<tr>
<td>Get in pool with child</td>
<td></td>
</tr>
<tr>
<td>Play ball or cars with child</td>
<td></td>
</tr>
<tr>
<td>Engage in looking and</td>
<td>naming</td>
</tr>
<tr>
<td></td>
<td>pictures in</td>
</tr>
<tr>
<td></td>
<td>book</td>
</tr>
<tr>
<td>Assist in cooking project</td>
<td></td>
</tr>
<tr>
<td>Practice Teaching/Learning</td>
<td></td>
</tr>
<tr>
<td></td>
<td>a Skill</td>
</tr>
<tr>
<td></td>
<td>With early</td>
</tr>
<tr>
<td></td>
<td>interventionist</td>
</tr>
<tr>
<td></td>
<td>guiding parent</td>
</tr>
<tr>
<td></td>
<td>learns water</td>
</tr>
<tr>
<td></td>
<td>exercises</td>
</tr>
<tr>
<td></td>
<td>Encourage</td>
</tr>
<tr>
<td></td>
<td>a child to</td>
</tr>
<tr>
<td></td>
<td>count objects,</td>
</tr>
<tr>
<td></td>
<td>turn key in</td>
</tr>
<tr>
<td></td>
<td>busy box, or</td>
</tr>
<tr>
<td></td>
<td>describe</td>
</tr>
<tr>
<td></td>
<td>objects and</td>
</tr>
<tr>
<td></td>
<td>activities</td>
</tr>
<tr>
<td>Prepare Noon or Evening</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Meal</td>
</tr>
<tr>
<td>Parent in kitchen to</td>
<td></td>
</tr>
<tr>
<td></td>
<td>prepare</td>
</tr>
<tr>
<td></td>
<td>next meal for</td>
</tr>
<tr>
<td></td>
<td>family</td>
</tr>
<tr>
<td></td>
<td>Go to store</td>
</tr>
<tr>
<td></td>
<td>to purchase</td>
</tr>
<tr>
<td></td>
<td>product for</td>
</tr>
<tr>
<td></td>
<td>meal</td>
</tr>
<tr>
<td>Make Personal Phone Calls</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Use time to</td>
</tr>
<tr>
<td></td>
<td>call a friend</td>
</tr>
<tr>
<td></td>
<td>Use time to</td>
</tr>
<tr>
<td></td>
<td>call a family</td>
</tr>
<tr>
<td></td>
<td>member</td>
</tr>
<tr>
<td></td>
<td>Use time to</td>
</tr>
<tr>
<td></td>
<td>call spouse</td>
</tr>
</tbody>
</table>

The open-ended statements and questions were used by both of the early interventionists. This communication style was typically used to obtain an update on a child's health or progress on a skill, or to present choices regarding methods to solve problems, or options in services or service delivery (Table 4.23). For example, the Lottos were told that sign language and augmentative communication boards
were options for encouraging Janie's communication if they did not want to wait until she had surgery to correct the webbed larynx and could possibly speak. By presenting the issue in this way, the early interventionist was able to find out how important communicating through vocalizations was to the Lottos.

This particular incident also provided insight into another preference of the family in communicating with professionals. Mrs. Lotto said "I really don't have any use for a FSC or early interventionist who just asks me, 'What do you want for Janie?'. I need someone who can give me ideas and then allow me to decide."

Open-ended statements and questions were also used to express interest in the whole family or to hear all the details of a story. The families generally responded positively to this style of communication, although Mrs. Cook said during one interview that sometimes it seemed the early interventionist just came to socialize.

From the families' perspectives closed statements and questions were used in both positive and negative ways by the early interventionist during a home visit. For example, the early interventionists, on occasion, needed to use a closed question or statement to get closure on an issue or to control the amount of time used in an early intervention session. On these occasions the closed style of communication was not viewed by the families as offensive.
Closed communication style was also used to limit the information and responses given by the family. Ms. Brown said "Sometimes, I don't think [the early interventionist] wants to know the whole story; she either doesn't have time to listen or has already made up her mind."

Active listening was viewed by all the families as family centered and positive, but as Ms. Brown indicated in the above statement, it was not always practiced. There were similarities in their comments about their early interventionists' listening skills. They liked it when the early interventionist tried to understand their point of view and to clarify issues. Mrs. Smith said, "I feel like my early interventionist really cares by the way she listens during our conversations."

Suggestions, recommendations, and commands were not labeled as such by the early interventionists, but in my observations and parental interviews they seemed to fall into those categories. During the interviews I asked the parents how they felt about the ideas given them for care of their child. The family's overall relationship to the early interventionist seemed to influence their interpretation of the ideas presented. Mrs. Smith and Mr. Cramer, for example, always viewed the ideas as merely suggestions or options to consider. Mrs. Lotto was the most adamant in her feelings about the format. She said, "If they don't present ideas as just suggestions and that the choice is mine, I don't want them working with my child."
Ms. White, Mrs. Cook, Ms. Brown, and Mr. and Mrs. Gordon tended to view the ideas presented by the early interventionist as suggestions, with one idea definitely pushed as the recommended choice. They all also said that at times the recommended choice seemed to become a command. For example, when both Ms. Brown and Mr. and Mrs. Gordon were told they should take the bottle away from their respective children, or when Mrs. Cook was told she had to call the doctor that day about Lisa's seizures. Ms. Regan and Mrs. Johnson viewed the suggestions made as commands or orders no matter what the situation or how they were presented.

Table 4.23

**Taxonomy of communication styles with families**

<table>
<thead>
<tr>
<th>Open-ended statements and questions</th>
<th>Used to present choices of methods and services</th>
<th>Used to ascertain more complete information or to hear an entire story</th>
<th>Used to encourage family to express their opinions</th>
<th>Used to communicate interest in family as a whole</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closed questions and statements</td>
<td>Used to obtain limited information</td>
<td>Used to obtain fixed responses</td>
<td>Used to state opinion without providing family an opportunity to respond</td>
<td>Used to control time constraints of session</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Used to get closure on an issue</td>
</tr>
<tr>
<td>Active Listening</td>
<td>Used to clarify issues</td>
<td>Used to better understand a family's feelings, needs, preferences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suggestions</td>
<td>Ideas presented to family in such a way that they make their own decision</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Recommendations</td>
<td>Ideas presented to family in such a way that it is obvious what the early interventionist thinks is best, encouraged make own decision</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commands</td>
<td>Idea or ideas presented to family in such a way that they feel it is an order they must complete to continue early intervention services</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Initial frustrations for families in enrolling their child in early intervention, presented earlier in the Domain Analysis (Table 4.14), included paper work, transportation, unsatisfactory responses from professionals, slowness of
initiation of services, and an unsupportive extended family.

In the taxonomy presented in Table 4.24, specific descriptions of the frustrations under each of the topical areas were described. The paper work included completing numerous forms that duplicated information and gathering medical records from many different sources. Mrs. Cook and Mrs. Smith both spoke about the frustration of having to answer the same questions repeatedly. Mrs. Cook said "It would seem that all these different services for Lisa could make copies for each other instead of wasting my time."

Transportation was another area of frustration. Services were not conveniently located for families. At the beginning of their child's enrollment in early intervention all eight of the families had traveled to Lafayette for all their services. When the early intervention program in Acadia Parish was established, some of the families still had to travel to Lafayette for related services, such as physical therapy, occupational therapy, and speech therapy.

If the family was dependent on medical transportation, the initial contact, calling and scheduling the service, dependability of the service, and the actual time spent traveling became a nightmare. Mr. Cramer told how he left one morning at 7:00 with Missy for a 10:00 occupational therapy appointment, and returned that evening at 5:30. Mr. Cramer and Missy had spent the entire day either sitting in the medical van or in the waiting room of the rehabilitation center. There were no eating facilities near the center, so
Mr. Cramer had fed Missy snacks from the vending machine. He very adamantly said at that point in the interview, "That is not family friendly!"

On another occasion I waited for Mr. Cramer at the rehabilitation center for over an hour, only to get a call from him that the medical van driver had not shown up. When Mr. Cramer called the transportation office, he was told they were short a driver that day and would not be able to take Missy to her appointment. They had not bothered to notify him of the cancelled trip. Ms. Brown told of similar experiences in her trips to Lafayette. She was grateful that Albert no longer needed the additional services and that Ms. Louise came to her home.

The next area of frustration was unsatisfactory responses from professionals. These frustrations included failure of the FSC to call on a regular basis and the FSC’s being viewed as too bossy. The therapists at the rehabilitation centers seemed to ignore the parents’ presence, and professionals failed to tell parents what their role was. Other frustrations with professionals centered around neglect by the professionals in emphasizing the importance of home therapy to parents and professionals not giving complete information.

All of the families found frustrating the length of time required to initiate services. Mr. Gordon said "Once you know your child has a problem, you want to get it fixed as quick as possible. But it takes so long to get things
started." Mr. Cramer said "Maybe it didn't seem long to my
FSC, but waiting over a month to get Missy's therapy started
was such a waste of time."

In Chapter 2, the importance and closeness of the
extended family was described in the Acadian families
(Ancelet, Edwards, & Pitre, 1991). This perhaps contributed
to the frustration expressed by Mr. Cramer and Mrs. Cook.
Both expressed a desire for their extended family members to
provide more emotional and physical support in the care of
their child with disabilities.

Table 4.24

**Taxonomy of initial frustrations with early intervention**

<table>
<thead>
<tr>
<th>Paper work</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Completion of numerous forms</td>
<td></td>
</tr>
<tr>
<td>Gathering medical information</td>
<td></td>
</tr>
<tr>
<td>Answer repeated questions</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Transportation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Distance to travel to services</td>
<td></td>
</tr>
<tr>
<td>Scheduling of transportation</td>
<td></td>
</tr>
<tr>
<td>Dependability of transportation</td>
<td></td>
</tr>
<tr>
<td>Actual travel time</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Unsatisfactory response from professionals</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>FSC not calling frequently</td>
<td></td>
</tr>
<tr>
<td>FSC being too bossy</td>
<td></td>
</tr>
<tr>
<td>Related services personnel ignored parents' presence</td>
<td></td>
</tr>
<tr>
<td>Constant need to advocate for child's obvious needs</td>
<td></td>
</tr>
<tr>
<td>Absence of guidance on parent's roles</td>
<td></td>
</tr>
<tr>
<td>Failed to provide complete information</td>
<td></td>
</tr>
<tr>
<td>Failed to emphasize the importance of home therapy</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Slowness of initiation of services</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapy services</td>
<td></td>
</tr>
<tr>
<td>Early intervention services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Extended family unsupportive</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not provide assistance with care or respite</td>
<td></td>
</tr>
<tr>
<td>Family did not help in taking to appointments</td>
<td></td>
</tr>
</tbody>
</table>

In the discussion of the domain analysis of ongoing
frustrations for families in early intervention (Table 4.15)
was the included term, "professionals' behavior." During the
interview process I attempted to clarify this included term
further. I discovered each family had experienced at least
one professional whose behavior they would not describe as
family-centered (Table 4.25). Mr. Cramer and Mrs. Lotto described professionals as acting threatened if they as parents did too much intervention with their child or became too knowledgeable. They also concluded this was why professionals did not tell them what to do with their children.

Mr. Cramer had an additional frustration with his FSC. He felt that whenever he made requests to the FSC he always received a fixed response of "Let's wait and see." Mrs. Cook mentioned that the need to advocate for her child, even to maintain the status quo (existing services), never ends.

Table 4.25
Taxonomy of ongoing frustrations with professionals

<table>
<thead>
<tr>
<th>Frustrations with professional behavior</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hassle/Advocacy to obtain and maintain services</td>
</tr>
<tr>
<td>Interventionist does not tell how I can help</td>
</tr>
<tr>
<td>Interventionist doesn't seem to know what to do</td>
</tr>
<tr>
<td>Professionals seem threatened if I take too much initiative</td>
</tr>
<tr>
<td>Fixed responses to parental requests (Wait and see)</td>
</tr>
</tbody>
</table>

Families described numerous changes they would like for early intervention. Mrs. Cook and Mr. Cramer did not express an interest in increasing services for their children, but Ms. Brown, Mrs. Gordon, and Mrs. Smith would have liked the early interventionist to come more often to their homes. In the Cook and Cramer families, the children were receiving services weekly already. Mr. Gordon, Ms. White, and Ms. Regan and Mrs. Johnson did not express any concern about the frequency of early intervention sessions.
Ms. White and Mrs. Johnson both said they were satisfied with the frequency that the early interventionists came. They had scheduled early intervention appointment times, and they said if it was convenient for them they would be there. It should be noted that there were in both cases several scheduled visits by the early interventionist and me in which the family was not at home; no explanation was ever given for their absence.

The families whose children needed additional services, such as home health, physical therapy, speech therapy, and occupational therapy (the Smiths, Cramers, and Cooks) all desired that the services be either more conveniently located or provided in the home. These same families also wanted informal parent groups formed. They felt this would have provided the opportunity to share information and concerns and to socialize.

Mr. Cramer also wanted a play group for his daughter. He felt she needed the experience of being with other children, but his limited income did not permit his placing her in a nursery school even one day per week. Mrs. Cook wanted respite or child care services for her child, particularly for days she went to school.

Families recommended changes in the structure of early intervention, too. They wanted to have more information provided to them about available services, what they should do with their child, their child's disability, and/or the progress their child was making. They wanted the information
presented in a format that indicated they were the primary decision maker. The families were unique as to the changes they would make, which is contrasted further in the componential analysis. An example of a proposed change in the structure was Mr. Cramer's suggestion that when new ideas were suggested at a therapy or early intervention session, half of the time be used for the child and the other half instructing the parent. While Mrs. Lotto and Mrs. Cook wanted all of the time devoted to working with their children.

Table 4.26
Taxonomy of changes desired for early intervention

<table>
<thead>
<tr>
<th>Frequency of Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase frequency of visits</td>
</tr>
<tr>
<td>Increase length of visits</td>
</tr>
<tr>
<td>Location of services</td>
</tr>
<tr>
<td>All services in home</td>
</tr>
<tr>
<td>Services in home or same town as home</td>
</tr>
<tr>
<td>Types of services available</td>
</tr>
<tr>
<td>Play groups/social integration of children</td>
</tr>
<tr>
<td>Opportunities for parents to socialize</td>
</tr>
<tr>
<td>Respite</td>
</tr>
<tr>
<td>Structure of services</td>
</tr>
<tr>
<td>Increase sharing of information with families on child's status and services available</td>
</tr>
<tr>
<td>Present suggestions in format of choices</td>
</tr>
<tr>
<td>All services directed toward the child</td>
</tr>
<tr>
<td>Divide therapy time between child stimulation and parent teaching time</td>
</tr>
</tbody>
</table>

Componental Analysis of Participant Observations and Interviews

The issues of communication and characteristics of FSCs and early interventionists were examined at the componential
level for similarities and contrasts across the dimensions of diversity within this study—gender, socioeconomic status, ethnicity, and locale. In Table 4.27 each family's perceptions of their experiences with family service coordination were categorized. The limited perceptions provided from the visits with Mrs. Lotto and with Ms. Regan and Mrs. Johnson were also included. I had hoped this contrast might clarify the attributes of FSC that were more sensitive to the diversity issues of this study.

In contrasting the six core families experiences according to gender and ethnicity the European American families had far more positive experiences. Despite some initial negative experiences, Mr. Cramer (European American) felt that his FSC was taking him seriously now and supporting his rights to make decisions. Mr. Gordon (African American) described nothing but negative experiences in his saga of their first four FSC, and they were to begin a fifth person during the last month of the study.

The Smiths and Cooks (European American) described the FSC as someone who was a good listener, understanding, sensitive, helpful, and caring. Mrs. Smith and Mrs. Cook had praise for their initial and ongoing experiences with their FSC. Mrs. Lotto described the attributes of her ideal FSC and indicated hers had some of these characteristics. It was difficult at times to separate her description of the ideal and her experiences. All of the European American families knew the name of their FSC and had some idea of their role
and responsibilities. However, none of the African American families knew their FSC's name. This probably reflected the infrequent contact. The contrast of dimensions (Table 4.27) described their negative perceptions of the FSC.

The only negative experience Mrs. Cook had with her FSC was more like the African American families than the European American families. The FSC had come unexpectedly to say he was taking another job, was pushy in his comments, and insisted on removing everything (i.e., demonstration toys, equipment) checked out in his name. Mrs. Cook described this once well liked FSC as disrespectful and demanding on that day. The departure of a FSC and the transition process to another FSC was a problem for most of the families. Mrs. Cook said another part of her frustration came because the two FSC (her old and new one) from the same agency could not share vital information.

I had to start from scratch in providing my new FSC with an understanding of Lisa's needs and our family needs. They could not even transfer Lisa's borrowed equipment list from one desk to another.

The experiences of the three African American families with FSC attrition were equally difficult. According to their IFSPs the Brown, Gordon, and Regan/Johnson families had collectively been served by nine FSCs in a little over two years of enrollment.

In contrasting the families' experiences with FSCs according to their socioeconomic status, the MSES families had more positive experiences than the LSES families. Three
of the four families who were MSES (Cook, Lotto, and Smith) described their FSC as helpful in the early intervention experience. The Gordons, who were African American, MSES, and living in a rural area, were the exception to the

Table 4.27

Dimensions of Contrast in Family Perceptions of FSC

<table>
<thead>
<tr>
<th>Family Pseudonym</th>
<th>Cramer*</th>
<th>White</th>
<th>Regan/Johnson</th>
<th>Brown</th>
<th>Gordon*</th>
<th>Smith</th>
<th>Cook</th>
<th>Lotto</th>
</tr>
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<tbody>
<tr>
<td>Socioeconomic Status</td>
<td>LSES</td>
<td>LSES</td>
<td>LSES</td>
<td>LSES</td>
<td>MSES</td>
<td>MSES</td>
<td>MSES</td>
<td>MSES</td>
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<tr>
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<td>E/A</td>
<td>E/A</td>
<td>A/A</td>
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<td>E/A</td>
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</tr>
<tr>
<td>Locale—Rural or Urban</td>
<td>Rural</td>
<td>Urban</td>
<td>Rural</td>
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<td>Rural</td>
<td>Urban</td>
<td>Rural</td>
<td>Urban</td>
</tr>
<tr>
<td>Provided inadequate information</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lacked respect for parents</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experienced multiple FSCs</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Did not honor parent requests</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Not a good listener</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Slow initiating services</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited understanding of FSC role</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Too bossy</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demanding</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Argumentative</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irregularity of visits</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Too many questions</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hostile</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Controlling</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Critical/made feel defensive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unaware of existence</td>
<td>X</td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>No assistance/worthless</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>H shed known could fire</td>
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<td></td>
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<td></td>
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<tr>
<td>Inability to transfer information</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited knowledge of child development</td>
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<td>Limited knowledge of children with disabilities</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Wanted someone with a plan</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Supportive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cares about whole family</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helpful</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responsive to needs</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desires someone who presents choices</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(The X indicates family perceptions of FSCs. The * indicates perceptions include a male caretaker.)
pattern of positive FSC perceptions by MSES families. Three of the four families who were LSES (Whites, Regan/Johnsons, and Browns) had negative or no experiences with their FSC. The Cramers, who were European American and living in a rural area, were the exception to this pattern for LSES families. The only family who provided all positive perceptions of FSC was the Smith Family. They lived in an urban community, were European American, and MSES.

The eight families' perceptions of the two early interventionists, Marsha and Louise, provided additional understanding of preferences in style and definitions of family-centered practices. These preferences were examined for patterns also across gender, ethnic, socioeconomic status, and locale diversities. The early interventionist styles were different from one another. However, their unique styles were also perceived differently by the families they served. The majority of the descriptions of the early interventionists were positive in contrast to the overall negative descriptions they gave their FSC.

Both fathers, Mr. Cramer and Mr. Gordon, described their respective early interventionists, Marsha and Louise as exhibiting family-centered characteristics. Mr. Cramer especially appreciated Marsha's willingness to take the time to show him how to work with Missy. He said "She really listens to what I say and respects my decisions whether she..."
as exhibiting family-centered characteristics. Mr. Cramer especially appreciated Marsha's willingness to take the time to show him how to work with Missy. He said "She really listens to what I say and respects my decisions whether she agrees or not." Mr. Gordon described Louise's strengths as knowledgeable and good with his child. He did state

My wife still thinks Louise was too pushy and demanding about Robert's bottle. She was so mad she went in the bedroom and stayed there during her visits for almost two months. But she got over it and she knows that's probably why Robert is talking so well now. It was kind of funny watching their struggle.

Louise said she won the battle only because Mr. Gordon believed she was correct. The Gordons were the only family I observed where the early interventionist was working with both parents at the same time. Both Louise and Marsha seemed to adapt their style of intervention to satisfy gender differences of the primary caretakers in the families of the study. Mr. Gordon and Mr. Cramer were given more opportunities than mothers with similar backgrounds (i.e., Mrs. Gordon or Ms. White) to exercise control in decisions.

Marsha's intervention style across ethnicity diversity was observed as she related to the Lotto family with an Italian background and to the cultural differences of the Acadians from her own Acadian/Texan background. Her four families described her as respectful of their cultural preferences and genuinely interested in them.

The families Louise worked with in this study included one with an Acadian (European American) ethnic background
and three with African American ethnic backgrounds. There were no differences among members of these two groups regarding how they described the activities of their early interventionist as family-centered that could be attributed to their ethnicity. Two of the African American families (the Gordons and the Regan/Johnson) described Louise as being too pushy at times, but the same characteristic was also an issue for the Cooks (Acadian family).

In contrast Ms. Regan and Mrs. Johnson and Mrs. Brown (all A/A) did not find Louise's intervention behavior as pushy. Mrs. Brown particularly liked Louise's socializing before, during, and after the early intervention sessions. However Mrs. Gordon and Mrs. Cook found this behavior offensive at times. Louise's socializing was described by Ancelet, Edwards, and Pitre (1991) as common among persons of Acadian heritage. I don't believe from Mrs. Cook's interview transcript that she disliked all the socializing but rather did not want it to interfere with Lisa's therapy.

Another example of ethnic diversity that was apparent within the Gordon family was Mr. Gordon reframing Louise's communication style. Whether she was just socializing or making strong recommendations Mr. Gordon would translate her message into what Willis (1992) described as plain talk among African Americans. His wife found his reinterpretations amusing and they seemed to diffuse some tense situations. On one occasion during the participant observations, Louise teasingly accused Mr. Gordon of
minimizing her intervention efforts to get Robert evaluated for possible public school placement. He had responded to her that it was just too late for her to get a bid in for Robert, that USL had already signed him up. Later in the conversation it became apparent that Mrs. Gordon was not ready to deal with the issue of special education for their son and Mr. Gordon had used the plain talk to divert Louise from her pushing too hard on his wife.

Both of the early interventionists' styles were perceived as family-centered despite the families' socioeconomic status. All of their families wanted to have control over the decisions involved in early intervention including transportation, the focus and frequency of the services, and the equipment to be used. One issue that was raised earlier in the discussion of the domain of early intervention equipment was the problem of bringing in special toys and then packing them up to take to the next home. I observed this as a problem in two MSES homes and one LSES home. Marsha and Louise each dealt with the problem by leaving the toy for a week, and then on another occasion had the child help pack the toy, and carry it to their car.

The families' perceptions of their early interventionists did not differ across the demographic dimension of locale. The rural families expressed the desire to have all services closer to them, and both early interventionists were very understanding and supportive of their needs. Both Marsha and Louise had accompanied several
of these families to appointments in Lafayette. This had occurred when the family was concerned about finding a new service or there were no extended family members to accompany them. Their familiarity and knowledge of Lafayette was viewed by both the rural and urban family groups as an asset for them.

Table 4.28

Dimensions of Contrast in Family Perceptions of Early Interventionists

<table>
<thead>
<tr>
<th>Family Pseudonym</th>
<th>Cramer*</th>
<th>White</th>
<th>Regan/Johnson</th>
<th>Brown</th>
<th>Gordon*</th>
<th>Smith</th>
<th>Cook</th>
<th>Lotto</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socioeconomic Status</td>
<td>LSES</td>
<td>LSES</td>
<td>LSES</td>
<td>LSES</td>
<td>MSES</td>
<td>MSES</td>
<td>MSES</td>
<td>MSES</td>
</tr>
<tr>
<td>Ethnic Background</td>
<td>E/A</td>
<td>E/A</td>
<td>A/A</td>
<td>A/A</td>
<td>A/A</td>
<td>E/A</td>
<td>E/A</td>
<td>E/A</td>
</tr>
<tr>
<td>Locale--Rural or Urban</td>
<td>Rural</td>
<td>Urban</td>
<td>Rural</td>
<td>Rural</td>
<td>Rural</td>
<td>Urban</td>
<td>Rural</td>
<td>Urban</td>
</tr>
<tr>
<td>Knowledgeable</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Encouraging</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Supportive</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Good Listener</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Willing to teach me and my child</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Respects me</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Helpful</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Not pushy</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>Professional</td>
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<td>X</td>
<td>X</td>
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<td>X</td>
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<td>Makes me feel important</td>
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<td>X</td>
<td>X</td>
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<td>X</td>
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<td>Good with my child</td>
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<td>X</td>
<td>X</td>
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<td>Helpful with extras</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Cares about needs of the whole family</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
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<td>Not a good listener</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Not sure knows what to do or how to help</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Pushy</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Knows what is best</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>attitude</td>
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<td>X</td>
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<td>X</td>
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<tr>
<td>Demanding</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>Socializes too much</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

(The X indicates family perceptions of Early Interventionists. The * indicates perceptions include a male caretaker.)

The communication styles of the two early interventionists were different, as were their styles with
particular families (Table 4.29). Despite the similarity in the early interventionists' definitions of family-centered early intervention, discussed in Chapter 3, they implemented their jobs in very different ways, and had different perspectives on the parents' role in the session.

After the initial update conversations, Louise used more closed questions (requiring a yes, no, or very limited response by the parent) and recommendations that almost sounded like commands than Marsha. The responses to this style of communication were varied. The families Louise worked with were obviously fond of her, as described in the domains and taxonomies of early interventionist characteristics, but they participated only minimally in their children's sessions. When the topic of the conversation was something Louise preferred not to handle, she used a closed question or statement to end it, or at times near the end of the study she deferred to me for an answer. Her recommendations/commands were frequently presented in a teasing manner.

The majority of Louise's conversations with the parent did not relate to the ongoing activities with the child, but to the family. For example, she asked Mr. Gordon how he had done on a recent mathematics test, or whether Ms. Cook had a babysitter arranged for the baseball game next Saturday night. These topics could be considered family-centered, but from the parents' perspective revealed in the interviews these were not always their preferred conversation topics.
Ms. Brown said "Sometimes when Louise leaves I realize I never had a chance to ask her about a concern—that we had spent most of the time talking about my GED classes." Mrs. Cook said once she wasn't sure exactly why Louise came to her home, but it was nice the way she came by and they just talked. As stated in the taxonomic discussion, Mr. and Mrs. Gordon, Mrs. Cook, and Ms. Brown felt the recommendations frequently came across as orders to follow.

The other early interventionist, Marsha, used open-ended questions and statements more consistently throughout the sessions. She would ask closed questions primarily to clarify issues. For example, she asked Mr. Cramer if he wanted her to contact the FSC about changing therapy locations. The families served by Marsha frequently volunteered information about their child and related topics. Mrs. Smith said she knew that Marsha really cared because of the way she would always listen to her conversations.

During an activity, Marsha often directly and indirectly invited parental participation. Mrs. Smith and Mr. Cramer usually became involved with either type of invitation at that point. For example, she said to Missy Cramer "Tell Daddy you want him to get in the water and play with you," or to Katherine Smith, "Give Mommy a cup of coffee." Mrs. Lotto and Ms. White usually did not respond to these types of invitations, but continued to interact verbally with the early interventionist. At other times
Marsha might simply ask, "Mrs. Smith, would you mind helping me with this activity."

Louise's style of communication with families did not vary across the dimensions of socioeconomic status, ethnic, or gender background. There was little variation in her style, even when a family was obviously concerned about an issue. At those times she seemed more hurried and anxious than usual to complete a visit. She was always cheerful, established rapport quickly, interacted with the child as she continued a conversation with the parent, made her strong recommendations, had the progress notes signed, confirmed the next appointment, and left the home. However, during these hurried visits, the progress notes and journal reflections seemed to demonstrate a lack of depth and understanding of individual families and their needs.

In contrast Marsha's style of communication was different with each of her families. She had two LSES families, the Whites and the Cramers and two MSES families, the Lottos and Smiths. With the two LSES families, Marsha tended to use more closed questions and statements. This series of questions from a conversation with Ms. White reflected a typical occurrence.

Was David at the doctor this past week? Did the doctor say he had an ear infection? Do you have to go back after he finishes the medicine?

Sometimes Ms. White took the initiative and gave more than the expected short response. When this happened Marsha usually responded in a somewhat open fashion by asking a few
open-ended questions or making a few open statements, but usually reverted back to control of the content and momentum of the session. For example, in the above situation Ms. White had shared her frustration about the waiting process for getting into new housing. Marsha's responses were supportive of Ms. White's efforts and the frustrations but she closed the topic with "It always takes a long time to get the good things in life." Her journal comments and progress notes about the family indicated she was trying to understand the situation but felt uncomfortable with the unpredictability of events in the home.

The Cramer family was also LSES. Marsha said she respected Mr. Cramer a lot for his initiative in wanting to be well informed in securing the best services for Missy. However, she believed Mr. Cramer just asked too many questions and could keep you all day. She said she felt like she had to limit his opportunity to ask questions if she wanted to get anything done. She used open ended questions and statements at the beginning of the session, and then it seemed about half way through the time period Marsha would start discouraging Mr. Cramer's conversation with closed questions and statements.

With both the Cramers and the Whites Marsha used active listening skills on certain issues. She indicated in her journal that these were issues she deemed important to the families. The choice of whether to use open or closed questions and statements along with active listening skills
in communicating with these LSES families seemed to be dictated by the topic and early interventionist's comfort level. Marsha readily shared ideas for working with the child and solving problems with both LSES families as suggestions or choices. There was no pressure to make a particular decision. She reminded both families it was their right and choice to make the decision.

Marsha's communication style with the two MSES families, the Lottos and the Smiths, was more similar to one another despite the diversity of the two families. With Mrs. Smith Marsha always used an open-ended communication style and active listening. Mrs. Smith and Marsha seemed comfortable discussing almost any topic, for example even particularly sensitive issues as the girls terminal prognosis, religion, and personal family activities. Marsha was often invited to view videos of family events that had occurred since the last early intervention session, after the girls activities had concluded.

In communicating with Mrs. Lotto Marsha had to be very flexible but always open in her approach, active in her listening, and careful to present everything as a choice. The unpredictability of the situation was seemingly due to Mrs. Lotto's mood swings, her current marital relationship with Mr. Lotto, and Janie's health. My first visit to the Lotto family had occurred three weeks after I began with the Whites. I expected the description of Marsha's communicative response to the unpredictability in the Lotto family to be
similar to her response in the White situation. She described feelings of discomfort in working with this family in her journal, however, her responses were not the mixture of closed and open communication styles or a demonstration of efforts to control that I observed with the Whites. She seemed to just go with the flow of the day's events.

**Table 4.29**

**Dimensions of Contrast in Communication Styles of Early Interventionists**

<table>
<thead>
<tr>
<th>Technique</th>
<th>How Louise used it</th>
<th>How Marsha used it</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open ended</td>
<td>*Establish rapport</td>
<td>*Information sharing</td>
</tr>
<tr>
<td></td>
<td>*Discuss topics not directly related to child</td>
<td>*Show interest</td>
</tr>
<tr>
<td></td>
<td>*Sometimes with LSES and MSES</td>
<td>*Clarify issues</td>
</tr>
<tr>
<td></td>
<td>*E/A and A/A</td>
<td>*Sometimes with LSES</td>
</tr>
<tr>
<td></td>
<td></td>
<td>*Always with MSES</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>*Observed only E/A</td>
</tr>
<tr>
<td>Closed</td>
<td>*Maintain control of session</td>
<td>*Achieve closure</td>
</tr>
<tr>
<td></td>
<td>*Avoid uncomfortable topic</td>
<td>*Regain control of</td>
</tr>
<tr>
<td></td>
<td>*Achieve closure</td>
<td>*Sometimes with LSES</td>
</tr>
<tr>
<td></td>
<td>*Always with LSES and MSES</td>
<td>*Seldom with MSES</td>
</tr>
<tr>
<td></td>
<td>*E/A and A/A</td>
<td>*Observed only E/A</td>
</tr>
<tr>
<td>Active Listening</td>
<td>*Seldom used</td>
<td>*Response to parental concern or question</td>
</tr>
<tr>
<td></td>
<td>*Ask someone else present later to clarify</td>
<td></td>
</tr>
<tr>
<td></td>
<td>*No difference in LSES or MSES</td>
<td>*Used more with MSES than LSES</td>
</tr>
<tr>
<td></td>
<td>*No difference in E/A or A/A</td>
<td>*Observed only E/A</td>
</tr>
<tr>
<td>Sharing of Ideas</td>
<td>*Recommendations</td>
<td>*Suggestions/Choices</td>
</tr>
<tr>
<td></td>
<td>*Commands in teasing manner, more with A/A</td>
<td>with both LSES and MSES</td>
</tr>
<tr>
<td></td>
<td>*Used recommendations both LSES and MSES</td>
<td>Observed only E/A</td>
</tr>
<tr>
<td></td>
<td>*Used more commands in</td>
<td></td>
</tr>
</tbody>
</table>

**Triangulation of Data**

The trustworthiness of the data was strengthened by triangulation, using observations, interviews, audio tapes, and documents. The documents included the IFSP, weekly progress notes, and six weeks progress reports for each family from August 1994 through December 1994.
The observations were further supported by the reflective journal summaries on each family written by the two early interventionists. Randomly selected portions of my observation notes, the interview tapes, and transcripts of interviews were reviewed and validated as to patterns and themes by two university professors with expertise in special education and early intervention.

The verbal descriptions of each family and drawings of their respective homes or place for early intervention were shown to the two early interventionists for verification of accuracy.

Finally, the Cook, Cramer, Smith, Brown, Gordon and White families were revisited. With each family a summary of their perspectives on family-centered early intervention was presented, and they were provided the opportunity to suggest changes or clarify areas of confusions.

Summary

This qualitative study used participant observations, interviews, and document analyses of eight families participating in the Acadia Parish Early Intervention program to better understand how they defined an early intervention program as family-centered. The study identified several domains that seemed to provide information that enhanced my understanding. For example, the location of an early intervention appointment was a reflection of whether a policy was family centered. If the setting did not address the child and family's needs as a
natural setting or the family had no part in the decision regarding the location for the services, these families would not define it as family-centered. Without exception these eight families also wanted input as to the type, duration, and frequency of services to be provided to their child. They were willing to permit the early interventionist to plan the specific activities for their child based on the needs assessed, but they wanted flexibility in that agenda. They appreciated the "extra" activities that addressed the whole family's needs such as helping a parent with a school work assignment.

The participants in the early intervention sessions for this study were always determined by the family. The importance of the extended family in both the African American and European American families was apparent. Each of these families also had their own unique preferences and definitions for their role in the early intervention program. The family-centered response seemed to be to allow the parent to decide what they wanted to do and for the early interventionist to support that decision.

Families expressed frustration about the large amount of paper work needed to enroll a child in early intervention, the unreliable transportation system, and the distance needed to travel to services. Other frustrations included the need to constantly advocate for their child in order to maintain services and the insensitivity of some professionals.
The FSC issue brought out many questions and frustrations. Some of the LSES families had limited understanding of the role of the FSC. Further some did not know who the person was or what their rights were with this person. According to the data collected in this study the FSC was the weakest link in the family-centered Part H early intervention system. FSC were described as bossy, hostile, critical, worthless, and lacking appropriate knowledge. Two families did assign some positive characteristics to their respective FSC, but they were the exception.

Finally, the families in this study identified characteristics of FSC and early interventionists they saw as family-centered and not family-centered. Some of the positive characteristics included were careful listening, respect for parents' roles, knowledge of child development and early intervention, understanding and caring about whole family, and willingness to teach both parent and child. For every trend noted in these eight families across gender, socioeconomic status, ethnic, and local diversities there seemed to be an exception. While more specific summaries and implications follow in Chapter 5, for these families the issues of diversity suggested and supported the need for family-centered early interventionists to be prepared to address them individually regardless of their background.
CHAPTER 5
SUMMARY, DISCUSSION, REFLECTIONS, AND IMPLICATIONS

The purpose of this study was to extend the knowledge and construct an understanding of how select families (consumers), whose children were Part H eligible, defined family-centered early intervention services, based on their experiences with early intervention service providers. The study also focused on family diversities such as socioeconomic status, gender, locale, and ethnic background and how these might have influenced definitions of family-centered early intervention. Participant observation, interviews, and document analysis were employed to answer the following questions.

1. How do families themselves define a family-centered early intervention?
2. Do families from diverse locales, ethnic backgrounds, and socioeconomic status define family-centered early intervention differently?

This chapter has as its beginning a summary of the study's results that were reported in Chapter 4. This is followed by a discussion of these results as applied to the selected families and early interventionists who participated and selected previous research on family-centered early intervention. This discussion serves as the basis of the personal reflections and implications of the study for early interventionists and trainers of early
interventionists. Finally, suggestions for future research are made.

Summary

Early childhood special educators have debated since the passage of PL 99-457 how family-centered early intervention should be defined and implemented. The research in Chapter 2 on parent and child interactions (Baumrind, 1983; Belsky, 1984; Silber, 1989), transactional development (Sameroff, 1975; Sameroff & Fiese, 1990), ecological theory of human development (Bronfenbrenner, 1979) and family systems theory (Krauss & Jacobs, 1990) all emphasized the need to consider and integrate the family and the contextual environment in order to understand and maximize a child's development through early intervention. The results of this study of selected families confirmed this approach.

The quantitative instruments developed and typically used to measure policies and procedures of an early intervention program have not provided the needed in-depth understanding of how individual families define family-centered early intervention. Early interventionists such as Louise and Marsha have struggled with what they should be doing with their families and how to find out what they want.

The results of this study of eight selected families had some similarities to the issues delineated in the review of the literature regarding family-centered practices (Dunst et al, 1991; McGonigle, Kaufmann, & Johnson, 1991). For
example the importance of looking at the uniqueness of each family, of allowing families to determine the nature of services and the level of their intensity, and of permitting families to decide on their level of involvement were confirmed as key issues to families as well as other issues identified in this study.

From the very simplest domain identified as kinds of equipment used in an early intervention session or the location of an early intervention session there was an inescapable message of families wanting to define the framework of their child's early intervention at varying levels. For some of these selected eight families it was even important to have a role in the decision making process relative to which toys were brought into their home. For example Mrs. Lotto's concern about possible germs on the toys brought by the early interventionist for Janie to play with or Mrs. Gordon's and Ms. Brown's distress when the early interventionist's brought toys that their children wanted to keep. Mrs. Cook wanted to have all of the early intervention services provided in her home to minimize the danger to Lisa's fragile health. Mr. Cramer had not wanted to be dependent on others for transporting his daughter to therapy. All of these issues illustrated the need for the family-centered early interventionist to understand the interdependence of child development, the family, and the contextual environment.
In the review of the literature in Chapter 2, it was discussed that the information gathered through sole use of quantitative survey instruments such as the Brass Tacks (McWilliam & Winton, 1991), FOCAS (Bailey, 1990), and The Family Report (McWilliam, 1991), provided families limited opportunities to tell their stories and needs. While the interview guide for this study was based on selected topics from FOCAS (Bailey, 1990) and The Family Report (McWilliam, 1991), it was modified from the fixed choices on those instruments to open-ended questions and statements as starting points for these families to tell their stories and concerns. The observations, field notes, transcripts of the interviews, and document analysis revealed the desire of these select eight families to be involved in both different and additional issues than those delineated on these instruments. They wanted to have control of key decisions, easily accessible services or transportation, a system sensitive to their needs, and effective family service coordinators. An in depth discussion of these findings included in this chapter also indicated the impact of locale, gender, ethnic, and socioeconomic diversities on these select families and the identified issues.

Discussion

The domains, taxonomies, and componential analyses described in Chapter 4 provided a picture of Part H early intervention as it existed in Acadia Parish for eight selected families. Within each of the domains, taxonomies,
and dimensions of contrast/componential analyses developed were issues related to the definition of family centered early intervention. The individuality of the participating families was reflected in the priority and understanding each ascribed to the issues. For three of the families selection of the equipment to be used was an area they wanted both input and control. The similarity in the desire for control crossed socioeconomic status, locale, and ethnic lines, while the reasons were different.

Mrs. Lotto's concerns were twofold. She was very concerned about the possibility of exposing Janie unnecessarily to the germs from the early interventionist's toys despite Marsha's reassurance that she disinfected between children's visits. She also seemed to see the use of toys other than Janie's as an indication that she lacked appropriate parenting skills and had not purchased the best toys. Mrs. Lotto was one of the urban, European American, and MSES parents.

The other two families who wanted control over the toys were Ms. Brown and Mrs. Gordon. Both families were African American and from rural areas, but Ms. Brown was LSES and Mrs. Gordon MSES. Both mothers found it frustrating to have unhappy children because of the toys Louise, the early interventionist, had brought into their homes temporarily. When I spoke to them about the issue only Ms. Brown had decided to talk to Louise about the situation. She just didn't want Albert to be so unhappy.
In both the Lotto and Brown situations, a family-centered early interventionist would need to attend to contextual issues of these families as called for in both the transactional theory of development and the ecological theory of human development. Also, the family-centered philosophy of enablement and empowerment as espoused by Dunst, et al. (1991) recommended enhancing families with skills based to their existing situation. Ms. Brown needed to learn how to work with Albert using the family's natural environment. In the follow-up discussions of interview transcripts, a part of my triangulation, Mrs. Gordon indicated she wished Louise would use Robert's own toys that, she like Mrs. Lotto, felt inadequate as a provider, but that she would not want to hurt Louise's feelings so she had not told her. Louise believed that the end result of child progress justified the means. Therefore, it was appropriate to bring in the most stimulating toys available.

In the domains, location of early intervention services, frequency/durations of services, and the types of early intervention services, families were unaware of their options. As their familiarity with me increased and the interviews progressed, it was apparent that they did not know they could have had more for their child. The system had told them what was available and where the services would be provided. Mr. Cramer indicated he would have liked to have had a play group for Missy, Mrs. Smith wanted a parent support group, and Mrs. Cook wanted all the services
for Lisa in the home. They didn't know these were all services, because of their need, they were entitled to have. The system seemed to be offering to them only what was convenient. There was no indication of these requests in the IFSP or progress notes despite the fact I had heard the families address these concerns to their early interventionist and in Mrs. Cook's case, to the FSC.

Dunst et al. (1991) wrote in their study about the importance of being sensitive to the overall family's needs particularly as it impacts the child and the necessity to plan programs that address these same concerns. Dunst et al. (1991) suggested in one situation helping a family to get a roof on their house along with providing an infant stimulation program as being family-centered.

Some families wanted the program to be strictly child focused and others wanted a family focus. But despite a preference for child focus by some families, the family's needs and issues were not isolated from the early intervention program. The principle of circular causality from the family systems theory prevented the isolation or exclusion.

The description of the early intervention activities domain portrayed vividly the diversity of family-centered early intervention programs. In this aspect both early interventionists practiced family-centeredness in their own unique ways. Louise was willing to take the time to tutor Mr. Gordon on basic math skills for his upcoming exam,
assist Mrs. Cook in writing a theme for an English class, and help Ms. Brown prepare a meal.

When Marsha's families expressed concern about an issue, she acknowledged it and addressed it as soon as possible. For example when Mr. Cramer felt the range of motion exercises were not adequately relaxing Missy's muscles, Marsha explored the option of water therapy and did research to find out how to do it and inquired as to whether she would be allowed to use it. (Range of motion exercises can be done only by a parent, licensed physical therapist, or licensed occupational therapist.) Ms. White was having difficulty getting into federal housing and Marsha helped her secure the necessary forms. Each early interventionist seemed to have her own limits on a definition of family-centered that varied with individual families.

The experiences during early intervention enrollment, current, and the transition time periods of these selected families, contained both similarities and differences across the locale, socioeconomic status, ethnic, and gender diversities. None of the eight families had escaped the early enrollment frustrations of endless questions and paperwork, frequent changes in family service coordinators, travel to Lafayette for all services, and slow initiation of services. None of these practices were viewed by the families as being supportive of family needs or family-centered. The lower SES families had the additional frustration of poor transportation services. Transportation
was not convenient and not reliable; another reminder to them of an area of their lives where they had no control.

The professional behaviors encountered by these select families were more differentiated than the enrollment experiences. The Brown, Regan/Johnson, White, and Cramer families (all low SES) had experienced professionals who had not listened to them, not answered their questions or had not included them in their program planning. The middle SES families had mixed experiences initially dependent on the professional. There were no patterns exhibited according to locale since all had to travel to an urban area or another urban area. The Gordons were the exception to the African American families' experiences with professionals. At certain locations they felt their treatment had been family-centered while other places they had felt it was negative. The therapists contracted to provide Part H services at rehabilitation centers were the least family-centered.

The initial frustrations with extended family members seemed to stem from a lack of understanding of the initial process, frequent turnover with FSC, and unintentional exclusion from significant early intervention activities as assessment and development of the IFSP. The frustration of these families indicated a need for professionals to invite or encourage parents to include members of their microsystem in the intervention sessions (Bronfenbrenner, 1979). This need was apparent to both low and middle SES families (Cramer and Cook) but only with families of Acadian,
European American backgrounds. This perhaps also reflects the emphasis on extended families in Acadian families, too.

While the domain of participants in early intervention sessions indicated a variety of people, for these two families that possibility had not addressed their problems with extended family members. Mr. Cramer and Mrs. Cook wished the early interventionist had encouraged and given more support to including extended family members at the beginning of their children's participation.

The early intervention program as it was implemented during the study, continued to present frustrations for some of the families in the same areas that existed during the enrollment period. However, these frustrations were now interspersed with satisfaction. Transportation and the location of related services such as physical therapy, occupational therapy, and speech therapy continued to be difficult for all the low SES and rural families.

Mrs. Cook, who lived in the rural area, was the exception among the MSES families as she too continued to experience frustrations regarding the location of approved services for Lisa and travel demands made on her. None of these families had felt their children should be penalized because of where they lived or their socioeconomic status.

All eight of the families were frustrated that they continued to have to advocate for the maintenance of services that in their opinion were obvious their child still needed. The only patterns noted from the observations
and interviews were that middle SES mothers, Mrs. Smith and Mrs. Cook particularly, seemed to pursue the battles for their child more adamantly and with greater endurance than the two fathers, Mr. Cramer and Mr. Gordon, who were low and middle SES respectively. The advocacy pattern was equally strong across the locale differences of rural and urban.

The ongoing frustrations of these families were now balanced with increased knowledge, positive feelings about their child's progress, and experiences with supportive, caring professionals. While none would have described their early intervention as perfect, they seemed to see the positive as out weighing the negative. For the middle SES families, Cook, Gordon, Lotto, and Smith along with Mr. Cramer, low SES, the increase in their knowledge/enablement (Dunst et al., 1991) was a stimulus to increased decision making and control—empowerment. While the Whites, Regan/Johnson, and Brown families had similar positive experiences they were less directly involved in the activities. Despite increased knowledge bases these families accepted the program as it was given.

The Brown, Cramer, Gordon, Smith, and Regan/Johnson families experienced transition into the 3-5 year old phase of early intervention programming. Only the experiences of the Cramers and Smiths were positive, reassuring, and supportive—family centered. They had been provided opportunities to ask questions, visit the proposed sites, and participate in the process. All of the families wanted
to know where their children would go next after early intervention, about the services available, and their role.

While the law (IDEA) stated the transition experience should be coordinated by the FSC with assistance from the early interventionists, the families had not experienced this phenomena. The Gordon, Brown, and Regan/Johnson families had only minimal assistance from their early interventionist and none from the FSC. They were frustrated that their child’s future educational plans were so vague.

How a family defined family-centered early intervention seemed to be built most upon their perceptions and relations to the FSC and to the early interventionist. As indicated in the discussion there were individual family exceptions across all of the dimensions of diversity in describing the role of the FSC. All of the African American families and three of the four rural and low SES families had very limited understanding of the FSC responsibilities and reported little support from this person. The LSES families and the three African American families were neither sure who this person was or what they should be doing to help. Only two families, the Cooks and the Smiths, gave the FSC positive marks from the beginning to the end of this study.

A family-centered FSC was someone who was friendly, respected family preferences and decisions, helpful, supportive, contacted family frequently, consistent and dependable, accessible, knowledgeable, and cared about the whole family. The negative comments suggested that the FSC
should also be a good listener and sensitive. The extensive negative experiences of these select families seemed to suggest that FSC were neither following the definition included in Chapter 1 or practicing the attributes desired by families.

The selected families' perceptions and relationships to their early interventionist added another dimension to the definition of family-centered. These families preferred a communicative style that was open-ended with suggestions made for parental roles in working with their child. The early interventionists that were observed, permitted their parents to engage in many different roles from active involvement to activities totally unrelated to the early intervention session. Marsha was observed more often attempting to pull her families into the session, yet she used the most open-ended style of communication.

Families described the characteristics of their early interventionists that were family-centered as patient, encouraging, supportive, good listening, cares about whole family needs, flexible, respectful, empowering, not pushy, and willing to teach. Because only two early interventionists were involved in this study the comparison of individual families reactions were limited and unique.

The African American families were served only by Louise. Louise was described by her families as pushy, used too many closed questions and statements, engaged in too much conversation and not enough listening, and her
suggestions were viewed as almost commands. Her use of this style was not unique to just the African American or low SES, families. She also used it with the Cooks, and they disliked the style too. In the case of the Cook and Regan/Johnson families, they also wanted an early interventionist who was more knowledgeable of their child's needs. Neither Mrs. Cook nor Mrs. Johnson were convinced that Louise had any idea of what to do with their child.

Despite these negative aspects and the absence of differences in patterns between LSES and MSES families or across ethnic backgrounds, Louise was well liked by her families. She was willing to do the extras to help the overall family. Families appreciated her willingness to address total family needs and to try to help even when she was not sure what to do.

While Marsha focused more on the child during her visits she always communicated to her families she was there for them. This understanding was apparent as they seemed to readily share information and to discuss real concerns without coaxing with Marsha. Marsha seemed to have some difficulty emulating the open ended style of communication and allowing for parent direction in the early intervention process with Ms. White, a LSES parent.

However, with Mr. Cramer another low SES parent, she was able to allow the parent control. Perhaps this difference was due to gender, but I tend to think it was because of Ms. White's youth. Marsha told me she had a
daughter who was Mrs. White's age and did not see that age as capable of effective parenting. Marsha was criticized by Mr. Cramer as having told him only part of the story or facts in their initial relationship but later in the interview he complimented her for extraordinary patience and willingness to make sure parents knew how to work with their child.

Both early interventionists and their style of interactions were accepted equally well with mothers as well as fathers. I was unable to compare rural versus urban as the families selected in the rural areas were all assigned to Louise and the urban all to Marsha.

Finally, these eight selected families made specific suggestions to make Part H early intervention service more family-centered. All of the families wanted more visits and longer visits. With the Regan/Johnson family and Lotto families it is hard to imagine that they would have participated more with an increase in frequency or duration.

The rural families, Brown, Regan/Johnson, Gordon, Cramer, and Cook all wanted the location of the services changed to either a closer facility or in their homes. It was difficult for Mrs. Cook to understand why she was made to travel to Lafayette and Opelousas for related services of physical, occupational, and speech therapies while Mrs. Smith received all of these services in her home. The two families were served by different early interventionists but
the differences in the services seemed to lie in the location (rural versus urban) and the FSC.

Mrs. Smith and Mr. Cramer were the only two parents who voiced the desire for additional services. From my observations there were many more services the children and their families could have benefitted from, but the families didn't know they could ask. For example Ms. Brown's concern about Albert's diet could have been addressed through nutritional counseling.

An additional issue of change was the structure or format of the early intervention service sessions. The families wanted the early interventionists to be flexible enough in their lesson plan for a given day to interrupt the flow of activities to make sure the parent understood how to teach a concept or to address a more immediate concern. The early intervention session needed to include more time for sharing of information regarding the child's status, progression, and other services that might be helpful. These eight families could not think of any situation where the early interventionists or therapists suggestions should not be presented as options or choices rather than mandates.

While the families viewed the early interventionist as an expert they saw themselves as the most knowledgeable person regarding their child. This difference reflects the importance of establishing common goals and objectives suggested by Bailey (1987) and avoiding conflict due to different agendas. The discussion of these domains,
taxonomies, and contrasts suggest additional reflections and implications for early intervention.

Reflections and Implications

These eight families expected the early interventionists to model family-centered behavior in their interactions with all family members and in their methods of teaching and working with the child. During this study the families' definitions of family-centered early intervention expanded and diversified as their experiences with the program increased.

This study demonstrated that early interventionists' values and conceptions of what they should do for a child and family can conflict with the family's values or needs at that point in time. Families seem to be saying they want to set both the content and the pace of the early intervention program for their child based on their perceptions and knowledge of the situation. The early interventionist should be prepared to provide parents support and an opportunity to understand and cope with their child's disability.

Within the support system parents may need early interventionists to assist them in building an objective information base to support their decision making and goal selection processes; that is to enable and empower, (Dunst et al, 1991). Professional values as Louise's insistence that both Albert Brown and Robert Gordon give up their bottles should not be imposed in a family-centered early
intervention program. Family values and preferences need to be the driving force in planning early intervention.

Another implication of this study is the need for early interventionists to gain a comprehensive understanding of the family's and child's strengths and needs. This can be gained through listening attentively and skillfully along with synthesis and reflective statements to families that convey warmth and respect. Nonjudgmental observations balanced with information gathering from both experts outside the family and within the family are a necessity in early intervention.

Early interventionists must value the family's expertise and view intervention as a shared process. This study also suggests that for each family an early interventionist and FSC will need to collaborate with the parents to problem solve and to find their family-centered balance of time and focus. Areas of time concern might be the child as a focus versus sharing information and skills with the parents, or listening and learning from the parents versus assessment and diagnostic teaching. The focus may also vary from child priorities in cognitive, affective, or motor areas versus family needs for housing or some other function.

An early interventionist's individual personality and experiences impact his or her interaction style with families similar to the influences of the microsystem within the ecological theory of human development (Bronfenbrenner,
1979, 1986). However, this study of these eight families seems to suggest it is critical that an early interventionist be confident and comfortable in modifying that style in order to be family-centered.

Marsha and Louise each had characteristics their families viewed as family-centered, but the families also described things they did not like. There was very little difference in Louise's styles between families, while Marsha exhibited subtle differences that addressed the needs of her less diverse families. To be family-centered calls for the early interventionist to be so sensitive to a family's needs and values that they can change from one home to the next incorporating whatever style is needed.

Each of these eight families had diversities in ethnic backgrounds which when they were combined with their locale and socioeconomic status made their definition of family-centered early intervention equally unique. Families must be recognized as the primary resources and decision makers for their child. Family-centered early intervention decisions must be based on a family's preferences, choices, and values and not on administrative expediencies.

This study also supported the need to facilitate programs that permit low SES families to have more control over their children's lives and services. The bureaucratic maze of complexities that parents encounter in trying to arrange for transportation, therapy, and intervention must be simplified if not eliminated. The process these families
experienced does not reflect the family-centered philosophy for these eight families.

Families, who live in rural areas, according to this study would also need assistance from the system to make services more accessible. The challenges of parenting a child with disabilities are great enough without adding the absence of needed services or having to travel great distances to use approved services.

For six of these eight families the concept of service coordination let alone family-centered was almost a nonentity. The one person who should have pulled the program together for them and addressed their frustrations and concerns (FSC) was either not available or knowledgeable or both. Collectively these families wanted information about how to obtain appropriate infant stimulation, therapy, parent training, home health, respite services, family and social support, financial assistance, and more. They wanted intervention to increase their own abilities to cope with parenting a handicapped child.

To both Marsha and Louise's credit they tried to pick up the deficiencies of poor or nonexistent service coordination. Both had been through the 60 hour training program and had at one time been a FSC. It was no longer legal for them to function in this capacity for their families as it was considered a conflict of interests. This study suggested that the family service coordinators were inadequately trained in these family areas of concern and in
how to facilitate a collaborative relationship between a family's early intervention service providers.

Perhaps the early interventionist and family would be better served by the system if the family and early interventionist were allowed to be co-family service coordinators (assuming that was the family preference). As the system existed during this study, these families wanted changes in the training and service provided by the FSC to make this person more family-centered. The latter concept suggests one area for future research.

**Suggestions for Future Research**

1. The stories related by these eight families suggested that research is needed on the role and training of family service coordinators. One specific question might be what kind of training both in content and format do these people need in child development, early intervention, and working with families to emulate the family-centered philosophy?

2. Additionally, the concerns expressed by the families within this study suggested that the content and format of early interventionists training should also be examined. Are topics as communication skills, sensitivity and respect for family diversities and preferences, collaboration with parents on goal setting and program planning and related areas focusing on the family-centered dimension addressed in teacher preparation programs? Are future interventionists
equipped with family-centered skills to effectively interact with them and ascertain their priorities?

3. In addressing the needs of low SES families whose children have disabilities, the research question might be: "Are there more effective ways of providing services that would be enabling and empowering experiences for them?"

4. The experiences of the families in this study with other professional service providers such as home health, physical therapy, occupational therapy, and speech therapy suggested that research was needed in how these professionals might be trained and encouraged to use a family-centered approach.

5. Qualitative research should extend opportunities for these eight families and others to continue to tell in their own words how they define family-centered early intervention to enhance the training and understanding of both FSC and early interventionists.
REFERENCES


187


Appendix A
from
State of Louisiana - Childnet MDE Interagency Training Handbook

Step 1 Enter family with child and concern

Step 2 Referral to local Child Search Coordinator
(Referral may be made by parent, physician, health unit, hospital, and other agencies)

Step 3 Multidisciplinary Process (45 calendar day limit)
   a. Developmental assessment to include vision, hearing, speech, motor, cognitive, self help, and social skills
   b. Planning by family and professionals to include review of information, discuss concerns, options, and family service coordination
   c. Review medical history and current health status
   d. Determine eligibility

Step 4 Summarize child and family's strengths, needs, and service needs

Step 5 Family, professionals, and family service coordinator develop IFSP

Step 6 Services initiated for child and family according to IFSP
APPENDIX B

LOUISIANA INDIVIDUALIZED FAMILY SERVICE PLAN
# INDIVIDUAL FAMILY SERVICE PLAN

**FOR**

**CHILD'S NAME:**

<table>
<thead>
<tr>
<th>I. GENERAL INFORMATION</th>
<th>II. FAMILY MEMBERS &amp; SUPPORT PERSONS</th>
<th>RELATIONSHIP TO CHILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ID #:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent(s):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phone #:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misc:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>III. PHYSICAL DEVELOPMENT:</th>
<th>IV. EVALUATION INFORMATION:</th>
<th>V. CHILD'S STRENGTHS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>Evaluation Date:</td>
<td>Motor</td>
</tr>
<tr>
<td></td>
<td>Test Used</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Completed By</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cognitive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social/Emotional</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Adaptive</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>VI. FAMILY'S IDENTIFIED RESOURCES*</th>
<th>VII. FAMILY'S IDENTIFIED PRIORITIES AND CONCERNS*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Information must be redacted as part of family, and may only be written with family's permission.
IX. IFSP CHILDNET SERVICES FOR

<table>
<thead>
<tr>
<th>CHILD'S NAME</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>FAMILY SERVICE COORDINATOR</th>
<th>AGENCY</th>
<th>PHONE #</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>X. CHILDNET SERVICES FAMILY FEEL ARE NECESSARY TO MEET NEEDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHILD/CHILDREN</td>
</tr>
<tr>
<td>----------------</td>
</tr>
<tr>
<td></td>
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<td></td>
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<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>OTHER RELEVANT SERVICES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>XI. FAMILY SIGNATURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have been an active participant in developing the IFSP. I understand and agree with all that pertains to these services. I understand that I may change the plan at any time.</td>
</tr>
<tr>
<td>SIGNATURE</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>XI. MEETING PARTICIPANTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The following individuals participated in developing the IFSP. Each person understands and agrees to carry out the plan or to apply to these roles in providing services.</td>
</tr>
<tr>
<td>SIGNATURE</td>
</tr>
<tr>
<td>-----------</td>
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<td></td>
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</tbody>
</table>

*Services will be provided in natural environments in which children without special needs would participate.*
VIII. IFSP CHILD/FAMILY GOAL SHEET FOR

<table>
<thead>
<tr>
<th>CHILD/FAMILY NEEDS</th>
<th>DESIRED OUTCOMES FOR CHILD</th>
<th>FAMILY RESOURCES</th>
<th>COURSE OF ACTION / MODIFICATIONS</th>
<th>FAMILY'S EVALUATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Adapted From: Family Evaluation (From the Family Support By Donna, Howard, and Ron)
PARENTAL RIGHTS
under the
CHILDNET INFANT AND TODDLER SYSTEM

1. To a timely, comprehensive, multidisciplinary evaluation;
   (This process from date of referral to completion of the multidisciplinary
evaluation and development of the Individualized Family Service Plan will
take no longer than 45 calendar days.)

2. To appropriate early intervention services for their child and family, if eligible;

3. To refuse evaluations, assessments, and services;

4. To receive notice before a change is made or refused in the identification,
evaluation, or in the provision of services to their child or family;

5. To confidentiality of personally identifiable information regarding their child
and family;

6. To examine and correct records regarding their child and family;

7. To attend and participate in all IFSP meetings;

8. To have an advocate assist them in any and all dealings with the early intervention system, and

9. To utilize administrative and judicial processes to resolve complaints.

________________________________________  ____________________________
SIGNATURE  DATE RECEIVED
APPENDIX C

LOUISIANA MULTIDISCIPLINARY EVALUATION FORM
# ELIGIBILITY SUMMARY REPORT

## CHILDREN INFANT and TODDLER SYSTEM

### SECTION A: IDENTIFYING INFORMATION

<table>
<thead>
<tr>
<th>Name:</th>
<th>Date of Dismissal:</th>
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<tbody>
<tr>
<td></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>ID:</th>
<th>Social Security No.</th>
<th>Medicaid No.</th>
<th>Telephone:</th>
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<td></td>
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</table>

<table>
<thead>
<tr>
<th>Date of Birth:</th>
<th>Race:</th>
<th>Sex:</th>
<th>Date of Referral:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent/Guardian:</th>
<th>Address:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### SECTION B: ELIGIBILITY INFORMATION

#### Criteria A: Established Medical Condition

<table>
<thead>
<tr>
<th>Condition</th>
<th>Score</th>
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</thead>
<tbody>
<tr>
<td>Cerebral Palsy</td>
<td>0</td>
</tr>
<tr>
<td>Other Neurological Disorders</td>
<td>1</td>
</tr>
<tr>
<td>Sensory Impairment</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
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</table>

#### Criteria B: Biological Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congenital Heart Defects</td>
<td>0</td>
</tr>
<tr>
<td>Other Congenital Anomalies</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
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</tbody>
</table>

#### Criteria C: Developmental Delay

<table>
<thead>
<tr>
<th>Developmental Area</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive/Emotional</td>
<td>0</td>
</tr>
<tr>
<td>Sensory Motor</td>
<td>1</td>
</tr>
<tr>
<td>Physical Health</td>
<td>2</td>
</tr>
</tbody>
</table>

### PHYSICAL HEALTH STATUS

- Vision: ___ Poor ___ At Risk
- Hearing: ___ Poor ___ At Risk
- Developmental Delays: ___ Very Good ___ Good ___ Fair ___ Poor

### Comments:

- Arial Font

---

<table>
<thead>
<tr>
<th>Developmental Areas</th>
<th>Date</th>
<th>Chrona Age</th>
<th>Instrument</th>
<th>Developmental Areas</th>
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<tbody>
<tr>
<td></td>
<td></td>
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</tbody>
</table>

---

*Add written additional medical information as needed

** Instrument may include HELP, GAP, Spinal Cord, etc.
SECTION C: IDENTIFIED CHILD AND FAMILY INFORMATION

Child's STRENGTHS:

__________________________

__________________________

__________________________

Child's NEEDS:

__________________________

__________________________

__________________________

Family's RESOURCES as related to enhancing their child's development (Voluntary):

__________________________

__________________________

__________________________

Family's CONCERNS and PRIORITIES as related to enhancing their child's development (Voluntary):

__________________________

__________________________

__________________________

I AGREE with the identified child and family information: Yes ___ No ___ Parental Initial ___

SECTION D: ELIGIBILITY DETERMINATION

Section: not eligible for services under the ChildNet system ___

SECTION E: RECOMMENDATIONS/CONSIDERATIONS FOR IFSP

- Early Intervention Services
- Assessment Followup
- Assistance with eligibility for financial assistance
- Day Care
- Family Education Support Group
- Family Counseling
- Home-Baby Sitting
- Transportation
- Medical Followup
  - Physical
  - Neurological
  - Orthopedic
  - Other
- Vision
- Hearing
- Communication
- Other
- Community Referrals
- Kid's Health Screening - Health Unit

SECTION F: PARTICIPANTS

Parent/Guardian ___ Name/Title/Agency ___

Name/Title/Agency ___

Name/Title/Agency ___

Name/Title/Agency ___

Coordination: Early Intervention Coordinator ___ 

Family Service Coordinator ___ 

Parent ___
APPENDIX D

Sample open-ended interview format for families

Demographic information to be gathered through observation, interview, and IFSP

1. Child's age and disability
2. Family structural membership
3. Geographic location of family
4. Ethnic background of family
5. Socioeconomic status of family
6. Parent's educational background
7. Length of time participated in early intervention program

Current program practices and experiences

1. Tell me about your child's program now. If further prompting needed+what is your child working on now (goals)? What are the services your child currently receives?
2. What do you think of your child's current program?
3. Is there anything you wish you could change? How would you change it?
4. How does the early interventionist determine if you think the program is the best/appropriate for your child?
5. What is your role in your child's program when the early interventionist is in your home and when he or she is not here?
6. Are other members of your family working with the early interventionist? If yes, who?

7. Who else helps you with your child?

8. How do they help?

Experiences entering the early intervention program

1. Tell me about your first experiences with your family service coordinator.

2. What kinds of things did your family service coordinator tell you or do for you?

3. How did you feel about what he or she did for you or the family?

4. When your child was first enrolled in the early intervention program what happened?

5. What kinds of questions did the interventionist ask you?

6. How did you feel about sharing the information requested?

7. What did the early interventionist tell you about your child?

8. What did the early interventionist tell you about the program services?

9. What did the early interventionist tell you about other available resources?

10. Could you reconstruct for me the choices and opportunities for decisions you were given during those first days?
11. If you had an opportunity to tell future early interventionists what to do or not do during the first visits, what would you tell them?

Assessment
1. Tell me about your child's initial evaluation.
2. What areas of your child's development did you think should be evaluated?
3. Were your areas of concern assessed?
4. What did the early interventionist do to include your input in the assessment process?
5. What information did you provide for your child's evaluation?
6. How did you feel about the process of assessment?
7. What were your relations to the results?
8. Is there any part of your assessment process experiences you would change?

Developing the IFSP
1. When you first began planning your child's program with the family service coordinator and/or the early interventionist, what were your experiences?
2. What were the goals?
3. What was your part in the planning process?
4. What was your role in the program implementation?
5. What have been your experiences with the related services staff as physical therapist, occupational
therapist, speech therapist, nurse, or audiologist in the planning process?

Questions selected from items contained in The Family Report by P. J. McWilliam and FOCAS: Family Orientation of Community and Agency Services by Don Bailey. Both authors give permission to persons interested in using part or all of the scales for research or evaluation as long as the source is recognized.
APPENDIX E

SAMPLE PROGRESS NOTES, PROGRESS REPORTS, AND INDIVIDUALIZED FAMILY SERVICE PLANS

209
ACADIA PARISH SCHOOL BOARD

EETH FOR INTERVENTION: HOME: □ CENTER: □ OTHER: □

PLANNED DATE OF INTERVENTION: 10/10/94

DATE TIME IN TIME OUT PARENT SIGNATURE
10/10/94 10:00 11:00 □

ESPERED OUTCOME FOR CHILD/FAMILY (IFSP GOAL): To hold kittens with an activity and increase attention.

ACTIVITY/MATERIALS: Explained to parent - exposed expat. gave opp. to discuss development and keep copy of HTP checklist

PROGRESS NOTES: She was very active in the activity. She held the kittens well. She was interested in the activity. She didn't seem interested in the activity. She held the kittens well. She didn't seem interested in the activity.

EQUIPMENT/MATERIALS (LEFT RETURNED):

PARENT CONCERNS:

HEALTH/MEDICAL INFORMATION:

PLANNING NOTES FOR NEXT VISIT: She needs to work on keeping attention at work and doing for short periods of time.

UNABLE TO COMPLETE PLAN: 1ST TRY □ □ 2ND TRY □ □

REASON: Parent did not keep appointment
Teacher attending meeting
Parent/Child/Teacher ill
Emergency school closure
ACADIA PARISH SCHOOL BOARD
PARENT/TODDLER EARLY INTERVENTION PROGRAM

CHILD'S NAME: _______ INTERVENTIONIST: _______

SETTING FOR INTERVENTION: SOME CENTER OTHER: Paul Enaux

PLANNED DATE OF INTERVENTION: 11/13/94 TIME: 7:45

DATE TIME IN TIME OUT PARENT'S SIGNATURE

11/13/94 7:45 8:20

DESIRED OUTCOME FOR CHILD/FAMILY (IFSP GOAL): To develop important

and communication skills in combination with overall

vocabulary. Read in a consistent

ACTIVITY/MATERIALS: Paul Enaux using materials with pictures

20 story books 

spider web 

progress notes:

In story time she looked at her hand

and asked question. She played with 

20 story books. She couldn't

read would hold book with finger moved

read

EQUIPMENT/MATERIALS (LEFT RETURNED):

PARENT CONCERNS:

Parent reported that

TV in correct position. She can read finger game

HEALTH/MEDICAL INFORMATION: No

Pediatrician's comments: good

From infection. General Well Being: Slightly improved

PLANNING NOTES FOR NEXT VISIT:

UNABLE TO COMPLETE PLAN: LET TRY ____/____ IF TRY ____/____

REASON: Parent did not keep appointment Parent/Child/Teacher ill

Teacher attending meeting Emergency school closure

Other:

211
### INFANT/TODDLER EARLY INTERVENTION PROGRAM

<table>
<thead>
<tr>
<th>CHILD'S NAME</th>
<th>INTERVENTIONIST</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SETTING FOR INTERVENTION:** HOME ✓, CENTER, OTHER  

**PLANNED DATE OF INTERVENTION:** 12/13/94  
**TIME:** 10:30

<table>
<thead>
<tr>
<th>DATE</th>
<th>TIME IN</th>
<th>TIME OUT</th>
<th>PARENT SIGNATURE</th>
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</thead>
<tbody>
<tr>
<td>12-13-94</td>
<td>10:50</td>
<td>12:30</td>
<td></td>
</tr>
</tbody>
</table>

---

**DESIRED OUTCOME FOR CHILD/FAMILY (IFSP GOAL &:** to ___________

Language and communication skills and maintain development given in all areas.

**ACTIVITY/MATERIALS:** Work with monkey's and colors.

Will have meetings by the teams will work smaller to draw on paper.

**Instructor HIPE checklist:**

**PROGRESS NOTES:** Went color testing. She did well.  
To add marks. She was very interested in colors. She would often slide out and put Hum-Bird in basket. She would scold on upder.

**BANDOUTS:**

**EQUIPMENT/MATERIALS (LEFT RETURNED):**

---

**PARENT CONCERNS:**

**HEALTH/MEDICAL INFORMATION:**

**PLANNING NOTES FOR NEXT VISIT:**

---

**UNABLE TO COMPLETE PLAN:** 1ST TRY _/_ / 2ND TRY _/_ /

**REASON:** Parent did not keep appointment  
Parent/Child/Teacher ill  
Teacher attending meeting  
Emergency school closure

**NEXT SCHEDULED VISIT:** DATE: 12-19-94  
TIME: 10:00
RECOMMENDATIONS FOR INDIVIDUAL FAMILY SERVICE PLAN UPDATE

1. Continue to participate in special instruction program sessions for 30 minutes 2 times per month.

2. Continue / obtain intervention services in the areas of:
   - Speech Pathology
   - Physical Therapy
   - Occupational Therapy
   - Other:

3. Refine and/or increase skills in the areas of:
   - Cognition:
   - Language: Consult with speech pathologist to implement some type of communication captain
   - Gross Motor:
   - Fine Motor:
   - Social/Emotional:
   - Self-Help: Mealtime, self-feed, self-groom

Acadia Parish Infant/Toddler Early Interventionist

Family feels that is very frustrated because she cannot communicate. She also
wants to bond, sharing when they don't understand
her actions. FSC and mom are trying to opt for
speech Path in home.
<table>
<thead>
<tr>
<th>DEVELOPMENTAL LEVELS</th>
<th>D.O.B.</th>
<th>AGE</th>
<th>DATE OF REPORT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitve Skills</td>
<td>1/1/91</td>
<td>18</td>
<td>10/10/91</td>
</tr>
<tr>
<td>Language Skills</td>
<td>1/1/91</td>
<td>18</td>
<td>10/10/91</td>
</tr>
<tr>
<td>Motor Skills</td>
<td>1/1/91</td>
<td>18</td>
<td>10/10/91</td>
</tr>
<tr>
<td>Social Emotional Skills</td>
<td>1/1/91</td>
<td>18</td>
<td>10/10/91</td>
</tr>
</tbody>
</table>

**INTERVENTIONIST:**

**ELIGIBILITY CRITERIA:**

- Cognitve Skills: 18 months.
- Language Skills: 18 months.
- Motor Skills: 18 months.
- Social Emotional Skills: 18 months.

**NOTES:**

- The child is making progress in all areas.
- The child needs additional support in motor skills.
- The child is showing improvements in language skills.
- The child's social emotional skills need further development.

**RECOMMENDATIONS:**

- Continue with existing interventions.
- Increase frequency of therapy sessions.
- Monitor progress closely.

**NEXT MEETING DATE:**

- 11/1/91

**DISCHARGE DATE:**

- 12/1/91
ACADIA PARISH SCHOOL BOARD
INFANT/TODDLER EARLY INTERVENTION PROGRAM
PROGRESS REPORT

INTERVENTIONIST
DATE OF REPORT: 1/13/94

ELIGIBILITY CRITERIA:

DEVELOPMENTAL LEVELS ARE APPROXIMATE AND BASED ON OBSERVATIONS USING THE P.E. I.P.

COGNITIVE SKILLS - 19 MONTHS: On Target

LANGUAGE SKILLS - 9 MONTHS: 

CROSS MOTOR SKILLS - 19 MONTHS: On Target

FINE MOTOR SKILLS - 19 MONTHS: On Target

SOCIAL/EMOTIONAL SKILLS - 19 MONTHS: On Target

SELF-HELP SKILLS - 17 MONTHS: 


## INDIVIDUAL FAMILY SERVICE FORM

### CHILD'S NAME

<table>
<thead>
<tr>
<th>Date: 8-9-94</th>
</tr>
</thead>
</table>

### I. GENERAL INFORMATION

<table>
<thead>
<tr>
<th>Date of Birth:</th>
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<tbody>
<tr>
<td>IID:</td>
<td></td>
</tr>
<tr>
<td>Oldest:</td>
<td></td>
</tr>
<tr>
<td>Parent(s):</td>
<td></td>
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<tr>
<td>Address:</td>
<td></td>
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<tr>
<td>Phone:</td>
<td></td>
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### II. FAMILY MEMBERS & SUPPORT PERSONS

<table>
<thead>
<tr>
<th>Relation to Child:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent:</td>
</tr>
<tr>
<td>Sister:</td>
</tr>
<tr>
<td>Grandparent:</td>
</tr>
<tr>
<td>Godmother:</td>
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### III. PHYSICAL DEVELOPMENT

<table>
<thead>
<tr>
<th>Vision: Paral</th>
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</thead>
<tbody>
<tr>
<td>Hearing: Poor</td>
</tr>
<tr>
<td>Health Status: Good</td>
</tr>
<tr>
<td>In spite of acting reflex</td>
</tr>
<tr>
<td>Tendency to getaggravly</td>
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</table>

### IV. EVALUATION INFORMATION

<table>
<thead>
<tr>
<th>Date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Evaluated by:</td>
</tr>
<tr>
<td>Notes:</td>
</tr>
<tr>
<td>Cognitive Development:</td>
</tr>
<tr>
<td>Social/Emotional:</td>
</tr>
<tr>
<td>Communication:</td>
</tr>
<tr>
<td>Adoptive:</td>
</tr>
</tbody>
</table>

### V. CHILD'S STRENGTHS

- Determined, strong
- A leader, curious
- Active, is smiling

### VI. FAMILY RESOURCES

- Strong family support, loving family
- Two parent family
- W 1

<table>
<thead>
<tr>
<th>Transportation</th>
</tr>
</thead>
</table>

### VII. FAMILY PRIORITIES

- Weight gain - so often have trouble
- Need repair: stroller, buggy
<table>
<thead>
<tr>
<th>Date</th>
<th>Objective</th>
<th>Action</th>
<th>Monitoring</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>8/1997</td>
<td>A. Will continue to use Early Education Services from a PSO in order to learn augmentative and alternative communication (AAC) until she has the language for vocal and signing.</td>
<td>intermittent</td>
<td>will work with on activities and methods suggested by Intervention.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>B. Will continue to have home health nursing services 3 times per week, 20 hours per week in order to give family assistance and despite in meeting her medical needs.</td>
<td>J &amp; E</td>
<td>will continue to use. Complete Home Health Nursing Service.</td>
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<td></td>
<td>C. Will continue to work on Vocal Chords.</td>
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### VIII. IFSP CHILD/FAMILY GOAL SHEET FOR

<table>
<thead>
<tr>
<th>CHILD/FAMILY NEEDS</th>
<th>DESIRED OUTCOMES FOR CHILD</th>
<th>FAMILY RESOURCES</th>
<th>COURSE OF ACTION / MODIFICATIONS</th>
<th>FAMILY'S EVALUATION</th>
</tr>
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<tbody>
<tr>
<td>5/9/01</td>
<td>To be able to communicate w/family</td>
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**Adapted From:** Family Evaluation (From the Family Support, R. House, Tribor, and Dela)

1. No change or need
2. Sustained unchanged, still a need
3. Implementations begun, still a need
4. Partially Accomplished
5. Accomplished
6. Modifications needed

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219
<table>
<thead>
<tr>
<th>CHILD/FAMILY NEEDS</th>
<th>DESIRED OUTCOMES FOR CHILD/FAMILY</th>
<th>RESOURCES PERSON RESPONSIBLE</th>
<th>COURSE OF ACTION / TIMELINE</th>
<th>FAMILY'S EVALUATION</th>
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<tbody>
<tr>
<td>Depression</td>
<td>Increase overall language skill to a more age-appropriate level</td>
<td>Family, Intervention</td>
<td>1) HELP activities</td>
<td>8-1-94</td>
</tr>
<tr>
<td></td>
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<td></td>
<td>2) Oral Language Development</td>
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<td></td>
<td>3) Sequence of Public move and words</td>
<td></td>
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<tr>
<td>Cognition</td>
<td>Increase overall cognitive levels to their age-appropriate peers</td>
<td>Family, Intervention</td>
<td>1) These HELP activities</td>
<td>8-1-94</td>
</tr>
<tr>
<td>12-15 mos</td>
<td></td>
<td></td>
<td>2) Play therapy for labeling skills of common objects</td>
<td></td>
</tr>
<tr>
<td>Motor Skills</td>
<td>Increase fine- and gross motor development to their age-appropriate level</td>
<td>Family, Intervention</td>
<td>1) Give exercises that will help the child learn to walk</td>
<td>8-1-94</td>
</tr>
<tr>
<td>1-2 yrs</td>
<td></td>
<td></td>
<td>2) Provide activities to increase expressive language from 1 word to multifold 2-3 word sentences</td>
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</tbody>
</table>
APPENDIX F

SPECIAL EDUCATION DIRECTORS LETTERS OF CONSENT
Dear Ms. Wadsworth:

This letter is in reply to your request for approval from the Acadia Parish School System to collect research data for your dissertation within the Early Intervention Program.

Authorization to conduct this study is granted with the following stipulations:

1. The early interventionists identified agree to participate.

2. Written permission is granted by the families and early interventionists to participate in the study.

3. The information obtained from the families will be anonymous and will remain confidential.

4. Acadia Parish Special Education Program will receive a copy of the completed study.

5. Acadia Parish Infant Interventionists, Pam Vidrine and Gail Bourque, will receive three hours of academic credit for an independent study in Early Childhood Special Education Methodology and program planning.

This authorization is based on the information that you submitted to this office in your abstract and letter. Should you deviate from the project proposal, please inform our office.

Should you have questions or need further assistance, please call this office.

Sincerely,

Michael B. LeBlanc
Director of Special Education
Donna E. Ougger Wadsworth  
University of Southwestern Louisiana  
Department of Curriculum and Instruction  
USL Box 42031  
Lafayette, Louisiana 70504  

Dear Ms. Wadsworth:

This letter is in reply to your request for approval from the Vermilion Parish School System to collect research data for your dissertation within the Early Intervention Program.

Authorization to conduct the study is granted with the following stipulations:

1. The early interventionists identified agree to participate.

2. Written permission is granted by the families and early interventionists to participate in the study.

3. The information obtained from the families will be anonymous and will remain confidential.

4. Vermilion Parish Special Education Program will receive a copy of the completed study.

This authorization is based on the information that you submitted to this office in your abstract and letter. Should you deviate from the project proposal, please inform our office.

Should you have questions or need further assistance, please do not hesitate to call.

Sincerely,

[Signature]

Early Care Coordinating Supervisor  
Special Education  
Vermilion Parish Schools
APPENDIX G

LETTER OF INQUIRY TO SPECIAL EDUCATION DIRECTORS
Mr. Larry Gage, Coordinating Supervisor  
Special Education  
Vermilion Parish Schools  
220 S. Jefferson St.  
P.O. Drawer 520  
Abbeville, LA 70511-0520  

Dear Larry:

Thank you again for your willingness to allow me to do my dissertation research within Vermilion Parish's early intervention program. As I indicated in our phone conversation the early interventionists responsibilities for the study will be limited. First, they will need to select two to four families from their respective caseloads who have been enrolled in the program at least six months and are willing to participate in the study. Second, they will need to allow me to observe during their home visits with these families.

I will have the interventionists and families sign a copy of the enclosed consent form. If there are additional components your parish requires for the consent form, please let me know so I may add them. This model is from the Louisiana State University Human Research Committee.

Following the observation period (three to four weeks) I will schedule appointments with each family to conduct individual interviews. I believe the information gathered during the observations and interviews will assist your early interventionists in developing family-centered methodology and program plans that will also reflect best practices for early childhood special education.

Finally, I need a letter from you similar to the model enclosed indicating your approval of the procedures and format of the study. If you have any questions, please do not hesitate to call me at my office 482-6415. Thank you again for your assistance. I look forward to working with you and your early interventionists.

Sincerely,
Mr. Mike LeBlanc  
Director of Special Education  
Acadia Parish Schools  
Crowley, LA

Dear Mike:

Thank you again for your willingness to allow me to do my dissertation research within Acadia parish's early intervention program. As I indicated in our phone conversation the early interventionists responsibilities for the study will be limited. First, they will need to select two to four families from their respective caseloads who have been enrolled in the program at least six months and are willing to participate in the study. Second, they will need to allow me to observe during their home visits with these families.

I will have the interventionists and families sign a copy of the enclosed consent form. If there are additional components your parish requires for the consent form, please let me know so I may add them. This model is from the Louisiana State University Human Research Committee.

Following the observation period (three to four weeks) I will schedule appointments with each family to conduct individual interviews. I believe the information gathered during the observations and interviews will assist your early interventionists in developing family-centered methodology and program plans that will also reflect best practices for early childhood special education.

I appreciate your willingness to share this information with Mr. Stringer and obtain his approval.

I will also be assisting and in an independent study in early childhood special education methodology and program planning. The content will relate specifically to their respective caseloads but we will be meeting on nonwork time for them.

Finally, I need a letter from you similar to the model enclosed indicating your approval of the procedures and format of the study. If you have any questions, please do not hesitate to call me at my office 482-6413. Thank you again for your assistance. I look forward to working with you and your early interventionists.

Sincerely,

Donna E. Waldsworth, Ed. S.
Instructor
APPENDIX H

Excerpts from Marsha's Journal

The Lotto Family. Janie is a very beautiful and active child. She can steal your heart with her smile. She is very intelligent, catches on quickly, and is extremely active. It is often hard to calm her down enough for engagement in play activities.

The home is very dark almost to the point of depression. The television is usually on; Mom does not like turning it off. Mom sits in on visits when home and the home health nurse when Mom is not home. Janie responds equally well to either Mom or the nurse. Mom also has her days (mood swings). At times, she is very receptive to activities and helps to elicit responses. At other times, she begins defending herself concerning Janie's play skills and toys. It is as if Mom feels that I am working on activities with Janie because I feel that she doesn't provide healthy activities. Mom will go on about how she does the same with her toys; that she and Janie play these games often. I just continually remind her of how wonderful a job she is doing and how beneficial it is for Janie.

When the nurse is there alone with Janie, we always turn the television off. I find the intervention is much better when the television is off because Janie is easily distracted and absolutely loves the television.

Mrs. Lotto is very impatient with professionals especially if they do not advise her of her child's needs.
She feels that they are the trained ones and she wants to be informed of what is best for Janie. She feels insulted when professionals ask her what she wants for Janie.

I really think Mrs. Lotto wants intervention and feels that it is important for Janie; but sometimes feels threatened or intimidated or maybe it's more like overwhelmed. I can't really figure Mom out.

I feel that intervention would be more beneficial overall if we had some type of communication system for Janie to use to communicate with us. She is at an age when she feels frustrations when not understood. The family does now want to develop a communication system which was not a priority to them nine months ago. Thank God for this realization on their part. Now I have to find a therapist that will work with us.

The Smith Family. Mrs. Smith has always been very receptive to intervention. She is very open and honest with her feelings. She always has the girls ready for instruction. She also participates in all sessions. The environment is always neat, clean, and quiet. At times, she has a video tape of the children playing on the television. Mrs. Smith feels that this is beneficial to the girls' security. Sometimes she turns the volume down and other times she turns it off; depends on the mood of the children. If they get upset, they will not participate.

I feel the intervention is going well; the girls are improving developmentally; they seem to enjoy activities
presented and engage fully in them. I feel that Mom is pleased with the services and children's performance.

We have teaming meetings regularly at the home. They are very informal. The FSC, physical therapist, interventionist, and mother are usually present. The meetings with just the FSC, interventionist, and parent are planned about once a month. When the physical therapist is present it is by chance, not planned. Everyone shares views, opinions, and ideas. We love it.

The White Family. Ms. White says that she really wants intervention. Mrs. White is the type to be easily swayed into accepting services she may not want. The environment is full of variables. Sometimes music or television is blaring. Often Ms. White and David are gone and nobody knows where or why. Sometimes they are sleeping. They never remember when intervention is scheduled. I have left note cards, calendars, and called ahead but nothing helps. They are often without a phone.

Ms. White is always polite and on the shy side. I think she really wants the service, and for David to achieve, but due to health problems (diabetic, etc.) and living conditions cannot always carry through with activities on a regular basis.

The environment does directly affect David's behavior. The more people and noise level, the more active he is. When it is just Ms. White, David, and grandmother, they will
offer to turn off television or radio, and they will participate in the intervention.

Intervention is a definite need, and I'm sure we are accomplishing some good despite overall picture. Some days I feel like we have really achieved, and other days I may leave wondering "what just happened" or "where did I go wrong?" When the house is full of people mulling in and out, children crying and fighting, and music blaring, David is wound very tight and little or nothing is achieved but I carry on as if all were quiet. I try very hard not to make the family feel degraded or that I am being judgmental. I feel that this life is not what they would choose if given a choice, but due to unknown circumstances they are in it. I think the reason they clam up on out of control days is because they are embarrassed they do not have control of the environment. They just sit there sometimes staring into space and other times just carrying on with visitors as if I weren't there. I do often change approaches and activities. Some are successful, others are not. These are the cases that keep the brain sharp(?) and/or wear it down.

The Cramer Family. In general the activities go over good, the family and child participate fully. I really believe dad and grandmother carry through with activities between visits. I feel the water therapy has made a difference in Missy's life style. Before I started the water therapy I did not feel that I was accomplishing much with Missy. Her Dad and grandmother work so intensely with her.
Not only does the water benefit her physically but it is a fun form of intervention and incorporates her skills in all development areas.

Sometimes Mr. Cramer has found a new idea for intervention and therapy that really doesn't make sense. He will ask me what I think of it. I try to present my opinion objectively and still let him make the final choice. I feel that if the family has a problem or is uncomfortable with an activity or progress they would speak up. We have a good working relationship.
Excerpts from Louise's Journal

The Regan/Johnson Family. Ms. Regan is quiet and had never had a whole lot of involvement until recently with my visits. I get the impression that Ms. Johnson has made comments on how she wants Ms. Regan to take responsibility for her actions and children; even though Mrs. Johnson makes appointments for the children. Mrs. Johnson in my opinion would like for Ms. Regan to enroll in a GED program, send Ann to preschool and Ursula to a sitter. I think she would really like to get them out of her home.

I am not sure how much is done with Ann when no one is there. Ms. Regan seems to attempt to get responses from Ann especially when toys are involved. She also was interested in toys for learning which she could get Ann for Christmas.

I am not sure if this family misses appointments on purpose or just does not find any value in them. Ann was receiving PT/OT at the early intervention program in Lafayette. The family missed so many appointments Ann was dropped from their program. They have also missed several appointments with doctors and Children's Special Services.

On one particular visit Mrs. Johnson expressed her anger about a visit with the pediatric neurologist. The doctor said that Ann would never do anything more than she is doing now. This really upset Mrs. Johnson, I did not get any strong feelings from Ms. Regan one way or the other. This may have something to do with them missing many of the doctor appointments.
Mrs. Johnson in my opinion rules the household. Ms. Regan does not have much say-so in anything that takes place with her children. You get the feeling sometimes that Mrs. Johnson does not feel Ms. Regan has enough intellect to make decisions for herself and her children.

The Brown Family. Ms. Brown has always been involved with the activities I brought into the house. The other boys have participated when they were home. The man has never stayed in the house while I was there. Mrs. Brown appears to have a good understanding of how to expand Albert's language usage. I also think she followed up with the activities I presented. She has not forced Albert to give up his bottle and I feel she would not force him to talk. Now that he is talking some; she is very proud and can see him growing up. In some ways, growing up may bother her—convincing her to cut loose has been difficult.

Albert also knows how to get one over on Mom. She could not stand to see him pitch a fit for his bottle. He also used his lack of verbal communication as a means of gaining attention (I believe). Mom would give Albert negative attention at times for his lack of speaking--this never seemed to stop him from pulling on her, pointing, or jumping up and down for attention.

My initial couple of visits were not received that well. The FSC set up our initial visit. Ms. Brown was set on speech therapy--which did not work out.
Ms. Brown has accepted me, but not all of my recommendations—example Albert's bottle. I do feel I have a good working relationship with Mrs. Brown and her boys.

The Gordon Family. The main concern Robert Gordon's Mom and dad had when I was contacted was the lack of communication skills. Robert did not speak at all. He did point and gesture. He was approximately 16 months old, was still taking a bottle, and sucking on a pacifier.

Mrs. Gordon is not very talkative and it made it difficult for me to know whether or not I was doing any good. She did accept suggestions made to her and followed through with them as far as I can tell on a regular basis. She is semiactive in the activities I do with Robert. I see her participation to be dependent on the other family members. When it is just Robert, the baby, and Mrs. Gordon she participates freely. When Mr. Gordon has been there, I find her to be more reserved.

Since Robert has begun talking Mr. and Ms. Gordon seem to be very proud of him. Robert did not speak to me for a long time; even though his parents reported he talked all the time. Now he does not appear to be apprehensive about carrying on a conversations with anyone. Mrs. Gordon has been great with follow through and has been great to work with when they are home, but they have missed a lot of appointments.

Mr. Gordon I find is much more over-protective than Mrs. Gordon. He finds Robert to be a small wounded bird that
should have been placed high up in a cage. My first couple of visits appeared to be somewhat stressful for dad. He did not think that I could make a difference. I also knew that he wanted speech therapy along with my service--due to lack of FSC that never materialized. Dad has now become a more active participant in my visits.

This family in my opinion has done very well--especially not having the assistance of a family service coordinator. This family is out to better themselves and are going strong on the right track. They are very involved with their children and I feel put their best interest first.

The Cook Family. I feel that Mrs. Cook is a concerned mother and would do anything asked of her. There are major limitations to what Lisa can and can not do. In many ways, I feel helpless when working with Lisa.

The working environment varies at the home. Many visits I will turn the sound down on the television or turn it off. There are visits when Mrs. Cook is the only one home and some when five other people are in the home. Mrs. Cook has always made me feel welcome--no matter what is going on in her home.

My lessons are based on gross motor development suggested by the PT and OT. Although many responses appear to be involuntary, I feel it gives Mrs. Cook and myself a comforting feeling when Lisa responds.

Sometimes I feel I do more good talking with Mr. and Mrs. Cook about concerns than I do working with Lisa. I do
get mixed messages at times from Mrs. Cook. I feel this is to be expected due to Lisa's medical involvement. When Lisa is responsive and alert I find Mrs. Cook to be much more attentive and comfortable with life in general.

Mrs. Cook appears to become very frustrated with other family members when she is not supported in her actions with Lisa. Dad appears to spend time with Lisa, but not as much as Mrs. Cook would like.

I am not sure, but I feel Mrs. Cook loses interest due to the fact that Mr. Cook does not have interest in the activities. When any activity is first introduced, she appears to be very interested and excited; but there is very little carry over with the activities. Mr. Cook does seem to attempt it, but I think he gives up easier than Mrs. Cook.

Overall, Mrs. Cook does not have a strong family which actively participates in helping her with Lisa. In the last little bit, Mr. Cook has assisted in a feeding. Mrs. Cook is limited to a couple of people that will keep Lisa and feed her. Most times I hear her complain that this is one of the biggest problems she faces. Her time away from Lisa is regulated by Lisa's feeding.

Mr. Cook appears to need time away for himself quite often, but did put up a small fight about Mrs. Cook going to school. Now he appears to be supportive of her decision making her guilt and anxiety lessen.
APPENDIX I

FAMILY INTERVIEW TRANSCRIPT EXCERPTS
Appendix I

TRANSCRIPTS

Selected Transcripts of Interviews with Mrs. Smith

HOW DID YOU FIRST BECOME INVOLVED WITH EARLY INTERVENTION AND THE PART H SYSTEM?

Well, my oldest daughter was ten months at the time, and she wouldn’t pull up on furniture or anything. We could tell she was really behind, and through the school board my little brother-in-law got a letter saying if you’re concerned about your child to write it. So we wrote down everything, and they sent it back to the school board. When we had our interview with my child, and then definitely they put her on the system. So it was through a letter through the school board—through the school system that we got on.

WHAT RECOMMENDATIONS OR CHANGES WOULD YOU MAKE ABOUT THAT INITIAL CONTACT FAMILIES HAVE WITH THE SYSTEM?

At first it was a lot of paper work, it’s like to get past that and to get into the program, you known. After we got in, it was fine, but was to get in, a lot of paper work. But, of course, I understand that. But it’s like you have to go and answer so many questions—but, you, it’s just—it was a lot of paper work. I just remember that. It was two years ago, but God, I remember that. I don’t know.

WERE YOU GIVEN OPTIONS IN TERMS OF WHEN AND WHERE INITIAL MEETING TOOK PLACE?

Well, with my case, I was right—it wasn’t far from me. It was right here in Crowley. We had a meeting, I went, but
I don't know... you have to get in, but once that was over with it, it was pretty good. It was just-- then for my second child, she had the same thing as my first child had, so she went right in. It wasn't no big deal. It was must to get them diagnosed. I think it was because they weren't diagnosed with anything at first. Then after that, it went pretty good... It's like we had to go and go, and it was like a long time before they actually started coming to the house and working with us. It's like-- I don't know how long. At the beginning the interventionists and family service coordinator were one person. She explained everything to me and we had to all her doctors' reports.

HOW LONG DID ALL OF THIS PROCESS TAKE?

It was a few months. At first, it was like, you know, I wasn't sure if it was ever going to get started

WHAT ELSE DO YOU REMEMBER ABOUT YOUR FIRST DAYS IN EARLY INTERVENTION?

They explained. It was like a lot. It's like she was going fast. It was too much to consume at one time. She (FSC) was going fast because we were going to be there for a while. So it was like, okay, you sign and sign. She was trying to explain but it's like it was a lot. So she was going fast just because it was a lot.

How well were the professionals listening to you at this time?

The doctors could have caught it, but anyway. They were saying I would just hold her too much that's why she
wouldn't crawl, and I wouldn't let her do, but anyway...it was me that noticed something was wrong with her. Then with my second child, I already had the interventionist. Then it was the same signs as my first child, so then we knew to go to a genetics doctor after that. So finally they started listening to me.

SO WHAT ADVICE WOULD YOU TELL PROFESSIONALS TODAY?

To listen. The parent knows their child more than anybody else does. So I knew something was wrong with her, but--so just listen to the parent for sure. They only see them once, maybe every two weeks.

WERE THERE ANY SPECIFIC QUESTIONS ABOUT YOUR CHILD THAT YOU WANTED ANSWERED AS A RESULT OF THE ASSESSMENT PROCESS?

Well, yeah--, my FSC interventionist, like I said, it one person in the beginning, and she was really good. In fact I--we would just all. We could talk on the phone every three days, you know. So I didn't have any problems. She would answer anything. She would do anything. So--and we always agreed. So I didn't have any problem at all. Now it is more difficult to keep up with everything since the early interventionist and FSC are separate people. Also, it seems like I have to do more of the observing and assessing to keep everyone informed. I feel like my early interventionist really cares by the way she listens during our conversations. She is genuinely interested in what we do in our lives.
DO YOU STILL HAVE THE SAME FSC?

It's not the same now. We've been through two or three since then, but my first one, she was my family service coordinator and interventionist. You know then it divided up. But she would, I mean, she was always there for me. She was really good. I didn't - I don't have no complaints with her at all. Anything I needed she did, you know. They have become a friend who really cares about my family.

WHAT DO YOU DO WHEN THE EARLY INTERVENTIONIST COMES TO YOUR HOME?

I want to see everything the girls do with Ms. Marsha, as they do so much better for her. It also gives me ideas of ways I can play with them and help. But sometimes I just need to get away. I am nearly always with them. I don't want to go very far, because, as my husband reminds me, their lives may be very short. I want to enjoy them while I can. It's just hard.
WHAT DO YOU DO WHEN THE EARLY INTERVENTIONIST COMES TO YOUR HOME?

I never get a break from David. He is constantly on the move. No one else will keep him for me so I use the time Marsha is here to get caught up, to be by myself.

WHAT DO YOU REMEMBER ABOUT WHEN DAVID'S IFSP WAS WRITTEN?

I don't know. I don't exactly remember writing one. So much has happened during this year. I really am going to have to start writing everything down. The early interventionist told me I should make a folder for David. I really have difficulty remembering important things for David. Because we don't really have a place of our own there is so much in and out. It seems like there is somebody different calling me every day about David and there is really no one that helps me organize it all. I think slowly but surely I am losing my mind. I really count on my mother and my grandmother to help me keep things going for David. Like remembering to go to the doctor and check on thing - they help with that. I am diabetic and I really should watch my health better.

WHAT IS YOUR RELATIONSHIP TO YOUR FSC LIKE?

I really don't know her very well. Like today she just showed up with her supervisor to tell me what I had to do with David. I knew you and Marsha were coming but I didn't know they were. Well I just can't remember it all so I don't
even try to write it down. It is just too much! You and Ms. 
Marsha (early interventionist) always call before you come, 
but the rest of them are just unpredictable. So if I feel 
like seeing them, I let them come in, and if I don't--I 
don't let them in.

I ASKED IF SHE LIKED HAVING MARSHA COME TO WORK WITH 
DAVID?

She quickly responded yes.
Selected Transcripts from Interviews with Mrs. Cook

IF YOU HAD THE OPPORTUNITY TO IMPROVE LISA'S PROGRAM

WHAT WOULD YOU CHANGE?

First, I would have in home therapy. Just because I am able bodied and I have a vehicle that works I am denied in home therapy. But my child can't take the cold, she is very prone to respiratory infection. In the summer she can get out, but like last winter she had pneumonia and for over four weeks I couldn't get her out at all. So everything she had learning in the fall, she lost all that. She backslid.

ANYTHING ELSE?

I also would like to have respite or child care. I have to pay my babysitter in order to go to school. They don't think that going to school full time is the same as working full time so I don't qualify for a waiver. They say I have to work at least twenty hours on a job or being less 20 hours a week and that's just ridiculous. I couldn't take care of Lisa and do that. I am taking twelve hours and that is full time according to LSU-E. I mean I'm on the list for respite but the lady said it would probably take three years before they get to me. I think my number is 147. When I finally get her respite, she will probably be in school. The help needs to be more immediate. I get tired of having to fight for everything Lisa gets.

TELL ME ABOUT YOUR FSC

Bruce used to call about every two weeks just to check on me but he always said I could call if something came up.
I liked that and I knew he meant it so I called. But then you saw what happened when he quit. All that stuff about having to take the equipment back and check it in so my new FSC could check it out. I haven't even seen my new FSC and its been three weeks now. I had to start from scratch in providing my new FSC with an understanding of Lisa's needs and our family needs. They could not even transfer Lisa borrowed equipment list from one desk to another. It would also seem that all these different services for Lisa could make copies for each other instead of wasting my time.

TELL ME ABOUT YOUR EARLY INTERVENTION SERVICES. WHAT DO YOU LIKE OR DISLIKE?

I'd have the therapists come more often. I need them here every week. I think Louise is supposed to come every other week for 30 minutes but since I am close to her office in the morning she just comes by every week.

I like having Louise come but I am not sure what she is doing. I try to tell her that when she comes and Lisa is sleeping that she needs to wake her up. Lisa knows that if she is sleeping that Louise won't mess with her. I told Louise she has to wake her up and go on and work with her, but she always says she hates to do that. She will say well maybe she doesn't feel good. I tell her no, she feels fine. But I really think Louise is so worried--I don't know if she is afraid she will hurt her or doesn't know what to do. I don't know how else to tell her. A lot of times she comes and she might notice some minor medical problem like the
feeding tube is leaking a little or she has a mild seizure or her nose is a little runny and Louise keeps saying over and over you have got to take her to the doctor. I try to be nice but I tell her I'm with Lisa and I know when she needs to go to the doctor. I am the parent! Maybe Louise is afraid that I might miss something, but I do know what I am doing. When I want her opinion I will ask for it. She just doesn't seem to recognize that I am the parent and I am the expert on Lisa. I know she doesn't know exactly what to do because she has come with me to therapy to see what they are doing. And that is ok with me, but I don't know. And another time I got really mad was when Louise, the FSC, and home health nurse were discussing where to eat lunch during Lisa's therapy time.

Another thing I would change is home health. They are definitely not family-centered. The home health people are so unresponsive to my requests for help and equipment. When I call and say I need new feeding tubes I thinks they should be able to get them to me with a week. My FSC even tried but it took weeks to get a tube. I tried being nice at the first and my child was not getting anything so I am going to fight to get what she deserves. It is really frustrating as the fight for services seems to never end.

I think all professionals need to give us more recognition, they don't understand. I really had no complaints until they started telling what to do with my child instead of giving me suggestions.
I know Lisa is difficult to work with and doesn't show much progress but I need them to keep trying. Sometimes Louise comes in with new ideas to try with Lisa and that's fine, but she is so gentle and she just tries it once or twice and quits. I tell Louise it takes a lot more hard work with Lisa. She is not fragile, but Louise just doesn't seem to listen.
TELL ME ABOUT YOUR FIRST EXPERIENCES IN EARLY INTERVENTION

I went to early intervention in Lafayette for a few months and we had one appointment per month. It was really hard to get there and I just saw this man. I think he was the physical therapist. He told me things to do to encourage Adam's motor skills and then someone sometimes helped with his talking. We were supposed to have transportation but it was not very regular. You never knew if they would come when you called. We had speech therapy at the rehab center in Lafayette but Albert did not talk there at all. Then Louise came to the home and she said she could work with him. I stopped going to rehab because the transportation was so difficult.

DID YOUR FSC HELP WITH YOUR TRANSPORTATION PROBLEMS?

I don't think I have one of those. I called. I knew Albert needed to learn to talk but sometimes the van would pick us up around mid morning and we wouldn't get home until early evening. It was not good for my other three children either.

I asked Ms. Brown again on the second interview about her FSC. She said then "If I have one, I don't know who it is. I guess it would be helpful to have one. Cause if I had one, maybe they could help me with getting Albert in Headstart (program)."
TELL ME ABOUT YOUR RELATIONSHIP TO YOUR EARLY INTERVENTIONIST

Sometimes, I don't think she wants to know the whole story, she either doesn't have time to listen or has already made up her mind. But I like Louise and she does a good job with Albert. It is just at times, I don't know sometimes when Louise leaves I realize I never had a chance to ask her about a concern—that we had spent most of the time talking about my GED classes. And then there was the time she got so pushy about Albert quitting his bottle so he could talk. Well, I wouldn't do it.

Sometimes Louise can get him to do something I have tried for weeks to do. It exciting to see him succeed and frustrating, too.

TELL ME ABOUT YOUR EXPERIENCES WRITING AN IFSP.

Well, when Louise first started coming we talked about what I wanted him to be able to do. I think talking about goals helped to know what I should be doing with Albert. Usually the decisions and choices Ms. Louise gave me were all good. But I could say no if I needed, too.

WHAT HAVE YOUR EXPERIENCES BEEN WITH ALBERT'S TESTING?

Usually, they just ask me a lot of questions. Sometimes I am not sure what they are asking. Like one time Ms. Louise asked if Albert ever used jargon. I didn't know what she was talking about. I guess she could tell that I was confused as she explained it to me. Some of the other professionals don't do that. Then they would always ask questions about
whether he could hop and I realized I had better watch him closer.
Selected Transcripts from Interview with Mr. and Mrs. Gordon

TELL ME ABOUT YOUR FIRST EXPERIENCES WITH EARLY INTERVENTION

Mrs. G.- At the beginning I wasn't sure what the FSC was supposed to do. Most of the therapy for Robert focused on his motor development. I never said anything because I thought at the time that they were doing all they were allowed to schedule. I didn't want to hurt anybody's feelings by demanding more than they could give. Now I know different and I am more demanding.

Mr. G. It got real old fast driving to Lafayette to that early intervention program. We had already been driving almost every day while he was in the hospital till got big enough to come home. I remember someone from the school board came out and had me fill out some papers and I think the school board lady is the one who sent us to early intervention. The first FSC's company went out of business, but we were going to change anyway as they weren't doing nothing. No one ever told us it was our choice for a FSC.

TELL ME ABOUT YOUR EXPERIENCES AND RELATIONSHIP TO THE FSC.

I think one or two times the FSC came to the house. They collect paychecks for doing absolutely nothing. When that woman came to our house I didn't think that she was listening to me at all. They didn't talk to me about what I wanted for my child. They just made appointments and demands.
Then someone at the school board called us about working with Robert. Once you know your child has a problem, you want to get it fixed as quick as possible. But it takes so long to get things started. The lady at the school board said that it takes preemies a while to catch up. She was right, but now since Ms. Louise has been coming he's been doing great—he is one sneaky bug.

WHAT WAS YOUR PART IN THE ASSESSMENT PROCESS?

Mrs. G. I was included whenever he wouldn't respond, she would ask me if he could do it. At first he didn't do hardly anything. He'd just sit there. I would have to try to get him to do it and he would usually do things for me.

TELL ME ABOUT THE EARLY INTERVENTION EXPERIENCES.

Mrs. G. — I feel he has made a lot of progress since Louise started coming. It did make me mad when she told me I had to take his bottle and pacifier away from him if I wanted him to talk. I didn't want to. I was so mad I stayed in the bedroom and wouldn't talk to her for several weeks.

At a later time I asked Mr. G. the same question.

Mr. G. — My wife still think Louise was too pushy and demanding about Robert's bottle. she was so mad she went in the bedroom and stayed there during her visits for also two months. But she got over it and she knows that's probably why Robert is talking so well now. It was kind of funny watching their struggle.
TELL ME ABOUT YOUR EXPERIENCES IN PLANNING FOR ROBERT'S TRANSITION OUT OF EARLY INTERVENTION.

The process is confusing to me. I'm not sure if I will need a babysitter for Robert next year or what will happen. I don't think he has completely caught up and might need more help like he is getting from Ms. Louise.

TELL ME WHAT YOU WOULD CHANGE IN YOUR EXPERIENCES IN EARLY INTERVENTION DURING THE PAST TWO YEARS.

Mrs. G. I wish I'd just put my foot down and told them what I wanted so he could have got motor and speech services. Then maybe he wouldn't have been slow in talking. I think he would have maybe caught up faster. It is just been so frustrating him trying so hard and not knowing how to help him. The FSC who came out to our house, they were supposed to be helping him and us, but they never really told us what we could do. We lost so much time.
Selected Transcripts from Interviews with Mr. Cramer

TELL ME ABOUT YOUR FIRST EXPERIENCES WITH EARLY INTERVENTION AND FSC

I am 38 years old and I think it is pretty tough to raise a two year old by yourself. When Missy was 10 months old she still could not hold up her head. We took her to see a doctor. The doctor is the one who told us that Missy had cerebral palsy. Her mother left us sometime between around the time that Missy was six to ten months old. My FSC should have told me then how important therapy was to a CP child, but he didn't. The message that my mother got from all our early contacts with early intervention services is if you don't want them you don't have to have them. I think all she thought about was the demands on our time and the traveling—not Missy.

The therapists did tell me about the importance of stretching her every day. I went and got a book on cerebral palsy and I found out how important therapy was. So I would know what to do with her. I feel like that first year or so we lost a lot of valuable time before therapy got started. Maybe it didn't seem long to my FSC, but waiting over a month to get Missy's therapy started was such a waste of time. When our FSC first visited the home, I told him what I thought she needed and all he said was "well we'll see". Instead of telling me this, I wish he would have told me we are going to try this therapy or that but it will take a little while to get everything started. Sometimes it also
seemed like the early interventionist, it was like she was trying to protect me from the facts.

It was bad enough all of the hassles I had to go through to get Missy in therapy and the FSC not really listening, but then my mother said Missy doesn't need to go to therapy. She wanted me to take her about once a month and Missy's cerebral palsy is pretty bad.

WHAT DO YOU WISH PROFESSIONALS WOULD HAVE TOLD OR DONE DIFFERENTLY?

They should have told me from the beginning how I could help and what the ultimate goals were. They needed to let me know something and not have wondering what in the world am I going to do with this baby. I think when we went for our evaluation at the rehab center, the therapists should have shown me how to stretch her right then. She was like a board. They could have given me just a few things. I got frustrated when no one told me at the beginning what should be going on and the help that I might get later on.

WHAT WERE YOUR EXPERIENCES WITH THE ASSESSMENT PROCESS?

Well, when Missy was 10 months old they tested her and I answered a lot of questions but I really did to get much information from them. I learned I needed to watch her every move so I could answer their questions. I wanted to know how she was doing. Now Ms. Marsha she tells me how she thinks she is doing and we look at the charts together.

IS THERE ANYTHING ELSE ABOUT EARLY INTERVENTION YOU WOULD CHANGE IF YOU COULD?
I would change the transportation. It has been terrible. My car needs about five or six hundred dollars worth of work done on it and I just can't afford it. I could go into Crowley or Eunice on it but I would never consider endangering Missy by driving to Lafayette two or three times a week. The transportation is really unreliable. A lot of times we miss an appointment because of transportation. On a good day it would take us five hours to go and come. I am doing it for that baby right there as she is the most important person in my life. Like yesterday they picked up about three hours before we were supposed to be there and then we didn't get home until right at 7:00 p.m. We had been gone over seven hours. That is tiring or me but it is really tough on Missy. I had to wait to feed her. I make her eat right before we go and then at the rehab center I will get her a little snack or bring her a snack to eat. She is so good on those days to not complain about her hunger. She really has a patient disposition. She pointed to the snack machine when we got there. Thank goodness its not always as bad as yesterday but they are long days. That is not family friendly!

Whether it is the FSC or a therapist, I can never be sure they are telling me the complete story. It is so frustrating. I think they figure I am just a dumb old Cajun, but I understand and I think I take good care of my daughter.
They also need to let the parents know what they are working on with the children. Ms. Marsha does that. But sometimes I think, the professionals are afraid that I am going to start doing too much and work them out of our job. But I am just making their job easier.
Comments made by Mrs. Johnson during participant observation

The early interventionist, Louise, had asked Mrs. Johnson during a visit whether the FSC had talked to her about getting an appointment to have Ann evaluated for school. Her response was "Not yet! He thinks we should jump every time he makes a suggestion. He doesn't know how it is!"

Mrs. Johnson also said of their FSC that he "had an attitude."
Comments made by Mrs. Lotto during participant observation

I really don't have any use for a FSC or early interventionist who just asks me, 'What do you want for Janie.' I need someone who can give me ideas and then allow me to decide. If they don't present ideas as just suggestions and the choice is mine, I don't want them working with my child.
APPENDIX J

LSU RESEARCH CONSENT FORM
TOLL COMMITTEE RECOMMENDATION

FROM: Institutional Review Board
TO: Dr. D. Wadworth
     Curriculum and Instruction
DATE: September 13, 1994
RE: Proposal # 1804

This is to certify that a quorum of the Institutional Review Board reviewed the proposal entitled:

Understanding Families' Definitions and Perspectives of Family-Centered Early Intervention Programs

The Committee evaluated the procedures of the proposal following the guidelines established for activities supported by federal funds involving humans as research subjects.

Recommendation of Committee: ______ APPROVED

Comments: License # 72-1
            Multiple Assurance # H1128

A review of this proposal by the Committee will be considered at least on an annual basis, and at more frequent intervals depending on the element of risk.

W. Sheldon Bivin, Chairman
Institutional Review Board
EARLY INTERVENTION RESEARCH CONSENT FORM

My signature, on this sheet, by which I volunteer to participate in the research study on "How families with Part H eligible infants and toddlers define family-centered early intervention" conducted by Donna E. Dugger Wadsworth, indicates that I understand that all subjects in the project are volunteers.

I also understand I can withdraw at any time from the research study.

I have been informed as to the nature of the study and that the data I provide through observations, interviews, and review of my child's Individualized Family Service Plan, will be anonymous and my identity will not be revealed without my permission.

I understand that my participation in this study may be used for additional approved projects.

Finally, I understand that I shall be given an opportunity to ask questions prior to the start of the study and after my participation is complete.

______________________________
Subject's Signature

______________________________
Date signed
VITA

Donna Elizabeth Dugger Wadsworth was born in Highland, Illinois. She received her B.S. degree from Southern Illinois University in 1969, with a major in special education and elementary education.

In 1983, Donna received her M.Ed. degree from the University of Southwestern Louisiana with a major in elementary education and minor in special education. Donna completed her ED.S. degree in 1990 from the University of Southwestern Louisiana. Her area of emphasis was early childhood special education and her research was a quantitative study of teacher preparation for early childhood special educators to work with families.

Donna has taught students with learning disabilities and moderate to severe mental retardation in the public schools. She worked for the State Department of Education in Illinois as a regional early childhood specialist and service coordinator for a 14 county area serving children with low prevalence handicaps.

In Louisiana Donna has worked as assistant program coordinator and early childhood specialist for a regional infant/toddler program and taught a noncategorical preschool paraprofessional training unit in public schools. During this same time period she taught as an adjunct instructor at the University of Southwestern Louisiana and McNeese State University.
Since 1992 Donna has been a special education instructor at the University of Southwestern Louisiana and faculty advisor to the Student Council for Exceptional Children. She also supervises the early interventionist student teachers in preschool and infant/toddler programs. Additionally, Donna serves as the university's College of Education representative to the state Comprehensive System of Personnel Development for special education and a member of the Learn and Serve America Advisory Board.

Donna is active in professional organizations including the Council for Exceptional Children, Division of Early Childhood, Teacher Education Division, Southern Early Childhood Association, American Association for Home-Based Early Interventionists, and their respective state affiliated organizations. She has served as president of her local CEC chapter and is current president of the Louisiana Division of Early Childhood of CEC. She is an ex-officio member of the Louisiana Interagency Coordinating Council for Part H Services and a member of the Infant Personnel Preparation Subcommittee. She has published several articles in both state and national journals.
DOCTORAL EXAMINATION AND DISSERTATION REPORT

Candidate: Donna E. Dugger Wadsworth

Major Field: Curriculum and Instruction

Title of Dissertation: Understanding Families' Definitions and Perspectives of Family-Centered Early Intervention Programs

Date of Examination: June 28, 1995