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# FAMILY-CENTERED PRACTICE IN EARLY INTERVENTION SERVICES FOR INFANTS AND TODDLERS: THE EXPERIENCE OF FAMILIES AND PROFESSIONALS IN ONE LOCAL INTERAGENCY COORDINATING COUNCIL

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Abstract

FAMILY-CENTERED PRACTICE IN EARLY INTERVENTION SERVICES FOR
INFANTS AND TODDLERS:  THE EXPERIENCE OF FAMILIES IN ONE
LOCAL INTERAGENCY COORDINATING COUNCIL

Patrick Shannon, Ph.D.

Part H [recently reauthorized as Part C] of the

Individuals with Disabilities Education Act (IDEA) mandates

the application of family-centered practice principles to

early intervention services. There has been a considerable

amount of literature published in early intervention

journals related to family and professional relationships in

early intervention and its connection to family-centered

care in early intervention services.  There is very little

literature, however, that examined the implementation of

family-centered principles from a perspective that
transcended the relationship between families and early
intervention providers.

This inquiry was a constructivist policy analysis of
the implementation of the family-centered intent of Part H
of IDEA in one Local Interagency Coordinating Council (LICC)
in Virginia. Perspectives about the implementation of the
family-centered intent of Part H were assessed through in-
depth interviews with several stakeholder groups, including
families receiving Part H early intervention services,
families who were never able to access services, members of
the LICC, professionals from center-based programs,
professionals from home-based programs, and professionals
from hospital-based programs. While data were primarily
collected via in-depth interviews with participants from
each stakeholder group, the inquirer also observed five LICC
meetings. Document analyses and observations of LICC
meetings also were used for triangulation of incoming data.
Twenty-two family participants were sampled that represented
variation according to socio-economic status. Twenty
professional participants were sampled who represented a
range of professional disciplines.

Findings from this inquiry highlight some issues
regarding implementation of a broad federal policy (i.e.,

Part H of IDEA) at the local level.  The intent of Part H
was to mandate the construction of state level service
delivery systems, local service delivery systems, and
suggested program and professional practices for the early
intervention field.  Very little guidance, however, was
provided to states on how to construct their systems and
even less was provided on developing local early
intervention service delivery systems.  Few financial
resources were committed for the construction of these state
and local service delivery systems adding additional
complications.  Specifically, the legislation provided no
financial support for new early intervention programs;
instead, the intent was for states and local service
delivery systems to coordinate already existing providers
using existing funds.

    There are many policy and practice implications
resulting from this inquiry. First, there are implications
for federal, state, and local early intervention policy.
Second, there are implications for early intervention
practice. Third, there are implications for empowerment of
families who have children receiving early intervention
services.  Fourth, there are implications for social work
practice in the field of early intervention.  Finally, there
are implications for future research related to family-

centered service delivery.

Chapter 1

Introduction

Early intervention involves identifying children between birth and three years of age who have or are at risk of having a disabling condition or other special need that may affect their development, and then providing services to the child and family to lessen the effects of the condition (Smith & Strain, 1988). Part H of the Individuals with Disabilities Education Act (IDEA), heretofore referred to as Part H, instituted the infant and toddler component of IDEA by encouraging states to develop comprehensive, coordinated services for infants and toddlers with developmental delays or disabilities (Part H, 1992). Part H (1992) was written with the intent of empowering families by mandating that early intervention services for infants and toddlers with a developmental delay or disability and their families be provided in a manner consistent with the principles of family-centered practice.

Dunst, Trivette, and Deal (1988) believed that providing family-centered early intervention services was

essential to quality care for infants and toddlers with developmental disabilities and their families. Dunst and Deal (1994) stated that:

> Family-centered practice means assessing child and family needs and family strengths and capabilities related to meeting those needs. It also means assessing needs and strengths from a family's perspective with assistance from professionals. Additionally, it means the use of a needs-based rather than categorical or service-based approach to assessment and resource mobilization and a positive and proactive rather than a pathological or deficit approach to assessment and service delivery. (p. 73)

Family-centered services were designed to improve the ability of families to cope with the unique needs of their infants and toddlers with developmental delays or disabilities (Shelton & Stepanek, 1994). Specifically, services were intended to assist families in coping with the challenges of having children with developmental delays or disabilities, empowering families to work collaboratively with early intervention service providers, and supporting families as they made decisions about their infant's or toddler's services (Dunst et al., 1988; McGonigal, Kaufman,

& Johnson, 1991a).

According to Bailey, McWilliam, and Winton (1992), a family-centered approach should be a part of all aspects of the early intervention process including the establishment of a program philosophy, screening, child evaluation and assessment, team meetings and program planning, intervention activities, service coordination, and transition planning. The initial rationale for including families in the early intervention process was to enhance child development and support parental caregiving to reduce the need for professional intervention (Bailey et al., 1992).

The concept of family-centered practice has evolved over the previous two decades as early intervention practitioners began to gradually involve families in the program planning and implementation process (McGonigal, Kaufman, & Johnson, 1991a). Additionally, family involvement began to be incorporated into federal standards of practice in early intervention (Task Force on Recommended Practices, 1993). Part H legitimized this shift from family involvement to family-centered practice.

Bailey et al. (1998) suggested that the essence of the family-centered approach resided within the relationship between families and professionals. They further suggested

that a new relationship between families and professionals should be forged. This new relationship should recognize the need for an individualized approach to accommodate the preferences of individual families as well as value and support families in ways that meet the individual needs of families. Additionally, a family-centered approach should enable families to feel competent as advocates for their child and family.

The Part H legislation mandates the application of family-centered practice principles to early intervention services. The purpose of this inquiry was to investigate the implementation of the family-centered intent of Part H. This was accomplished by seeking the perceptions of families, professionals and other individuals involved in one local early intervention system through in-depth interviews. To increase our understanding of the family-centered intent of Part H, it is important to first describe some of the basic tenets of early intervention.

## Early Intervention Services

As defined by Part H, early intervention consists of a variety of services intended to meet the diverse needs of infants and toddlers with developmental delays or disabilities and their families (IDEA, 1992). These

services include but are not limited to assistive technology, audiology, family training, health services, medical services, nursing services, nutrition services, occupational therapy, physical therapy, psychological services, respite care, service coordination, social work services, special instruction, speech/language, transportation, and vision services.  Additionally, these services require the involvement of a host of professionals from many disciplines such as special educators, speech and language pathologists, audiologists, occupational therapists, physical therapists, psychologists, social workers, nurses, and nutritionists (Silverstein, 1989).

There are three primary reasons for intervening early in a child's life.  The first is to enhance the child's development.  Child development research has established that the rate of human learning and development is fastest in the preschool years (Smith & Strain, 1988; Sroufe, Cooper, & DeHart, 1992). Children develop their most basic motor, sensory, cognitive, social, and language skills during this period (Sroufe et al., 1992).

The second reason for providing early intervention services is to render support and assistance to the family. According to Coughlin (1989), the family of a child with a

developmental delay or disability often experiences disappointment, social isolation, added stress, frustration, and a sense of helplessness. Families may experience a grief reaction to discovering that their child has a delay or disability, leading to feelings of disappointment as a result of increased demands on their time, interactions with early intervention professionals, financial issues related to medical/health related expenses, and/or marital and family discord that can result from the sometimes overwhelming needs of a child with a developmental delay or disability (Coughlin, 1989). Such a grief reaction can have a negative impact on the ability of the family to meet their child's developmental needs. Services such as respite care, parent and sibling support, and financial support for families whose children are medically fragile can be helpful to families (Beckman & Bristol, 1991).

Finally, early identification and intervention can lessen the impact of a developmental delay or disability by improving developmental outcomes for infants and toddlers. Developmental outcomes can include improvement in fine and gross motor movement, speech, psychological well being, and cognitive skills. As a result, society in general may benefit from the child's decreased need for societal

resources as a result of increased opportunities for
independence and self reliance (Smith & Strain, 1988).

There is a substantial need for early intervention
services for infants and toddlers with developmental delays
or disabilities. In 1994, it was estimated that 750,000
infants and toddlers each year have or may be at risk for
having developmental disabilities in the United States
(Saunders, 1995). In Virginia, it is estimated that there
are 7,200 infants and toddlers with diagnosed developmental
disabilities (Brown, 1992). Virginia provided Part H early
intervention services to 4,626 children between December 2,
1996 and December 1, 1997, which represents a ninety-three
percent increase from the number of children being served in
1992 (Virginia Part H Early Intervention Office, 1998).
Regardless, this number is still well short of the estimated
7,200 infants and toddlers with diagnosed developmental
disabilities.

Early intervention services have been offered in a
variety of settings. In Virginia, services have been
provided in early intervention classrooms/centers, family
child care settings, nursery schools or formal child care
centers, the homes of families, hospitals [inpatient],
outpatient service facilities, and residential facilities.

The most prevalent site where early intervention has taken place in Virginia has been in the homes of families. In a recent statewide survey, forty-nine percent of the respondents reported services were received at home, while nearly 30% received these services at outpatient facilities and 19% received services in an early intervention classroom/center. These three settings account for nearly ninety-eight percent of the sites where early intervention has taken place (Virginia Part H Early Intervention Office et al., 1998). As part of the family-centered intent of Part H, it has been mandated that services be provided in the family's natural environment whenever possible (Hebbeler, Smith, & Black, 1991). In Virginia, this would account for nearly one-half of all children and families who received services in 1996 through 1997 (Virginia Part H Early Intervention Office, 1998).

Part H has had an impact on early intervention services in many important ways such as establishing the importance of the role of the family in early intervention, what services should be available to families, and guidelines for early intervention services that are family-centered. Additionally, Part H has had a significant impact upon state and local service delivery systems. Therefore, it is

essential to provide some of the basic information about the legislative intent of Part H and its impact upon services at the state and local level.

## Impact of Part H of IDEA on Early Intervention Services

The purpose of Part H was to provide discretionary funds to interested states to render early intervention services to infants and toddlers [birth to three] who have developmental delays or disabilities or who are at risk for developmental delay (Education of the Handicapped Act Amendments (EHA), 1986). The bill was re-authorized in October 1991 and renamed Part H of IDEA (Individuals with Disabilities Education Act, 1992). Part H was recently re-authorized (July 1997) for a third time, and is now Part C of IDEA. This inquiry occurred prior to the Part C re-authorization and is therefore an analysis of Part H. The enactment of Part H represented a culmination of a drive for a national policy aimed at setting standards of comprehensive services to children [birth to three] and their families (Hebbeler, Smith, & Black, 1991).

Each state was required under Part H to design and implement statewide early intervention systems of service delivery. There was considerable flexibility given to states to design these systems. In Virginia, there are

forty Local Interagency Coordinating Councils (LICC)across

the state. Each of these LICCs received its Part H funding

from the state's lead early intervention agency, the State

Department of Mental Health, Mental Retardation, and

Substance Abuse Services, Part H Early Intervention Office.

The LICCs were charged with developing coordinated local

early intervention systems with Part H funds. The amount of

annual funding received was based on the number of infants

and toddlers to whom they provided services in the preceding

year. Each LICC, however, had considerable flexibility in

their use of resources to coordinate service delivery in

their Councils (Department of Mental Health, Mental

Retardation, and Substance Abuse Services [DMHMRSAS], 1991).

There were many provisions within Part H that improved

the opportunities for families to influence what, where, and

who provided early intervention services (IDEA, 1992).

However, there has been little research in early

intervention that has focused specifically on the family's

experience with these services (Guralnick, 1997). The

purpose of this inquiry was to investigate and understand

how the Part H mandate to provide family-centered early

intervention services has been experienced by families,

direct service providers, and other individual stakeholders

such as LICC staff, program administrators, and family advocates involved in the early intervention system in one LICC in Virginia.

## Constructivist Policy Analysis

There has been a considerable amount of literature published in early intervention journals related to family and professional relationships in early intervention and its connection to family-centered care(Bailey et al., 1991; Bailey et al., 1992; Caro, & Derevensky, 1991; Dinnebeil, & Rule, 1996; Dunst, & Deal, 1994; Kraus, 1997; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). There was very little research, however, that examined the implementation of family-centered principles from a perspective that transcended the relationship between families and early intervention providers (Guralnick, 1996). Constructivist research holds the potential for the researcher to examine the implementation of family-centered principles into direct practice from the perspectives of many key stakeholder groups. Therefore, this inquiry was a constructivist policy analysis of the Part H intent to mandate implementation of systems of service delivery that were family-centered.

Policy within a constructivist frame of reference is

actually a statement of values (Guba, 1985; Guba & Lincoln, 1981, 1989). From this perspective, policy is most easily understood as existing on three different levels. First, policy-in-intent refers to what the framers of the policy "intended" the policy to be. The next level, policy-in-implementation, refers to how the intent becomes converted into actual programs. Finally, policy-in-experience refers to how the targets of the policy interpret their experience of the policy. Thus, the core research question for this inquiry was, "What have the experiences of families and other stakeholder groups been [policy-in-experience] in relation to the Part H mandate to develop coordinated systems of care that were family-centered [policy-in-intent] in one LICC in Virginia [policy-in-implementation]?"

<div align="center">Importance of Inquiry</div>

This inquiry may be important to families because it focused on adding their voices to the early intervention process, voices that have often not been heard (Sands, 1990). In general, the perceptions of families have rarely been sought in early intervention research (Guralnick, 1996). Much of the research has concentrated primarily on the needs and concerns of service providers, and the need to legitimize early intervention by demonstrating its

effectiveness(Minke & Scott, 1995).  This inquiry may be

important to early intervention professionals as well.

Professionals have concerns regarding their professional,

legal, and ethical responsibilities in providing services to

children and families (McBride, Brotherson, Whiddon, &

Demmit, 1993).

This inquiry may be relevant to social work on several

levels.  Specifically, Part H requires that social workers

be included as members of early intervention teams serving

infants and toddlers with developmental delays and/or

disabilities and their families (IDEA, 1992).  Second,

according to Saunders (1994), social workers have struggled

to define a consistent role for themselves in the early

intervention service continuum, yet their skills and

expertise in relation to working with families are needed.

Next, interdisciplinary practice is important because social

workers continue to practice in settings that require

collaboration with multiple disciplines (Sands, 1990).  A

focus on the family has been a central feature of the social

work profession from the earliest home visits of charity

workers and the community outreach of settlement houses

(Weick & Saleebey, 1995).

Finally, this inquiry was an attempt to redistribute

power in early intervention through the constructivist process of negotiating outcomes [described in Chapter 3]. Social work, as a profession, is dedicated to assisting the disenfranchised and empowering the powerless. Empowerment of families in the early intervention process is a central feature of the Part H legislation and is considered to be an important goal for early intervention professionals (Dunst et al., 1994). Empowerment, as defined by Breton (1994), means "gaining control over one's life, that is, gaining control over the factors that are critical in accounting for one's state of oppression or dis-empowerment" (p.24). However, empowerment is ambiguous and difficult to detect (Koren, DeChillo, & Friesen, 1992). Rappaport (1985) suggests that it is easy to notice the absence of empowerment but its presence is difficult to detect because it takes various forms in different contexts. The concept of empowerment also has a long tradition in social work (Weick & Saleebey, 1995). The concept of empowerment and its relation to this inquiry will be described in Chapter 2. The remainder of this dissertation consists of four chapters.

Chapter 2 is a comprehensive literature review. First, the principles of family-centered services are presented

with an emphasis on their importance to Part H. Second, research related to perceptions of families and professionals about family-centered services and barriers to implementation are presented. Finally, the framework of empowerment is described along with its relevance to family-centered services in early intervention.

Chapter 3 provides an overview of the unique characteristics of constructivist inquiry, especially related to policy analysis and the logic for using constructivist research as a means to understand the experiences of family-centered services across multiple stakeholder groups. Equally important will be a presentation of the emergent design as it unfolded throughout the inquiry process.

Chapter 4 is the presentation of the findings through the use of the case report method. The case report method provides the reader of this inquiry with a vicarious experience of what it was like to be a family that included a child with a developmental delay and/or disability in one LICC in the Commonwealth of Virginia. The perspectives of early intervention professionals from various service providing agencies and members of the LICC were also captured and presented in the case report.

Chapter 5 presents the implications from the case report.  Addressed in this chapter are implications about implementation of the family-centered intent of Part H, for family empowerment, for social work, and for future research.  Finally, a discussion of the lessons learned about the constructivist research process is presented.  A general discussion of each of these implications is provided.

Chapter 2

Literature Review

The following literature review will cover several important areas necessary to understand the nature of family-centered services in early intervention. First, the purposes and legislative intent of Part H is presented with an emphasis on its structure and impact on services at the LICC level. Second, the concept of family-centered services is explored with an emphasis on its importance to Part H. Third, research related to the perceptions of family-centered services from the perspectives of families and direct service providers in early intervention is presented. Fourth, a discussion of research related to barriers that have accompanied the implementation of family-centered services is presented. Fifth, the concept of empowerment is presented with an emphasis on the possibility for improving the direction and control families have over services in early intervention. The literature review will conclude with a discussion of the gaps in the literature.

### Purpose and Legislative Intent of Part H of IDEA

Part H established important rights and essential

services for children with disabilities ages birth through three years [birth through two years in Virginia] and their families (Stephens, 1993). Part H has several overall purposes. First, to develop and implement statewide, comprehensive, interagency programs of early intervention services for infants and toddlers with disabilities and their families. Second, to facilitate coordination of federal, state, local, and private funding sources. Third, to enhance each state's capacity to provide quality early intervention services and expand and improve existing services. Fourth, to enhance the capacity of state and local providers to serve historically under-represented populations (e.g., minority, low-income, inner-city, and rural) (Stephens, 1993). A final purpose of Part H is to assist service providers in meeting the developmental needs of children in partnership with families. It was hoped that this would be accomplished through family-directed identification of family concerns, priorities, resources, supports, and services that were needed to enhance the family's capacity to meet their child's developmental needs (IDEA, 1992).

Professionals in the field of early intervention, as well as the agencies for which they work, also have been

targeted by the Part H legislation. Part H mandated that the states' Interagency Coordinating Councils facilitate collaboration between agencies and individual professionals in the provision of services to infants and toddlers at-risk and their families (McCollum & Hughes, 1988). In order to understand the Part H mandate to include families in the early intervention process, it is important to include the perspectives of families, direct service professionals, and individuals involved in the design and implementation of the local early intervention system. To understand the mandate we must also examine the levels of regulation and the legislative intent of Part H.

All states have opted to participate in the Part H program for infants and toddlers. By agreeing to participate, states agreed to abide by a very unique regulatory structure. Federal regulations required states to submit plans for participation in the Part H program. The states were required to indicate in their plans how they intended to implement them and to provide assurances that they would comply with all federal requirements. States interpreted the federal regulations and developed state regulations to meet the federal mandates. The governor of each state was responsible for appointing a 15 member

Interagency Coordinating Council, made up of professionals, family members, and public and private agency administrators. They in turn appointed a lead agency and together they coordinated the implementation, regulation, and evaluation of early intervention services for the state (Brown, 1992).

On June 3, 1987, the Governor of the Commonwealth of Virginia designated the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS) as the lead agency to administer the development and implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency service delivery system for infants and toddlers with disabilities and their families (DMHMRSAS, 1991). Virginia's service delivery structure has traditionally been decentralized and has been carried out through a system of forty Community Services Boards (CSBs). CSBs are agents of local governments that are funded, monitored, and evaluated by the DMHMRSAS. In keeping with this tradition, Part H funds were allocated to a local fiscal agent in each CSB geographic region to establish forty LICCs. The LICCs were established separate from the CSB system and have no administrative ties to them. The LICCs were intended to promote local collaborative planning

as an integral part of Virginia's design and implementation of a statewide early intervention system. LICC membership included local persons representing parents [families], local CSB staff, early intervention program staff, medical and health providers, education agencies, social service agencies, advocacy groups, university affiliated personnel, and other service organizations (DMHMRSAS, 1991).

The LICC that served as the site of this inquiry was located in an urban environment. Funding for this LICC is unique. Federal Part H funds have been allocated annually to the LICC through the early intervention office of the DMHMRSAS. There are 22 organizations and programs affiliated with the LICC. Members of the LICC include the local CSB, the local Department of Health, the city's public schools, the local Department of Social Services, the Housing Authority, a developmental disabilities institute, two hospital-based early intervention programs, four community-based early intervention programs, and an informal parent organization.

Brown (1992) estimated that there were 450 Part H early intervention eligible infants and toddlers residing within this LICC in 1992. However, since 1992 the LICC has been consistently serving less than fifty percent of this

estimated total. For example, the LICC provided services to 153 infants and toddlers and their families from December 2, 1996 through December 1, 1997 (Virginia Part H Early Intervention Office, 1998). As a result, efforts to find eligible infants and toddlers has been an ongoing concern for Council staff. Another ongoing struggle for this LICC has been working with all twenty-two providers regarding the successful implementation of family-centered services (LICC Annual Report, July, 1997). This has been a significant concern for this LICC because of the emphasis placed on family-centered service in Part H of IDEA.

<div align="center">Family-Centered Services</div>

The clearest evidence of a family-centered philosophy in Part H of IDEA is the mandate for an Individualized Family Service Plan (IFSP) for programs serving infants and toddlers and their families. The IFSP must include documentation of family strengths and needs, specification of major family outcomes, description of services to be provided for the family, and the name of a service coordinator [case manager] to assist the family in implementing the IFSP and the coordination of services with other agencies (Bailey, Buysse, Edmonson, & Smith, 1992). Additionally, families were mandated to be important members

of the early intervention teams working to develop and implement the IFSP (Roberts, 1991).

The IFSP is an indicator of an early intervention practice movement away from child-centered services that focused solely on enhancing the developmental outcomes of infants and toddlers to an approach that included family support  (Bailey et al., 1992).  Enabling and empowering families were the foundation of the family-centered philosophy and the IFSP process.  Enabling families, as defined by Dunst et al. (1988) referred to the creation of capacities for families to apply their existing strengths and skills, and to acquire new ones as needed to meet the needs of their child and family.  According to McGonigel (1991), empowerment means interacting with families to assist them in obtaining a sense of control over their family lives and to attribute positive changes in themselves and their children to their own efforts.  The concept of empowerment has been used and described in many different ways, making it difficult to measure (Rappaport, 1985).

Family-centered services as outlined by Shelton and Stepanek (1994) include eight key principles.  These eight family-centered principles were considered to be the driving force behind the writing and implementation of the Part H

legislation (Shelton & Stepanek). The first element was the recognition that the family was the constant in a child's life, while the service systems and personnel change. Second, was the need for collaboration at all levels of care (e.g., one-to-one therapy, service coordination) between families and professionals. Third was the complete exchange of unbiased information between families and professionals. Fourth, was the recognition and honoring of cultural diversity, strengths, and individuality within and across all families. Cultural diversity in this context included ethnic, racial, spiritual, social, economic, educational, and geographic differences. The fifth element in Shelton and Stepanek's conceptualization of family-centered care was the recognition and respect for different methods of coping by families and then implementing comprehensive policies and programs that provided developmental, educational, emotional, environmental, and financial supports to meet the diverse needs of families. Sixth, was the responsibility of service providers to encourage and facilitate family-to-family support and networking. The seventh element dictated that hospital, home, and community services and support systems for children needing specialized health and developmental care and their families be flexible,

accessible, and comprehensive in responding to diverse family-identified needs. Finally, was the appreciation of families as families and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support. The structure and intent of Part H were designed to mandate the development of early intervention systems that promoted the principles of family-centered philosophy.

Several specific mandates were written into Part H requiring states to develop early intervention service delivery systems that were family-centered (IDEA, 1991). Specifically, elements of Part H that reflected the principles of family-centeredness included providing services solely to family members if the services would assist a family member and/or the family in general to better provide for the young child with a disability; mandating that a "written individualized family service plan be developed by an interdisciplinary team, including the parent or guardian"(p.67); and allowing the family to choose when to begin services (IDEA, 1992).

The intent of policy makers and funding sources involved in the writing of Part H was to design legislation

that would create family-centered early intervention services in each state. According to Dunst et al. (1991), more than ninety percent of the language and directives embedded in Part H reflected family-centered principles and practices. It was truly a landmark piece of legislation in this respect.

Family-centered services in early intervention did not begin with the passage of Part H. Rather, Part H formalized a trend toward family-centeredness that had been evolving for twenty years. Simeonsson and Bailey (1990) provided a summary of evolving forms of family-practices in early intervention. The earliest forms of early intervention consisted of prescribed programs of stimulation or therapy administered to the infant or toddler by an early intervention professional who assumed the role of the primary therapist. Parents were most often passive bystanders, and parent involvement was limited.

A second form of early intervention evolved with the recognition of the importance of family involvement in programs on behalf of children with disabilities. The concept of family involvement was formalized in 1975 with the passage of the Education for All Handicapped Act (EHA)(Education for All Handicapped Act of 1975). The EHA

specified the rights of parents to participate in the educational planning process on behalf of their school-aged child.

The importance of parent involvement was recognized as vital in early intervention as well. Parents began to emerge as critical members of the early intervention process, even though the concept of family-centered services was not yet formalized in early intervention. Parents were increasingly encouraged to become involved in their child's program, even though the nature of that involvement was not well defined (Simeonsson & Bailey, 1990).

In a third form, family involvement became more ingrained in actual practice by training family members to extend the teaching and therapist roles of early intervention professionals. Parents were encouraged to carry out instructional or therapeutic activities with their children as co-therapists with early intervention professionals.

The fourth form of family involvement recognized that families were both recipients and providers of services. This form of family involvement has been formalized within the provisions of Part H and has evolved into the concept of family-centered practice. It is now clear that family-

centered practices in the intervention process and the recognition of the family as a legitimate client are both accepted aspects of early intervention practice (Simeonsson & Bailey, 1990). What is not as clear is how the implementation of the principles of family-centered practice into early intervention settings has been perceived by families and service providers.

## Perceptions of Family Involvement

There has been little empirical research related to how professionals perceived the Part H mandate to include family-centered principles in early intervention services and even less research related to how families perceived the family-centered mandate. The major reason for the absence of research is that Part H has been in place only since 1986 and states had five years to design their systems for full implementation of its mandates (Bailey, Palsha, & Simeonsson, 1991). The research to date has focused on general perceptions of family involvement from the perspectives of professionals and families, and on perceived barriers to successful inclusion of the family in the early intervention process (Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992; Able-Boone, Sandall, Loughry, & Frederick, 1990; Bailey et al.; Beckman, & Bristol, 1991; Caro, &

Derevensky,1991; Gallagher, Malone, Cleghorne, & Helms, 1997; Gamel-McCormick, 1995; McBride et al., 1993; Minke, & Scott, 1995; Summers et al., 1990; Virginia Department of Mental Health, Mental Retardation, and Substance Abuse Services, Part H Early Intervention Office, 1996)

Translating the concept of family involvement into early intervention practice has proved to be difficult. Bailey et al. (1991) studied the extent to which 142 early intervention professionals from two states felt competent in working with families, valued family roles, and were concerned about adopting a family-centered practice model. The professionals surveyed, generally, felt that roles associated with working with families were an important aspect of their work. However, significant differences in perceived skills and valued roles emerged as a function of discipline. For example, nurses and social workers endorsed more family roles than did educators and allied health professionals. They also rated their family skills as significantly higher than did educators and allied health professionals. The professionals surveyed agreed, in general, that a family focus carried out in the context of an interdisciplinary team working in close collaboration can lead to uncertainty about the division of roles and

responsibilities in working with families.  Professionals
were especially concerned about how this change would affect
children and families.

Caro and Derevensky (1991) implemented the Family-
Focused Intervention model developed by Bailey, Palsha, and
Simeonsson (as cited in Caro & Deverensky, 1991) with
sixteen families to assess the effectiveness of family-
centered services.  The framework of the model postulated
that family relationships are key to achieving mutual
pleasure, increased child competencies, and understanding of
the child's role as a family member and as an individual.
Additionally, parent input is considered to be essential to
the successful development of individualized family-centered
plans and must include the entire family to ensure that the
needs of all family members are balanced, parents feel a
sense of control, and child progress is realized.

In this study, each family received a 2-hour weekly
home visit over a 5-month period.  Assessment and
intervention followed the six step procedures in the family-
focused intervention model.  Infants and toddlers were
evaluated using assessment instruments such as the Battelle
Developmental Inventory developed by Newborg, Stock, Wnek,
Guildubaldi, and Svinicki (as cited in Caro & Deverensky,

1991) and the Movement Assessment of Infants developed by Chandler, Andrews, and Swanson (as cited in Caro & Deverensky, 1991). Parents were assessed using the Family Resource Scale developed by Leet and Dunst (as cited in Caro & Deverensky, 1991), the Parent Behavior Progression Scale [Forms 1 and 2] developed by Bromwich (as cited in Caro & Deverensky, 1991), a parent satisfaction scale developed by the authors, and the Teaching Skills Inventory (Rosenberg & Robinson)(as cited in Caro & Deverensky, 1991). Finally, open-ended interviews were conducted with all 16 families at the conclusion of the five-month intervention period to obtain qualitative data about families' perceptions.

Through a combination of qualitative and quantitative data analysis, Caro and Deverensky (1991) concluded that the family-focused intervention model was effective. Family skills in several areas of parent-child interaction were enhanced. Additionally, high levels of parental satisfaction, accelerated rates of progress by children with moderate or severe disabilities, and acquisition of functional skills by families were all noted.

Gallagher, Malone, Cleghorne, and Helms (1997) conducted a study to assess the perceived in-service training needs for early intervention personnel. One

hundred fifteen personnel from public and private agencies assessed their current and future training needs in the areas of typical/atypical development, family systems/families' involvement, assessment, program implementation/evaluation, administrative team process, professional development, and technology. The results of this study indicated a strong need for more intensive in-service training for early intervention professionals. The authors felt that professionals were not receiving education in the above content areas in their professional education programs and should be addressed through in-service training.

Of the respondents with six or more years of experience, sixty-four percent indicated a need for training in several basic competency areas such as family systems/family involvement and assessment (Gallagher et al., 1997). Specifically, special educators and allied health professionals indicated the greatest need for training in the area of family systems/family involvement. Psychologists and social workers appeared to be the best trained to deal with family-related issues. Finally, professionals with more than six years experience were better prepared to work with families than personnel with

three to five years experience.

McBride et al. (1993) conducted a study to evaluate perceptions of families and professionals implementing IFSPs in Iowa. The sample consisted of fourteen families and fifteen professionals, all selected through a nominational or snowball sampling procedure. Findings indicated that while professionals understood the concept of family-centered early intervention, that understanding often did not translate into actual practice. Professionals remained more child-focused. However, families expressed overall satisfaction with the services they were receiving, especially in regards to decision making during the IFSP process.

In their study of IFSP development, Minke and Scott (1995) presented data on parent-professional relationships during the IFSP process. Parents and professionals emphasized the importance and benefits of personal relationships. Staff also reported significant concerns, however, especially doubts about whether parents had the necessary skills for full participation. These concerns appeared to make it difficult for staff to fully support parental decision making.

Although there may have been some agreement about the

values inherent in the IFSP, there was some disagreement between professionals and families about the appropriate areas of family life to include.  In their analysis of the IFSP process, Summers et al. (1990) reported several interesting findings regarding family involvement in the early intervention process.  First, families expressed concern about early intervention professionals demonstrating sensitivity to families, acknowledging the family as the ultimate decision maker, and acknowledging individual family preferences.  Second, families overwhelmingly requested a greater need for professionals to provide information about the disability, child development, services, and future expectations.  Finally, families expected early intervention professionals to assist them in developing a sense of community and belonging with other families who have children with similar needs.

Beckman and Bristol (1991) completed a content analysis of seventy-two IFSPs in Maryland and North Carolina to examine the types of goals present in the plans. Additionally, they conducted a survey with ninety-six early intervention professionals and sixty-four families to assess their perceptions of the family-centered approach to early intervention.  Findings from the content analysis revealed

that of the family goals they examined from IFSPs, only

sixteen percent of the family-defined goals involved

activities on the part of families.  The majority of the

goals were designed for professionals to carry out. Findings

from the survey revealed that there appeared to be some

basic perceptual differences between families' and

professionals' views of family-centered practice in the

early intervention process.  Professionals were concerned

that families did not have the necessary skills, while

families felt that professionals were not providing them

with information they needed.

In Gamel-McCormick's (1995) study of the experiences of

low-income mothers, the perceptions and experiences of Part

H early intervention services from the perspectives of

mothers from lower socioeconomic backgrounds with young

children with disabilities were investigated.  There were

six major findings from this study.  First, the mothers felt

that the quality of services they received was linked to

thirteen characteristics of early intervention staff

members.  The characteristics included the perceptions that

staff members were (a) caring, (b) good listeners, (c)

supportive, (d) consistent in their interactions with

families, (e) trustworthy, (f) open, (g) respectful, (h)

friendly, (i) accepting, (j) comfortable with the family,
(k) positive, (l) flexible, and (m) accessible. Second, the
mothers perceived early intervention staff members as
resources to assist them with their children, but they
wanted the early intervention professionals to treat them as
competent, intelligent caregivers. Third, the mothers
wanted early intervention professionals to work
collaboratively with them and with other early intervention
professionals. Fourth, they valued services that taught
them skills and techniques to make their daily lives and the
lives of their children better. Fifth, they valued services
that linked them to other agencies and programs that could
assist them. Sixth, the mothers were generally satisfied
with the services they received and were grateful for having
had the services.

Another study that directly solicited the views of
parents about early intervention services and family-
centered practice was conducted by Able-Boone, Sandall,
Loughry, and Frederick (1990). They identified several
themes regarding early intervention services and family-
centered services in particular. Parents were concerned
with the ability of early intervention professionals to
understand their family's needs and what services they

needed. Parents were not sure if professionals understood the upheaval that can occur when there is a child with a disability in the house. For example, such things as daily schedules and routines become very difficult to manage and the amount of time devoted to caregiving for the child with the disability can result in other children in the family feeling neglected. They also stated that they expected early intervention professionals to permit them to be the primary decision-makers about what was best for their children. Many of the parents stated that they had difficulty finding and accessing services. Finally, families indicated that information about their children's disabilities and available options for services should be provided to them by professionals so they could make informed decisions about services.

In another study, Able-Boone, Goodwin, Sandall, Gordon, and Martin (1992) conducted a 72-item survey with 290 family members to assess their perceptions of early intervention services. The survey asked families questions grouped into five categories including (a) accessing early intervention services, (b) delivering early intervention services, (c) identifying family priorities and resources, (d) developing and implementing IFSPs, and (e) coordinating early

intervention services.  Respondents in this study felt that

they were able to access early intervention services.

However, they indicated several concerns about the IFSP

process, including the desire for it to be a working

document instead of a document that is revisited annually or

semiannually.  Respondents indicated a concern about the

service coordination they were provided.  They felt that the

service coordination they received did not provide them with

supportive services and information, and their knowledge

level to enable them to make informed decisions was not

increased.

In their statewide survey of 1,029 families in Virginia

to assess the level of family satisfaction with early

intervention services, the Virginia Department of Mental

Health, Mental Retardation, and Substance Abuse Services,

Part H Early Intervention Office (1996) reported that

overall, families were satisfied with the services they

received.  Specifically, families: reported receiving the

services they were mandated to receive; felt listened to,

respected, and a part of early intervention teams; and

believed their goals and desired outcomes were present in

their IFSPs.  Some problems were reported, as well.  About

one-third of the families indicated that they wished they

had known about early intervention services earlier than they did. About ten percent of the families reported that they were unaware that one individual was assigned to them as a service coordinator. Finally, many families reported not being aware of their rights and protections under Part H, and about services available once they left early intervention.

## Barriers to Family-Centered Service Delivery

Research has uncovered numerous barriers that may make it more difficult to implement family-centered services. Moxely et al. (1989) claimed that the current nature of family-centered practice has been defined by service agencies and professionals rather than by families. Additionally, they pointed out barriers to family involvement such as resource availability, training needs, and skill development. Resource barriers referred to variables such as time available to work with families. The most frequently cited barriers to family involvement were family and system related barriers. Professionals suggested that many families may not have the knowledge or skills to participate fully in early intervention. Professionals also reported concern about families lack of interest in taking an active decision making role. Systemic barriers included

lack of administrative support, inadequate resources, and difficulty in changing established patterns of practice.

Several studies identify collaboration between families and their service coordinators as crucial element to successful delivery of family-centered services. Dinnebeil and Rule (1994) identified several variables that affected family and service coordinator collaboration. Using an open-ended interview format consisting of seven questions, interviews were conducted with 30 service coordinators and 60 families. Additionally, an expert panel of five early intervention researchers and program developers were mailed a questionnaire, asking the respondents questions about what they felt were important family/service coordinator characteristics.

Results of the expert panel questionnaire identified the need for professionals to be supportive of families as the most important characteristic. Support was defined by families as being good listeners, respecting families' wishes, and advocating for their needs with other providers. Family respondents rank-ordered the most important service coordinators' characteristics to be building rapport (57%), providing information (17%), demonstrating concern for children (9%), and maintaining a positive attitude (5%).

Characteristics that were considered to be barriers to
collaboration included actions that were unhelpful (33%),
attitude (16%), not spending time with the family (10%), and
threatening parents' self-esteem (4%).

Productive characteristics of families identified by
service coordinators included helpful actions (39%), good
communication skills (20%), positive parenting attitude
(17%), and demographic characteristics (10%). Demographic
characteristics referred to such things as perceived social
class and socioeconomic status. An example of such a
comment was "the kids that are clean, you are more likely to
want to pick them up" (Dinnebeil & Rule, 1994, p.358).
Unproductive characteristics of families included unhelpful
actions (23%) such as not being on time for appointments;
demographics (22%) such as socio-economic status; negative
attitudes (18%); and poor communication skills (17%).

The results of a survey by Mahoney and O'Sullivan
(1990) regarding early intervention practices with families
suggested several issues related to family-centered
services. There appeared to be little evidence that the
family-centered agenda embedded in Part H has enabled
families to become collaborative agents in the intervention
process. Several possible impediments to family-centered

intervention were identified in this study. One impediment
was the difficulty service providers had in allocating the
extra time required to carry out family-centered services.
Another impediment was the lack of preparation of service
providers to implement family-centered services. A final
impediment was the lack of appropriate resources and
effective programs for implementation of family-centered
services.

Nash, Rounds, and Bowen (1992) conducted a study to
examine the relationship between social worker membership on
early intervention teams and parental involvement in team
activities. Data were collected from 80 individuals who
took part in training workshops conducted by staff from the
Carolina Institute for Research in Infant Personnel
Preparation. All participants were members of
interdisciplinary teams working with infants and toddlers
with developmental disabilities. The dependent variable
[current level of parental involvement] was measured using
Family Orientation of Community and Agency Services
(FOCAS)survey developed by Bailey. The independent variable
[presence of a social worker on the early intervention team]
was measured by means of a background survey completed by
each participant.

Nash et al. (1992) found that team members who reported the involvement of a social worker as a regular member of the team reported a higher mean level of parental involvement (M=6.0) than did participants who indicated that they did not have a social worker on their team (M=4.15). Additionally, they identified several factors believed to affect the level of family involvement on early intervention teams. These factors included the disciplinary composition of the team, the organizational and community setting of the team, the values of team members, the team's conflict resolution and decision making styles, and the stage of development of the team. The authors cautioned that determining level of family involvement is largely dependent on the unique characteristics and composition of each team encountered.

Given the complexity of the early intervention service delivery system and the numerous barriers to involving the family, it is important to look at ways to overcome the barriers and provide families with the necessary supports to become meaningfully involved. Many of the components of Part H that referred to family-centered services had their roots in the concept of empowerment (Dunst & Trivette, 1992). Dunst and Trivette proposed that family empowerment

was the most important feature of Part H.  Understanding
empowerment was thus important to the understanding of the
experiences of stakeholders involved in early intervention.

Family-Centered Services and Empowerment

The proposed inquiry will be guided by the concept of
empowerment.  Identifying a unified meaning of the concept
of empowerment has been elusive, as there have been many
interpretations of the concept (Rappaport, 1985). In their
review and synthesis of empowerment literature, Dunst,
Trivette, and LaPointe (1994) found that the term
empowerment has been used in six different ways.
Empowerment has been described and discussed as philosophy,
paradigm, process, partnership, performance, and perception.
They attempted to combine these diverse descriptions of
empowerment to define a unified concept that would have
practical value for families and professionals in early
intervention.

From their synthesis of the empowerment literature,
Dunst et al. (1994) developed a model of empowerment that
depicted the major relationships among the six key elements
they extracted from their literature review.  Within the
model, the elements of philosophy and paradigm represented a
basic ideology from which empowerment activities would

emerge.  For example, stating that all individuals have

strengths that can be called upon could be considered a

component of an empowerment ideology.  The elements of

process and partnership represented participatory

empowerment activities that professionals and families would

engage in such as collaborative planning.  Finally, the

elements of performance and perceptions represented outcome

indicators of the empowerment process.

In addition to the Dunst et al. (1994) synthesis of the

empowerment literature, another consistent theme emerged

from a review of the literature related to empowerment.

There was a discussion of the nature of power leading to

several basic assumptions and propositions pertaining to

power relationships (Simon, 1994).  Several authors have

also discussed the concept of empowerment in relation to the

outcomes of these power relationships in relation to

oppression and domination (Cox, 1989; Freire, 1972;

Guiterrez, 1989a).  Empowerment in this context is change

oriented and assumes that the individual desires to change

the circumstances in their lives that are leading to

oppression and domination.  Change occurs as a result of the

individual's desire and ability to alter their environmental

circumstances to overcome oppressive circumstances (Parsons,

1991; Rose, 1990). The following brief review of the concept of empowerment will address these fundamental assumptions.

In order to understand the concept of empowerment, it is important to have a working knowledge of a few of its fundamental assumptions about power and its impact on individuals and groups. First and foremost, power is unevenly distributed in society. Power is defined by Simon (1994) as the ability to exert control over others and to have control over one's life. There are individuals and groups with power and many more who experience powerlessness. The powerless experience oppression, discrimination, and a general lack of control over their lives. Conversely, those who have power use it to dominate and control the powerless (Simon, 1994). The concept of empowerment serves as a tool for understanding the nature of power and powerlessness and then applies this knowledge to equalize the balance of power.

Powerlessness is not solely the result of one individual or group oppressing another individual or group, but is a more complex phenomenon. Cox (1989) posits that powerlessness is the result of multiple factors such as economic insecurity, lack of an understanding of the

political arena, an inability to access information, and lack of training in critical and abstract thought (Simon, 1994). Additionally, powerlessness can result from physical and emotional stress, learned helplessness, and the particular person's emotional or intellectual makeup that hinders the person from actualizing possibilities that do exist. Thus, powerlessness is the result of social and political phenomenon, economic conditions, interpersonal interactions, and individual characteristics.

Thoughts about how human beings respond to these power differentials in society have also been discussed by individuals in relation to the concept of empowerment. For example, Rose (1990) posits that human beings have the capacity to grow and change, regardless of their situation in life. Further, this capacity can involve the ability to change oneself and the environment. Additionally, Simon (1994) postulated that every individual, no matter how disadvantaged or incapacitated, has unique resources and abilities to exercise shared power in partnership with others. Finally, strength is best exercised in concert with others rather than alone (Simon, 1994).

From these basic assumptions, several propositions have been presented by various authors regarding empowerment.

First, person and environment are interactive. It is difficult to understand one without also understanding the other (Parsons, 1991). Change is most substantial when there is a change in both the individual and the environment. Thus, personal transformation and social change are interdependent and mutually reinforcing processes and serve as the ultimate goals of empowerment (Simon, 1994). Regardless of the fact that the individual and the environment are interactive and interdependent, Staples (1990) states that the individual remains the primary agent of change. If the individual is not motivated to change, then power does not rest with the individual and self-directed change does not occur.

Simon (1994) asserts that if individuals are to achieve personal empowerment, then they must be able to define a promised land for themselves, believe themselves worthy of it, and then be able to envision incremental steps to its achievement. Freire (1972) referred to this process as the development of a critical consciousness. A critical consciousness develops through a process of dialogue with others and education. Critical consciousness and knowledge of oppression are forms of power. Transformation occurs as people are empowered through consciousness raising to see

alternatives.  Guiterrez (1989a) adds that development of a

critical consciousness reduces self blame and enhances the

willingness to engage in personal-change directed behaviors.

The development of a critical consciousness by no means

assures oppressed individuals and groups the elimination or

even reduction of their oppressive circumstances; it merely

provides them the knowledge that they can change their

circumstances.

Oppression is one of the most important concepts in the

framework of empowerment.  Oppression is the result of more

than the actions of a specific individual or specific group

oppressing another individual or group.  Rather, oppression

is the result of multiple societal factors that create

oppressive conditions for certain individuals and groups

(Moreau, 1993).  As a result, no apriori assumptions can be

made about any hierarchy of different forms of oppression

regarding any individual or group.  Instead, Staples (1990)

argues that only empirical investigation of a particular

group, and of a particular individual, with a particular

problem, and at a particular time can verify the existence

of a hierarchy of oppressive circumstances for that

individual or group. The framework of empowerment posits the

existence of a dynamic interaction of individual internal

constructions, constructions of others, and a complex web of structural (e.g., social, political, and economic) phenomena that are necessary for the understanding of oppression and domination. Empowerment must be a process of thought and action that is dynamic and constantly evolving with ever-changing individual constructions and within social, political, and economic contexts.

Lee (1994) takes much of the above into consideration in delineating three dimensions of empowerment. These dimensions include: (a) the development of a positive and potent sense of self; (b) the construction of knowledge and capacity for more critical comprehension of the web of social, political, and economic realities of one's environment; and (c) the cultivation of resources and strategies, or more functional competence, for attainment of personal and collective goals. Lee's dimensions skillfully pull together the basic needs for individual and environmental change by pooling pre-existing natural supports through a process of education and mutual exchange. This is the essence of the empowerment process.

For empowerment to occur, Kieffer (1981) believes there are several requisite conditions that families need, including: (a) a personal attitude that promotes active

social involvement; (b) a knowledge and capacity for
critical analysis of the social and political systems that
define one's environment; (c) an ability to develop action
strategies and cultivate resources for attainment of one's
own goals; and (d) an ability to act in concert with others
to define and attain collective goals.  Additionally, Deal,
Dunst, and Trivette (1989) believed that the helping
behaviors of professionals should be viewed as a means of
enabling and empowering families to acquire skills to
provide support and mobilize resources for meeting needs.

   According to Dunst et al. (1995), the IFSP is the key
to family empowerment because of its emphasis on enabling
families and on strengthening families' natural support
networks without either usurping their decision making power
or replacing their natural supports with professional
services.  Additionally, the IFSP places emphasis on
enhancing a family's acquisition of a wide variety of
competencies that assist the family in becoming capable of
meeting their own needs with natural support (e.g., family,
friends, community supports, religious beliefs).  The
professional role is to assess the family's needs and
resources and then provide support and education to the
family to achieve its own goals.

Thompson et al. (1997) examined how the method of delivery for early intervention services affected perceptions of empowerment among families. A random sample of 270 respondents was obtained from a case list of families participating in the Early On [Part H services] program in Michigan. Family empowerment of parents of children with developmental disabilities was assessed using the Family Empowerment Scale developed by Koren, DeChillo, and Friesen and measured families along two dimensions: (a) level of empowerment, and (b) the ways in which empowerment is expressed. Empowerment was assessed at the family-level, service-level, and community/political-level. Additionally the Family Implementation Scale (FIS) was developed by the authors and the Family-Centeredness Scale was constructed from 14 items measuring the degree to which Part H principles guided service delivery.

Findings indicated that the implementation of Part H has had two effects on early intervention. First, implementation of Michigan's Early On, Part H Program elements as perceived by families, increased families' feelings of empowerment in the early intervention service delivery system. Second, implementation of Early On, Part H Program elements, as perceived by families, helped families

to engage or help families to employ others in their immediate family, extended family, and community in supporting their needs. In turn this improved the abilities of families to cope with the challenges and stresses that they faced.

Pinderhughes (1995) discussed the need for professionals working with families to focus their attention on culturally competent family empowerment. Specifically, professionals should possess the ability to respond to and appreciate the values, beliefs (e.g., religious), and practices of all families, including those who are culturally different. Pinderhughes believes that professionals must possess the ability to be comfortable with difference in others and to avoid defensive behavior in reaction to differences.

Pinderhughes (1995) discussed the dynamics of power and its implications for empowerment practice. To empower families, should early intervention practitioners be knowledgeable about the dynamics of power and powerlessness and how these forces operate in human functioning? Does knowledge of the dynamics of power in early intervention facilitate competence in developing strategies for empowering the family? Does power for families involve

leadership, influence, and decision making with the team; knowledge about child development and their child's developmental delay/disability; knowledge and understanding of Part H policies and procedures; or knowledge and understanding of the early intervention service delivery system?

Summary

Very little research has been published related specifically to family-centered services in early intervention. There are several possible explanations for this. First, Part H was enacted in 1986 and each participating state had five years to construct and implement their service delivery systems. As a result, research in this area is just beginning to emerge. Second, family-centeredness is a difficult concept to measure due to the variation in the types of settings in which early intervention takes place, the unique needs of children with developmental delays and/or disabilities, and the unique strengths and needs of families. Finally, families in early intervention interact with a range of service delivery providers, making it difficult to draw comparisons.

The preceding literature review revealed several important issues related to the implementation of a family-

centered philosophy to early intervention services. Research with early intervention professionals has demonstrated that there may be some barriers related to the successful implementation of family-centered principles in early intervention. First, it was clear that professionals understood the principles of family-centered practice, but they may not have translated them into actual practice. There was also evidence that professionals doubted the ability and motivation of families to participate fully in the early intervention process. Professionals felt that making early intervention services family-centered led to uncertainty and confusion about the division of roles on early intervention teams. Regardless, professionals seemed to value the attempt to incorporate family-centered principles into practice.

Research that has solicited the perceptions of families also revealed possible barriers to the implementation of a family-centered approach. The most significant barriers raised by families were the need for information about their child's delay or disability, the availability of services to meet their needs, and the availability of assistance with building support networks with other families. A related issue was the need for professionals to provide training to

families in skills relevant to the care of their children with special health care needs.  Families were also concerned about professionals demonstrating sensitivity to families, buying into the concept that families are the ultimate decision-makers, and recognizing the diversity of families and its impact on their needs.

Families were not sure that professionals always understood how challenging it can be to care for a child with a developmental delay or disability.  Families felt that the quality of services they received was linked most directly to the personal characteristics of the professionals with whom they worked.  Families also had to cope with resource and skill barriers such as transportation, child care, and lack of education and training in areas pertinent to caring for their children with developmental delays or disabilities.  Overall, however, families appeared to be satisfied with the services they received, even though they questioned some aspects of their experience.

Even with a willingness to involve families, barriers existed that made it difficult to implement family-centered services.  For example, many families did not have the knowledge of intervention techniques and access to service

delivery systems to participate meaningfully in the early intervention process. As a result, it was incumbent upon families to take active roles in learning the necessary skills and for professionals to teach these skills. Professionals were concerned that this was an unrealistic expectation because practicing family-centered services takes considerably more time and effort. Relationship building between families and professionals may have been problematic and the establishment of trust may have served as a barrier for the effective implementation of family-centered services as well. Finally, the service delivery system itself presented barriers to family involvement. Professionals were restricted by funding sources (e.g., providing only those services that were directly billable) or organizational constraints (e.g., lack of administrative support) when it came to implementing family-centered principles.

The concept of empowerment is useful for improving our understanding of the complex interpersonal, social, political, economic, and systems interactions that combined to influence the experience of families in early intervention related to the implementation of family-centered services. Additionally, the concept of empowerment

helps to focus us on the needs and desires of families who have children with developmental delays or disabilities. Understanding the nature of power relationships in the early intervention system, and the fact that person and environment are interactive, may lead families and professionals closer to the development of a critical consciousness. A critical consciousness may be achieved through education and dialogue between relevant stakeholders in the early intervention system with the ultimate goal of true family-centered services and thus, empowerment of families. Constructivist inquiry is a method for beginning this dialogue and for assessing whether change has occurred through the development of a critical consciousness.

Each of the above factors combines to present a confusing picture of the nature of family-centered services in early intervention. This inquiry is an attempt to improve our understanding of the nature of family-centered services in early intervention from the perspectives of those most intimately involved. It is hoped that as a result of this inquiry, all stakeholders (e.g., families, early intervention professionals, program administrators), will have an improved understanding of each other's perspectives of family-centered services as well as an

improved understanding of their own perspectives through open dialogue. Additionally, it is hoped that this inquiry will result in an improved understanding of how the concept of family-centered practice, as defined within the Part H legislation, has been translated and implemented in one local early intervention system. Finally, it is hoped that this inquiry will contribute to the empowerment of families by assisting them in making their voice heard so that they can have a say in the course of intervention with their child and family.

Chapter 3

Methodology

This study employed constructivist inquiry methods to examine the implementation of the family-centered intent of Part H of IDEA. The inquiry involved families and early intervention providers in one LICC in the Commonwealth of Virginia. Constructivist inquiry was the most appropriate method to investigate stakeholders' experiences with the implementation of family-centered services in this LICC for several reasons.

First, this inquiry was an investigation of the perceptions of families, professionals, and other stakeholders regarding their experiences with the early intervention process. The goal of this inquiry was to uncover highly subjective information from multiple stakeholder groups. Constructivist methods are well suited for research that seeks subjective information from multiple stakeholders because of the use of qualitative methods and sampling strategies that include participants from each stakeholder group. Second, because of the focus on context, constructivist inquiry is best used when understanding of a

single case (e.g.,individual, group, organization) is desired. Part H is a unique federal policy providing states considerable flexibility to interpret its regulations. In Virginia, this flexibility trickles down to the local level. The case in this inquiry was one LICC in an urban service delivery system.

Presenting the philosophical foundations of constructivist research is critical before presenting the constructivist methodology. Constructivist inquiry is fundamentally different from research conducted within a positivistic paradigm (Anderson & Barrera, 1995). The constructivist paradigm is founded upon five axioms highlighting the nature of inquiry. These five axioms are presented along with a discussion of their implications for constructivist policy analysis. The elements of the constructivist design as applied in this inquiry are also described, such as sampling, instrumentation, data collection, data analysis, and establishing methodological rigor (i.e., trustworthiness and authenticity). The chapter will conclude with a consumer's guide to the case report, providing some technical information for reading the case report that follows in Chapter 4.

## Constructivist Axioms

Of the five axioms guiding constructivist inquiry (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985), the first is ontological: what is the nature of reality?  It is asserted in the constructivist perspective that multiple, socially constructed realities exist that are shaped through the day-to-day experiences and interactions of individuals.  There is no single reality waiting to be discovered, instead reality is individually and socially constructed (Anderson & Barrera, 1995; Guba & Lincoln, 1989; Master, 1991; Robertson, 1994).

The second axiom is epistemological: what is the relationship of the knower to known?  Constructivist methods suggest it is impossible to separate the constructions of the inquirer from the constructions of the inquiree (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985; Rodwell, 1990). Data emerging from the interaction between the two--knower and known are inseparable.

Third, constructivist inquiry is not concerned with generalizable truths that may be applied across time and context (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985; Rodwell, 1990).  The purpose, instead, is to undertake an ideographic process to develop deep understanding of

individual cases within a particular context at a particular
time.  Through the use of a case report, this understanding
is presented in a way that others can make use of the data.

The fourth axiom states that all entities are in a
state of mutual shaping resulting in the impossibility of
distinguishing cause from effect (Guba & Lincoln, 1989;
Lincoln & Guba, 1985; Rodwell, 1990). The constructivist
inquirer does not concern himself/herself with cause and
effect relationships.  The essence of the mutual shaping
process is what the constructivist researcher finds most
interesting.

Finally, values are central to constructivist inquiry
(Anderson & Barrera, 1995; Guba & Lincoln, 1981, 1989;
Lincoln & Guba, 1985; Rodwell, 1990).  The constructivist
researcher does not attempt to control or hold values in
check; rather, he or she recognizes that all inquiry is
value-bound.  The emergent values are clearly defined so the
inquirer and the case report consumer can determine their
influence on the outcome.  The inquirer's values shape the
research by influencing the problem chosen for study, the
selected methodology, and the paradigm in which the inquiry
occurs.  The inquiry is also influenced by the values
inherent in the context in which the investigation takes

place. Most importantly, to conduct meaningful research, there must be congruence between the values of the inquirer and the research paradigm (Lincoln & Guba, 1985).

The preceding axioms yield fourteen implications for conducting constructivist research (Lincoln & Guba, 1985). To begin with, research is carried out in natural settings and humans are used as the primary instruments for data collection. The inquirer employs tacit knowledge, qualitative methods, purposive sampling, and inductive data analysis. The constructivist inquirer engages in grounded theory building, uses an emergent design, and negotiates the final outcomes with stakeholders. The case study reporting mode is used in place of a scientific or technical report, as it is more amenable to thick description [descriptive to the point of providing a vicarious experience for the reader] of the many realities present within any single inquiry (Geertz, 1973). Data are interpreted ideographically and the results are tentative. The constructivist sets boundaries to the inquiry to define proper terrain for the inquiry by selecting a specific focus (Lincoln & Guba, 1985).

## Methodological Rigor

Methodological rigor is demonstrated with

trustworthiness and authenticity (Lincoln & Guba, 1985,

1990).   Trustworthiness consists of four elements that

roughly parallel the more traditional criteria of internal

and external validity, reliability, and objectivity (Lincoln

& Guba, 1985, 1990).   The elements are (a) credibility, (b)

transferability, (c) dependability, and (d) confirmability.

The criteria for these elements establish the quality of the

final product of the inquiry.   Credibility exists when there

is congruence between the constructions of the respondents

and the reconstructions presented in the final report.

Transferability is established when the case report provides

a thick description of the setting and participants which

the case report consumer can use to determine applicability

of the findings to other settings.   Dependability is

demonstrated when evolution of the methodology is

understandable and deemed appropriate for the particular

inquiry.   Confirmability is demonstrated by the quality of

data management and data analysis--can assertions made in

the case report be traced back to raw data?

        Authenticity is the other method of establishing

methodological rigor.   Authenticity is unique to

constructivist inquiry, and criteria to demonstrate it are

in the early stages of development (Lincoln, 1995; Rodwell,

1995).  An element of the research process, authenticity

relates to the interaction between the inquirer and

subjects.  It is first concerned with the fairness of the

process-did the inquirer seek all perspectives and was equal

consideration given to all perspectives?  Second,

authenticity is concerned with how involvement in the

research process affects participants.  Specifically, it

refers to four "states of being" that indicate depth of

understanding and motivation to act (Lincoln & Guba, 1990,

p.2).  As a result of participation in the inquiry, do

participants have an improved understanding of their

individual perspectives and of the systems they represent

(i.e., ontological authenticity)?  Do participants have an

improved understanding of and respect for the perspectives

of others (i.e., educative authenticity)?  Are there actions

that may result in change generated or facilitated by the

inquiry (i.e., catalytic authenticity)?  As a result of the

inquiry, has power been redistributed among and between

participants and are the participants empowered to act

effectively (i.e., tactical authenticity)?

Constructivist inquiry, by its very nature, is a

political act (Guba & Lincoln, 1989).  This type of

research, conducted rigorously, has the potential to empower

every participant and facilitate social change. Mutual

understanding and possible consensus, may be reached through

the process of eliciting the constructions (i.e.,

participant views of phenomena) of participants and

reconstructing them during the course of the inquiry. The

process is referred to as the "hermeneutic dialectic" (Guba

& Lincoln, 1989). The hermeneutic dialectic process is an

interpretive technique that involves continuously comparing

and contrasting different perspectives in an attempt to

reach the highest level of mutual understanding and

sophistication about the subject of the inquiry. This

process requires that all participants engage in the inquiry

from a position of integrity; that competent communication

is possible; that participants are open to shared power,

change, and reconsideration of value positions; and, that

adequate time and energy are available to be committed to

the process (Guba & Lincoln, 1989). Paramount to a rigorous

constructivist inquiry is a skilled and committed inquirer.

## Inquiry Design

Constructivist inquiry cannot be pre-designed; it must

emerge, develop, unfold throughout the inquiry process

(Lincoln & Guba, 1985). To quote Lincoln and Guba (1985),

Designs must be emergent rather than preordinate

because meaning is determined by context to such a

great extent; because the existence of multiple

realities constrains the development of a design based

on only one [the investigator's] construction; because

what will be learned at a site is always dependent on

the interaction between investigator and context, and

the interaction is also not fully predictable; and

because the nature of mutual shapings cannot be known

until they are witnessed. (p.208)

Emergent design is necessary because meaning, to a large

extent, is determined by the context in which the inquirer

is seeking understanding (Patton, 1990). The inquirer must

then be free to change as the inquiry evolves [emergent

design].

For a design to be truly emergent, the inquirer must

not be guided by any preordinate theory. Having stated

this, it would appear that the use of grounded theory

building within an emergent design is a contradiction.

However, grounded theory building is part of the

constructivist inquiry process and not the ultimate product.

The inquiry process is cyclical. It begins with purposive

sampling, followed inductive data analysis and grounded

theory building of emerging data which sets in motion an

emerging design leading back to purposive sampling.

Theoretical assertions that are presented in the final case

report are not intended to be statements of fact, rather,

they are tentative assertions about the theoretical

relationships within the context of the inquiry site.

Findings are not generalizable, rather, they are tentative.

It is the responsibility of the reader of the case report to

determine the applicability of the contextual theoretical

assumptions to other sites.

This particular inquiry design emerged along several

dimensions. The focus of the inquiry evolved from an

emphasis on interdisciplinary teams to a focus on family-

centered services in early intervention, because as

interviews were conducted, it became clear that issues

surrounding interdisciplinary team functioning were not

important to families or professionals.  Participants voiced

concern for issues regarding whether and how this early

intervention system was family-centered.  As a result of

this shift in focus, decisions regarding sampling,

instrumentation, phases of the inquiry, data collection, and

data analysis were made. These shifts are outlined in detail

in the remainder of this chapter.

Steps were taken to ensure the trustworthiness of the

findings and authenticity of the research process. The inquirer engaged in extensive peer review and peer debriefing, conducted ongoing member checking, as well as a comprehensive member check at the completion of preparation of the case report. Also, a thorough audit trail was maintained, so an independent audit of the research process could be conducted.

## Sampling

Purposive sampling is the sampling method of choice in a constructivist inquiry (Guba & Lincoln, 1981, 1989; Lincoln & Guba, 1985; Patton, 1980). The first step in collecting a purposive sample is to identify a few members of the phenomenal group one wishes to study. Next, the inquirer asks already identified members to nominate others until the inquirer feels he or she has reached the point of redundancy [repetitive information]. Further, the sample should be selected to provide for maximum variation, a method of purposive sampling that selects respondents to ensure inclusion of diverse perspectives (Patton, 1980). Lincoln and Guba (1985) suggest the constructivist inquirer consider four elements in the sampling process to: (a) provide for identification of initial elements, (b) provide for the orderly emergence of the sample, (c) provide for the

continuous refinement or focusing of the sample, and (d)
plan for termination.

Sampling for this inquiry was completed in accordance
with the above criteria.  These sampling tasks were
accomplished by selecting initial participants from the
family and professional stakeholder groups.  The LICC
coordinator, the LICC family services specialist, a family
support coordinator group, and an employee from the state
Part H office were the initial elements in this inquiry.
These individuals helped to identify additional stakeholder
groups, as well as recommend individual participants.  As
part of the maximum variation sampling process, participants
were asked to nominate individuals who would help extend,
test, and fill in information provided by prior
participants. For example, as it became evident that
families who chose not to enter the early intervention
system could provide unique insight, participants were asked
to nominate such individuals.  Sampling constantly focused
the inquiry on salient aspects of family-centered practice
in this LICC.  Sampling in the professional stakeholder
group was discontinued when the participant pool for the
selected sites was nearly exhausted.  Within the physician
group, however, only three physicians agreed to participate

in this inquiry.  Sampling was also discontinued in the
family group when the point of redundancy was reached.

    This inquiry occurred in one LICC in an urban service
delivery system with a range of programs and agencies
providing early intervention services.  While 22 programs
[sites] provide early intervention services in this LICC,
four fundamentally different types of providers were
initially selected as study sites: a center-based provider;
a home-based provider; a hospital-based provider; and a non-
Part H provider [hospital].  These sites were chosen because
they represented what was originally considered the range of
early intervention service providers that participated in
team-based intervention.  As the focus shifted from
interdisciplinary team issues to the implementation of the
principles of family-centered practice, additional
stakeholder groups and sites were identified.  The local
service delivery system itself became the focus of the case
study, as a result sites chosen for this inquiry needed to
be representative of the overall service delivery system.
Sites added included the local school's early intervention
program, physicians offices, and the CSB. Individuals
representing each site were nominated by participants during
interviews and were included in the sample.  In addition to

the early intervention program sites, interviews were
conducted in families' homes.

Table 1 presents the characteristics of individuals who
comprised the sample for this inquiry.  Twenty early
intervention professionals were interviewed, representing a
range of disciplines and providers.  Participants in the
professional group included five social workers, two
occupational therapists, one physical therapist, one nurse,
four early childhood educators, two service coordinators,
two pediatricians, and one family practice physician.  Four
individuals were employed by a home-based program, five
worked with a center-based program, two worked with a
school-based program, two worked with the CSB, one worked
for an organization that collects early intervention data,
three were physicians (e.g., one family practice physician
and two pediatricians), and five were LICC employees.  Five
of the twenty professionals were African American; the
remaining participants were white/Caucasian.

Table 1

Participant Characteristics

|  | Family Participants | Professional Participants | Total |
|---|---|---|---|
| **Race/ethnicity:** |  |  |  |
| African American | 14 | 5 | 19 |
| Caucasian/white | 8 | 15 | 23 |
| **Sites:** |  |  |  |
| Center-based | *NA | 5 | 5 |
| Home-based | NA | 4 | 4 |
| Hospital-based | NA | 2 | 2 |
| School-based | NA | 2 | 2 |
| LICC | NA | 5 | 5 |
| CSB | NA | 2 | 2 |
| **Income level (receiving some form of public assistance):** |  |  |  |
| Low-income | 15 | NA | 15 |
| Middle-income | 7 | NA | 7 |
| **Type of household:** |  |  |  |
| Dual parent | 12 | NA | 12 |
| Single parent | 9 | NA | 9 |
| Grandparent | 1 | NA | 1 |

| Discipline of provider:<br>    Administrator | NA | 3 | 3 |
|---|---|---|---|
| Educator | NA | 3 | 3 |
| Family Practice MD | NA | 1 | 1 |
| Nurse | NA | 1 | 1 |
| Pediatrician | NA | 2 | 2 |
| Occupational Therapist | NA | 2 | 2 |
| Physical Therapist | NA | 2 | 2 |
| Service Coordinator | NA | 2 | 2 |
| Social Worker | NA | 4 | 4 |

**\* Many families received services from multiple providers**.

To improve understanding of the experience of families in the early intervention system in this LICC, it was important to interview families with a wide range of backgrounds and experiences. Twenty-two family participants were interviewed. All but three interviews were conducted with the mother of the child with the developmental delay and/or disability--two were conducted with the father and mother together and one interview was conducted with the

grandmother and primary caregiver for the child. Nine of
the parents were single parents. Fourteen family
participants were African American and eight were white.
Fifteen family participants classified themselves as lower-
income while the remaining seven indicated they were middle-
income. Six of the family participants were active members
of the LICC. One family participant had a developmental
disability herself and another participant had a physical
disability. Finally, four family participants had children
who were eligible for early intervention services, but never
obtained services from the early intervention system.

Data Collection

LICC staff provided initial access to early
intervention program [for programs included in the sample]
documents such as annual reports, brochures, and other
similar descriptive sources. These documents were reviewed
for content related to program philosophy and family-
centered practice. This information was used to provide a
conceptual base regarding each program and to distinguish
between the types of services each provided (e.g., hospital-
based, community-based, school-based). This process helped
the inquirer ensure sampling for maximum variation occurred.

While data were primarily collected via in-depth

interviews with participants from each stakeholder group,

the inquirer observed five LICC meetings. Document analyses

and observations of LICC meetings were also used for

triangulation of incoming data.  Prolonged engagement

[extensive exposure to data sources] and persistent

observation [in-depth exploration of data] (Lincoln & Guba,

1985), important elements in constructivist research, were

assured through a commitment on the part of the inquirer and

the reflections of the peer reviewer (see peer review

journal, Appendix B).  The inquirer maintained contact with

data sources by becoming a participant in many of the LICC's

activities.  For example, the inquirer developed instruments

and a process to assess family satisfaction with early

intervention services.  Concepts that emerged during data

collection became the topic of discussion for numerous

meetings with LICC staff, early intervention program staff,

and families.  Data collection continued until information

collected became redundant and the data collection process

approached one year in length. The inquirer had the luxury

of being able to test emerging concepts with data sources.

This involvement continues today.

The primary data recording mode was field notes.

Lincoln and Guba (1985) discussed the data recording

dimension of fidelity. Fidelity refers to the ability of the inquirer to exactly reproduce the data obtained in the field at a later time (Guba & Lincoln, 1989). The greatest fidelity can be obtained using audio or video recordings. As a result, a possible limitation of relying solely on fieldnotes is that the content of direct quotes is dependent upon the inquirer's ability to accurately record respondents statements.

While less fidelity is obtained through the use of field notes, there are several advantages to using field notes as opposed to recordings. First, field notes may be less threatening to respondents than audio recording. Second, note taking forces the inquirer to pay attention and remain alert. Third, technical problems with mechanical equipment are avoided (e.g.,a broken recorder or defective tape). Fourth, field notes provide easy access to interview content if the inquirer needs to follow up on specific information or return to a pertinent point made by the respondent or inquirer [this becomes especially useful for member checking during each interview]. Finally, as the interview unfolds, the interviewer can record his or her thoughts regarding nonverbal cues or inconsistencies in the respondent's answers (Bogdan & Biklen, 1992; Guba & Lincoln,

1989; Lincoln & Guba, 1985). Lincoln and Guba (1985) feel that the advantages of using field notes are so great that they do not recommend recording devices, except in special circumstances.

For this inquiry, each interview or observation was recorded in a field note journal and expanded within 24 hours of the interview. The expanded field notes were compiled using WordPerfect 8.0. The average interview length was approximately 90 minutes and average size of data files was 8 double spaced pages. Each expanded interview was contained in a separate data file. All data recording activities were completed by the inquirer.

<u>Instrumentation</u>

The instrument of choice in a constructivist inquiry is the human instrument (Anderson & Barrera, 1995; Lincoln & Guba, 1985; Rodwell, 1990). Field notes were recorded during each interview and expanded within 24 hours to include observer comments, non-verbals, and descriptions of the setting. Since interviews were not audio tape recorded, it was especially important for the inquirer to diligently record all pertinent information during the interview and expand each interview as expeditiously as possible. Lincoln and Guba (1985) stress the human instrument is not perfect.

Thus, serious attention was paid to the human instrument during the inquiry process to continually refine and improve the ability to conduct effective interviews. For example, the inquirer continually read and critiqued completed interviews to develop and improve data recording techniques. Additionally, the inquirer reviewed several completed interviews with a peer reviewer who provided feedback on the inquirer's data recording style.

## Data Analysis

Data collection and data analysis are interactive processes in constructivist inquiry (Guba & Lincoln, 1981; Lincoln & Guba, 1985). It is important to note that the interaction between data collection and data analysis shapes initial findings and assists in the structuring of subsequent interviews. The interactive process between data collection and data analysis stimulates a hermeneutic dialectic process wherein understanding of the multiple perspectives present in early intervention is achieved (Lincoln & Guba, 1985). Practically speaking, the hermeneutic dialectic process involves the establishment of a communication loop between and among all participants. This process was initiated in the data collection process by sharing information received with each successive

participant. Additionally, the inquirer completed follow-up interviews with many participants to provide them with analyzed information received since their interview and to ask for their response to this information. A reflexive journal was used during data collection and analysis to make note of emerging themes and working hypotheses generated by this interactive process. Additionally, the reflexive journal was a place to record thought processes, philosophical positions, and justifications for methodological decisions made during the inquiry.

While data analysis occurs throughout the data collection process, formal data analysis does not begin until the inquirer decides to begin unitizing data. Unitizing data involves the breaking down of data into the smallest piece of information that can stand on its own (Lincoln & Guba, 1985). A unit can be a word, a sentence, a paragraph, or a whole page, as long as it "is interpretable in the absence of any additional information" (p. 345). Each data unit is coded so it can be traced back to the original "raw" data [field notes], and meet confirmability requirements [confirmability is discussed below]. Each data unit received a specific code including the following: (a) a code for each interview such as F7 which stands for family

participant number 7; (b) page number(s); and (c) line
numbers where data unit appeared.  An example could include
*F7:2-3:12-19.*  Within the case report, each assertion was
often linked to multiple data units, so a sequential endnote
reference list was created to account for each data unit.
For example, endnote number 256 could include several data
units (e.g., F7:2-3:12-19; P3:2:29-30; RefJ:45:1-23).

　　Constructivist data analysis occurs in an open-ended
way using the "constant comparison" method (Glaser &
Strauss, 1967). Constant comparison involves comparing each
data unit to every other data. For this inquiry, data
analysis began with the first interview, which set the
emergent design in motion, the grounded theory process, and
further structured later data collection (Lincoln & Guba,
1985).  Upon completing each interview [after expanding
field notes], the inquirer compared the new data to existing
data to identify emerging themes.  Thoughts about these
comparisons were recorded in the reflexive journal, so the
inquirer would have a record of analyses and decisions made
based on these analyses.  This information was used for more
formal data analysis after all data were collected. It was
also used as a record of logical methodological decision
making for the final audit.

Data analysis was conducted manually.  Each data unit
was coded on individual index cards.  Each index card
contained the data unit and information linking the data
unit to a specific  interview, page, and line. Approximately
1,800 data units were coded on index cards. Once data were
unitized, they were compared to each other and sorted into
conceptual piles (e.g., data units that conceptually fit
with one another).  Literally, this involved sitting on the
floor with all 1,800 index cards and reading them over and
over and stacking cards in piles around the room.
Initially, there were 22 separate conceptual groupings.
These conceptual piles were assigned labels (i.e., child
protective services), and were compared with each other to
discern patterns that later evolved into themes. This
process continued until all units were grouped into major
constructs that gave meaning to the process.  These
constructs served as the foundation for the major assertions
made in the case report regarding family-centered service
delivery in this LICC. This process is the essence of
grounded theory development (Miles & Hubberman, 1994).

It is during this stage of the constructivist process
that the inquirer must be most on guard (Lincoln, 1995).
Interpreting data at higher levels of abstraction requires

intellectual rigor.  With the inquirer as the primary data
collection and data analysis instrument, it was imperative
to have a well-developed professional self.  The inquirer
had to be flexible to adapt to themes that emerged
unexpectedly, to adjust to new, unexpected data, and to be
patient and thoughtful throughout the data analysis process.
For this inquiry, intellectual rigor was accomplished by
diligently recording thoughts and feelings in the reflexive
journal, using family and professional consultants, a peer
reviewer to check for logical thinking, and returning to
pertinent stakeholders when gaps and inconsistencies were
uncovered.  When initially interviewing respondents,
permission to contact them again if necessary was requested.

Phases of the Inquiry

A constructivist inquiry proceeds through several
phases allowing the inquirer to determine salient elements.
Three major phases compose the constructivist research
process (Lincoln & Guba, 1985): (a) orientation and
overview, (b) focused exploration, and (c) member checking.

Orientation and overview begins with prior ethnography,
information gathered before beginning data collection.  For
this inquiry, prior ethnography included a preliminary
analysis of early intervention services within this LICC in

the summer of 1995. Several issues pertaining to early intervention were identified and assisted in informing this inquiry. It was discovered that families often received services from more than one early intervention provider. It was also discovered that teams were often composed of professionals assigned to a team by their department (i.e., Department of Occupational Therapy in a hospital-based program), not by individual or team choice. Additionally, preliminary contacts were made with direct service professionals, agency administrators, early intervention program administrators, and LICC members. Several of these individuals were gatekeepers to both family and professional participants in this inquiry. Finally, a thorough review of literature related to early intervention was conducted to provide the inquirer with the basic concepts of early intervention, empowerment, family-centered practice, and an overview of Part H of IDEA, as well as recent legislative developments in early intervention.

Questions for stakeholder interviews during phase I provided the inquirer with the "the grand tour" of family-centered practice in this inquiry (Spradley,1979). The questions in phase I revolved around issues related to family-centered practice in this LICC. Simply put, what was

important information to know about family-centered practice
in early intervention that also needed to be addressed in
detail during phase II of the research process.

Phase I interviewing consisted of several important
steps. First, two key informants from each stakeholder
group were identified by contacting several individuals that
the inquirer knew professionally and requesting some initial
contacts. As key informants were identified, interviews
were conducted. Interviews were open-ended. Questions
included: "What do you think I need to know about family-
centered practice in early intervention" or "What are some
of the major issues with family-centered practice in your
Council, program, or family?" Phase I lasted for
approximately four weeks and resulted in the formulation of
the following foreshadowed questions:

Foreshadowed Questions.

As part of an emerging design, interview schedules
evolved as issues were identified in this inquiry. However,
initial research questions or foreshadowed questions were
formulated so the inquirer could begin interviewing. These
initial foreshadowed questions formed the basis of the first
few interviews. There were five foreshadowed questions.

1. Are families empowered by receiving the

information they need in order to fully
participate in the early intervention process?

2.  Are families willing and motivated to participate
    in the early intervention process?

3.  Are professionals sufficiently empowered to be
    able to include the family in team decision
    making?

4.  Are professionals willing and motivated to
    actively assist families in participating?

5.  Are there systems barriers that prevent
    professionals from including families, and
    families from choosing to participate?

The goal of phase II was to obtain an in-depth
understanding of stakeholder identified issues. The
questions above were used to delve more deeply into the
issues regarding family-centered practice that emerged in
phase I.  As new issues were identified, additional
questions were included in the interview format. Some
questions that did not appear relevant to the experiences of
stakeholders were eliminated from the interview format.

Sampling during phase II was the same as in phase I,
except that each participant chosen considered to be
competent to address the issues identified in phase I.

Selecting qualified participants was achieved during the purposive sampling process. At the conclusion of each interview each participant was asked to nominate individuals they felt would have knowledge of the identified issues. Competence was also ensured by making preliminary contacts with nominated individuals to assess both willingness to participate in the inquiry and their level of knowledge regarding specific issues.  A focus on the emerging issues was pursued during this phase by constant member checking (i.e., checking previously identified issues with each successive respondent for their perspectives). Member checking also built a hermeneutic circle of information to raise critical consciousness in participants.

Sufficient time was allowed between phases II and III to analyze data collected in phase II and to write an initial case report.  During this phase, the initial case report was mailed to twenty participants representing each stakeholder group. Accompanying the case report was a cover letter that outlined the purpose of the member check, four questions that asked respondents to consider while reviewing the case report, and a postage paid return envelope for sending responses back to the inquirer. Only two individuals responded to this initial mailing.  Attempts were made to

contact stakeholders via telephone to increase the response to the member check. An additional eleven stakeholder were reached and interviewed via telephone to increase the total number of individual responses to thirteen. Each participant was asked to scrutinize the case report, confirm, correct, and/or extend the data to establish credibility. This aspect of the constructivist inquiry process allows for negotiated outcomes as opposed to solely researcher defined outcomes. Data from all thirteen member check interviews were analyzed for information relating to confirmation of findings, errors in inquirer reconstructions, and/or incomplete information. Analysis of the member check data revealed consistent confirmation of findings and no need for changes to the case report.

The comprehensive member check process is intended to be a strategy for assuring the trustworthiness of the inquiry process. This process, however, also facilitated an examination of some dimensions of authenticity. Overall, participants reported that many of the issues identified in the inquirer have changed, or at least, are no longer issues for them. They attributed this change to their involvement in this process.

## Trustworthiness

Lincoln and Guba (1985) outline criteria for achieving trustworthiness in a constructivist inquiry--credibility, transferability, dependability, and confirmability. The first criteria is *credibility*, which seeks to assure that the findings accurately reflect the constructions of stakeholders.  It assesses the degree to which the inquirer has represented the multiple constructions adequately and that the reconstructions accurately reflect original stakeholder constructions. Additionally, it is important to assess the degree to which the stakeholder reflections are accurate and truthful.  Planning for credibility requires that time and resources allotted are sufficient for prolonged engagement and persistent observation to assure capturing the scope and depth of data collected, to enhance the level of trust between the inquirer and participants, and to reduce the potential for the inquirer to be misled (Lincoln, 1986).

The schedule for this inquiry provided the necessary time for prolonged engagement and persistent observation. Data were collected for one year from participants and the inquirer also attended monthly LICC meetings and other early intervention meetings during this time.  Additionally,

consultants employed during the inquiry process were regularly contacted [formally and informally] for nearly three years. Also, triangulation with other stakeholders through observation of LICC meetings and review of documents were used to verify incoming information and achieve depth of information.

A peer debriefing process was also used to promote credibility. Peer debriefing and review involved regular meetings with a peer, to ensure that methodological decisions, data analysis and interpretation were logical and grounded in the data. The peer debriefing and review process provides an opportunity for the inquirer to test working hypotheses and to help clear the inquirer's mind of emotions and feelings that may interfere with his or her judgement (Lincoln & Guba, 1985). The peer debriefer is especially crucial to the conducting of a constructivist inquiry and important in establishing credibility.

Susan Ainsley-McCarter, Ph.D., was my peer debriefer and reviewer for this inquiry. Susan is a graduate of the doctoral program in social work at Virginia Commonwealth University (VCU) and has experience both conducting a constructivist inquiry and in serving as a peer debriefer and reviewer. The peer debriefer and reviewer serves as a

research consultant/advisor whose role is to support and monitor the inquiry process.  Lincoln and Guba (1985) stated that the peer debriefer should be an individual of equal standing with the inquirer, a person knowledgeable in the substantive area and experience in the methodology, accepting of the difficult and time-consuming process, and willing to diligently maintain a record of the peer debriefing process.  Based on previous personal and professional interactions with Dr. McCarter, I believed she possessed all of these qualities.

Records of our peer debriefing sessions were maintained by Dr. McCarter in a peer debriefing journal and by me in the reflexive journal. Approximately forty hours of formal peer debriefing and review were conducted during the course of this inquiry; however, many more peer debriefing hours were logged informally through telephone conversations, email exchanges, and impromptu meetings.  Thoughts and reflections about methodological decisions were maintained by Dr. McCarter and myself, in our respective journals.  I also noted the impact of the interactions between Dr. McCarter and me regarding methodological discussions in my reflexive journal.  At times, Dr. McCarter merely confirmed my decisions, but she also challenged me on several

occasions to justify decisions she did not feel were grounded in the data. She was most important to me during the final stages of data collection when decisions needed to be made about terminating data collection. Finally, Dr. McCarter was an important sounding board for coping with the stress of analyzing data and writing the case report.

Member checking is an important strategy to ensure credibility; it took place on two levels. First, member checking involved a process in which data were continuously assessed for accuracy. While collecting data, study participants were asked for input regarding how data should be interpreted and summarized. On a more informal level, the inquirer sought verification of ideas regarding developing concepts that emerged during interviews, conversations with participants and more formal conversations with inquiry consultants. Member checking was an ongoing activity.

The second level occurred prior to completing the final case report. The member check was completed by providing twenty participants, representing all major stakeholder groups, with copies of a completed draft case report. Three individuals completed the summary sheets. A follow-up telephone call was made to the remaining 17 individuals.

Four of these individuals could not be reached and one
individual chose not to complete the process. The remaining
thirteen individuals agreed to complete the member check
process via telephone interview. Each participant was asked
to review the report and assess it for accuracy and provide
any feedback that he/she felt was necessary. Specifically,
participants were asked if he/she felt the case report
provided an accurate description of early intervention in
this LICC, if they could identify their voice in the case
report, and if they felt that the case report needed to be
modified in any way. Changes indicated during the member
checking process were included in the final case report.
Necessary changes were recorded in the reflexive journal and
the methods journal. Summary sheets of feedback from each
individual were compiled and included as components of the
audit trail. Preparation of the final case report began
when the comprehensive member check was complete.

*Transferability* refers to the inquirer's task to
present the case report in a manner that provides a thick
description of the context to enable a case report consumer
to reasonably decide the transferability of the findings to
another context (Skrtic, 1985). In other words, is the case
report sufficiently descriptive for others to determine if

what has been learned has been meaningful to them and should working hypotheses be assessed in the context of different environments?

Several strategies were used in the case report to provide a thick description of the context. First, the LICC's purpose, location, staffing, and functions were described to present the case report consumer with an understanding of how the early intervention system was organized to facilitate the implementation of the principles of family-centered practice. Second, each site from which participants were sampled, was described in detail providing an image of how services were actually provided by professionals. Third, the two non-Part H provider sites were detailed to provide a description of other systems that affected families. Finally, a short story about the experiences of one family illustrated how the system, providers within that system, and non Part H providers actually affected a family.

Planning for *dependability* and *confirmability* means preparing for the last task of constructivist inquiry, the audit. Lincoln and Guba (1985) believe that a single audit can assess the criteria for both dependability and confirmability. Each, however, involves distinct measures

of trustworthiness. Dependability requires assessment of
the process, in which the inquirer engaged to carry out the
inquiry. Specifically, dependability includes assessing
methodological shifts, the degree and incidence of inquirer
bias, the overall design and implementation of efforts, and
integration of the outcomes for dependability. Record
systems were created (e.g., journals, data files, document
log and documents, and coded data units) for this inquiry to
account for methodological decisions as the inquiry evolved,
to assure that the assertions in the case report could be
traced back to raw data, and to confirm that the process
emerged in a logical manner. The inquirer kept a
methodological journal to record changes, serving as the
foundation for the dependability audit. The emergent design
indicated changes in methodology occurred as the inquiry
progressed.

Confirmability is attained when all elements of the
case report can be traced to the raw data and the inquirer's
interpretations of the data and subsequent methodological
decisions were deemed logical (Lincoln & Guba, 1985). In
this case, confirmability involved assessing whether the
findings were grounded in the raw data, inferences based on
the data were logical, the structure of categories were free

of overlap and at the same level of analysis, the inquirer accounted for negative evidence, and the level of inquirer bias was examined. A coding system was developed to allow an independent auditor to trace findings back to raw data. Additionally, records were kept regarding data interpretations and category development summarizing the inquirer's decisions during this process.

## Authenticity

Authenticity refers to the quality of the inquiry process. Five authenticity criteria should be considered in a constructivist inquiry: (a) ontological authenticity, (b) educative authenticity, (c) catalytic authenticity, (d) tactical authenticity, and (e) fairness. Each criterion assesses different aspects of possible change in participants and the system that may be linked to the inquiry process (Lincoln & Guba, 1985).

Ontological authenticity is assessed by determining the degree to which participants become more aware of the complexity of the social environment. Educative authenticity is evaluated by ascertaining the extent to which participants experience an increased awareness and respect for other stakeholders' viewpoints. Catalytic authenticity is determined by considering the degree to which the inquiry

process facilitates and stimulates action leading to change in the service delivery system.  Tactical authenticity is assessed by examining whether power is redistributed among stakeholders.

Finally, planning to meet the criteria of authenticity requires attention to the criterion of *fairness,* which ensures that all stakeholders have an equal voice representing and the case study presents a balanced view of all the voices. Guba and Lincoln (1989) describe fairness as a process to assure that all stakeholders are included and have an equal voice in both the presentation of their own constructions and in negotiating the outcomes. Sampling methods are especially important in the planning of fairness. It is important to engage in a sampling process that includes representatives from each stakeholder group to ensure fair representation of each stakeholder group perspectives.

Several strategies were used to assure fairness. First, methodological decisions were explained and justified to the peer reviewer.  On several occasions, the peer reviewer pointed out inquirer biases that may have detracted from the fairness of the process. For example, the peer reviewer identified the inquirer's reluctance to pursue

sampling physicians as a possible bias.  This could have resulted in misrepresentation of issues related to the connections that physicians had to the early intervention system. Second, the process of recording design, methods, and personal thoughts in the self-reflexive journal served as an important tool for assuring fairness and continually reviewing entries as the inquiry unfolded forced the inquirer to consistently re-visit methods decisions.

The third strategy to increase the likelihood of fairness involved using several consultants from the major stakeholder groups.  Three individuals representing the family group, direct service professional group, and the LICC agreed to participate as consultants.  They were contacted, either in person or by telephone, at least once a month during the data collection phase to review emerging sampling decisions, working hypotheses, and other aspects of an emerging design.  Their role was to advise the inquirer regarding methodological decisions, such as sampling throughout the inquiry to facilitate fair stakeholder representation.  Entries in the reflexive journal included issues regarding authenticity throughout the inquiry. Specific decisions resulting from discussions with the consultants were also recorded in the methodological

journal.

Ontological and educative authenticity refer to change in individual stakeholders (i.e., increased awareness of the complexity of the social environment and improved understanding of the perspectives of other stakeholders). Post-case study, focused interviews with participants who were unaware of the complexity of the early intervention system and individuals who held extremely biased views about other stakeholders were conducted to assess change in perspectives. Purposive sampling was used to select individuals. For example, a family that was initially uninformed about the local service delivery system was selected to assess the degree to which their understanding improved. The goal of the focused interview was to determine the degree of consciousness raising [ontological authenticity] and increased understanding of, and respect for, the values of other stakeholders [educative authenticity].

*Catalytic* and *tactical* authenticity are much more difficult to assess, as they illustrate change resulting from the inquiry process. Specifically: Did the inquiry stimulate action on the part of stakeholders to improve methods of involving families in the early intervention

process [catalytic authenticity]?  Were families empowered

to meaningfully participate in the planning and delivery of

early intervention services?  Were other stakeholders

empowered to include families in the service delivery

process [tactical authenticity]?

The degree to which catalytic and tactical authenticity

were achieved was assessed through post-case study

interviews with selected individuals representing each

stakeholder group, analysis of authenticity journal entries,

several research reports, and review of relevant program and

policy documents.  The post-case study interview schedule

included questions reflecting the degree to which the

inquiry stimulated stakeholder action and the extent to

which families were empowered in the early intervention

system in this LICC.

### The Audit Process

Lincoln and Guba (1985) recommend using the Halpern

algorithm to conduct an audit.  The Halpern algorithm

consists of five stages: (a) pre-entry; (b) determination of

auditability; (c) formal agreement; (d) determination of

trustworthiness; and (e) closure (p. 320).  Appendix B

provides a copy of the contract negotiated between the

inquirer and auditor, as well as a detailed list of the

tasks completed to carry out this audit. Appendix C
contains the audit report.

The most crucial element for a successful audit is a
well-maintained audit trail (Lincoln & Guba, 1985). The
audit trail consisted of detailed data collection records of
data collected (e.g., raw field notes, expanded field notes,
documents analyzed, unitized data, and categories consisting
of multiple data units); journals chronicling thought
processes, methodological decisions, and interpretation of
data (e.g., methods journal, reflexive journal, peer review
journal, and authenticity journal); instrument development
(e.g., interview questions); and summary feedback forms used
during the comprehensive member check.

The authenticity journal, program and policy documents,
and data obtained from post-case study interviews were used
to complete an authenticity audit, while the trustworthiness
audit simultaneously assessed the degree to which
authenticity was achieved. The authenticity audit evaluated
the degree to which the process was considered fair and the
criteria for ontological, educative, catalytic, and tactical
authenticity were achieved. In essence, the methods for
evaluating authenticity added a fourth phase to the inquiry
process as it occurred after preparing the final case

report.

Mr. Michael Crosby, a Clinical Social Worker and a Doctoral Candidate in Social Work at the Virginia Commonwealth University School of Social Work, conducted the final trustworthiness and authenticity audit. Mr. Crosby has the experience with constructivist inquiry to qualify as an acceptable auditor. Further, he is a peer [doctoral candidate], so I was not in a position of power over him, nor he over me.

A draft contract was developed, along with a table delineating the requirements of conducting an audit using the Halpern algorithm. Mr. Crosby was provided the contract and table along with a copy of the methods chapter and case report. Mr. Crosby reviewed the material, then we discussed the details of the audit to determine whether to move forward with the audit. Once we reached agreement about the expectations of the audit, we met to review all the inquiry materials to determine the auditability of the inquiry records. The inquirer explained the record keeping strategy (e.g., journals, raw field-notes, and expanded field-notes) and the audit trail. We reviewed the Halpern Algorithm and conducted several sample assessments such as tracing an assertion in the case report to raw data.

When agreement was reached that the records were of sufficient quality to conduct an audit, Mr. Crosby took all of the inquiry records and began the audit. The inquirer remained available to the auditor via telephone, email, and in-person if necessary throughout the process. The audit process was completed in one week. Once it was complete, the inquirer and auditor met to discuss the results of the audit.

The final phase of the audit was the preparation of the audit report. The auditor prepared a draft of the report and forwarded it to the inquirer. The inquirer reviewed the report to ensure it contained all the necessary elements. Upon receiving the inquirer's comments, the auditor prepared the final audit report and forwarded it to the inquirer.

Understanding the purpose and intent of the constructivist research methodology is essential to interpret constructivist results presented in a case report. The case report has unique features that need to be described to make the task of reading the report easier. Thus, the final section of this chapter is a brief consumer's guide to the case report.

### A Consumer's Guide to the Case Report

The findings presented in the following case study

represent individual reconstructions of the information collected from families and early intervention professionals in the LICC.  These reconstructions were derived from the stated issues and concerns related by the participants.  The case study is organized around themes which emerged regarding key issues and concerns.  The importance of an issue or concern as presented in the following case study is a function of the frequency with which  stakeholders mentioned it, as well as by the attachment of stakeholders' emotional investment in the issue.  Highlighting and valuing certain issues and concerns is an interpretive process based on constant reflection by the inquirer, resulting in tentative conclusions that are subsequently confirmed or challenged by further inquiry.

Direct quotes from study participants are indicated by quotation marks and numerical footnotes that correspond to footnote references, that are linked back to expanded fieldnotes for each interview found in Appendix A. The numerical references appear as lowercase Arabic numerals directly to the right of a quote.  They represent the transcribed interview code name, the page of the interview and the line numbers where the quote appeared.

Chapter 4

Findings

I believed, and still do, in the guiding principles of
family-centered services; however, when I started this
inquiry, I did not understand how families perceived family-
centered services or how agencies and professionals have
translated the concept of family-centered practice into
actual interventions.  This inquiry was undertaken because
of the need to understand the connections between the intent
of the Part H legislation to mandate family-centered service
delivery systems [policy-in-intent], the struggle to develop
family-centered and coordinated systems of service delivery
at the local level [policy-in-implementation], and the
experience of families in one LICC [policy-in-experience].
The goal was to increase understanding of the intentions of
professionals in this LICC attempting to develop a family-
centered system and the impact that implementation of these
intentions would have on the experiences of families who
have children with developmental delays and/or disabilities.
This understanding will lead to a dialogue between
professionals and families that will translate into further

empowerment of families in the early intervention system.

The major focus of this chapter is the case study. However, the chapter begins with a description of the settings in which this inquiry took place. Transferability of findings is dependent upon the researcher providing a thick description of the setting in which the inquiry took place. The reader of this case report must decide whether the findings are transferrable to different settings and contexts (Lincoln & Guba, 1985). A brief description of the LICC where the inquiry was conducted is provided. Within the LICC there were a host of early intervention programs and providers for infants and toddlers with developmental delays or disabilities and their families. A brief description of four different types of early intervention programs is provided. An overview of the case report is provided. One family's experience is described in detail. This family's story will provide the reader with a thick description of one family's home as well as their experience in the early intervention system. This family's story also introduces the consumer to the overarching themes that emanate from the case report. The case report concludes with a section on the lessons to be learned from the case report.

## Setting the context: The Local Interagency Coordinating Council

The major functions of the LICC were to construct a coordinated system of service delivery for families in the city. The LICC was expected to design activities to meet a set of priorities identified by the state Part H Office that included: (a) guiding the development of an interagency system of early intervention services, (b) establishing and participating in an ongoing system of monitoring and evaluation, (c) implementing family support activities to enhance the family-centered nature of Part H, and (d) implementing training activities to enhance the local Part H system (IDEA, 1992). It was up to the LICC to decide how it will meet these priorities.

The LICC consisted of 3 full-time staff: a Council Coordinator, an Information and Resource Specialist, and a Training Consultant. The Training Consultant position is currently vacant. The Council also employed several part-time Child Find workers. The Child Find workers were parents of children who are or have been through the early intervention system. The purpose of these positions was to have families with experience in the early intervention system available to contact families who may have been

reluctant to speak with a professional about early
intervention services. The Child Find workers went door-to-
door trying to provide families with information about early
intervention services. The Council also employed an
undergraduate student worker part-time to assist with
various clerical tasks.

The LICC offices were located on the 16th floor of a
hotel in two converted hotel rooms. The LICC was one of
many programs and projects that composed a larger
developmental disabilities institute. The Institute
occupied the 15th and 16th floors of the hotel. It was a
unique environment from which to conduct the business of
early intervention and interagency collaboration. The two
small offices were joined by a door at the back of the
offices, there were two entrances from the hall. The
offices served as both work space and storage area for
everybody and everything. The offices were jammed with
Council materials. There was very little space for anything
else on the desks, tables, bookshelves, or even the floor.
All the activities of the Council was based in these two
small offices. (aa)

The LICC, however, was much more than the two small
offices or the staff employed there. The LICC was a system

that consisted of many shareholder agencies and programs.
There were 22 state and local service delivery agencies
represented on the Council.  There were many different types
of service providers involved in early intervention
activities in the city such as the Department of Health, the
Department of Social Services, the Visiting Nurse
Association, hospitals, the public schools, private for-
profit providers, public non-profit agencies, and the local
CSB.  There were also several parent representatives who
were members of the Council and who participated in many
Council activities.  Families were encouraged to attend all
meetings and to be very active.  Their participation was
supported by providing on-site daycare for all Council
meetings and by providing money for  transportation.

     Representatives from many of these agencies attended
monthly Council meetings held at different locations in the
city.  Families were always in attendance.  The purpose of
the Council meetings was to involve families in LICC
planning, encourage interagency collaboration, and to
problem solve as an interagency team.  The Council meetings
were held on the third Wednesday of every month.  They were
generally well attended, active meetings.  While each
meeting had a focus, there was still open discussion about

issues in the LICC between and among providers and families.

The LICC itself provided very little direct early intervention to families.  Intervention was carried out by the 22 member agencies and programs that were members of the Council.  Four fundamentally different types of providers were selected as sites for this study: a center-based provider, a home-based provider, a hospital-based provider, and a non-Part H provider [hospital].  Additionally, three interviews took place in physicians' [family-practice and pediatrician] offices.

Center-Based Program

The center-based program was located in an old elementary school building directly behind a hospital on the city's north side.  Offices were located in small rooms up and down the high-ceilinged hallways.  One of the staff interviewed had an office that resembled a converted utility closet.  It was very small, cramped, and had no windows. The developmental play rooms were full of toys and games all directed towards therapeutic activities.  These rooms were very large and spacious, they resembled small gymnasiums, with many large windows that provide the room with a well lit, cheerful atmosphere.  The building itself resembled a square donut.  There was one hallway with classrooms on

either side that formed the square shape [the donut] and there was a large courtyard in the middle of the building [the donut hole]. They had just finished construction on an accessible and developmentally appropriate playground in the courtyard. The general atmosphere of the staff and the building itself was positive and hopeful. It was a comfortable safe place to be. It must have been inviting for families to come in for therapy.(bb)

## Home-Based Program

The home-based program was a program within a much larger agency that provided services to individuals with developmental disabilities of all ages. The physical surroundings were unique. The agency was located in a large, dreary building in an industrial part of the city. The building was probably once a small factory. The program was located on the ground floor in a corner of the building. The program itself was a mixture of open offices, developmental playrooms [small rooms] and a large group play room complete with toys, games, and equipment. While the building itself was old and dreary, the atmosphere of the infant program was very inviting because of the combined office and intervention space. The staff conference room doubled as a play therapy room--developmental toys were

piled all around the table. A staff person could be sitting
at their desk and hear and see a child and parent engaged in
play in one of the rooms within a few feet of their office.
This made for a warm, cozy, and welcoming atmosphere.(cc)

## Hospital-Based Program

The hospital-based program had a very different feel to
it from the other early intervention programs. First, it
felt like a hospital; it had a cold sterile feel. It was
not uncomfortable but it was certainly not inviting. The
program itself was solely center-based. Families had to
come into the hospital for services. Clearly the staff
followed the medical model: there was a distinct patient-
professional relationship. In addition, there were several
major changes underway while I was interviewing there that
gave the perception of underlying tension and anxiety.
Staff appeared to be protecting what they had. The final
difference was that there was a much stronger emphasis on
billing for services.(dd)

## Hospital (non-Part H provider)

This hospital was the largest in the city and it served
the majority of the city's population. It was located in
the downtown area of the city and was in the middle of the
medical campus of a university. Hospital staff were

organized around disciplinary departments or services. For example, there was a social work department and an occupational therapy department.

Professional staff from each department saw a variety of patients each day. None primarily saw early intervention eligible patients. They were, however, an important access point for families into the early intervention system. They saw many infants and toddlers considered to be at risk for developmental delays whose families otherwise may never have known that early intervention services existed.

One of the staff interviews was conducted in the hospital's cafeteria. The participant was late to the interview because she had a crisis to respond to that involved a case of suspected child abuse. She said that this was not uncommon for her in a normal work day. This interview and another interview conducted on a service floor provided a sense of how hectic and chaotic this environment was and how intimidating and frightening it must have been for families. It was loud, people were moving about quickly and anonymously. There were no friendly exchanges. In fact it was almost as if you did not exist because nobody payed attention to you unless you demanded it. (ee)

Family Practice Office

Three physicians participated in this inquiry. One of these physicians was a family practice physician and his office is described here to provide some feeling for the environment families face in a physician's office. The family practice doctor was the member of a practice that consisted of 6 physicians. It was a very busy and hectic office. The doctor had his own small wing with four exam rooms. Each of the exam rooms were typical of any doctor's office (e.g., exam table, chair, stool with wheels, small sink with overhead cabinets--an overall clean and sterile feel). The interesting thing about the exam rooms was that there were personal pictures of a ski trip and a trip he took several years ago to the Carribean. Also, he had little signs that said things like, "Dr. Bob says to exercise to lower blood pressure." Every room had both of these types of items in them.

There were two things that you noticed about the atmosphere of the practice right away. First, the noise level and the pace of the staff was intense. The nurse and the doctor were moving very quickly and spent only a few minutes with each patient. Second, the exam room walls were thin, you could hear what was going on in every room. This

could not have created a very comfortable environment for a family to speak openly with their doctor about a suspected developmental delay with their child. Also, it was not a conducive environment for the doctor to notice anything but glaring developmental concerns. (ff)

The preceding descriptions of the various settings in which this inquiry took place set the stage for the remainder of the case report. The transferability of the findings from this inquiry are dependent upon both a description of the context of the inquiry as well as on the reported and observed experiences of participants. The next section of this case study provides a brief introduction to the presentation of the findings.

<u>Case Study</u>

The following case study is a presentation of a dialogue that took place between and among the many stakeholder groups in the early intervention system in this LICC.  Because the case is a large complex service delivery system, the issues present are similarly large and complex. This posed some challenges in presenting the case study findings in a way that would provide the reader with a vicarious experience while remaining true to the perspectives of all participants.  The challenge was to describe this system and the perceptions that many individuals have of this system in a personal and meaningful way.

The Smith's early intervention story introduces the reader to this case study and provides a framework for connecting the major themes that emerged.  The Smith family's early intervention experience embodied each of the major themes present in the findings.  Even though they are only one of many family participants in this case study, their story exemplifies the overall family experience in this LICC.  At the conclusion of each section, the reader will be reintroduced to the portions of the Smith's story related to that theme.  The purpose of this approach will be

to connect the Smith's story to the larger case report as well as to transition the reader to the discussion of the next theme.  We begin with the Smith's story.

The Smith's Story

Mary was standing at the cutting table with several bolts of brightly colored fabric in her arms, patiently waiting her turn.  She was keeping an eye on 3-year-old Monica who was busy pushing her play shopping cart around the table.  The cart was more for the purpose of stability than for play.  Monica has Cerebral Palsy and has braces on both of her legs.  Mary thought proudly of how strong-willed that little girl is.  "She wants to walk around the store just like the other little girls her age so she pushes her shopping cart around wherever we go, it gives her the stability she needs to walk independently."(1)

A woman with another bolt of fabric was standing behind Mary with an impatient look on her face.  She sighed loudly as Mary began talking with the sales woman who was preparing to cut the fabric. They were discussing the merits of purchasing your own fabrics to make children's clothes as opposed to paying the exorbitant prices in stores like Kids-R-Us.  Just then, Monica came around the corner of the cutting table pushing her shopping cart.  She passed between

Mary and the impatient woman.  As she passed she looked up at Mary, smiled and said "beep-beep mommy."  Mary smiled back at Monica, whose plump, soft smile exudes warmth and friendliness to those with the ability to notice.(2)

Monica had stopped just a few feet from Mary to inspect something in a basket next to the table when the impatient woman stepped up and interrupted Mary's conversation with the sales woman.  "Why do you bring that handicapped child out in public places and she looks stupid pushing that cart?" she snapped.(3)  Mary immediately looked at Monica to see if she had heard what this insensitive person had said. Monica's hands were no longer on the shopping cart and the joy that was there a minute ago was gone.  Mary had her answer.

Mary thought to herself that she could accept one comment or chalk an incident such as this up to the actions of one individual except for the fact that it has happened all too often.  Like the time at the playground, she thought, when I was sitting with some mothers watching our children play.  We were watching Monica struggle with putting her hat on correctly because she has a problem with understanding herself spatially.  One of the mothers sitting there said, "'What is wrong with that damn disabled kid?

And what is wrong with her mother for letting her try to play with normal kids?' I was so mad I couldn't even speak to her, so I just walked away and started playing with Monica."(4) Mary continued, "People say the most hurtful things, I sometimes can not believe what they say."(5)

Driving home from the fabric store Mary found herself in a reflective mood.  This was partly due to the incident in the store, partly because of how much it hurt to see her child's self image assaulted by a careless stranger, but mostly because of how tired she was of fighting with people all the time.(6)  Monica had fallen asleep in the back seat as she always does after a hard day of shopping.  Mary could see her sweet face when she looked in the rear-view mirror and she wondered how anybody could be so cruel to a child with such a beautiful face.  She thought to herself, "But it has always been that way, we have had to protect our children and fight for them every step of the way.  If you slack off for a moment, the world walks all over you."(7)

Mary pulled the minivan into the gravel driveway just as Monica awoke.  Mary and Bob were in the process of building an addition onto the south side of the house.  She sighed when she saw the construction debris around the house.  With four children, two of whom have Cerebral Palsy

and need adaptive equipment, and another child experiencing
an unspecified developmental delay, the extra space was very
much needed.  Bob was standing by the side of the house
talking to one of the contractors.  The contrast between Bob
and the contractor was noticeable.  The contractor was tall,
thin, and in good physical condition.  Bob was short,
rotund, and pale as a ghost--except for his frequently
flushed face.  Bob is a little more conservative than Mary,
but he is a genuinely friendly man.  Bob simply reserves
judgement about people until he has had time to thoroughly
assess them.(8)

Mary grabbed the shopping bags and called for Bob to
come help get Monica out of the car and into the house.
Monica was still half asleep.  Mary walked up the front
steps and through the door.  As she walked in she tripped
and nearly fell over one of Johnnie's crutches. Clutter she
thought to herself, I can not stand this clutter.  She was
right, the house was very cluttered with boxes, toys,
tricycles and other items of everyday living in a large
family.  Someone might say the house looks very lived in,
but Mary would say "no, it's a mess."(9) With construction
comes temporary chaos.  Boxes and furniture are piled up
against walls in the living room, hallway, and dining room--

and then there are the children's things scattered everywhere.

Monica was fully awake by the time Bob had carried her into the house. She wanted to help put some of the day's shopping haul away, but she quickly tired of this and drifted toward the sounds of her brothers and sister watching *Snow White* in the living room. This left Mary and Bob in the kitchen alone so Mary took this rare opportunity to tell him about what happened in the fabric store. But Mary needed to do more than just tell him what happened, it was one of those times where she needed to get it all out. She and Bob agreed that they needed to have a long talk that night after the kids were all in bed. Mary hoped her anger and frustration could be kept at bay until then.

Mary quietly pulled the door shut to the girls' room. Monica shared a room with Alisha, the family's youngest child. She tiptoed down the hall, taking care to avoid all the creaky boards in the floor. Bob is always amazed at how skillful Mary is at this ritual because he never makes it more than five feet down the hall before he steps on a loud board that is loud enough to wake the children, which starts Alisha crying again. He watched Mary creep down the stairs with a big smile on her face because she knew that if she

made it to the bottom of the stairs, Alisha would be asleep
for the night.

"Well, how did it go with the insurance company
today?", asked Bob.

Not good, in addition to the services they have already
cut back on they gave me the impression that they would
like to drop Johnnie and Alisha altogether.  It makes
me so angry, because both of them need early
intervention and if the insurance company will not pay
for them, we will pay for it ourselves.(10) It is so
frustrating, Bob.  Remember when they would not pay for
Monica's evaluation and you gathered up all the
paperwork and forms ordering the evaluation from the
doctor's office and went down to the insurance company
to fight for the evaluation and they still would not
pay for it?(ll)

'Of course,' he sighed, 'how could I forget.'

"They will not pay for Monica's horse therapy even
though it is doing wonders for her.  They will not pay for
physical therapy at home for any of the children, and now
this."(12)  Mary handed Bob a letter that they had just
received from the insurance company.  The letter said that
the company was no longer going to pay for any therapies

provided at the early intervention center where their children receive therapy. The insurance will now only pay for therapy at the HMO health center. "They do not do early intervention there," Bob exclaimed, "they are not early intervention providers or even pediatric specialists. We have to do something Mary!"(13)

Yes, I know, I contacted the early intervention center and our pediatrician. The center is going to work with us to stop this from happening and our pediatrician is very fired up about it. He feels that this is totally ridiculous and is going to help us fight this battle. They think we can work this thing out but it still might require another visit to the insurance company from you.(14) Even so, it is just a constant battle with the insurance company and I am getting tired of fighting with them over every single issue.(15)

"We have been very fortunate with our pediatrician. Would not it have been nice, Mary, if all of the other pediatricians had been this helpful?"(16)

Yeah, I know, Mary agreed. "Do you remember that before Monica was born we loved our pediatrician, we thought he was great?"(17) We were so naive then and we definitely did not know what we were in store for. "We had no idea what

Cerebral Palsy was and had never heard of early intervention
before. We did not even know whether there was a problem or
not."(18)

I think it was when she was about 18 months that we
first started to become concerned.  Monica was not
walking, sitting-up, and just not doing well.  But
every time we approached the doctor he kept putting us
off.  He kept saying 'Oh do not worry, she is just a
little behind but there is nothing wrong, some kids are
just later than others.'(19)  Then Alisha was born and
had 'failure to thrive.'  That was when the real
trouble started for us.  The pediatricians in the
practice started to gang-up on us.  They said that she
was not gaining weight because I wasn't feeding her.
They were accusing me of neglect! Thank God we fired
that set of pediatricians otherwise we may never have
found out what was really going on.(20)

Yeah, you're right, Mary.  If we hadn't moved to
another practice and requested our medical records we
never would have seen the letter from the
Gastroentologist to the pediatrician saying that they
were wrong, it had nothing to do with us, we were
feeding Alisha fine but she wasn't gaining weight.

There was no reason to believe that we were neglecting
our child. They were going to report us for child
abuse!(21)

Mary and Bob just sat on the couch for a few minutes,
not saying a word.  They were lost in the feelings and
trauma of that difficult time.  Both were wondering why
their pediatrician had not consulted them and why the
doctors had planned to make a report behind their backs.(22)
Mary had been a child protection worker so she knew how
close they were to being reported.(23)

Mary broke the silence:  "That was so scary and it has
made me really conscious and afraid of what I tell
physicians and what I do not tell them.  I'm still terrified
that people might think I am hurting my children because of
something I have no control over."(24)  "I think this
experience gave us the courage to fire our second
pediatrician.  Without it, I do not think we would have
questioned it when he did not diagnose Johnnie correctly for
the sake of making it easier for him to bill the insurance
company."(25)

Thank God we went to that parenting class and met Dr.
Smith.  He has just been wonderful.  Bob, after what we
went through, I never would have believed that a

pediatrician would say that the parent knows best and that they actually listen to what we have to say.  Do you realize that he has taken every concern I have ever raised about the kids seriously?(26)

"Yeah I know Mary.  I'm so used to fighting with everyone that I notice it when someone is helpful and understands our concerns."(27) "I think it is because he has a child with cerebral palsy himself--he is going through the same stuff we are."(28) Mary smiled, "by the way Bob, he called today and asked if he could come over and talk to Monica about using a wheelchair, is not that something?"(29)

Mary's smile faded,

I guess I'm starting to feel overwhelmed after what happened today.  We have to do everything ourselves, and sometimes I do not feel like we get any help from the people who are supposed to be there for us.  We can not count on family, they think our kids' problems are our fault and that we overreact.(30)

We went to the Medical Center Library and did our own research but when we gave this information to our old pediatrician she ignored it even though she had been unable to diagnose Monica.  So then I contacted the National Center for Rare Diseases and they sent us

the information on the disease and referred us to a specialist in Manhattan.  We were on a plane to New York two weeks later and he was able to diagnose her, finally.(31)  But we did that all on our own, with no help from our doctor.

Mary, do you remember what our pediatrician said to us once Monica had a diagnosis?  That we should not expect anything from Monica because of her disability. She said that Monica would not walk and couldn't learn, but then we talked to a woman who has the same disability and she is a doctor now!(32) I do not think we would have made it without the support we have had from other parents.  Talking to other parents and exchanging information with parents has made all the difference.(33)

"We have been lucky, Bob," said Mary, "The early intervention services we have received have been great.  The staff at the early intervention center have been very professional, wonderful and supportive.  It has almost felt like a second home."(34)

"Yeah, they have been wonderful to us.  I feel like I know everybody there and they know our whole family.  It has made it a lot easier for us."(35)

Mary thought for a moment, the only complaint I really have has been with the service coordination. I know we were supposed to have a service coordinator in there somewhere but I only saw her one time for five minutes. She showed up in the middle of Monica's therapy and I did not even know who she was or where she was from. But other than that, the actual early intervention services have really worked out for us.(36)

I always wonder what happens to other families. You and I are fighters, we always have been. We also have experience working with professionals and we understand their language. It can be very intimidating when professionals talk in their language and flash their titles around. Some parents do not know that they can take the upper hand.(37) Also, we are by no means rich, but we have some resources. What happens to those families who do not have any resources? After the pediatricians accused us of neglect with Monica I wondered what would have happened to a parent who did not know how to stand up for themselves. That had such an impact on me but I stood up for us because I knew we were right.(38)

I was talking to one mother the other day about how

difficult it is if you live in a public housing project and
do not have transportation.

She said that even if they hold therapy at the
community center in the housing project it is hard when
you have to pack your baby up, especially one with
health needs, and walk to the community center in the
rain.  Too often, it just is not going to happen, the
parent is not going to take their child to therapy.
Think about how hard it would be to have to take a bus
across the city with this same child.  These families
need in-home services.(39)

Bob responded,

But that is the way it is, Mary.  It is a constant
battle for all families.  I think that the battles we
are fighting are similar to the Civil Rights Movement.
As a kid in Louisville I remember seeing black people
being forced to sit at the back of the bus and I
remember white only rest rooms.  The only way they were
able to make any progress was to force people to listen
to them and to force change.  I see it as the same
thing for us with this law [Part H].  We have to force
change, Mary.  Nobody is going to just decide to do it
for us.  So I see it as the same thing except we are

the one's being discriminated against.  It really gives
me an appreciation for what they went through.(40)

I wish I could say that it is going to get easier
for us but I can not.  Things like what happened in the
fabric store today with that woman and what the
insurance company is trying to do to us now are going
to continue to happen.  But we have to remember that we
keep fighting because of our four beautiful children.
We are good, committed parents and we will never settle
for second best when it comes to them.(41)

"I know, Bob. I will do anything for them.  I guess I
am just tired.  But this really helped Bob, just talking
about it made me feel better.  So, who are we going to fight
with tomorrow?"

<u>Overview</u>

The Smith's story embodies many of the issues that family participants who have children with developmental delays and disabilities experienced in this LICC. The Smith's issues transcended the Part H early intervention system, to include, for example, interactions with various non-Part H systems and providers such as the insurance industry and individual physicians. The Smith's had to rely very heavily on their own initiative and skills to navigate the confusing interaction between Part H and non-Part H service delivery systems. Success in the early intervention system for the Smith's was achieved through persistence and a tenacious approach to their children's care. Their experience as well as the experience of families in general in this LICC are represented in Figure 1 as an intersection between these three systems, with the family's empowerment resting at the intersection point.

As shown in Figure 1, four major themes emerged in this study [see Figure 1]. The first theme is related to issues with the Part H early intervention system. In the Smith's case they did not feel that the service coordination met their needs, yet service coordination was intended to be one of the most important services provided to families. The
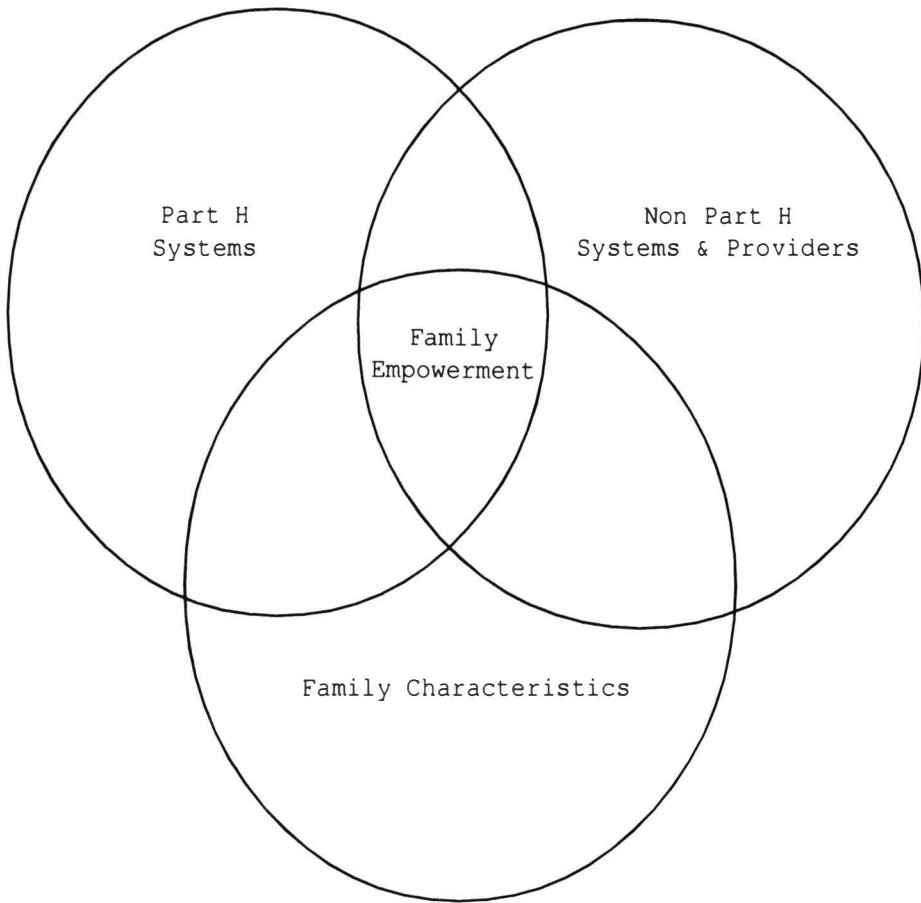
**Figure 1**

**Overall Systems Interactions**

Part H legislation lists many important rights for families and attempts to mandate a family-centered system where the family's needs direct the actions of the professionals with whom they work. Part H was designed to serve as a mechanism for the establishment of local coordinated interagency service delivery systems to ensure that services were family-centered, that families were afforded certain rights, and that each family was guided through the system with the assistance of a service coordinator.

The second theme moves beyond Part H policy influences and addresses the many non-Part H systems influences that had an impact on families. For participants in this inquiry, many of the rights for families spelled out in the Part H legislation were difficult to take advantage of because of the influence of systems outside the realm of Part H early intervention services. For example, the Smith's issues with their insurance company and with several physicians was an example of an experience families had with systems and providers outside the realm of Part H early intervention services. In addition to physicians and the insurance industry, other systems had an impact on early intervention services, as well, including child protective services, hospitals, private therapy providers, the Health Department,

the Department of Social Services, and others.

The third theme is related to family characteristics. In order to cope with the confusing and often frustrating interaction between Part H and non-Part H systems and providers, many participants adopted a tenacious approach to interacting with these systems. In the Smith's case, they were relentless, they fought for what they felt their children needed. In addition to an aggressive approach to early intervention, family participants felt that they needed some basic prerequisite skills for working with the multiple professionals and agencies with which they interacted. Families also reacted to the stress of their situations in different ways which influenced their interactions with professionals.

The final theme is focused on change--how does empowerment occur for families in early intervention? Families are faced with many obstacles inherent in Part H early intervention programs and they are faced with many barriers to early intervention services that place pressure on families and Part H providers. Further, families in this LICC had to rely on their own abilities to navigate this confusing system. Empowerment for families may involve a process of tying the Part H and non-Part H issues together

and generating ideas for giving families the information, skills, and self confidence they need to take a more active role in early intervention. The Smith's compared it to the Civil Rights Movement when African Americans used their skills and resources to force changes in American society. Empowerment represents both the need for change and a vision for it. Developing family-centered service delivery systems has been the standard for Part H early intervention services, but designing family-centered services may not lead to family empowerment.

The findings are presented according to the four major themes and the specific categories within each major theme. Interpretive comments by the researcher within the findings are clearly distinguished from the stakeholders. All references to stakeholder perspectives and the researcher's interpretive comments are cited using numerical footnotes and the full citation is presented in the audit trail list in Appendix A.

<u>Perspectives about Part H Early Intervention Services</u>

Part H has many features that make it exciting and
unique. Stakeholders, however, held conflicting perspectives
about what the intention of IDEA, Part H was, how it was
implemented, and how it has been applied in terms of
programs and services. Stakeholders' concerns were related
to the family-centered features of Part H, knowledge and
awareness of the existence of early intervention services,
the rights of families as outlined in the legislation, the
method for providing service coordination, as well as some
general concerns with some of the specific requirements of
Part H.  Finally, on a systems level, there were
perspectives about the attempted establishment of a
coordinated system in this LICC.  Figure 2 provides a
graphic representation of where Part H services fit into the
overall model [see Figure 2].

<u>Family-Centered Services</u>

One of the features of the Part H legislation that made
it exciting was its provision for the establishment of
family-centered services (IDEA, 1991).  Several
stakeholders, however, were unsure of whether or not early
intervention services in the Council were family-centered.
When asked what she would like to see change in the early
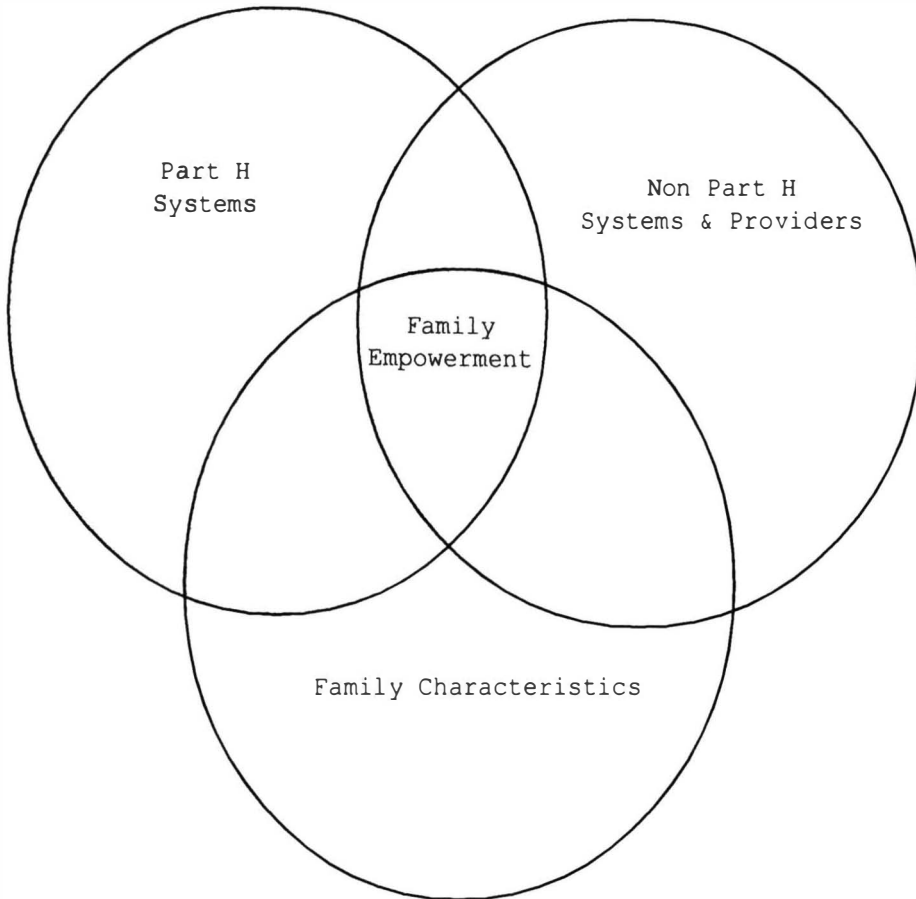
**Figure 2**

**Part H Systems Interactions**

intervention system in the LICC, a mother replied that she
would like professionals to be more family-focused.(42)
Families were offered what services were available rather
than what they actually needed.(43)  According to several
professionals, the system seems to focus on the needs of
professionals instead of on the needs of families.(44)

The team setting itself may not be conducive to family-
centered practice.  The family is at a disadvantage working
with professionals on a team. (45)  Several family
participants felt that in the team environment professionals
take control unless the family is assertive.  Additionally,
these same family participants were not aware that they had
the right to question professionals.(46) For example, one
family participant reflected on a team meeting where she did
not agree with what the team was proposing for her child and
family when she said, "I just sat there shaking my head
because I did not want to sound dumb."(47)  Not all family
participants felt this way.  When one family participant was
asked if this had been her experience she said, "no, I had
an active role in team decisions," while two other family
participants said they make sure professionals hear families
and they would not tolerate anything else.(48)

Individual Family Service Plan (IFSP) meetings can be

stressful and difficult for families.(49)  A professional

participant said that even "family members who are

professionals [other than early intervention] themselves say

how hard it is.  They have gone into IFSP meetings and were

anxious looking at the group of professionals waiting for

them."(50)  It is difficult and stressful for families

because they are not knowledgeable enough about their

child's problem, about the role of the specific disciplines

in addressing the problem, and there can be competition

between agencies when more than one agency is involved. (51)

   Knowledge about the health care system can be an

advantage for families.  Discussing her family's early

intervention team, one mother said, "I have been able to

handle them [professionals] because my husband is a nurse so

I understand a lot about what they are talking about, but

other families."(52)  A family participant believed that

"families should be leading and controlling the early

intervention teams.  The rest of the team should be there

just to support the family.  Families know best what their

child's skills and needs are."(53)

   There were families who had good experiences and who

felt that the system was family-centered.(54)  One of the

early intervention professionals felt that families tended

to lead their early intervention teams at their agency.(55)

At time of intake, one professional felt that her program

focuses on the whole family and not just the child's

developmental delay or disability.(56)

One professional felt strongly that if professionals

think in terms of a family-centered system only involving

professionals and families, an important group of people are

left out who have a considerable impact on the family's

experience: support staff at early intervention programs.

Support staff are part of the team because they take the

phone calls, process the paperwork, and deal with insurance

companies.  If the support staff are not made to feel a part

of the team and important to the overall experience for

families, then a family-centered system may be difficult to

achieve.(57)

## Knowledge of Early Intervention

When a family identifies a potential delay or

disability with their infant or toddler, the first thing

they want to do is find someone who can help them understand

and cope with their child's delay or disability.  Often,

however, families do not know where to find assistance and

they do not know that early intervention services are

available.  Many family and professional participants said

that when a family first recognizes a developmental concern with their child, they were often completely unaware that early intervention services existed.(58)  There were family participants who had no idea about the availability of early intervention but found the system by chance.(59) One family participant thought that if your child did not have mental retardation they would not qualify for any services so they never looked.(60) Families who knew what early intervention was and were actively trying to access services had a very difficult time trying to find a program, and some families never found an early intervention provider.(61)  The search became so discouraging for some families that they gave up trying.(62)

A husband and wife who have a child with autism relayed an experience that highlights how difficult it can be to access early intervention programs and services.  They live in one of the public housing projects on the city's east side.  Their son Henry was about 2 ½ years old and they did not know what was wrong with him until he ran out of their apartment one day wearing only a diaper.  Because Henry is big for his age it appeared that he was older and should not still be wearing a diaper.  By chance he ran by the Public Housing Coordinator, Miss Baker, who stopped Henry and

talked to his parents about what was going on.(63)

Fortunately Miss Baker recognized that Henry's issues were more than behavioral and she also knew about one access point for early intervention--the Public Schools.(64)  From this point Henry was assessed, referred, and placed in one of the schools.  Later he was referred to an early intervention program.(65)  Before this incident Henry had been assessed by physicians, but not given in a diagnosis or referral.  It was a long, frustrating, and difficult process for his parents.(66)

There was also a general feeling that the early intervention system has struggled with a lack of visibility in the community.(67)  Many professionals and LICC members believed that they have to do a better job of informing the public about early intervention and how to connect with the system.(68)  An early intervention professional who was new to the area said "when I was looking [for a job with an early intervention program], I had to make several phone calls before I was able to find an infant program, and that is with a knowledge of the types of places to look!"(69) The issue extended to professionals outside of the early intervention system who were also unaware of the existence of early intervention services in the city.(70)  According

to several family participants and a professional
participant, physicians in particular had little knowledge
of the existence of early intervention services.(71)

The LICC does put a considerable amount of time and
effort into Child Find activities.(72)  Local physicians
offices were targeted for distribution of early intervention
information materials. Some other examples of Child Find
activities include dissemination of early intervention
information in the public schools, distributing LICC
brochures and other information house-to-house during child
health month, and some special summer Child Find
activities.(73)  Two members of the LICC who were both early
intervention professionals felt that the Council has done a
better job of promoting the early intervention system
lately.(74)  Regardless of these efforts, the Council was
still only serving one-third of the estimated number of
eligible infants and toddlers.  There were still many more
in need of early intervention services.(75)

Several strategies have been suggested by families and
professionals: pay parents to go door-to-door in their
communities to inform people; signs and flyers in grocery
stores, schools and other places; conducting screenings in
the mall; or having an early intervention day.(76)  As one

LICC member said, "The only way we are going to find them [families] is to be a part of the community in which we work."(77)  It has also been proposed to try to register infants/toddlers who are receiving services outside of the early intervention system from private providers.(78) Another possible strategy may be to develop a tracking system for those children who are referred at birth due to high risk factors but who, so far, are ineligible for services.  Following up with these families may lead to finding more children who are eligible for services as these risk factors lead to the occurrence of developmental delays in these children.(79) Since referrals come from other systems such as social services, hospitals, public schools, Visiting Nurses Association, and physicians, they need to be targeted for information distribution as well.(80) Almost in despair, a family participant wondered, "How else can the LICC and other early intervention providers get the information out there?"(81)

Once families have been identified and referred to an early intervention provider, the battle is not over.  Many families drop out of programs and/or do not follow-through with services.  The system loses families after working hard to identify and refer them to early intervention programs.

We can learn from the stories these families tell about why they left early intervention.(82)

Participants identified many possible reasons why a family may leave early intervention once they have gone to the trouble of seeking out services, had an assessment done, and were referred to a program. For example, a professional participant said that one family was ready to leave their program because a speech referral was taking too long.(83) According to another professional, some families leave because they have difficulty saying no to a therapy offered to them that they do not want.(84) Another family participant felt that families leave the system when the initial connection to a program was not right for them, regardless of other available programs.(85)

Families sometimes do not make it through the initial assessment and referral process because too much time elapses between the initial assessment and actual services.(86) Regarding the amount of time between assessment and actual service, a professional said, "I guess they only get one shot, ready or not."(87) Another possible reason families may not access early intervention services is that some families experience a grief reaction when they first discover their child has a developmental delay or

disability. One professional asserted that "we lose families because they have not dealt with their grief."(88)

Sometimes, professionals prioritize the amount of time and energy put into working with families. A professional felt that she could predict whether a family was going to make it through the initial assessment and referral process when she said, "I usually know from the first meeting that they may start out with us but that it is not going to happen--they are going to stop working with us."(89) As one professional said, "I work hard with the team here to work with these families, but it is hard when you have just as many other families who need your help, who do show up for appointments."(90)  A family participant who was also a member of the LICC stated her concern about families when she said, "we wonder what happens to families [who leave early intervention] who do not have the resources."(91)  One of the issues was that families who live in low-income housing tend to move often and there is currently no system for tracking them.(92)  A family participant felt strongly that tracking these families is important to ensure that they do not fall through the cracks, so that early intervention professionals can follow-up with them.(93) Another issue related to families being discharged from the

hospital, there is no system for identifying them and connecting them to the early intervention system.(94)

When families do leave an early intervention program there is no current method for connecting them to other service providers.  One suggestion was for early intervention programs to obtain a pre-release of information from families who leave services so the program staff can notify their pediatrician and ensure that they are still receiving some services.(95) A member of the LICC felt that they have been doing a better job of filling in the gaps in the system to enable them to keep families connected longer.(96)  But, a professional participant made a good point when she said, "I have to be better at respecting their decision to leave, but I always leave it open ended so if they decide to come back it is easier for them" when they do come back, she continued, "they are vulnerable at that point and I have to let them know they have support."(97) During the initial stages it is important for professionals to work hard to find the right program and services for a family so they feel this support from the beginning.(98)

Knowledge and awareness of early intervention is an issue for families when they first identify that their child is experiencing developmental delays and they want to access

services that can help their child. Families, however, continue to face challenges even after they have discovered and accessed the early intervention system. The Part H legislation promises certain rights to families in early intervention. Whether or not families were able to exercise these rights in this LICC was not clear.

## Family Rights

Part H of IDEA (1991) guarantees several important rights for families involved in early intervention such as the right to choose the most appropriate program for their children and the right to be active participants on the early intervention teams working with their children. Early intervention professionals are obligated to uphold these rights for the families with whom they work. For example, some families who have infants or toddlers with developmental disabilities have made a conscious choice not to get involved in early intervention services. Professionals may not understand why a family would refuse early intervention, but they should respect the decision.(99) According to several family participants, families may have a rational reason for deciding they do not want early intervention services. First, families are sometimes confronted by professionals in early intervention

too soon and they are not ready to accept the child's delay
or disability. (100) Second, a family may not see the
importance of early intervention if the delay does not
appear too severe.  Third, sometimes, it is a practical
issue.  For example, one mother told professionals that she
wanted to wait until her other children were back in school
before she would commit to early intervention for one child.
(101)

    If a family chooses to receive early intervention
services, the next right they have is to choose which early
intervention program or programs they prefer to use.
Families can choose to receive services from more than one
provider to maximize the amount of therapy for their
child.(102) Professionals value this right and respect the
fact that families need to know all their options in order
to make an informed decision about what is best, but one
professional felt that they actually provide families with
limited choice.(103)

    From a professional's perspective, presenting all of
the possible early intervention provider options to families
can pose some difficulties.  According to two professional
participants and a family participant, some families,
particularly families that described themselves as low-

income, take a "more-is-better" attitude about choosing

providers and accept any services offered to them.(104)

This can be difficult for professionals who feel they need

to make families think realistically about what they

actually need.(105) Professionals do provide the options for

early intervention providers to families but, as a

compromise they may make recommendations regarding which

services they feel the child needs.(106)  One professional,

however, stated that she does not try to influence families

to choose the program where she works, but to choose one

they feel is best for their family.(107)

     Not all families understand that they have the right to

choose an early intervention provider.(108) Informing

families of their rights so that they can make informed

decisions is the professional's responsibility.(109)

According to one family participant, families who were not

presented with all the service options when they first

entered the system left early intervention altogether if

they were unhappy with the provider with whom they were

working because they were unaware of other options.(110) It

is the service coordinator's role to provide families with

their options, but service coordinators may not be

consistently providing this option to families, thus

limiting choice.(111)

Families are emotionally vulnerable and may not be in the best position to absorb information when a child is born with a developmental disability or when the family is made aware of the presence of a delay.  Yet this is the time when families are bombarded with information and forced to make choices about services.(112)  A mother who has been through the birth of a child with a developmental disability felt that "families need to have the option to decide how much information you can get about disability after birth.  Do not assume they are ready for it."(113) A professional agreed and expressed a concern that they push families too hard into therapy sometimes.(114)

Professionals do consider the rights of families, but sometimes all the rules and regulations that must be followed can impede their ability to fully respect the families rights because of the amount of time it takes to meet these rules and regulations.(115) Sometimes choice is out of everyone's control.  For example, a child who is medically fragile needs specialized health care services. As a result, the choice of what services the child needs is determined by the severity of their medical condition. (116)

According to several participants, there were several

possible reasons why families had a difficult time taking an active role on their early intervention teams. For example, families may know they have the right to question a professional's decision but they choose not to because they believe the professional has the knowledge and skill to make decisions.(117) Additionally, families may not have exercised their right to disagree with professionals because they respected the fact that professionals on their team are trying to help them and it would be rude to disagree.(118) Some families felt reluctant to say "no" to a decision with which they did not agree with because they did not feel qualified to say no.(119) Professionals, however, were worried that parents sometimes exercise their right to disagree with a team decision because they do not have the knowledge or expertise to understand the purpose of the team's decision.(120)

Another right families have is the right to receive services at home or at a center-based program.(121) However, families were not always provided this option. For example, one mother wanted physical therapy at home but the insurance company refused to pay for home-based services so she was forced to take her child into a center-based program.(122) Professionals in early intervention tend to assume that the

home is the best place to provide early intervention services and they push families in this direction.(123)   A family member agreed that home-based services give families more control, while another stated that families need home-based services because transportation to access a center-based program is too difficult. (124) Several professionals, however, were not convinced that providing services in the home was always the best option because families did not feel comfortable with letting professionals into their homes.(125)

The best part, according to one professional, was that "we have both center- and home-based services"(126) and another professional added that "we can do whichever works best for families."(127) Sometimes, depending on the child's and family's needs, a combination of home- and center-based services works best.  This is difficult, however, because this usually requires involvement in multiple programs.(128) A professional added that she wished that each program could offer home- and center-based services so that families always have the option to choose.(129)

Families in this LICC experienced some challenges with exercising some of the rights guaranteed them in the Part H legislation. Service coordinators have played an important

role in educating families about their rights and then assisting them in exercising these rights.  Family participants, however, reported experiencing several issues with how service coordination was carried out in this LICC.

## Service Coordination

A primary goal for service coordination is to provide support to families while promoting parental independence, responsibility,  decision-making, and to reduce the complexity and fragmentation of local service systems for families (Bailey, 1989). The methods for providing service coordination in this LICC, however, were considered to be a problem for both families and professionals. In this LICC, the CSB has two service coordinators who ideally tie the system together; all families entering the system should be temporarily assigned to one of the service coordinators.(130) After families have entered the early intervention system they are informed of their service coordination options.(131) For example, families may choose to have a service coordinator from the local CSB, or a professional from one of the early intervention programs with which they are working.

Service coordination was important to families in early intervention in this LICC because many families received

services from more than one agency.(132) A member of the
LICC felt that "service coordination can be that link that
helps keep families connected to the system."(133)  When it
works, service coordination can be very important for
families.  The service coordinator is knowledgeable about
the system, they are responsible for referrals to other
programs, and they serve as the family's private
consultant.(134)

There were some concerns, however, about the current
CSB driven service coordination system.  For instance, it
may be confusing for families to have a service coordinator
from the CSB and then see therapists from other
agencies.(135) It is a difficult system for the CSB Service
Coordinators as well. It is challenging for them to form
strong working relationships with families because service
coordinators do not have the amount of contact with families
as a therapist in an early intervention program.(136) The
system may be confusing for families because they are not
sure with whom they are supposed to work closely, the CSB
service coordinator or the professionals on their team.(137)

To further confuse families, agencies provide service
coordination as well.(138) According to one professional,
families and professionals may prefer that a member of the

family's team act as the service coordinator because the
family member already has a working relationship.(139)
However, it may be difficult for a member of a team to
perform the service coordinator role because team members
are forced to serve two roles--therapist and service
coordinator.(140)  Additionally, several professionals
stated that service coordination is not something that they
enjoy doing because it involves additional responsibilities
on top of their already busy schedules.(141)

    Some participants believed that families can and should
act as their own service coordinators.  Some teams assisted
families in becoming their own service coordinators
regardless of whether they were supposed to or not (e.g.,
for billing purposes the family is not allowed to be their
own service coordinator).(142)  One professional believed
that if families were motivated enough to do service
coordination, then they should be supported in doing
so.(143)  In response to this perspective, another
professional said that families cannot do service
coordination because of the required paperwork, especially
related to billing, and because early intervention
professionals have mandated guidelines to follow.(144)

    Both professionals and families recognized that there

were families who were not aware of who their service

coordinators were or that they even had one.(145) Some

families who knew about and used a service coordinator were

frustrated with the service.(146)  Families, however, made

it clear that they did not care as much as professionals did

about who the service coordinator was; they cared about the

other services they received.(147) Some families would like

to see the therapist most involved with their child act as

the service coordinator.(148)

Families involved in early intervention in this LICC

were in need of support from their service coordinators.

For example, service coordinators were instrumental in

advising families of their rights when they entered the

system.  Another issue that arose for families in this

Council was the challenge of entering a system that requires

contact with multiple providers.  Coordination of these

services was a challenge for service coordinators and a

challenge for the LICC to construct a coordinated system of

service delivery.

A Coordinated System

A primary objective for each LICC in Virginia is to

facilitate the establishment of coordinated early

intervention service delivery systems (Bailey & Wolery,

1991). The LICC in this study has made considerable efforts to accomplish this task (Infant Council Newsletter, 1997). Yet, there were issues out of the control of the LICC staff that interfered with the development of a coordinated system.

Accomplishing coordination of services among early intervention service providers has proven difficult. There has been a tendency for agencies to compete with each other for consumers and to stake out professional turf.(149) One professional felt that this competitiveness extended to turf issues within an agency as well. For example, professionals within agencies were under pressure to maximize billable hours, which may have stimulated competition between departments for billable therapeutic hours with individual families. (150) Another professional lamented that "we could do so much more if we could just work together--both within agencies and between agencies."(151)

Each agency was subject to different policies and constraints; as a result, they did things differently. This made life very complicated for families who were working with more than one agency at the same time.(152) Before a professional could participate in activities coordinated by the LICC, they were subject to the rules and regulations of

their agencies which sometimes made interagency coordination difficult.(153) Families were confused about the role of agencies in early intervention, and were not sure how each agency was supposed to support them.(154)  The final issue that was confusing for both professionals and families was the fact that some services cross LICC boundaries.  For example, one of the providers was used by three LICCs in the metropolitan area, which only added to the confusion experienced by families because it made paper work very difficult for families and providers to complete.(155)

Collaboration did occur in the LICC despite the above concerns.(156) However, there were some ideas about strategies for continuing to improve collaboration.  For some professionals, meeting each month for half a day may be too difficult.  One professional suggested exploring new methods for seeking input from members, especially physicians.(157) Establishing a true central point of entry for this LICC's early intervention system was believed by several participants to be an important strategy for establishing a coordinated system and for improving collaboration between providers.(158)

Participants in the LICC held a vision of what a coordinated system would be like and what it could

accomplish. Professionals in several agencies felt that one of the most important things they could do for a family was refer them to another program if they were unable to meet their needs.(159) Going a step further, agencies need to work together to coordinate services to eliminate overlap of early intervention services.(160) A professional and family participant envisioned a "system team" where professionals from several agencies would work as a team with families.(161) One professional felt that participation in LICC meetings was one way to work towards coordinated services, and this was valued by agencies.(162) The current system for providing service coordination has not accomplished this task. The Smiths experienced many of the same issues with knowledge of early intervention, exercising their rights, adequate service coordination, and coordinated services. The Smiths found methods for coping with these issues regardless of the support they received.

The Smith's Perspectives of Part H

Overall, the Smiths perceived their experience with the Part H early intervention system to be positive. They did, however, feel that the service coordination services were inadequate. Mary knew that she was supposed to have a service coordinator but she was not sure who the service

coordinator was supposed to be. In fact, she could only recall one interaction with a service coordinator from the CSB.

The Smiths experienced many of the same issues with Part H services as other stakeholders. For example, the Smiths felt that they lacked a strong service coordinator who could have assisted them in dealing with the many difficulties they had with providers outside of the Part H early intervention system. A service coordinator could have helped the Smiths with the problems related to pediatricians, the insurance company, and Child Protective Services. In addition to the Smiths, many other families in this LICC experienced problems with providers outside of the Part H early intervention system. Systems and providers outside of the early intervention system influenced many families' experiences with early intervention services.

<u>The Impact of Non-Part H Systems and Providers</u>

Participants in this inquiry identified several non-Part H systems and providers who had an impact on Part H Early Intervention services. The three main non-Part H systems and providers were physicians, insurance providers, and child protective services. When confronted with issues related to non-Part H systems, Part H early intervention providers were often powerless and were relegated to a reactive role. Figure 3 provides a graphic representation of where non-Part H providers fit into the overall model [see Figure 3].

<u>The Impact of Physicians</u>

The role physicians played in early intervention was an important issue for both family and professional participants. Primarily participants were referring to their experiences with pediatricians and family practice physicians. Family and professional participants expressed a considerable amount of frustration with family practice physicians and pediatricians who adopted a "wait and see" attitude when a child presented with a developmental delay.(163) Families were repeatedly told by physicians that their child would simply grow out of the problem and that the best thing to do was to wait and see.(164) Some
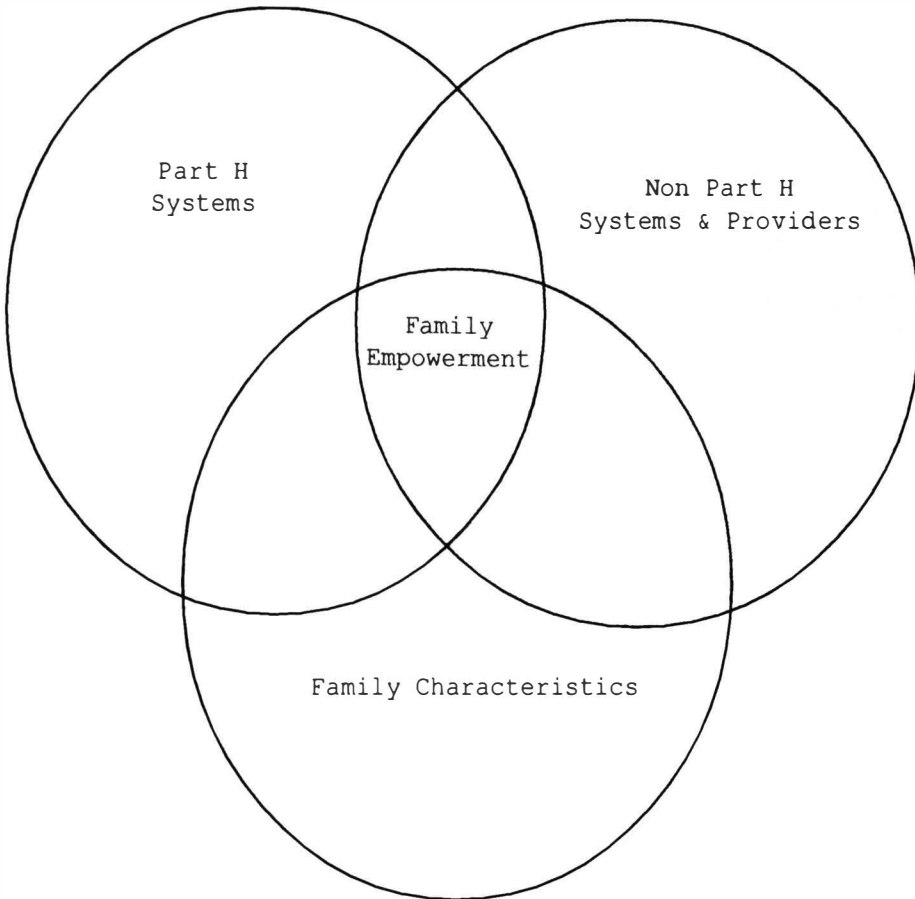
**Figure 3**

**Non Part H Systems Interactions**

families and professionals felt that physicians had this attitude because they did not know what the problem was and they did not know what to do, so physicians decided to wait and see.(165)

When families first recognized a problem with their child, the first professional they usually went to was a physician. As a result, physicians were often the primary access points into the early intervention system.(166) This began a process of many referrals and appointments that were taxing on parents.(167) The typical first step for physicians was to refer to another physician, a specialist.(168) These referrals often did not result in a diagnosis or early intervention referral. Families also had some negative experiences with specialists.(169)

Gloria is a determined, politically active middle-aged African-American woman who has been an involved member of the LICC. She was active on the Council because she did not want other families to have to experience what she did with her oldest son, who was diagnosed with verbal apraxia. Gloria felt that the problem for her and her family was that her son was not diagnosed early enough, he was not diagnosed until he entered school, to benefit from early intervention. She was told time and time again by physicians that her son

would just outgrow the problem, but he never did.(170)

Physicians acknowledged using the wait-and-see approach to treating children presenting with developmental delays, but they responded by explaining the rationale behind the approach. First, according to an employee of the LICC who has had numerous interactions with physicians, physicians only see children when they are sick. Many children do not develop as quickly as others, so if you just wait it out, they often do outgrow the delay.(171) Literature on child development and parenting discuss developmental stages according to the child's age. Two physicians cautioned that these stages are based on averages and are not exact determinants of when a child should reach a specific developmental milestone. The physicians felt that parents tend to interpret these developmental milestone ages as exact times for when their children should reach a specific milestone. They say parents become concerned that something is wrong if their child is not rolling over at four months, for example, even though they may be ahead in another developmental area.(172)

A pediatrician cautioned that they see parents every day who think that something is wrong with their child and that 99 out of 100 times everything is fine.(173) This same

pediatrician felt that early intervention providers felt that a wait-and-see approach was a big problem because early intervention providers only interact with that one percent of families where there really was an issue.(174)  A family practice physician said that his knowledge of developmental delays and early intervention is limited but that a wait-and-see posture has worked for him.(175)  Finally, when asked how long he felt a physician should wait before making a referral, this family practice physician said, "it depends on how acute the problem is, and how distressed the child and parents are. There is no 'pat' answer. Each case is different."(176)

Families and professionals perceive physicians to be a barrier to family access to early intervention services.(177) According to one professional, physicians may not refer families to early intervention programs because physicians may feel they can handle developmental problems themselves.  At the same time, this professional felt that families often report that the physicians with whom they have had difficulty did not listen to them and did not value their opinions.(178)  According to a member of the LICC, "part of the problem may be that physicians do not talk to families."(179)  Families have been accused of being

noncompliant if they disagreed with their physician, but a family participant responded by saying that physicians will not listen to them in the first place.(180)

An African-American man from a low-income neighborhood who is the father of a child with autism told a story about an interaction he had with a physician that demonstrated the communication gap.

They had him on Ritalin and it did not work. It never worked. The doctor never listened. If he would have just listened, we could have saved a whole lot of time. I would tell him that it was not working and all they would do is increase his dose, whereas I found that if I only gave it to him once every two days it worked a little. But he never listened, I was a 'non-compliant parent,' I think he called me.(181)

Physicians did not always treat family participants with respect. For example, one mother felt that her physician spoke to her like she was "dumb."(182) Family participants felt that physicians used too much professional jargon with families to cover up what they did not know.(183) One mother said that she confronted this issue by demanding that her pediatrician talk in English so that she understood.(184)

Physicians did not take into consideration the emotional and psychological impact on families that a child with a developmental delay or disability can have. One mother said that their family doctor diagnosed her daughter with a disability and then did not tell them where to go for help. They were expected to deal with it themselves.(185) Another family said that their doctor told them that it was their fault their child was delayed because they did not bring the child to see him soon enough.(186) Another mother felt that a heart specialist to whom her child received services, treated her poorly when he told her to take her son out into the hall to get dressed after he was done examining him.(187)

Several family and professional participants believed that physicians may have a tendency to focus on the medical symptoms a child is presenting and miss some of the other aspects of the delay.(188) They may only look at the immediate presenting medical issue and not consider some of the long-term developmental effects of the issue.(189) Several professionals suggested that physicians focused on medical symptoms because they did not have an in-depth understanding of child development.(190) According to an employee of the LICC, some pediatricians and family practice

physicians hold the opinion that some children develop above the normal line and below it and they should not interfere with this.(191)

According to family and professional participants, another issue was that physicians often did not value early intervention and they told families that it was not useful.(192) According to several participants, physicians do not believe that some of the related disciplines such as occupational therapy, physical therapy, and speech pathology can be of assistance to families. Additionally, these participants felt that physicians did not value early intervention because there was no empirical evidence to support the effectiveness of early intervention.(193) According to several family and professional participants, pediatricians believe that there are too many programs offering services to families and that families need to become more self-reliant.(194)

On the other hand, physicians are not irrational or illogical professionals who are attempting to prevent families from benefitting from early intervention services.(195)  Physicians have their perspective which must be recognized. First, physicians are extremely busy and overworked.(196)  They may only have a few minutes with each

patient.(197)   One pediatrician put it into perspective when he said,

> I see 30 patients a day and when there is a waiting room full of impatient parents who have been waiting for a long time it is not easy to pick some stuff up (e.g., signs of developmental delay) with any one patient.(198)

The situation is not easily remedied by providing training and information to physicians about early intervention because they are tough to target for training due to their busy schedules. (199)

It is impossible for physicians, especially family practice physicians, to know all the resources available for their patients.(200)   Working with families can become very difficult for physicians because there are so many possible reasons for a delay.(201)   A family practice physician said that what he needed to know was to whom he could refer a difficult case.(202)   When asked what type of training or information he would like to receive about early intervention, one pediatrician said, "educate my staff, come in at lunch."(203)

Many children receive the temporary diagnosis of unspecified developmental delay.(204)   This diagnosis can

serve as a barrier to finding and accessing the early

intervention system for families for several reasons.

First, not having a more tangible diagnosis can lead

families to believe that the problem will work itself out,

so they do not pursue any type of intervention.(205)

Second, insurance companies may not pay for early

intervention without a more specific diagnosis.  Third, the

child's physician may treat the symptoms of the delay

medically or diagnose the problem incorrectly and not refer

the family to an early intervention provider.(206)  Finally,

some family participants reported either being ignored by

their physician or asked to find a new physician when the

physician could not make a diagnosis.(207)

It was a very different experience for families when

their child was born with a physically apparent disability

such as Down Syndrome.  These families were referred to

specialists and even to early intervention programs

immediately.(208)  Unfortunately, many developmental delays

slowly manifest themselves and are more subtle. Diagnosis

can take time.(209) To emphasize this point, a pediatrician

said,

You have to understand that a lot of these things do

not fit into nice neat diagnostic categories.  I had a

patient in here last week with a rare syndrome that

there are only 80 known cases of in the entire United

States.(210)

He added that there was no information to be found on the

syndrome and it was very difficult to diagnose.(211)

Finally, this same pediatrician said that he always gets a

second opinion with a difficult case because he knows that

he does not have all the answers.(212)

Many stakeholders felt that there were physicians who

referred to early intervention programs, but they tended to

refer families to the same agency or person each time

regardless of the family's needs.(213)  Some physicians did

not refer families directly, but they instructed families to

call an early intervention program without explaining to the

family why they needed to call.(214)  One professional

lamented that if pediatricians would just explain to

families why they were being referred to early intervention

the whole process would work better.(215)

Even if a family was referred directly to the early

intervention system, the referral process often took a long

time.(216)  One family said that it took early intervention

so long to respond to their doctor's referral that their son

was too old for early intervention by the time the referral

came through.(217)  Speaking generally about families, a member of the LICC felt that there were many families who never made it through the referral process because of the patience it required.(218)  Initially families were often bounced around in the system until an appropriate program was found.(219)  One professional suggested that she would just do away with some of the referral processes that families have to deal with.(220) But another professional stated that it was the family's responsibility to follow-through with the process and to make themselves available for appointments.(221)

Some families had good experiences with pediatricians. For example, one family participant said that her pediatrician identified a problem with her child right away and made an appropriate referral.(222)  Another family participant talked about how her pediatrician had always been there for her family.(223)  Two other family participants described their pediatricians as extremely supportive.(224)  Also, according to a family participant and several professional participants, physicians collaborated with other professionals and referred families when they were not sure what to do.(225)  Finally, some family participants believed that their pediatricians

considered them to be the experts about their children and they listened to the parents and consulted with them.(226)

Some family participants and professionals identified physicians as an obstacle for families' access to the early intervention system. Physicians, however, were not the only non-Part H obstacle for family participants. Insurance companies often served as a barrier for families being able to pay for early intervention services, once they accessed the system.

## The Impact of Insurance Systems

The insurance industry had considerable influence over early intervention services, for families using public insurance (i.e., Medicaid and Medicare) or private insurance. Insurance has served as a barrier for families and it had an impact on the ability of early intervention professionals and physicians to provide services. For example, insurance companies were continually cutting back on the services they would cover for families.(227) The insurance system was also a very complicated system to understand and was always changing, making it difficult for professionals and nearly impossible for families to cope with the changes.(228)

One professional felt that insurance companies probably

had the most influence over what types of early intervention services families received.(229) For example, a mother said that her child who had serious medical needs had a visiting nurse coming to her home until the insurance company stopped paying for the visits, even though the family felt they still needed the home visits.(230) Due to managed care, insurance companies began placing more limits on what types of services they would pay for and the list of billable services began to shrink.(231) With some HMOs, for example, therapists could not act as service coordinators. They could only provide billable therapies.(232) Families had difficulty obtaining insurance coverage for speech therapy for infants and toddlers.(233) Insurance companies have been limiting the amount of time therapists (i.e., occupational therapists, physical therapists, and speech therapists) can bill for reimbursement. For example, an occupational therapist working for a home-based early intervention program said that she can now only bill for half-hour therapy sessions instead of one-hour sessions.(234)

One professional participant felt that this put early intervention professionals in the difficult position of having to explain to families that they cannot do much to

help their child as a result of the insurance
limitations.(235) In general, professional participants felt
constrained by the limitations placed on them by insurance
companies.  One professional described a dream she had of
"being able to walk into a family's home and provide
services whenever the family needs it, rather than only when
it is billable."(236)  Insurance is a difficult issue for
physicians as well.  Physicians have to fight with insurance
companies to get some services covered for families. A
family participant, for example, felt that her child's
physician may have made a diagnosis based on what the
family's insurance would cover.(237)

     Another issue was related to the cost of early
intervention for middle-income families.  A pediatrician
believed that middle-income families make too much money to
qualify for public assistance; their insurance will not pay;
and they do not make enough money to pay out-of-pocket.(238)
Because insurance companies are refusing to pay for early
intervention services, one early intervention professional
posited that it is harder for a middle-income family to
afford early intervention than it is for a lower-income
family.(239)  Another professional felt that middle-income
families are upset by the fact that their tax dollars are

used to pay for early intervention for the poor; but when
they need the same services, they have to pay for it
themselves.(240)  As a result, some middle-income families
chose not to use early intervention services in favor of
medical services that their insurance would pay for.(241)

According to many participants, the question of whether
socio-economic status played an important role in the
experience for families in early intervention was difficult
to answer.  For example, a professional said, "I have seen a
difference between low-income and middle-income families and
their problems with accessing early intervention services,
but they both have problems."(242)  Families who have lower-
incomes have an easier time accessing the system because
they do not have to deal with insurance companies or
HMOs.(243)  But families with higher incomes tend to have
more education and resources to call upon, so they fared
better than lower-income families once they were in the
system.(244)

A middle-income family participant felt that SES did
not play a role in family access to the early intervention
system.(245)  She felt that "disability does not
discriminate, and the services associated with disabilities
are not easy to get even for people with money."(246)  She

went on to say that "there is no difference according to income or status. All families are lonely when they have a child with special needs."(247) A pediatrician agreed and felt that the issues cut across ethnic and income lines, "I find they all have their own problems that relate to the experience of having a child with a disability or delay."(248)

According to a family participant and a professional participant, families were affected the most by the policies of insurance companies.(249) Families felt they had to fight with their insurance companies over everything and that there were always major problems.(250) Kathy has a disease with a side effect of degenerative vision. As a result, she needed new glasses about every six months, but her parents' insurance would only pay for glasses once every two years. They would not make an exception in Kathy's case. Kathy's parents were forced to bear the cost of the extra eye exams and glasses.(251) Insurance companies also influenced which physician families could use.(252) They determined where therapy could be provided(253), and they frequently decided to stop paying for some services that they had paid for previously.(254)

There were many other examples of insurance companies

becoming a barrier for families.(255) In one case, insurance would not pay for an evaluation for a child experiencing developmental delays which postponed the child's entry into the early intervention system.(256)  It was felt by a professional that "insurance companies can stall for so long regarding paying for early intervention that families get frustrated and leave the system."(257)  Both families and professionals felt that HMOs do not want to include children with  developmental disabilities because they have to pay for expensive services for the long-term, so they make it difficult for families to get any services.(258)  An early intervention program administrator said that she is always telling families "to hang in there and wait it out.  Some do and some do not."(259)

Jenny, a mother of a child with a developmental disability who was also a member of the LICC had taken action against insurance companies to fight this problem. Jenny said that it bothered her that she payed for private insurance that should cover her son's care, but the insurance company refused to pay for the services, forcing her to apply for Part H funds.  It bothered her to think that there may have been some child out there who did not receive early intervention because her son took the last

Part H money, when they had insurance that should have covered the services.(260)  Jenny has spearheaded a bill with the Virginia General Assembly Bill that would mandate insurance companies to pay for early intervention services.(261)  Currently, most insurance companies do not even mention early intervention services in their policies.(262)

Families have taken other action with insurance companies.  Families have gone directly to insurance companies to fight for such things as paying for an evaluation.(263)  One mother had a unique, but effective approach she used when her family's insurance company refuses to pay for an early intervention service.  She said that she goes to her insurance representative with what she calls her little bag of threats.  The little bag of threats contains the names of all the local television reporters who do investigation pieces and the list includes names from national shows such as *Prime Time Live*.  She says that it works wonders, but she is sure they dislike her at the insurance company.(264)

Finally, there was a difference in the experience of families receiving Medicaid and families with private insurance.  According to several family participants,

Medicaid tended to pay for more services than private
insurance.(265) According to one family participant,
families receiving Medicaid may soon start to experience
some of the same difficulties as Medicaid begins to utilize
the HMO model (e.g., Medicaid Medallion) in an attempt to
become more cost efficient.(267)  Welfare reform may also
affect families because fewer and fewer people will qualify
for public assistance including Medicaid.(268)

In summary, physicians influenced the ability of
families to access early intervention services and insurance
providers exerted considerable control over what and how
services were provided once families accessed an early
intervention provider.  Another non-Part H system that had
an impact on the early intervention system was Child
Protective Services (CPS).  The CPS system influenced how
early intervention professionals were perceived by families.

Child Protective Services

A family participant believed that families of children
with developmental delays or disabilities from low-income
neighborhoods feared their children may be taken away by
child protective services.(269) Fear of CPS being connected
to early intervention professionals resulted in families
turning down early intervention services.(270)  A family

participant who was also a member of the LICC discussed how this fear impeded child-find efforts.

We have the screenings outside, like on a corner or in a center. These parents are not going to bring their children out to a screening--no way! They do not want to bring them out to where professionals of all kinds can see them, they hide in their homes.(271)

A father felt that the media, television shows, and movies perpetuate this fear. He said "have you noticed that every time there is a movie about a social worker taking a child, it is always a middle-aged white woman?" To demonstrate how someone may react to seeing an early intervention professional approach their home, this same father said to his wife "Oh Lord, there is a white woman walking up our sidewalk!"(272)

The fear was based in reality. Children were removed from homes and these occurrences were talked about in neighborhoods.(273) According to one family participant, families who have children with disabilities are at risk for being reported to CPS, particularly for children who have yet to be diagnosed or identified by the early intervention system.(274) A mother who was reported to CPS said that the experience has made her think about everything she does and

says to people for fear that she may be reported again.(275)
One strategy that the LICC has used to deal with this fear was to hire families to work in their own neighborhoods to try to identify families.  But one family worker said that when she has canvassed neighborhoods many of the families slammed the door in her face, like they have done to early intervention professionals.(276)(277)

According to one professional, an unsanitary home can be considered medical neglect and as a result, a CPS issue.(278)  As an example a professional said that there was a case in the past where the home was so unsanitary that the children contracted tuberculosis.(279)  In response to this, one professional said she makes a point of telling families that she is not a CPS worker and that she will work with a family if she feels the condition of the home is unsanitary.(280)  Another professional reported that she and her colleagues inform a family if they intend to make a CPS complaint.(281)

The issue was complicated for professionals because they wanted to build trusting relationships with families, but they also were obligated and mandated by law to protect the children by reporting abuse.(282)  According to a service coordinator and a family participant, the irony was

that most reports to CPS did not come from professionals.
The reports came from friends, family, or neighbors.(283)
Several family participants felt that families should not
take advantage of early intervention services because they
are afraid CPS.  The two family participants felt that if
they were good parents, then any reports will be unfounded.
Therefore, these family participants felt that if an
individual is worried about CPS, then they must be doing
something wrong and professionals should be reporting these
families to CPS.(284)  An employee of the LICC believed that
professionals applied their values to families living in
depressed environments, rather than trying to understand the
situation from the families' perspective and work with
them.(285)  A professional felt that most professionals
acted too quickly when they report families which has
resulted in the mishandling of cases.(286)

Child protective services presented many issues for
families and professionals in this LICC.  Families and
professionals were especially challenged when they
confronted a combination of issues with physicians, the
insurance industry, and child protective services.  In
addition to these non-Part H systems, there were other
external systems that influenced families' early

intervention experiences. This last category of non-Part H providers includes several different types of providers that presented unique challenges to families and professionals.

Impact of Other Non-Part H Systems

Participants felt that non-Part H systems such as hospitals, the Department of Social Services, the Department of Health, and the public schools also affected the families experience in this LICC. Each of these systems has their own set of policies and procedures for families which can give families conflicting messages.(287)

It was felt by professionals and families alike that welfare reform has had a huge impact on families and the early intervention system in general. A member of the LICC described welfare reform as "the next tidal wave that will force the early intervention system to action again."(288) Members of the LICC were not sure that the early intervention community fully realized the impact that welfare reform was going to have on families.(289)

According to a family participant, families are going to be affected by welfare reform in three important ways. First, mothers are going to have to go to work and leave their children with someone.(290) One family participant described the impact it will have on a friend of hers when

she said, "you can not raise babies on four dollars an hour.
Now she will have day care for awhile, but that will run
out, leave her babies home alone, well then child protective
services will come and take them."(291)  Second, families
are going to lose basic benefits that they have been able to
count on such as Medicaid, Food Stamps, and children's
SSI.(292)  Finally, families may become homeless and poverty
will increase as families lose their basic benefits.  The
end result will be more children in need of early
intervention because they are not having their basic needs
met.(293)

     Local hospitals also had an impact on the Part H early
intervention system.  The unique issues with hospitals made
it difficult for them to connect families to early
intervention services.  According to an occupational
therapist at one of the hospitals, "a professional does not
have much time to make a referral because families are often
discharged with no notice, leaving little time to prepare
them."(294)  Also, once a family has been discharged, a
provider in a hospital has no contact with them unless they
are re-admitted to the hospital.(295)  Even if an early
intervention provider calls for information about a family
that was referred to them, the professional in the hospital

does not have access to their records, so they cannot provide any information.(296) In the public hospital in this LICC, therapy was provided piecemeal according to which services were involved (i.e., Occupational Therapy, Physical Therapy, Social Work).  According to one professional, the result was that families were rarely viewed holistically, which made it difficult for providers in the hospital to think in terms of the full range of early intervention services.(297)

In addition to issues with the local public hospital, many families had difficulty because they were forced to interact with many different providers in different service delivery systems.  Being involved with multiple systems had the largest impact on low-income families.  Many low-income families had already been through and continued to be involved with several other service delivery systems by the time they reached an early intervention program.(298) Families involved in other service delivery systems were concerned that accepting early intervention services would affect their other benefits resulting in families turning down early intervention services.(299)  Also, being involved in multiple service delivery systems lead to confusion and overlap of services for families.(300)

There was a positive side to being involved in many different service delivery systems for low-income families. For example, a family participant believed that because they have been involved in public service delivery systems, they were able to cope with the barriers and frustrations than middle-income families were.(301)  Also, because these families were experienced at working with professionals, they felt less intimidated.(302)

Families in this LICC had to confront issues related to their interactions with non-Part H providers.  Professionals were challenged to provide family-centered services even though their ability to do so was affected by these same non-Part H providers.  The Smiths also faced many issues presented to them by non-part H providers.

The Smith's Experience with Non-Part H Systems and Providers

The Smiths experienced difficulty in accessing early intervention services because of their interactions with their insurance company and with several pediatricians. Additionally, they were not able to obtain in-home physical therapy for one of their children and were denied access to a specialized form of therapy that they felt would have benefitted Monica.  The Smiths also had a brush with child protective services which changed how Mary interacted with

pediatricians (e.g., she is now more cautious with revealing information for fear that it will be used against her). As a result of her brush with child protective services, Mary has become skeptical of all professionals with whom she works.

The Smiths found themselves fighting battles with non-Part H providers for access to Part H early intervention services. Through their struggles, Bob and Mary found that they had to be tenacious in regards to their interactions with both Part H and non-Part H providers. They had to rely on their own skills and initiative to access the services they needed. For example, they did their own research, they traveled to Houston for a conference on rare diseases, and they took Monica to New York and Baltimore to see specialists. Their tenaciousness was a characteristic that they exhibited in dealing with the many issues they encountered in trying to access and use early intervention services. Many other family participants and professional participants felt that family characteristics such as tenaciousness were very important to the ultimate experience families had in this LICC.

## Family Characteristics

Participants felt that how families ultimately experienced early intervention was due in part to characteristics intrinsic to the families themselves. Participants also felt that the motivation of a family to cope with the stress and frustration of working with professionals from multiple agencies, both inside and outside the Part H system affected the family's experience and the amount of control they had while enrolled in early intervention. Additionally, the personality of the primary care provider had an impact on their ability to react to the multiple obstacles families faced in the early intervention system. How families coped with their emotional reactions to the stress and frustration was also important. Finally, the above characteristics ultimately affected the family's ability to overcome the barriers, the amount of control they felt they had over them, all of which may have determined how successful their early intervention experience was. Figure 4 provides a graphic representation of where family characteristics fit into the overall model [see Figure 4].

## Motivation of Families

The motivation of families to pursue services and then

Part H
Systems

Non Part H
Systems & Providers

Family
Empowerment

Family Characteristics
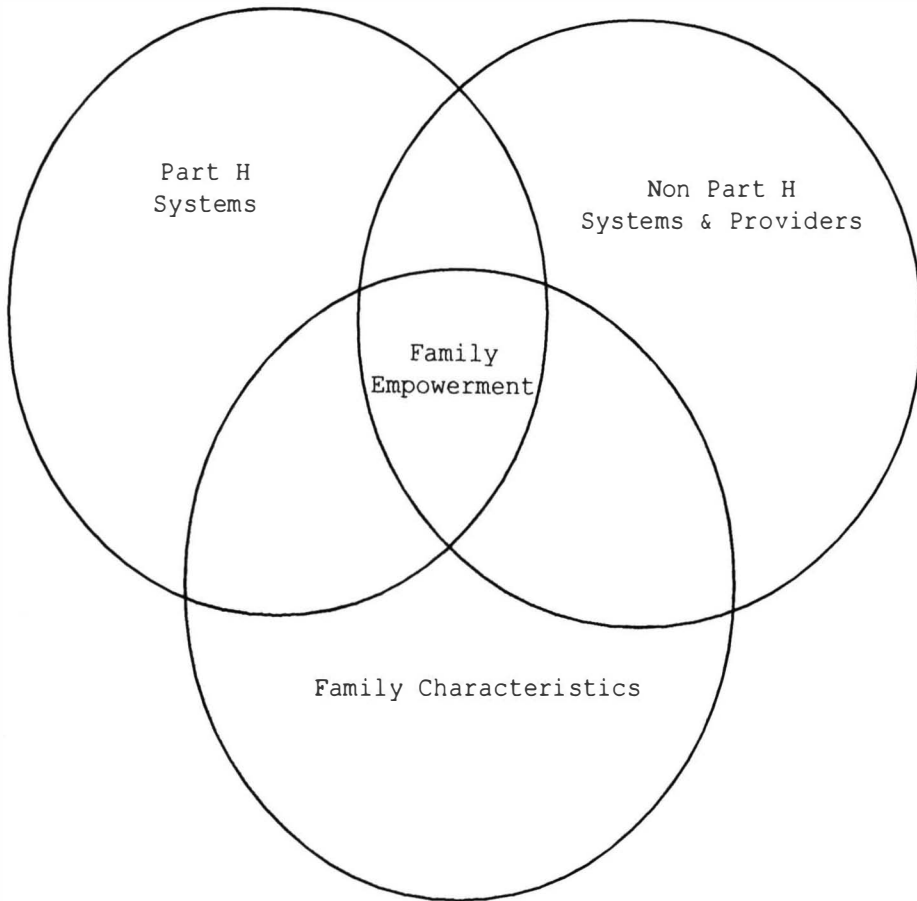
**Figure 4**

**Family Characteristics Systems Interactions**

to follow-through with the actual process has been called into question by both early intervention professionals and other families.(303)  Some participants felt that family motivation was the most important factor in the success of the early intervention process because of the many obstacles families faced when utilizing services.(304)  For example, a family participant felt that "a parent who does not stick with it no matter how difficult it gets, does not care about their child."(305)  She also stated that "if pride is an issue for a parent, they should swallow it and get the services they need for their child and family."(306)  A professional felt that some families take the same "wait and see" attitude that physicians take and they delay contacting an early intervention provider.(307)

Motivation was perceived differently by families who described themselves as low-income and families who described themselves as middle-income.  Low-income families felt that middle-income families complained were "whiners" because they were always complaining, while middle-income families felt that low-income families were non-compliant because they did not show up for appointments.(308)  The early intervention system "is guided too much by a middle-income perspective that negatively impacts the experiences

of low-income families" was how a low-income family

participant felt.(309)  At the same time a professional

described middle-income families as a population that would

not use early intervention services. Yet, middle-income

families were not using early intervention services,

according to some professionals, because there was more of a

focus on low-income families in the early intervention

system.(310)

Several professionals felt that middle-income families

avoided early intervention services because they associated

them with public assistance.(310a) Also, middle-income

families were sometimes not aware that they were even

eligible for early intervention services because they

believed that you had to be "poor" to qualify.(311) Some

professionals felt that physicians reinforced this belief

and told middle-income families that early intervention was

for the poor.(312) Regardless, one mother felt that families

should "suck it up and get past the ego. I would do anything

for my son and I expect that any other parent would do the

same. Deal with it. I do not find that to be a valid

excuse."(313)  As a result of the issues with middle-income

families, one professional felt that the LICC should develop

special marketing approaches to attract middle-income

families to early intervention.(314)

Families with medically involved children have unique concerns and often chose not to pursue early intervention services. When a child was born with severe medical problems, the medical services the child needed for survival were the priority for the medical service providers and the family.(315) According to several family participants, there were many children with multiple health problems who could have benefitted from early intervention, but they never connected to early intervention services.(316)

Families with children with medically involved children are often referred to early intervention services but they never access the services. These families have been viewed by professionals as unmotivated regardless of the medical issues they were coping with. According to two professionals, when children with multiple health needs were discharged, their families were happy their children were alive and doing well enough to leave the hospital. They were not thinking about early intervention.(317) Several professionals perceived the issue to be lack of follow-up with these families. Follow-up should be aimed at keeping them connected to the system so they can access services when they are ready.(318) This may not be effective with all

families because, even if they want early intervention
services, the medical concerns may keep bringing the child
back to the hospital, making early intervention
difficult.(319)  This was unfortunate because families with
children with multiple health issues had many unmet needs
due to the increased stress and pressure of having an infant
or toddler with developmental delays and multiple health
concerns.(320) For example, these children have many
appointments which can be very hard on a family that has to
manage the appointments along with jobs, other children, and
other daily life activities.(321)

Motivation to pursue early intervention services may
have been an issue for families experiencing issues with
substance abuse.  According to several professionals,
families who had substance abuse problems were not
identified by the system or actively avoided any contact
with the system because they were suspicious of any
professional for various reasons (e.g., fear of legal action
for substance abuse during pregnancy), and may have been
unwilling to bring their children in for an evaluation.(322)
 Working with parents who were abusing substances can be
frustrating for professionals.  One professional stated the
problem this way:

The toughest kinds of families we work with are

substance abusing families. Their minds just are not

there with their child. They are focused on their

addiction and they do not see that there is a problem

with their child.(323)

Another professional felt that motivation was the issue with

these families.(324)

Motivation may also be influenced by the education and

experience families have working with professionals.

Several professionals felt that a combination of education

and experience working with systems can be very effective

for families in early intervention.(325)  Some families

wondered how families with no higher education coped with

having a child in early intervention. They felt that it must

be very difficult for them.(326) Not everybody agreed that

education was one of the more important variables for a

family's success in early intervention.  For example, one

parent said that she had a degree in education that meant

nothing to her when she started early intervention.  She

stated, "I was in a new environment with nurses and doctors.

I was just as lost as a parent with no degree."(327) One

professional felt that if a parent is "aggressive and 'in

your face' with early intervention professionals, then they

will fight for what they want for their family, regardless of their level of education."(328)

It was important for professionals to say that motivation was not an issue with most families. It was actually a very small number of families who did not appear motivated.(329) Several professionals and families felt that most families were very motivated and they worked hard to overcome all the barriers that they encountered in early intervention.(330)  A family participant who was also a professional and member of the LICC felt that the problem was that you focus on the tough cases (e.g., families who did not appear motivated to bring their children to appointments or become involved in learning how to work with their child) which made the motivation issue seem larger than it actually was.(331)

One family participant would like to ask professionals two questions when they perceive families who leave early intervention as not motivated: "did they know the family when they dropped out? Did they know what their needs were?"(332)  Sometimes professionals just needed to ask why families were not making appointments.  If they were truly concerned about the family they would have talked to them and found out what was going on in the family's life that

made early intervention difficult to continue.(333)  One

professional agreed, "there is usually a reason. If you talk

to them you will uncover these reasons and find there are

some things that you can work out with them."(334)

Families in early intervention faced many barriers

while trying to receive early intervention services.  These

barriers often made it difficult for families to regularly

attend appointments and stay actively involved in their

child's care.  Professionals may have confused poor

motivation on the part of families with inconsistent

participation in early intervention by families faced with

many barriers.  Low-income families in particular were often

perceived by professionals to be uncooperative and

unmotivated.(335)  Barriers included transportation, daycare

for other children, work, appointments being scheduled at

inconvenient times, or having too many appointments.(336)

To demonstrate the extraordinary lengths a family has to go

to in order to keep up with the number of appointments in

early intervention one mother described her family's

experience:

Before our son was born, my husband had his own

business but when things got crazy with all the

appointments, he had to stop.  He went out and got a

job working nights so that we could work our schedules

out to cover all the appointments.(337)

One family participant felt that many early

intervention professionals were middle-income women who did

not understand many of the basic issues that low-income

families faced each day such as "putting your kids in the

bathtub to protect them from stray bullets and having to

stay up all night long to protect the children."(338)

Instead it was easier for these professionals to blame the

parent for not being motivated when they missed an

appointment. Another family participant said "I was told by

a speech therapist that if you ever want your son to speak

he has to be in therapy four days a week for an hour each

day. She never said can you do this!"(339) According to

one professional, it was not that low-income families did

not care about the child with the delay or disability, they

just had to cope with basic needs first.(340) Families

prioritized their many needs and often, early intervention

for one child was not the top priority.(341)

A family participant who is also a member of the LICC

described the issue of motivation in terms of important

daily life decisions. She described the situation of many

low-income families this way: "families have to make very

basic choices about survival, early intervention is a luxury."(342)   To illustrate the prioritization of needs that one low-income family, one family participant described her situation:

> I was on Aid to Dependent Children (ADC) for a short
> time and there were times that I had to make that
> choice--pay the rent, but they turn the electricity
> off, or pay the electricity, but you are on the street.
> People need to understand that, it's not that families
> do not care.(343)

As an African-American mother living in a low-income neighborhood said:

> Families in this neighborhood do not have
> transportation and they tryin' to get by on $231 a
> month from the city.  Now how you gonna feed your kids,
> pay for heat, electric, rent, and go to the doctor's on
> $231 a month?(344)

For these families, motivation to participate in early intervention was not the reason for their lack of participation. They were coping with more immediate needs that took precedence over early intervention.

    According to one member of the LICC, there were a substantial number of families who did not have

telephones.(345)  As a result, professionals had to send letters announcing appointments with no way to confirm the appointments.(346) When families missed these appointments, professionals sometimes believed that lack of motivation on the part of the family was the issue.  Two professional participants linked this issue with the fear that many families have that any professional they allow into their home may report them to Child Protective Services, "it is no wonder that they miss these appointments after receiving an official letter in the mail announcing that a professional will be coming to their home."(347)  Another professional added that "it is difficult enough to convince a family to trust you enough to let you into their home when you can talk to them."(348) In both these instances, families had good reasons to miss scheduled appointments so motivation was not the issue.

Transportation was a significant issue for families from low-income neighborhoods.(349)  Even when an agency provided transportation, it was still difficult for families because they had to be picked up on the van driver's schedule, usually an hour and a half before an appointment, go to the appointment for an hour or more and then wait another two hours for a ride home--it was a whole day.(350)

"What seemed like a non-compliance thing was often a non-transportation thing" was how one professional stated the problem.(351)  Combine a lack of transportation with appointments several times a week in different parts of the city and it is easy to understand how transportation alone prevented families from being able to utilize early intervention services rather than lack of motivation.(352)

A professional in a center-based program stated the issue concisely when she said "what good does it do to refer a family to a program when they are unable to get there."(353)  Relaying the same sentiment, a family participant said, "any parent will tell you that it is hard to pack your baby up, especially one with health needs, and walk in the rain to the community center.  It just is not going to happen."(354)  A related transportation issue was that if a family moved to a different part of town that would make it difficult for them to continue attending the same program, the services were not replaced.(355)

Another issue that families confronted that led professionals to view them as unmotivated was related to other children in the household.  Families who had a child with developmental concerns often had other children with and without developmental delays.(356)  It was difficult

trying to balance a weekly schedule with several children all of whom had doctor's appointments, therapy, and school. A single mother described her experience with early intervention this way:

> I have four children altogether and three of them are asthmatic. In the summer when it is hot they have trouble breathing. To get to therapy [for one child in the early intervention system] we all had to walk a mile to the bus stop in the heat; take a hot smelly bus across the city; go to the appointment; and then go back the same way.(357)

Again the issue that prevented families from making appointments was not related to their motivation, it was a practical issue of how to care for other children.

Difficulty obtaining daycare was a significant issue for many families as well.(358) It was also difficult for them to attend family support groups because they could not find a babysitter.(359) Devona, a mother of a child with Cerebral Palsy who lived in a low-income neighborhood said that when she had to go to work, she needed to find daycare. What she discovered was that the daycare providers wanted to charge her twice as much because her daughter had a disability. Devona felt that what they were really telling

her was that they did not want to accept her child and this
was just their way of telling her.(360)

Devona's solution to her daycare problem was to start
her own daycare in her home. Devona did more than just
start a daycare, however, she designed her daycare center
specifically for children with disabilities.(361) She was
very proud of the fact that she had a child with autism and
several other children with speech and motor delays
attending the daycare facility. She said that she
specifically looked for these kids because she knew that the
families had no where else to go.(362) She charged families
$65 a week because that was all social security or ADC will
pay for daycare.(362a) The daycare service was so well
known in her community and the need so great that Devona
said she had to turn many families away because she did not
have room for their children. She wants more space to
accommodate them.(363) Devona is also an advocate for these
families and she pushed them to get involved in early
intervention.(364)

Some professionals modified their stance on judging
families as unmotivated. They believed that families who
experienced difficulty with aggressively pursuing early
intervention did so because of their difficulty in coping

with the overwhelming stress they faced with having a child with a developmental delay. According to a service coordinator, many low-income families were overwhelmed by the many issues in their lives because they were not organized in how they dealt with the issues. She believed they were in chaos.(365) Another professional felt that the chaos distracted some families from their child's developmental needs to the point where the need went unnoticed.(366) According to a service coordinator, families who were more organized in their approach to coping with the same issues were better able to handle barriers they ran into in the early intervention system.(367)

Professionals who linked a family's motivation with the ability to approach caring for their child in an organized manner felt that these families needed assistance. For example, an adequate informal support structure was important for families with children with developmental delays. A supportive family was very helpful for low-income families with a child or children with developmental delays.(368) Younger families and single mothers, however, were at-risk for not having a strong support network to assist them with their issues.(369) A family participant who had a disability that qualified her for SSI benefits

felt that SSI provided her a measure of security that many other families in the early intervention system did not have.(370)  These families had to rely heavily on professionals for even the most basic needs because they did not have a support network.(371)

Middle-income families suffered from lack of support as well.  One mother felt that she and her family lost the support of their friends who had children who did not have developmental delays or disabilities because of their own child's developmental disability.(372)  She reported missing interactions with typically developing children and with their mothers.(373)  She also felt that she always associated everything her daughter had difficulty with to her disability when it really may have been normal developmentally.(374)  If she were around typically developing children she may have been in a better position to see what was related to the disability and what was just typical child behavior.(375)

Professional perceptions of motivation may be based on incomplete information.  For example, a professional cautioned her colleagues when she said "professionals need to remember that they are putting families under a microscope."(376)  They also need to understand that

families have legitimate reasons for not wanting services
and not following through.(377) Barriers such as
transportation, time of day therapy is offered, and fear of
CPS may have appeared to be lack of motivation to
professionals, when the barriers may have affected parents
ability to follow-through with services.(378) One of the
reasons families may not have been motivated was because
they did not understand that there was really a problem.
Other families may drop out of early intervention because
they were discouraged by not seeing progress.(379) A
professional on one team said that the social worker on
their team was very good at reminding team members that
there were many other variables in a persons life that were
just as important as early intervention.(380)

One participant felt that the success of a family in
the early intervention system was more attributable to how
professionals dealt with families than the motivation of
families.(381) For example, an employee of the LICC felt
that the system overwhelmed families when they first entered
the system, this often resulted in families not following-
through with services.(382) Another possible issue was that
families may not always be comfortable with professionals
coming into their homes.(383) Just saying that a family was

unmotivated may have been an easy way out for professionals when maybe what they should have done was be more persistent with providing the information and supports to better meet a family's needs.(384)

Participants had different perspectives regarding the lack of motivation to pursue early intervention services. Some participants believed that lack of motivation was the most important factor in determining the early intervention experience for families.  Other participants believed that families who did not appear motivated to participate in the early intervention system were instead trying to balance other issues and concerns in their lives.  Some participants suggested that perceived motivation and lack thereof may have been the result of an individual family member's personality.

## Impact of Personality Characteristics

An individual family member's personality can play an important part in their early intervention experience and on the family's perceived level of motivation.  Some families were tenacious and were adept at confrontation and fighting for what they desired. Others were more timid and did not handle confrontation well.  Their basic personalities influenced their ability to cope with the many issues in the

early intervention system.

One family participant felt that people who were timid were "railroaded" by early intervention professionals because they did not realize that they had the right to say no to things.(385) It takes some of these families a great deal of effort to say they want to be involved in their child's intervention plan.(386)  One member of the LICC felt that passive families were not always treated very well and did not have their needs met.(387)  A professional felt that families had to be able and willing to fight for what they needed and wanted in the early intervention system.(388)

A common personality characteristic exhibited by families who fared well in the early intervention system was tenacity.(389)  Families who approached early intervention tenaciously appeared to have been more successful accessing needed services than families with a more passive approach.(390) According to one employee of the LICC, tenacious families were more likely to fight for what they wanted in the system and access needed services.(391)  As one family participant said, "they do not do it for you," meaning that the family has to take control and make sure things get done.(392) Tenacious families felt that all families should be tenacious if they care about their

child.(393)

Some families that considered themselves tenacious were adept at working with early intervention professionals. For example, one family felt that it was important to pick your battles and not fight over everything--"fight for what you want most."(394) "Once you have decided what is most important to you, do not let anyone know it until it is time to bear down, then use it to negotiate and get what you need."(395) Another family said that "it is important to not be confrontational, be more subtle and use negotiating skills."(396)

One father's tenacious fighting spirit came from watching his parents fight for the rights of his two sisters who had mental retardation.(397) He felt that the services his sisters received were because of his mother's tenacious approach. A mother who has a disability herself said that she did not want her daughter to go through what she went through [like being hit and kicked] when she was a kid and was placed in the "retardation" classes.(398) This tenacity and fighting spirit for their children is not just reserved for physicians and early intervention professionals. One mother said:

I have had people in the grocery stores say how sorry

they are for her, but I do not let 'em get away with
that.  I say do not be feeling sorry for this girl,
this girl is gonna go after and get anything she
wants.(399)

Families who were tenacious felt that they would do
whatever they had to do to secure services for their
children.(400)  For example, one mother scheduled her
child's therapy over lunch so that she could be with him two
times a week.(401)  Another mother went to a conference in
Chicago to learn more about Prader-Willi Syndrome.(402)  Two
other families have learned how to write grants and use the
public library to do research about their child's
disability.(403)  Finally, a single mother described the
lengths she had to go to every day to ensure that her son
received early intervention:

I am a single mother and was working when he first
started going to therapy.  I would wake up dead
exhausted and still have to get my baby to the doctor's
office.  I did not even have a car to get him there at
the time.  That is how important that kid is to
you.(404)

One mother said that she ran into barriers here and
there but she did not let them stop her from pursuing early

intervention. She speculated that having the tenacity to
overcome the barriers may be the difference between families
who stick with early intervention and those who drop
out.(405) According to many family participants, what they
really meant when they defined themselves as tenacious was
that they had confidence in themselves and were willing to
fight for what they needed with professionals and others
involved in early intervention.(406)

Families who have been through the early intervention
system were intolerant of other families' decisions not to
participate in early intervention.(407)  One mother said "I
can not accept a logical decision to not have your child
receive services that they absolutely need. Suck it up and
do it."(408)  A parent who was also an advocate for parents
new to early intervention said "I talk to parents who say
they do not even want to help their children with their
homework." Another mother said that she could not understand
why families were so unwilling to get involved in a state
Part H planning group in which she participated.(409)
Finally, when a parent advocate asked another parent why she
discontinued early intervention she replied, "they always
want to come over during the *Young and the Restless*, so I
told them I did not want to work with them anymore."(410) As

a result of this comment, the parent advocate felt that the parent who made the comment was not motivated.

Family participants and professional participants believed that the personality of a family member trying to negotiate the early intervention system was an important determinant of whether they had a successful experience or not. They felt that tenacity or timidness influenced a family member's ability to access services and to work with professionals, teams, and agencies in the early intervention system. In addition to these basic personality characteristics, family participants felt that professionals also failed to consider some of the emotional reactions families experience because of their child's developmental concerns.

Emotional Reactions

A professional participant believed that denial and grief appeared as a lack of motivation for many families who were coping with the presence of a developmental delay or disability regardless of their personality.(411) Some families were simply busy dealing with grief issues related to their children's developmental delays or disabilities, or they were denying that there was a problem at all. A professional cautioned, "We are all taught to have the

perfect child and when you do not have the perfect child,
you do not want to believe there is a problem. You deny it
to yourself and to others."(412)   Denying that there was a
problem was felt to be a particularly big issue by
professional participants and some family participants.(413)
For example, an employee of the LICC said that families deny
a problem that is clearly evident to others.(414)

There are many reasons why parents may have experienced
denial with their children.  According to two professional
participants, the family may feel that the child will grow
out of it, they do not want to enter the world of the "short
bus" [as one professional referred to having children with
special needs who ride on buses that are shorter than buses
for children who are not in special education].  In other
words, a family may deny the existence of a delay because
they fear the implications of having a child with special
needs.(415)

Trying to explain denial in a cultural context, a
mother who is African American and has a child with a
disability described how she felt and how other African
American families may have felt when she said:

In the black community it has to do with how you think
about a child.  It is like a ritualistic thing--like in

*Roots* where the baby is held up to the night sky. It
is the idea that your baby is the "one," and when you
try to take this idea that this is the "one" away from
a parent, it is like you are taking her dreams away. A
child with a disability is not the one, so of course
you are going to have parents who deny the problem.
When I was pregnant I was convinced that I was going to
have the "one," and when that did not turn out to be
the case I couldn't understand why. Looking back now I
think I was in denial.(416)

Family participants felt denial of their children's
developmental issues were associated with fear. They
experienced denial because they feared what it meant for
their children.(417) There was also a fear of what it meant
for them. They feared losing their friends who had children
without disabilities or delays because their friends would
not want their children exposed to children with
disabilities.(418) Other participants felt that families
convinced themselves that their child was only a little slow
because they did not want to deal with the
implications.(419)

There were other possible explanations for what
professionals perceived as denial. For example, some

families denied the existence of the problem because they were afraid of the stigma attached to the label of developmental delay.(420) Also, families may have not understood that their children had delays which may have appeared to professionals as a denial of the issue.(421) Other families may not have seen the severity of the delay that professionals saw. Professionals view this as not accepting the delay.(422) One professional believed that parents may deny the existence of a delay because they were embarrassed that their child was different.(423)

Another reaction some families experienced was self blame. Families sometimes blamed themselves for their child's delay.(424) Parents were even made to feel by their own families that their child's delay was their fault.(425) Professionals also assigned blame to the family. For example, one family participant said, "Sometimes you are left responsible for the child's problem. They [professionals] make you feel that it is your fault."(426) Regarding the early intervention team on which she worked, one professional felt that some members of the team were not able to look at the other needs and concerns of the family. Instead, all they saw was a family who did not appear to be cooperating so they placed the blame of the delay on the

family.(427)  A mother cautioned professionals when she said, "we can not understand what other people are going through, just like they can not understand what we are going through."(428)

A family participant felt, "It is nothing but God's will unless they do not get prenatal care, or they use drugs or alcohol while they are pregnant."(429) The end result for some families was that they began to believe all those people who were telling them that their child's difficulties were their fault.(430) According to one family participant, families ultimately say, "Forget this, I'm walking out."(431) In other words, families resent being blamed for their child's delays and they leave the system. When this happens, the family is lost to the system and the child and family do not benefit from early intervention services.

Fortunately, there were other families involved in early intervention who told family participants that it was not their fault that their child had a delay/disability. (432)  For example, one mother said "I always thought that if your baby was born with something wrong with them then you must have done something to them. You must have caused it.  It was good to hear from other families and find that it was not true."(433)  Overall, the general feeling was

that professionals needed to be dealing with these initial grief and guilt reactions more effectively.(434) However, families who were tenacious and were able to cope with any grief or guilt reactions still faced many barriers that made it difficult to participate in the early intervention system.

## Other Family Barriers to Early Intervention Services

Establishing trust in the working relationship between families and early intervention professionals was often a barrier for families.  If the initial trust bond was not established, families often chose not to pursue services.(435)  A professional acknowledged that getting through the initial trust issue was often difficult for many reasons such as racial issues, appearances (i.e., style of dress), using professional jargon, or personality clashes.(436) Building trust took time, especially when it was a home-based program and the family was letting a stranger into their home several times a week to work with their child.(437)  Professionals felt that they may only have one chance at establishing trust with a family.(438) A therapist in a home-based program emphasized this point when she said:

  I only have one visit before the evaluation to build

rapport while doing all the paperwork with them.

Because of insurance companies and what is billable

time, I usually only have one-half to one hour to do it

in when I probably need 100 hours to gain their

trust.(439)

A social worker's advice to all early intervention

professionals was that they have to take the family's lead

in order to establish that initial bond of trust.(440)

A significant barrier to building trust between

families and professionals was related to race.

Professionals tend to be middle-income white women and many

families in the system are lower-income, African American,

and often single mothers.(441) A professional felt that the

early intervention system in general has not been supportive

of African Americans.  She also felt that African Americans

were blamed for their children's problems because of abuse,

neglect, drugs, and teenage pregnancy.  They were made to

feel that they had done something wrong because their child

needed early intervention.(442) On the other hand, a service

coordinator believed that race was not the issue with

establishing trust with a family.  She thought the issue was

more of a general mistrust of all professionals and that it

did not have anything specific to do with early intervention

professionals.(443)

It appeared that diversity among early intervention
professionals was rare.  A professional felt that having a
therapist of color would be very helpful on her team.(444)
But it has been difficult for early intervention programs to
recruit and hire minorities.(445)  According to a
professional, the early intervention system needs to attract
minorities to be better able to relate to the populations
with whom they work in the system.(446)

Professionals and families acknowledged a need to
address the issue of race in early intervention in this
LICC.(447)  As one professional stated it, "We all have our
little prejudices and fears, especially on first impression.
But if you can overcome them you usually find that people
are decent and do not cause a problem."(448) According to
one family participant, families need to be able to work
with professionals of all kinds, regardless of their race or
gender.(449)  Professionals also need to be cognizant of
different cultural norms so they do not misinterpret any
behaviors that may appear to be non-compliance or lack of
motivation.(450)

Early intervention professionals often had attitudes
about families that served as barriers.  One family

participant felt that some early intervention professionals treated children with special needs like they were dumb.(451) There were families who missed appointments or did not answer the door when therapists arrived because they felt they were judged by professionals, and families wanted to avoid this.(452) Professionals had to remember that they were going into people's homes and entering into families' private lives.(453) On the other hand, there were professionals who avoided making home visits in low income neighborhoods, even if that was what the family wanted. As a result, according to a professional participant, these families may have not been provided the services they needed.(454)

Professionals were sometimes caught up in their own needs and disregarded how a family was being affected. A family participant thought that professionals did not want to work with each other to support families because they were afraid that if they let other early intervention professionals know what they were doing they would "steal their glory."(455) Professionals may have also fit families into their programs the way they worked best for the professionals, not the families.(456) One mother described a transition meeting from early intervention into the

schools where several occupational therapists disagreed with each other and began to openly argue with each other in the meeting. She felt that they were more concerned about their own issues than about the family's needs.(457)  Finally, a family participant said how frustrated she was with early intervention professionals who would not tell her that there was a problem with her child. She felt that the professionals withheld the truth from her so that she would not become upset.(458)

The attitudes of other staff in early intervention programs also became a barrier when these staff were not sensitive to the needs of families.  For example, the staff who handle all of the insurance and billing responsibilities were very important to the smooth functioning of early intervention teams.  These staff were truly the gatekeepers to early intervention.  When families had difficulty working with these staff, the staff became a barrier to early intervention for families.(459)  Because they did not have contact with families and did not know their overall issues, they treated families poorly when they missed appointments.(460)

Another barrier for families in the early intervention system was the use of professional jargon. Families said

that they had to be able to learn professional jargon if they wanted to communicate with professionals and understand what was happening with their early intervention team.(461) Families and professionals often disagreed over what was best for the child because of misunderstandings that resulted from professionals using jargon with families.(462)

It was not always easy for professionals to walk into people's lives and feel comfortable either. One professional admitted that there were times that she was not comfortable with families.(463) This became a barrier for families who preferred or needed in-home services because some professionals were not comfortable going into the homes of families with ethnic backgrounds different from the therapist's. One team's social worker commented on this issue by saying that she routinely goes to families' homes first to pave the way for the therapists so they knew what to expect.(464)

There were many other barriers for families in accessing early intervention services. For example, language differences-such as families who speak only Spanish-are barriers for families and professionals due to lack of interpreters and funds to pay for interpreters.(465) Illiteracy was a barrier for many families because of the

amount of paperwork that was thrown at families when it was assumed they could read.(466) Sometimes this resulted in families not accessing the early intervention providers because it was not clear to them where the entry point was.(467)  Despite all the obstacles and difficulties families experienced with the early intervention system in this Council, there were families who were very satisfied with their overall experience and felt that they were empowered by the process.(468)

The Impact of the Smith's Family Characteristics on their Early Intervention Experience

The Smiths were tenacious in their approach to working with both Part H and non-Part H service providers. In a sense, the Smiths were able to empower themselves in the early intervention system which led to them having what they described as a satisfactory experience. They expressed concern, however, for those families who they felt were unable to stand up for themselves and fight with professionals. They were concerned that these families did not know that they had the right to stand up for themselves and that this message was not communicated to them. As a result, the Smiths assumed that these families were not empowered to make decisions about services.

Empowering families was a key concept embedded in Part H but families have rarely been asked what this concept means to them (Dunst & Trivette, 1994). Empowering families was important to family participants and professional participants and it emerged as a theme in this study.

## Empowering Families

Empowering families is considered an important component of family-centered care. Empowerment emerged as a concern for families and professionals. One of the possible reasons for this was the expressed need for families to cope with the many barriers they faced. Early intervention providers were often powerless to do anything about many of the Part H and non-Part H barriers. The discussions in which participants engaged in about empowerment were focused on strategies about what needed to happen in the future to empower families. Many of the participants ideas appear as suggestions or strategies for empowerment. Empowerment is represented in Figure 5 [see Figure 5].

Participants felt that strategies for empowering families should address the multiple levels of systems' influence on the early intervention experience for families to maximize the control families have over the services they received. A first step in the empowerment process for many
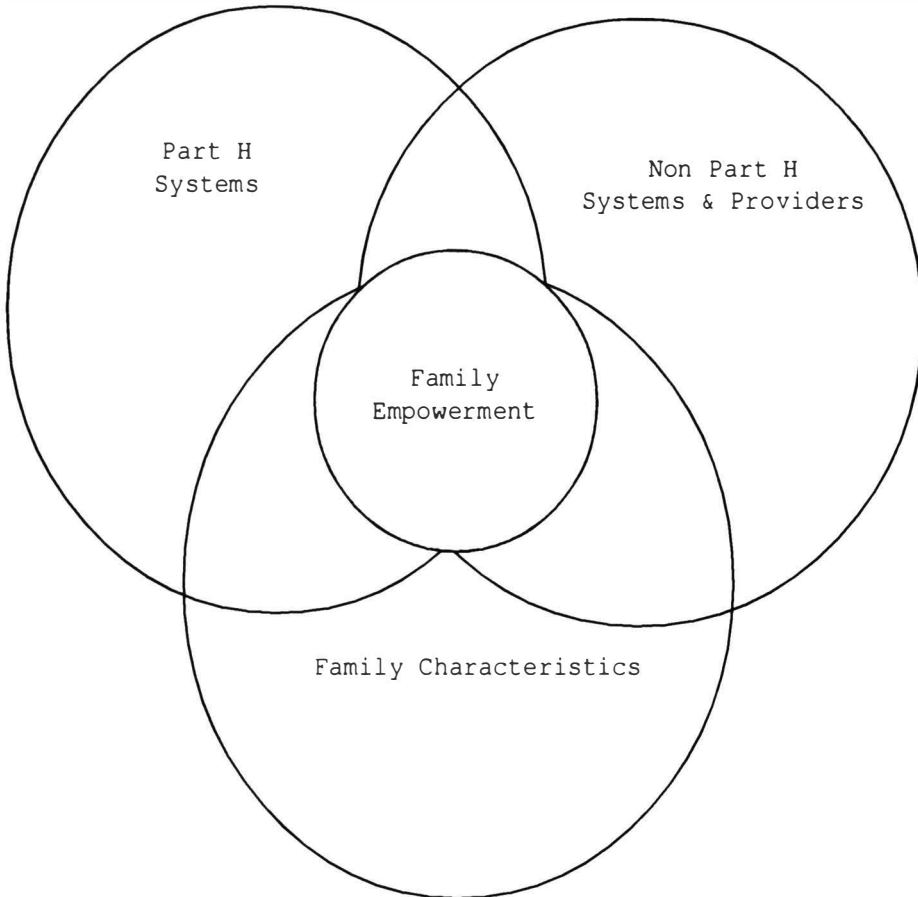
**Figure 5**

**Family Empowerment**

families was having their basic needs met.  One professional felt that the only way families could be empowered was to be provided assistance in gaining some control of these problems. Many of these problems were what placed children at risk for experiencing developmental delays in the first place.(469)  Another professional believed that many families were in crisis when they first entered the system and that professionals often jumped too quickly into "empowering" families when what they really needed was crisis intervention.  This professional defined empowerment as "allowing families to make decisions."(470)

A single mother described her experience with a public health nurse who was making home visits.  She said, "do you know that when I got Levon and we had a nurse coming over to help out with her, she would tell me to sleep while she was there.  She was so sweet, she knew how exhausting it was with three boys and Levon."(471)  Another mother described her experience with a temporary service coordinator from the LICC: "She [Council employee] started coming in and seeing me when I was in the Perinatal Substance Abuse Center before my son was born."(472) Additionally, the temporary service coordinator continued to follow her after she was discharged and referred her to a hospital-based program where she

received other forms of assistance.(473) This mother felt that she was empowered when she said,

> She was very helpful to my situation, she helped me learn that there were other people like me and that my baby was a blessing, and that I could be a good mother. She also told me how to get other help I needed.(474)

One family participant felt that families needed information once their basic needs have been met.(475) Information can be a form of power for families. As one participant stated, "If you just understand that you have power, then you really have power."(476) According to several family participants, families need information about their children's delay/disability(477), information about child development(478), information about the early intervention system(479), information about basic parenting skills(480), and what services were available.(481) Additionally, they needed this information presented to them in a format they could understand.(482)  As one family participant who was also a member of the Council said, "Families just need information. Once they get the information, hell, they do not need us anymore."(483) Finally, a family participant felt that families have a responsibility for empowering themselves.  For example, if

they are given a phone number for a referral, they need to call.  She believed that families often want others to do the work for them. (484)

According to a family participant, a good way for professionals to initiate the empowerment process with families was to boost their self-esteem.  Professionals could begin by teaching families simple tasks that they are likely to complete successfully, thus building confidence in their ability to learn and carry out more complicated tasks.(485)  Also, professionals could help families deal with other people, such as family members, who did not feel they were capable of assisting in their child's intervention.(486) Working with professionals required skills, skills that many families often did not possess.(487)  Describing how important it was for her to have worked with a professional willing to teach her, a family participant said, "We had a great case manager early on who taught us the language and how to work with professionals and agencies, it was so valuable."(488)

The family participant above brought up a key for many families: understanding the language of professionals.  A service coordinator believed that generally the parent was a lay person and did not understand professional jargon.

Consequently, if they did not understand what they were being told and what was being discussed by professionals, how could they possibly become involved in the planning and decision-making process?(489)

A family participant felt that professionals can empower families by serving as a conduit for information and they can help families sort through what can sometimes be an overwhelming amount of information.(490) One family participant cautioned professionals about information they give families when they are first approached about early intervention when she said, "I did not hear anything they told me in those first few days, and that was when they told me all the stuff I needed to know."(491)

Professionals can also empower families by teaching families skills that they will need to begin taking control of their experience in the early intervention system. Professionals can guide families who request help and teach them what they need to know about the early intervention system, without holding their hands and preventing them from taking control over their experience.(492) A family participant believed that families can not do anything for themselves until they learn the system; and she felt that professionals have been reluctant to teach them.(493)

For professionals, there was a fine line between being paternalistic with families and empowering families. As a professional said, "We try and help them [families] without telling them what to do."(494) One professional acknowledged telling families that she would not do it for them because they needed to learn how to take care of their own child, even if families wanted her to take control.(495) An early intervention professional who was a social worker stated that she enjoyed the empowerment part of her practice with families which she defined as "strengthening a family's ability to take care of their own needs."(496) A family member summed up the need for professionals to teach families how to take care of their own needs when she said, "If empowerment does not mean helping families to do it themselves, then I do not know what empowerment is."(497)

Family participants felt strongly that professionals needed to take the time to teach them how to carry out many of the functions traditionally reserved for professionals.(498) A family participant reflected this feeling when she said:

   We [families] learn from a whole lot of different

   people--family, ministers, parents, friends, but mainly

   I'm referring to professionals who are working with

families in early intervention. They need to teach

families how to care for their special child.(499)

Regardless, some professionals appeared to be concerned

about turning over some of their responsibilities to

families because they were uncomfortable with family members

doing some of the technical aspects of their work. In

response to this a mother said, "Parents can learn. I did. I

never would have dreamed that I would be suctioning my child

and changing feeding tubes and all that, but I did it. I

learned."(500)  "Training is the key to successful family

involvement" is how another mother felt. "A parent who has a

child with a special need has never had to deal with that

before, they need to be trained how to care for a child with

special needs."(501) A professional from one of the early

intervention programs felt very strongly that the parent

must be present at therapy sessions so that they can learn.

Another professional at this program said that she was

concerned about other early intervention providers sending a

van to pick up the child for therapy at their center,

without the parent.  She said, "We will not do that because

we feel it is too important for the family to be there. They

need to be there to learn."(502) Without this training,

families become dependent upon early intervention

professionals.(503)

Professionals believed that there was a price to pay for empowering families. Several families felt that there was some reluctance on the part of professionals to relinquish some of this power to families so they did not take the time to teach families. A family participant who was also a member of the Council felt that professionals have purposefully left families out of much of the planning and intervention process. Her response to this attitude was, "We will not lose our jobs if we teach families how to do this. We strengthen families instead. That is what we are supposed to do."(505) It was important to teach families skills, but it was also important to help them incorporate the activities associated with the skills, like fine motor therapy into their already established schedules [daily routines].(506)

Families supporting each other in the early intervention system was considered to be an essential method for empowering families.(507) Families who had experienced early intervention were an extremely useful resource for families just entering the system.(508) As an example one mother said, "People like me think they are by themselves until they meet other people who have the same experiences--

you do not feel as alone."(509) The LICC has organized an annual event called "Parents Speak Out" where parents get together to share experiences, information, support, and advice. One mother said, "I think that has been the most positive experience for me, it helped me with my son and I have made friends. They are people who I can talk to when I have a question or to just talk."(510) In fact, she would prefer to have the "Parents Speak Out" event more than once a year.(511) An organizer of the event said the purpose was to encourage dialogue with every parent and exchange information. Meeting and talking to other people was the most important aspect of the event.(512)

Families have formed both formal and informal parent support groups.(513) One family in particular found a support group to be very helpful when her family needed it.(514) The family participant who felt she benefitted from the "Parents Speak Out" event felt that while it was very helpful, she did not see many people from lower-income neighborhoods.(515) It has not been easy to organize parent support groups, however. An early intervention program tried to organize a support group but they were unable to get a large enough group to attend on a regular basis so they had to cancel it.(516) While families felt they

benefitted from support groups, they had trouble attending because of other commitments.(517)

One family participant described an additional support mechanism for families. It was a parent training program designed for parents to empower other parents. Parents were used as surrogates for parents entering the system. A parent who has been in the system teams up with a new parent to provide support for families going into their first IFSP meeting.(518) The LICC has organized this and is recruiting parents to act as surrogates.(519)

A family participant felt that professionals needed to be aware that what may be true for families today will undoubtedly be very different in a few years. As a result, she felt that professionals need to always be changing and evaluating families in order to adequately meet their needs.(520) To empower families, professionals need to listen to families to understand their needs.(521) A professional stated that early intervention professionals need to learn more about other cultures to be effective at empowering and working with families.(522) While another professional believed that it was important for professionals to move at the family's pace, not their own.(523)

## The Smith's Experience with Empowerment

The Smiths did not feel empowered with many of their interactions with their pediatricians and with their insurance company. Initially, Mary felt that the issue was their lack of knowledge about Cerebral Palsy. The Smiths felt that they empowered themselves by firing their first pediatrician whom they felt was not meeting their needs. This action helped them to realize that they could make choices, disagree with professionals and get what they wanted. With their next child who was experiencing delays, they questioned their child's physician more quickly and pushed him for a diagnosis. When they did not get the answers they wanted, they chose a new pediatrician. The Smiths feelings of empowerment may have been related to their personality, specifically, their tenacious approach to working with physicians and with early intervention professionals.

### Summary

The purpose of this inquiry was to examine the intent of the Part H legislation to mandate the construction of family-centered service delivery systems from the perspectives of relevant stakeholders in one LICC. What emerged was a model that represents the confluence of Part H

policy intentions, systems and providers that existed outside the realm of Part H, and the individual characteristics of families. Family empowerment is what rests at the confluence. Family empowerment emerged as the key to making this system family-centered.

Families experienced issues with the operationalization of some of the key aspects of Part H such as the mandate for service coordination, coordinated services, and certain rights. Families also experienced many barriers that confronted them from outside of the Part H early intervention system. It was ultimately their responsibility to cope with the issues that emerged from Part H and non-Part H providers. Therefore, in this conceptual model, family empowerment rests at the point where these three categories intersected.

The experience of the Smiths and the many other participants in this inquiry revealed a considerable amount of information about how the early intervention service delivery system in this LICC affected families and providers. If this is an accurate reconstruction of family and professional experiences, then many important lessons can be learned. These lessons can assist other families in understanding and coping with the many issues they may

experience when seeking services for their children with
developmental delays or disabilities and their family.
Additionally, professionals both within the Part H early
intervention system and outside of it can learn lessons
about how to more effectively support families.  The final
section of this chapter describes these lessons to be
learned.

## Lessons To Be Learned

The lessons to be learned from this inquiry emanate from the apparent interconnectedness between the local Part H service delivery system, non-Part H systems and providers, and individual family systems as they reflected the intent of Part H, the implementation of Part H, and how early intervention in this LICC·was experienced by families. The struggle for providers in this LICC has been with attempting to implement the principles of family-centered practice while simultaneously interacting with families and non-Part H providers. The experience for many families in this LICC and how they fared in the early intervention system was influenced by their own skills, resources, and initiative.

If this is an accurate reconstruction of the experiences of these families, then some lessons can be learned from this inquiry. First, lessons can be learned about the family-centered intent of Part H. Second, there are lessons to be learned about how the family-centered intent of Part H has been impacted by non-Part H systems and providers in this LICC. Third, there are lessons to be learned about how the characteristics of families have affected their early intervention experience. Finally, there are lessons to be learned about empowering families in this

LICC.

## Lessons About the Family-Centered Intent of IDEA, Part H

The intent of the Part H legislation to construct systems that were family-centered proved to be difficult to achieve for the providers who participated in this study. For example, the first lesson about the family-centered intent of Part H relates to how providers were reimbursed for services. Professionals were under pressure to provide only those services that were billable and were profitable for their employers.

Lesson 1: In a family-centered service delivery model, decisions about which services the child and family receive should be decided primarily by the family, not by the needs of the service providers.

A second lesson about the family-centered intent of Part H relates to how the legislation stimulated agency competition. The Part H legislation tied reimbursement directly to individual families. As a result, agencies were concerned about keeping their family counts high because Part H funding was linked to each family.

Lesson 2: When reimbursing for services provided by early
intervention programs, agencies may be interested in
providing services to some families and not to others
because it increases their funding support.


A third lesson about the family-centered intent of Part
H is linked to organizational constraints experienced by
providers.  Early intervention programs in this LICC did not
exist as independent operating programs, rather, they
resided within larger organizations such as hospitals,
private developmental disability agencies, or within public
developmental disability agencies.  As such, the early
intervention programs were under the direct control of the
larger organization.


Lesson 3: When early intervention programs reside within
larger agencies, issues present within their host
organizations took precedence over the needs of families and
the early intervention program.


A fourth lesson relates to issues with the
implementation of the family-centered intent of Part H.  An
important way for such a confusing system to become family-

centered was for families to have a "system expert" at their
disposal to guide them through the complex web of service
providers. Service coordination was the mechanism
envisioned to meet this need for families. But service
coordination was not a billable service, and agencies did
not want to utilize valuable staff time providing it. Also,
families did not have a clear understanding of the role of
their service coordinators.

Lesson 4: Because service coordination was not a billable
service, families may not receive effective service
coordination.

There were many issues encountered with Part H services
by families and providers. Many of these issues, however,
may have been associated with systems and providers that
operated outside of the Part H service delivery system in
this LICC. The next seven lessons learned are related to
the issues associated with non-Part H systems and providers.

## Lessons about Non-Part H Systems and Providers

There are several lessons about the possible influence
that non-Part H systems had on the implementation of the

family-centered intent of Part H and how this was

experienced by families. The three major non-Part H systems

and providers were physicians, insurance providers, and

Child Protective Services. The fifth lesson learned relates

to the lack of visibility of the Part H system to family

practice physicians and pediatricians in this community.

Lesson 5: Participants felt that there may be an association

between a lack of visibility of the early intervention

system and low referral rates by physicians to early

intervention providers.

The sixth lesson learned relates to the issue

identified by participants that physicians may not have

access to information and research findings that would

legitimize the effectiveness of early intervention. The

absence of evidence in medical publications to support early

intervention as an effective approach to working with

infants and toddlers with developmental delays may have

influenced how physicians perceived early intervention

services and providers.

Lesson 6: When physicians do not have access to research

findings demonstrating the effectiveness of early intervention, physicians may not always believe in the effectiveness of early intervention as a treatment approach and may even discourage families from pursuing early intervention services.

A seventh lesson relates to how physicians approached the presence of developmental delays in infants and toddlers. Participants felt that physicians in this LICC adopted a wait-and-see attitude with families when their children first presented with developmental delays. When physicians did refer infants and toddlers, they tended to refer them to other physicians and not to early intervention providers. This process turned into a long process for some families with many referrals to many different types of specialists.

Lesson 7: When physicians use a wait-and-see approach with children with developmental delays, many infants and toddlers may be closed out of the early intervention system. This process can be disheartening for many families and lead to some families never being referred to an early intervention program.

The eighth lesson relates to the perspective held by participants that physicians sometimes used too much medical jargon with families which was difficult for families to decipher.  Also, some families felt that physicians did not value the opinions of families regarding their children's treatment and therefore disregarded their input and wishes. Finally, participants felt that physicians also focused on the medical symptoms the child presented and did not pay attention to the family's needs.

Lesson 8: Physicians can be difficult for families when they use medical jargon, disregard the opinions of families, and focus only on the medical symptoms of the child.

The ninth lesson relates to the perspective held by participants that physicians have legitimate constraints in their practices that makes working with infants and toddlers and their families challenging.  The perspective of physicians was that they were extremely busy and overwhelmed in their practices which may result in their missing some of the subtleties of developmental delay.

Lesson 9: When physicians are overwhelmed in their practices

they may miss subtle developmental delays, but they felt
that most children presenting with delays do outgrow the
delays, and it does not make sense to refer children too
quickly.

The tenth lesson about the implementation of the
family-centered intent of Part H relates to the influence
insurance providers had over services provided to families.
In some respects insurance companies were the primary
decision-makers regarding services rendered to families.
Insurance companies were felt to exert influence over the
types and duration of the therapies they would accept as
billable.  Family-centered service delivery was further
complicated by the fact that not only were families
sometimes removed from the decision-making process,
professionals were similarly constrained by insurance
companies.  Middle-income families were often hit hard by
the insurance constraints as they were more likely to have
private insurance. Medicaid covers the majority of the
services offered by early intervention.

Lesson 10: Family-centered service delivery is difficult to
achieve when both families and early intervention providers

are removed from the treatment decision-making process by insurance companies.


The eleventh lesson about the implementation of the family-centered intent of Part H is linked to perspectives about the CPS system. Reports to CPS have created an atmosphere of mistrust between professionals and families. The atmosphere of mistrust related to CPS has resulted in families avoiding contact with early intervention professionals for fear that they were either CPS workers themselves or that they would report them to CPS.

Lesson 11: The atmosphere of mistrust created by the fear of CPS made finding families and keeping them in the early intervention system difficult.


As Part H was implemented and issues began to arise such as the impact of non-Part H systems, families were confronted with many challenges.  Families had to look to their own skills and resources to confront many of these issues.  Four lessons about the characteristics of families emerged from this inquiry.

<u>Lessons about Family Characteristics</u>

Many families were forced to be strong advocates for their family which was often tiring, frustrating, and emotionally draining.  The twelfth lesson learned relates to families feeling that in order to get the services their child and family needed, they had to be highly motivated and persistent.  Not all families had this ability and their early intervention experience may have suffered as a result. Families who were assertive or tenacious found ways to obtain the services they needed.  For example, professionals felt that if the family was confident in their ability to work with professionals in a team setting they were more willing to challenge the team when they did not agree with something. Whereas families who approached the system passively were not able to challenge the team.

Lesson 12: The families' ability to cope with the stressful interaction with Part H and non-Part H providers may have been the most important factor in determining the families' ultimate early intervention experience in this LICC.

The thirteenth lesson relates to the notion that early intervention was not just about a child's therapy or a

family's support group, it was about how it affected a family's entire life. Families have other children, financial concerns, transportation issues, family issues, and work schedules. When a family member appeared to be unmotivated, some professionals would take this as a sign that they were better off letting them drop out of their early intervention program. The lesson however, was that many of these families needed help in other areas besides early intervention that were more pressing problems for the entire family.

Lesson 13: When working with families, professionals should consider how early intervention will impact families' entire lives and they should avoid labeling families as unmotivated.

A related lesson [fourteenth lesson] is that many of the professionals in the early intervention system do not have training to address psycho-social and systems issues that families experience. Therapists for example, are trained to provide specific therapies to individuals. They are not trained to provide counseling to families or to provide service coordination. Yet, they are often expected

to provide these services.


Lesson 14: When working with families, many early
intervention professionals are not trained to address the
psycho-social issues that families experience.


   Because of the many issues present in the early
intervention system in this LICC and the need for families
to be strong advocates for themselves, empowerment of
families emerged as a concern for families.  There are three
lessons related to empowerment of families in the early
intervention system.

Lessons about Empowerment

   The concept of empowerment is intimately linked to the
concept of family-centered practice.  Families need to feel
empowered to take a leadership role in the provision of
services to their family. The fifteenth lesson learned
provides acknowledgment of the need for professionals to
assist in empowering families by providing them information.
Knowledge was power for families in early intervention.
They could not exercise their rights without first having
knowledge of what those rights were and what services were
available to them.

Lesson 15: When professionals provide information to families about their child's delay, the early intervention system, and early intervention services, they may be contributing to the empowerment of families. Providing information to families about their options as provided under Part H, may be an important step in the empowerment process.

Lesson sixteen relates to the perspectives professionals had about the ability of families to become active and competent decision makers regarding the needs of their children. Professionals played an important role in educating parents about the early intervention system. Some professionals felt that families were not capable of understanding early intervention well enough to assume a major decision-making role. Others referred to constraints on their time as a reason for not engaging families in education and training.

Lesson 16: Professionals were somewhat ambivalent about empowering families through education and training.

The final lesson learned relates to the concept of

empowerment itself.  Empowerment means many different things to many different people.  The concept of empowerment, however, is prevalent in early intervention practice related literature as well as in the Part H legislation.

Lesson 17: Professionals have discovered that applying the concept of empowerment to practice has proven to be difficult.  This may be due in part to the fact that there is no clear definition of empowerment.

Epilogue

Many circumstances have changed in this service
delivery system since the completion of data collection.
First, Part H was reauthorized in 1997 and renamed Part C of
IDEA.  Second, one of the sites where interviewing was
conducted, merged with a  hospital-based site.  Finally,
most families and many professionals who participated in
this inquiry are no longer part of the early intervention
system. In response to this, the purpose of this epilogue is
to determine the relevance of the findings to current
stakeholders in early intervention in this LICC and the
impact of the research process upon the stakeholders who
participated in this inquiry.

The issue of the usefulness of the data can be
addressed through an assessment of authenticity.
Specifically, the criteria for ontological, educative,
catalytic, and tactical authenticity can establish the
relevance of the findings to the current reality of early
intervention.  The authenticity criteria of fairness is not
relevant to this discussion because it establishes a process
oriented authenticity standard that assesses the degree to

which there was a fair representation of stakeholder
perspectives while the other four criteria establish whether
or not changes occurred in individuals and systems as a
result of the inquiry process. Each of these criteria assess
different aspects of possible change in participants and the
system that may be linked to this inquiry. Ontological
authenticity is assessed by determining the degree to which
participants became more aware of the complexity of the
social environment while educative authenticity is assessed
by determining the extent to which participants experienced
an increased awareness and respect for other stakeholders
viewpoints. Catalytic authenticity is assessed by
determining the degree to which the inquiry process
facilitated and stimulated action that led to change in the
service delivery system. Finally, tactical authenticity is
assessed by examining if power among stakeholders has been
redistributed creating lasting change.

Ontological, educative, catalytic, and tactical
authenticity were assessed through post-case study
interviews with selected individuals from each shareholder
group, authenticity journal entries, several research
reports, and relevant program and policy documents.
Purposive sampling was used to select individuals for post-

case study interviews. For example, to assess ontological authenticity, a family that was initially uninformed about the local service delivery system was selected to assess the degree to which their understanding improved. Interviews were also conducted with a family participant who described herself as passive or timid with early intervention providers, a family member who is also a service provider, an occupational therapist, and the Council coordinator.

The purpose of the following discussion of authenticity is not to establish a causal relationship between this inquiry and subsequent changes in participants and the service delivery system. Rather, the purpose is to assess the degree to which participants attributed change to their participation in this inquiry. We begin with a discussion of ontological authenticity.

## Ontological Authenticity

As this inquiry progressed, it became increasingly clear that early intervention services in this LICC were very complex. Part of the change process for participants was a recognition and understanding of the complexities of how services were provided and funded. Consciousness raising was evident in each of the three major shareholder groups. There are several examples of consciousness raising for

family participants, Part H participants, and non-Part H participants that occurred during the course of this inquiry.

Families have experienced consciousness raising along several dimensions. First, many family participants appeared to be unaware of many of the important issues for their child and family such as who their service coordinator was and awareness of their rights and responsibilities. Family participants in this inquiry felt that they became more aware of their rights and responsibilities through their participation in this inquiry.(E1) Second, according to the temporary service coordinator from the LICC, families are beginning to call the LICC's information number more and they are asking very detailed and informed questions about their rights. (E2) Finally, one family participant who had difficulty accessing early intervention now questions why providers do not do a better job getting information out to families in low-income neighborhoods. This same family participant said that she wants to push the system to do a better job of providing services to families living in low-income housing. (E3) In general, families appear to more aware of the complexity of the early intervention system in this LICC.

Professionals also appear to have become more aware of the complexity of this system and how it affects families. For example, one professional felt that she has learned that the early intervention system imposes constraints on all types of families. She used to feel that only low-income families struggled with the frustrations associated with early intervention but now she understands that families at all income levels struggle. (E4) The issue of physicians not referring to early intervention emerged during the course of this inquiry. According to a member of the LICC, physicians appear to have gained a better understanding of the importance of early intervention because they are referring more often. (E5) Discussions between members of the LICC, the inquirer, and professionals translated into a focus on the need to provide information and training to physicians.(E6)

In addition to this increased awareness of some of the complex issues present in early intervention, participants also increased their understanding and respect of the perspectives of other stakeholders in early intervention. For example, one family participant felt that she learned more about how early intervention services are provided and that professionals experience many challenges to providing

services to families.(E6.1) A professional participant felt
that she gained some insight into the challenges that
families face, especially related to accessing services.
(E6.2) In addition to an increase in awareness as a result
of participation in this inquiry, participants also
expressed an increase in understanding and respect for
alternative points of view.  This is what is examined when
educative authenticity is assessed.

Educative Authenticity

There is evidence of increased understanding of and
respect for the perspectives between stakeholders who
participated in this inquiry. First, several participants,
including the inquirer, have changed how they view
themselves in relation to the early intervention system and
the individuals associated with it. For example, a family
participant feels that she is a partner in the process with
professionals and not just a recipient of services.(E7)
Second, several participants felt that they now have a
better understanding of the issues that other stakeholders
face.  For example, a professional felt that she now works
more closely with passive families because she learned that
they simply lack the confidence they need to be assertive.
She felt that through modeling of assertive behavior she

could teach families skills for working in this system. (E8)
A family participant felt that she has changed how she
perceives physicians. Prior to participating in this
inquiry, she perceived physicians as unwilling to work with
her, whereas, now she understands that they are extremely
busy. She feels that because she understands this about
physicians she can work more effectively with them. (E9)

Third, increased understanding of all stakeholder
perspectives is evident at the systems level. Members of
the family satisfaction sub-committee of the State Part C,
Standards of Care Committee, [which includes two
participants from this inquiry] stated that they have gained
a better understanding of how families perceive early
intervention. (E10) Fourth, the issue of families viewing
early intervention professionals as possible CPS workers was
discussed in several LICC meetings. (E11)

Finally, the issue of motivation of families was
discussed by a professional participant and a family
participant during this inquiry who had felt that families
who did not follow through with services were not motivated.
Both these individuals have modified their views. For
example, both the family and professional participant said
that they now understand that families often experience

serious obstacles that make it difficult for them to attend therapy sessions and that follow-through with appointments is not always related to the motivation of the family. (E12)

Ontological and educative authenticity focus attention on individual change related to increased awareness of other perspectives and understanding of the system. The knowledge that participants have gained in this inquiry has the possibility of direct application to how families approach services and how professionals provide these services. For family participants, the information they shared with other families and with professionals has the potential to change how many families approach early intervention services. For example, family participants who approached early intervention providers passively may have learned from tenacious families that they need to be more tenacious themselves. Professional participants may have learned that they need to work with tenacious and passive families differently. Catalytic authenticity is a measure of systems change. Possibly some of the most valuable evidence of the usefulness of the case report findings can be seen in how this inquiry may have facilitated change in this LICC.

Catalytic Authenticity

Assessing potential for change in the early

intervention system is the challenge of examining catalytic

authenticity.  This inquiry process may have influenced

change along several dimensions.  Evidence can be seen in

the actions of participants as well as changes in policies

and procedures.  One change with many participants that has

taken place since the start of this inquiry has been in the

amount of family participation in Council activities. Two

participants reported that there has been a dramatic

increase in the number of families participating in Council

activities.  (E13) They felt that this was due to the

increased awareness about issues such as access to services,

interactions with physicians, and family characteristics

that this inquiry stimulated in families and professionals.

Awareness of the issue of physician knowledge and

understanding of early intervention may have increased

during the inquiry process.  Physician referrals to early

intervention programs have increased dramatically. (E14) The

concerns about physicians taking a wait and see attitude and

not referring families to early intervention that were

raised by participants, may have influenced the state Part H

Office to contract with the inquirer to conduct a statewide

training needs assessment with pediatricians and family-

practice physicians.  This project involved three focus

groups with family participants in other LICCs, a survey of all 40 LICC coordinators in Virginia, and a survey of 1100 pediatricians and 800 family practice physicians. The findings from this study have been distributed to Council coordinators around the state and the findings were also presented to Pediatric residents at the local teaching hospital.

The findings from this dissertation led to a follow-up contract with the State Part H Office to implement a training model with physicians and LICC coordinators to improve physician awareness and understanding of early intervention services. (E15) This contract focuses on providing information and training to physicians in community practices as well as physicians in residency training programs and in medical school. Additionally, the training model targets LICCs in the state with an emphasis on introducing and evaluating new strategies for working with physicians in their communities. The hope is that this training effort will improve physician referral rates and increase physician participation in LICC activities.

Another change that has taken place at the Council level has been the development of an early intervention resource book for families who are identified by the early

intervention system.  The book includes information about eligibility, funding, types of services offered, detailed descriptions of providers, options for where services can be provided (i.e., home or center), family rights under Part C, and information about family support groups.  The concept for this book evolved out of discussions about families expressing a fear that early intervention professionals were either CPS workers or would report them to CPS.  The intent of the book is to give families who may have this concern a descriptive document that would lend credibility to early intervention professionals.  Members of the LICC felt that they were at least providing families with valuable information regardless of their decision to follow-through with services. (E16)

Another element of catalytic authenticity in the system that has occurred since the beginning of this inquiry has been the desire to improve the delivery of early intervention services by evaluating services more thoughtfully and staying up-to-date on relevant research. There is a system-wide commitment to developing, piloting, and implementing two family satisfaction evaluation instruments that were developed by the inquirer in collaboration with members of this LICC and the State Part C

Office. The lessons learned in this inquiry about the many barriers that families faced as recipients of early intervention services were used as justification for developing the more enduring family satisfaction evaluation process. The hope is that this process will provide state and local early intervention systems with ongoing feedback from families regarding the services they are receiving. (E17)

The final element of catalytic authenticity is related to the need for current research in early intervention. An early intervention research group consisting of Council staff, professionals, families, and the inquirer was formed for the purpose of reviewing current early intervention research to improve how services are provided in this LICC. The hope for this group was that this review would improve how early intervention services are provided. For example, recent research has examined a resource-based model of providing service coordination to families (Dunst et al., 1994). This approach focuses more directly on the needs of families, their resources, and the best methods for meeting identified needs that the community has to offer. This approach has the potential to make service coordination more effective for families rather than make service coordination

more effective for systems.(E18)

As part of their participation in this inquiry, participants may have increased their understanding of the system and each other, and this increased awareness and understanding has possibly led to the potential for change in this LICC. What has not been provided is an assessment of any change in the power relationships between stakeholders to assure effective change or an assessment of empowerment of individual participants, especially family participants. Assessing redistribution of power in a site is the task of tactical authenticity.

Tactical Authenticity

With regard to this inquiry, evaluating whether power was redistributed in this LICC probably has the greatest implications for early intervention policy and practice. For this case, participants have become more aware of the complexity of the system, and are more conscious of how the system affects individuals from all shareholder groups. Individuals in the system have been committed to changing the system to reflect this new understanding. In addition to these changes, there is evidence that shareholder groups have increased their own power.

First, there is evidence that professionals have more

confidence when they work with families, possibly because they now recognize that even highly motivated families may have sound reasons for choosing to not pursue early intervention services. For example, one professional said that because she now understands that families are faced with many barriers (i.e., transportation, child care, financial concerns) she has learned to give families more choice and not push them too hard. She feels that this makes it easier for her to develop trust with families, thus improving the experience for her as well as for families. (E19) She has changed her position and practice with families.

Second, a professional felt that her participation forced her to think critically about what she does and where she fits into the larger early intervention picture in this LICC. She feels that this has increased her confidence in working with providers in the system and has resulted in her being a better advocate for families. (E20) She feels that she has changed her attitude and her practice with her early intervention colleagues.

Increased understanding of the difference between passive and tenacious families has possibly resulted in professionals supporting families more effectively. There

has been a recognized need to provide more education and support to passive families to assist them in working with Part C and non-Part C providers. Professionals and families feel that this has increased passive family members ability to assert themselves. (E21) For example, a member of the LICC feels that she does not have to provide families with as much information when they call the help line. Families are finding information out from talking with professionals when an assessment is completed. (E21.1)

According to a family participant, participation in this inquiry improved her ability to work with physicians. She felt that she is more confident and can ask for what she needs. (E22) Another family participant said that when she learned that the system was confusing for other families, it improved her confidence. She had felt that it was her fault that she was confused so she was reluctant to question things with which she disagreed. (E23)

Finally, there are indications that changes at the systems level have resulted in a redistribution of power. Implementation of the family satisfaction surveys has assisted families in two important ways. First, their voice is now being requested and heard by individual providers as well as by the early intervention system in this LICC.

Families are completing the surveys, and providers are taking the results seriously. Second, the process of completing the surveys is empowering families because families are asked questions about the types of services they should have received and their rights are according to Part C. According to a member of the LICC, families are calling the infant information number to ask questions when they experience a discrepancy between what they should have received and what actually happened. At this point the LICC is able to provide resources and advice to families about possible strategies. Additionally, the LICC can advocate for the family with the early intervention provider. (E24)

Another member of the LICC feels more confident that the LICC is providing services that families need because the data they are receiving from the surveys is providing detailed feedback from families. Also, the number of referrals to the early intervention system has increased and the child census has steadily increased. She feels that this has given her more credibility and leverage with agencies in the LICC because the census is up and she can provide agencies detailed feedback from families about services. This is important to the LICC because of the mandate to coordinate services without having any real

authority over the individual service providers.(E25)

## Summary

The length of time that this inquiry has covered allowed for a thorough assessment of authenticity.  Active involvement with this infant Council provided a unique opportunity to observe change in participants and in the early intervention system.  The length of time has also proved useful for advancing strategies for assessing authenticity.

Change has occurred for individuals who participated in this inquiry as well as in the system itself.  While no causal links between this inquiry and subsequent change can be made, there is some reason to suggest that this process played a role in facilitating some of the individual and systems change.  Through the various strategies to assess ontological, educative, catalytic, and tactical authenticity, some evidence was accumulated to lend credence to this claim.

Chapter 5

Implications

This inquiry was a constructivist policy analysis of the implementation of the family-centered intent of Part H of IDEA in one LICC in Virginia. Perspectives about the implementation of the family-centered intent of Part H were assessed through in-depth interviews with several stakeholder groups, including families receiving Part H early intervention services, families who were never able to access services, members of the LICC, professionals from center-based programs, professionals from home-based programs, and professionals from hospital-based programs. Families were sampled according to income level and professionals were sampled to represent a range of professional disciplines.

Findings from this inquiry highlight some issues regarding implementation of a broad federal policy (i.e., Part H of IDEA) at the local level. Part H was a unique piece of federal legislation because the intent of Part H was to mandate the construction of state level service delivery systems, local service delivery systems, and

suggested program and professional practices for the early intervention field. Very little guidance, however, was provided to states on how to construct their systems and even less was provided on developing local early intervention service delivery systems. Few financial resources were committed for the construction of these state and local service delivery systems adding additional complications. Specifically, the legislation provided no financial support for new early intervention programs, instead the intent was for states and local service delivery systems to coordinate already existing providers using existing funds.

There are many policy and practice implications resulting from this inquiry. First, there are implications for federal, state, and local early intervention policy. Second, there are implications for early intervention practice. Third, there are implications for empowerment of families who have children receiving early intervention services. Fourth, there are implications for social work practice in the field of early intervention. Finally, there are implications for future research related to family-centered service delivery. This chapter presents the implications and concludes with a brief discussion about

lessons learned about constructivist research.

## Implications for Federal, State, and Local Policy

One of the stated purposes of Part H was to facilitate coordination of federal, state, local, and private funding sources (Education of the Handicapped Amendments, 1986). A major implication of the findings, however, is that the framers of the Part H legislation neglected to envision the impact that interactions with other systems would have on local early intervention systems. For example, the concept of promoting families as active members of early intervention teams has little meaning if, in practice, implementation of the Individualized Family Service Planning is controlled by the services the insurance company will reimburse. In this case, neither the family members nor professionals on the team have the ability to make final treatment decisions, rather, the insurance company makes the decision about what services the child and family receive.

An implication of the insurance reimbursement issue may be for support of insurance laws that will help to ensure that the early intervention services will be covered by both public and private insurers. In the state where the inquiry was conducted, for example, a coalition of families, early intervention advocacy organizations and some providers was

organized to lobby for the introduction of an insurance bill that mandates private insurers in the state to pay for early intervention services. The coalition was successful in having a law passed that mandated private insurers to pay for up to five-thousand dollars of early intervention services per year. This is a particularly important issue as both private insurers and Medicaid move to managed care health insurance models.

In addition to insurance companies, some thought physicians were another group of non-Part H providers that may have influenced how Part H early intervention services were provided in this LICC. Physicians were considered a primary contact point for families in this LICC, yet participants felt that pediatricians and family practice physicians were not aware of early intervention services, did not know whom to contact, and/or failed to accept the efficacy of early intervention services. Families perceived that their children lost valuable early intervention time because their physicians did not refer them to early intervention programs. A possible federal or state policy implication may be for the recognition of physicians as Part H early intervention providers. If physicians were designated as early intervention providers then they would

be in line to receive Part H funds from local Councils for the services they provide. This strategy could potentially improve the LICC's ability to coordinate services between early intervention providers and physicians, since both would receive Part H funds from the LICC and be asked to participate in LICC planning activities. This could ultimately result in greater collaboration between physicians and early intervention programs.

Another policy implication related to the lack of physician awareness and understanding of early intervention is the need to fund large scale physician education initiatives. This LICC has put a considerable amount of time and effort into educating physicians in their Council area about early intervention. While this important effort should continue, long term, systemic change should also be encouraged. Integrating early intervention information into medical school and residency training programs is a possible avenue to stimulate systemic change. On a national level such change could be facilitated by the United States Department of Education's Office of Special Education Programs (OSEP), through their model demonstration projects and pre-service training project grant competitions. Specifically, OSEP could emphasize physician training in

grants competitions.

Change needs to occur at the local level, in addition to the state and federal level. The LICC is the mechanism by which local early intervention policy is developed in the state where this inquiry was conducted. The findings from this inquiry have the most direct implications to the LICC in which this inquiry was conducted. The implications, however, may have meaning to other LICCs that have had to respond to the same federal mandates, albeit in other contexts.

Agency competition for families has been an issue in this LICC. Participants felt that early intervention programs were forced to compete with each other for families, possibly because Part H funds were linked to services provided to individual families. Strategies may need to be explored to reduce the perceived need for competition between agencies, so referring a family to another program for services does not diminish the billable services of the referring agency. The families' needs, rather than the needs of providers, should be the driving force for early intervention services.

The LICC has attempted to respond to agency competition and assist families by establishing a comprehensive service

coordination system implemented by the local CSB. The
purpose was to provide families with a system expert not
linked to an individual program. Service coordination was
intended to minimize inter-agency competition; however,
providers continued to provide service coordination to
families in their programs as well. Families found this
system very confusing and difficult to understand. They
were not sure what the service coordinator's role was or
were not even aware they had a service coordinator.
Families were mainly interested in those professionals with
whom they worked. Thus, families in this inquiry de-
emphasized the importance of the service coordinator.

A less confusing system of service coordination may
make the early intervention system more manageable and
demonstrate the value of a good service coordinator to
families. The current CSB system has the potential to work
for families, if more service coordinators are available to
share the large caseloads. Smaller caseloads could allow
service coordinators to focus more time and energy on each
family.

The findings from this inquiry has resulted in several
important implications regarding early intervention
practice. Federal, state, and local policy implications

described above may help to reduce some of the systems barriers present in this LICC.  Also, valuable information was gained about professional practice and the impact it has on families.

## Implications for Early Intervention Practice

Many implications emerged for early intervention practice that affect both how professionals provide services and how families experience interactions with early intervention providers in this LICC.  Arguably, the most valuable implications are related to the families' experience with services in this LICC and for professionals providing services to families. The experiences of families and professionals may indicate the need to revise how early intervention services are provided in this LICC.

### Implications for Families

A conception of early intervention service delivery was provided in the Part H legislation, describing a logical flow from identification of a developmental issue, through referral, to a central point of entry with subsequent referral to the most appropriate programs based on the needs and desires of the family.  The literature review presented in Chapter 2 revealed consistent attempts to assess various components of this process, without questioning its

practical connection to what families actually experienced.
Families' experiences with services in this LICC, suggest
that they may not have encountered family-centered services.
This is not to say that the programs and individual
professionals in this LICC have not worked hard to promote
family-centered ideals by incorporating them into practice--
family and professional participants believe they have.  But
constraints imposed on families, professionals, and early
intervention programs may have removed control from each of
them regarding how services were provided.  Striving to be
family-centered may require professionals to become
effective service "brokers" with non-Part H providers.  For
example, Part H professionals may have little power to make
decisions like what services an insurance provider will
agree to cover.  Part H provider's only option may be to
effectively advocate for the family and assist them in
negotiating with the insurance company to pay for a needed
service.

Several family characteristics may influence the
experiences families have in the early intervention system
and how professionals perceive these families.  Families
reactions to the early intervention experience may have been
determined in part by their personality and the resources

they used to cope with the situation. Many stakeholders
believed services in this LICC were driven by funding
pressures, the needs of agencies, and the needs of
professionals. Despite this recognition, many stakeholders
believed that there are families who lack the personal
motivation to pursue early intervention services. For
families that include children with developmental
disabilities, then, the importance of their own
participation in the early intervention process is essential
to a successful experience. There will always be problems
and difficulties with the early intervention system. New
laws will be enacted, new policies will emerge, service
delivery systems will fluctuate, and professionals within
these systems will change. The only constant on which
families can depend is their own involvement. Families will
always be there to work with their children and cope with
the joys and stresses of having a child with a developmental
disability or delay. Thus, families must develop skills and
learn to maximize the resources available to them to best
meet their child's needs. They must place themselves in a
state of continuous professional development to learn as
much about their child's developmental delay or disability,
the early intervention service delivery system, and the

roles and responsibilities of the providers and

professionals within the system. Professionals can assist

families by providing encouragement to participate and offer

as much information as families request. In addition to

implications for families receiving early intervention

services, there were several implications for professionals

providing early intervention services.

Implications for Professionals

Family participants who described themselves as

tenacious felt that they were able to cope with the barriers

they encountered in the early intervention system. They

also felt that families who were more passive in their

approach to early intervention were less likely to have

their needs met. Some family participants may have dropped

out of the early intervention system because they had

difficulty coping with the many barriers they faced.

Family characteristics, specifically level of

involvement in their child's care, clearly affects early

intervention professionals. Early intervention

professionals should attempt to assess the type of

personality exhibited by the families they support. They

need to explore both the needs and coping capacity of

families. Passive families need more guidance from service

coordinators and understanding and supportive therapists. Families who are more tenacious can be a support for families who are less aggressive. At the very least, professionals must not jump too quickly to labeling a family as noncompliant or unmotivated.

Another practice implication for professionals relates to how families react emotionally to discovering their infant or toddler has a developmental delay. When families were first confronted with the fact that their infant or toddler had a developmental delay or disability, they reported experiencing strong emotional reactions. While coping with this news, professionals simultaneously approach families with an overwhelming amount of information about early intervention programs and services. Families were often expected to make important decisions about the types of services they needed, where these services would be rendered, and how they were going to pay for the services. The implication is that early intervention professionals should be attuned to the emotional reactions families experience when discovering their child has a developmental delay or disability. Many early intervention professionals, however, are not trained to address these more psycho social issues. Providing early intervention

professionals with at least some basic in-service training in counseling to address possible emotional reactions such as grief, denial, stress, anxiety, anger, and depression is critical.

Families in this LICC were faced with many barriers to obtaining early intervention services such as transportation, daycare, inconvenient meeting and therapy times, and the need to care for other children. As a result, fully participating in recommended early intervention services was difficult for some families. The results of this inquiry indicate that professionals should recognize that early intervention is not just about a child's therapy or a family's support group, but how it affects a family's entire life. Each professional needs to become adept at assessing each family's situation to best design service delivery plans to meet the unique needs of each family.

Family participants in this LICC described other issues and concerns that they faced each day that threatened their basic safety and security needs, such as food and shelter. This suggests early intervention professionals must realize that early intervention will not be a priority until the family's safety and security needs are met. Early

intervention professionals need to become more aware of these concerns and assist families in meeting these needs. Regardless, some families will choose not to pursue early intervention services because there are other more immediate concerns in their lives. Early intervention providers should track these families over time and periodically re-approach them to ascertain their need and/or readiness for early intervention services.

Many barriers identified through the inquiry can be addressed only through coordination with other providers, not ordinarily thought of as early intervention providers. The circle of services traditionally considered important to families with children with developmental disabilities needs to expand to include daycare centers, transportation companies, social services, and physicians/medical providers.

Physicians receive early intervention information from multiple sources. General information (e.g., referral points, resources) is typically provided by LICC staff, while child-specific information is usually given to the physician by early intervention professionals. Participating physicians reported that more specific information about when and how to refer a child to early

intervention, rather than providing general early
intervention information would be more useful.  Also,
information provided to physicians should be concise and
provide information clearly applicable in daily practice.

Finally, the concepts behind Part H family-centered
services may not reflect the multiple organizational
realities of early intervention providers.  The limitation
of billable early intervention services has translated into
agency rules that make it difficult for early intervention
professionals to provide needed early intervention services
to families.  This means professionals need to work hard to
gain access to other early intervention providers who can
provide a service (e.g., physical therapy), when they
themselves are not able to provide the service because of
agency constraints.  The needs of families must be the
guiding force for professionals, even if it means having to
work around the constraints of their own organizations.

Results of this inquiry suggest development of an
alternative early intervention practice model.  While the
combined practice implications from this inquiry may not
provide enough substance for a complete alternative practice
model, the recommendations above may suggest some core
elements for an alternative model.  Proposed elements for an

emerging alternative model are presented in the next section.

## Elements of an Emerging Alternative Practice Model

Professionals working in the field of early intervention will always have a clear role to play based on their specific disciplinary skills and expertise. For example, a speech therapist will always be needed to assess a child's need for speech therapy. The implications from this inquiry suggest a need for all early intervention professionals to learn and apply skills that may transcend their disciplinary skills and expertise, if professionals desire to become family-centered practitioners. Meeting family needs may imply a need for professionals to develop a systems-related expertise (i.e., Part H systems and non-Part H systems), family training/education, and family support. These practice elements and their connection to already existing disciplinary expertise and the desire to move towards a more family-centered practice model are represented in Figure 6 [see Figure 6].

## Systems Expertise

In order to effectively support families as they struggle to access, manage, and pay for early intervention services, early intervention professionals need to be

Systems Expert

Family Trainer/Educator

Family Support

Application of Disciplinary Skills

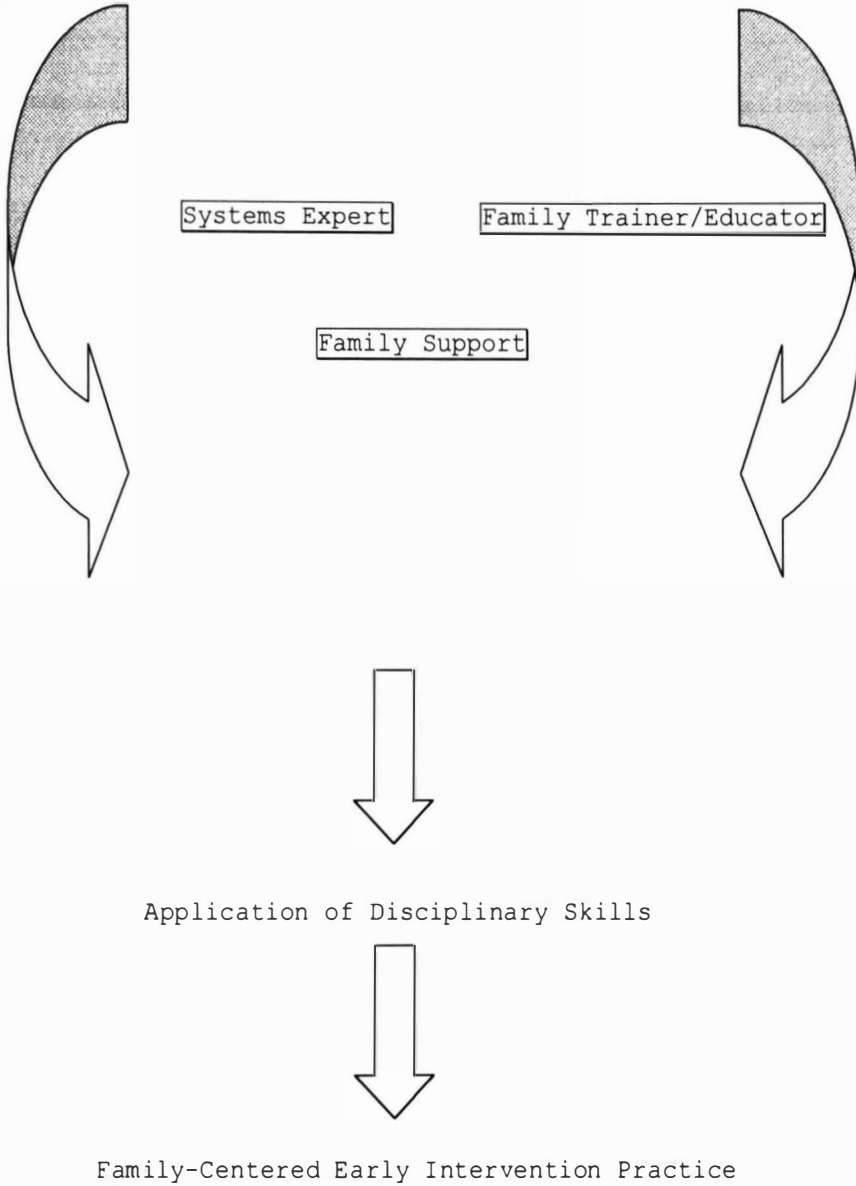Family-Centered Early Intervention Practice

Figure 6
Alternative Early Intervention Practice Model

knowledgeable of the intricacies of both Part H and non-Part H service delivery systems. Traditionally, the role of systems expert has been relegated to the assigned service coordinator. The lessons from this inquiry, however, suggest that all early intervention professionals should be familiar with the systems issues to effectively support families. The role of a systems expert may include: (a) service coordination, (b) referral coordinator, (c) systems mediator, (d) advocate, and (e) trouble shooter for specific systems barriers. In addition to developing systems expertise, early intervention professionals also need to develop competencies in family training and education.

Family Training and Education Expertise

The implications from this inquiry suggest that there is considerable variability among families related to their ability to take an active role in the early intervention process. A system cannot be family-centered if participating families are unable to take an active role in the service delivery process due to little knowledge, skills, or confidence. Traditionally, early intervention therapists have trained families to carry out basic therapy techniques with their children so that the family could continue to work with the child in between therapy visits.

Families, however, need training and education on broader
issues that will make them more informed decision-makers
when it comes to services for their child and family.
Examples of some of these areas include information about
child development, specific disabilities, service delivery
systems, federal and state policies such as Part H, roles
and responsibilities of different early intervention
professionals, and information about the importance of their
own involvement.  These are just a few critical areas of
which families need knowledge and understanding in order to
make the transition from service recipient to collaborative
partner in the service delivery system.  The final element
of the emerging alternative model is expertise in the area
of family support.

Family Support Expertise

Families may need support in many different areas of
their lives when they are participating in the early
intervention system.  They may need emotional support as
they experience frustration with barriers they encounter,
stress related to the added pressures of having a child with
unique needs, and sadness because of their struggles to be a
good parent under difficult circumstances.  Families may
also need support from professionals to overcome feelings of

powerlessness in an intimidating system.  Finally, families

need to feel the support that other families who have

experienced the early intervention system can provide.

The implication for early intervention professionals is

that they should have some basic competence in providing

emotional support to families as issues arise.  This does

not, however, imply a need for an occupational therapist,

for example, to have the clinical skills of a clinical

psychologist or clinical social worker.  It implies a need

to have some basic counseling skills to provide short-term

support to families until an appropriate referral can be

made.  This is an important issue because services like

social work are often not reimbursed by insurance companies.

So, if the occupational therapist is the only professional

working with the family, they may be the only professional

available to meet the families emotional needs. In addition

to direct counseling skills, early intervention

professionals should be aware of available family support

organizations and other resources that could assist families

in crisis.

The preceding elements of a developing alternative

practice model imply a further blurring of the disciplinary

roles of professionals in early intervention.  It does not,

however, discount the important disciplinary contributions of each professional. What it implies is a need for early intervention professionals to first be comfortable with the knowledge and skills of their discipline to feel comfortable with assuming roles that transcend their discipline.

In addition to implications for early intervention policy and practice resulting from this inquiry, there are implications regarding family empowerment in early intervention. Implications for early intervention policy and practice may have the greatest affect if they are considered within the context of family empowerment. Changing policy and early intervention practice to conform to a more family-centered view of early intervention may not be enough to ensure family empowerment. Empowerment must occur through an interaction between policy initiatives, professional practices, and family involvement in early intervention.

## Implications for Empowerment of Families

Acknowledging the preeminence of individual family perspectives regarding the early intervention services they receive may be an important component of family empowerment, but many other factors are involved. The empowerment propositions that were presented in Chapter 2 can be used as

a lens to view the empowerment experience of stakeholders in this LICC. The three propositions were: (a) person and environment are interactive, (b) individuals are ultimately responsible for their own empowerment, and (c) oppression is the result of multiple societal forces that combine to oppress an individual or group.

The first proposition refers to the interaction between person and environment. Understanding the dynamics of families and professionals interacting within their environments was vital to understanding early intervention in this LICC. The Smith's story provides a poignant example of this interaction. The Smiths were faced with many barriers to obtaining early intervention services. They had problems with the CSB service coordination system, but they also faced many other issues that transcended the early intervention system. The Smith's physicians and their insurance provider impeded access to early intervention services. The Smith's experience can be understood only in terms of their interactions with Part H providers, non-Part H providers, and their characteristics as individuals and a family.

The second proposition is that individuals are ultimately responsible for their own empowerment.

Professionals, however, can assist families through education and dialogue, to develop a critical consciousness. The Smith's, as well as many other family participants, attributed their success in obtaining early intervention services to their own efforts. Both family and professional participants felt that families who did not take an active role in the early intervention process did not fare well, demonstrating that families are ultimately responsible for their own empowerment.

The final proposition is that oppression is the result of multiple societal factors combining to create oppressive circumstances for certain individuals or groups. Families who have infants or toddlers with developmental delays or disabilities are faced with oppressive circumstances resulting from societal forces such as managed care; federal, state, and local policy; poverty; prejudice; insensitivity and misunderstanding; and numerous others. These forces affected family participants in many different ways, with the result being barriers to access and services driven by providers rather than families. Providers developed service delivery systems that focused more on the needs of their organizations than on the needs of families. Keeping these three general principles of empowerment in

mind, there are several specific implications for family empowerment.

## Implications for Family Empowerment

Family empowerment should start with families identifying and addressing their most basic needs. Meeting basic needs first, followed by providing early intervention information, implies a thoughtful and careful approach for providers. Too often, professionals are ready to push families directly into therapy without first assessing basic needs and desire for information.

Second, family education may be one of the key ingredients to empowering families engaged in early intervention. For example, a better understanding of the early intervention system, and a more clear understanding of the effect non-Part H providers can have on the early intervention experience, may have improved the Smith's encounter with the early intervention system. Most importantly, perhaps, would have been a more complete understanding of their own strengths and their rights to work with providers and assume control over the early intervention process. These conclusions imply an educational process for families to help them gain these competencies and insights into their own strengths and

capacity to lead the process. The need for families to
assume control of their involvement in the early
intervention process ties into the second empowerment
proposition.

Professionals can assist families in developing a
critical consciousness by providing families with
information and knowledge about early intervention, as
described above. Education merely provides the basic
knowledge and skills to participate, but does not
necessarily facilitate family participation. Professionals
need to take the next step and encourage families to become
actively involved in the early intervention process,
treating families as equal participants. This does not,
however, imply a paternalistic form of empowerment where
professionals turn over power to families out of the
goodness of their hearts. Rather, it implies a
responsibility on the part of professionals to assist
families in making decisions and providing families with the
support needed to assume control over decision making that
is rightfully theirs.

Fourth, this inquiry suggests the early intervention
system in this LICC needs constant family feedback about
changing child and family needs. Services are provided

according to the needs and concerns of early intervention

professionals and providers, not necessarily needs

identified by families.  Outside forces are constantly

changing and affecting families in new and different ways.

A feedback mechanism needs to be designed and put in place

that will result in periodically collecting information from

families about their needs and concerns.  Without this

mechanism, early intervention providers may find themselves

providing services to families that are no longer relevant.

This strategy also enhances family empowerment, because it

adds the family's voice into the service delivery process.

Fifth, teaching families to do as much on their own as

possible may be the critical element to improve the

experience for families in the early intervention system.

The responsibility for accomplishing this goal is shared

equally between families and professionals.  Families must

be open to learning and persistent in their desire to learn

and explore the complexities of the early intervention

system.  Professionals must be committed to teaching

families about both the early intervention system and the

actual therapies they provide.  This is a unique way of

approaching treatment for many professionals but one that

may be necessary.  In service training for professionals

could include strategies for training families on how to complete early intervention tasks on their own. Additionally, general in service training offered by providers could be open to families who are interested in learning more about relevant therapy techniques.

Sixth, support from other parents can boost families' self-esteem and make them feel more capable of working with multiple providers. Also, experienced families can provide practical tips and advice to families new to early intervention to improve the initial early intervention process for new parents. This type of peer support has taken several forms in this LICC, including parent support groups. Groups to discuss the concerns of families participating in early intervention, share a telephone contact list that allows for informal support relations to develop between families, and provide formal advocacy where experienced parents accompany new parents to assessment team meetings. Family support holds considerable promise for new families entering the early intervention system in this LICC.

In addition to implications for early intervention policy, practice and family empowerment, there are implications for social work practice and education. Social

workers play an important role in the early intervention
system, little is written about the social work role
(Saunders, 1994). There are several implications for social
work based on the findings.

<u>Implications for Social Work Practice</u>

The findings of this inquiry demonstrate the need for
competent social work practitioners in all aspects of the
early intervention process. Families need understanding and
support from professionals. This is where the role of the
social worker becomes important for two reasons. First, the
family needs emotional support, for which social workers are
ideally prepared. The goal of social work education is to
promote effective coping with the many challenges that life
presents individuals, families, and groups. Specifically,
social work education emphasizes helping individuals solve
their own problems, resolving emotional conflicts, and
developing social networks that build upon strengths and
capacities of individuals (Council on Social Work Education,
1999). In essence, social workers have the skills to
provide direct emotional support to families, as well as
knowledge of other community resources to assist in meeting
the mental health needs of families.

Second, early intervention professionals from other

disciplines may not receive the same level of education and training in interpersonal interactions as social workers. Thus, the social worker becomes an important advocate for the family on the early intervention team. Additionally, the social worker can educate other members of the team, so they can become more sensitive to the emotional and psychological needs of the family.

Finally, social work education emphasizes the person-environment interaction, a concept that appeared to be so important to families in this inquiry. Again, social workers can work with the team, including the family, to most fully understand the needs of the child and family within the unique contexts of the child's environment. This ability can help shift the focus intervention away from the child's developmental deficits to a focus on the overall developmental picture within the context of the child's environment. Additionally, social work education emphasizes a dual emphasis on micro and macro approaches to intervention, providing social workers with the knowledge and skills to assist families and early intervention professionals to better understand the multiple layers of systems that affect families. Thus, social workers can be effective service coordinators and provide emotional support

to families.

Social workers in the field should become more involved in developmental disabilities-related organizations, such as *Zero to Three* and the *American Association of Mental Retardation,* to infuse the social work perspective into the field of early intervention. The primary role for social workers in early intervention remains supporting families and advocating on their behalf. This is accomplished by the social worker acting on many levels. First, social workers need to continue to be active members of the early intervention teams to support children and families. Second, social workers must advocate for needs of families within the organizations in which they work. The findings emphasized the problem that the needs of children and families are sometimes secondary to the needs of organizations. Third, social workers should be actively involved at the local systems level with their LICCs. Local planning and allocation of resources is determined at this level, has dramatic impact on families. Finally, social workers need to be actively involved in both state and federal policy and planning. This can be accomplished via participation in their own professional organization, advocacy organizations, and parent support organizations.

## Recommendations for Future Research

This inquiry occurred in an urban environment with a fairly well developed service delivery system. While the LICC may have struggled with coordinating many of the providers in the area, the basic services were generally present and available to families (e.g., home and center-based programs, hospitals, transportation, daycare). Many findings could provide the foundation for research conducted in both a interpretive and positivist paradigm.

Several concepts identified via this inquiry could be further examined in the positivist paradigm. A logical next step would be to compare the local context across different types of early intervention service delivery systems (i.e., urban, rural, suburban). Rural service delivery systems may not have many basic services available to them. This may be a considerable issue, because Part H services were designed to build upon an already existing service delivery system. Part H resources were not intended to build local capacity, only to coordinate existing service providers. Suburban communities may have different issues. For example, managed care may be a much more significant concern for suburban communities where there may be a higher percentage of middle to high income families with private insurance.

Interpretive research may be useful to study families who never gain access to early intervention services because of barriers or their own choice. A basic research question may be "What are the characteristics of these families and what prevents them from obtaining services?" Several families were interviewed in this inquiry who never received services. There were various reasons why they never received services, but very little was learned about their family characteristics.

The challenges of nominational sampling were important methodological issues in this inquiry. In particular, identifying individuals who never participated in the early intervention system proved difficult. Some possible strategies to improve sampling might include coordination with Neonatal Intensive Care Units (NICU) to track infants with identified developmental delays or disabilities but who never accessed early intervention services, contacting non-Part H providers such as physicians and private therapists may be another valuable source for participants, as could Part B school programs that identify children with developmental delays who did not receive early intervention services.

Research with physicians is another significant need.

Physicians are the primary access point for many families,
yet they rarely refer children to early intervention.
Often, when they do refer, a lot of time elapses between
time of identification of a delay or disability to referral.
Many families were never able to obtain services or lost
months and even years of valuable time before being referred
by their physicians for early intervention services.  It is
unclear why physicians are reluctant to make early
intervention referrals.  It may be important for LICC's to
have a better understanding of the perspectives of
physicians so they can improve their working relationships
with them in their Councils and potentially increase early
intervention referral rates.

In addition to interpretive research with physicians,
research with other non-Part H providers such as child
protective services, social services, and insurance
companies could also prove valuable to understanding the
multiple system interactions families face.  Focusing on
increasing understanding of how systems operate, perceptions
of early intervention, or types of supports with whom
professionals need to work more effectively would also be
useful.

Finally, interpretive research on the evolving role of

social work in early intervention would be beneficial.
Important questions like how social workers perceive their
role in early intervention and what early intervention
providers perceive the role of social workers to be must be
answered. Social workers are struggling with defining a
role for themselves, as managed care changes how agencies
have to operate. Research that explores other roles that
social workers can play within their agencies could prove
useful for social workers, early intervention providers, and
the children and families they serve.

### Lessons Learned About Constructivist Research

Constructivist research is an invaluable tool for
developing in-depth understanding of an individual case.
Change can result from case report consumers transferring
the findings from the individual case setting or context to
other similar settings or contexts. The constructivist
research process itself may facilitate change, as well. In
this context, the change process begins with the first
interview and continues well after the inquiry is complete.
Through a process of mutual shaping, participants in the
inquiry process may engage in a process of change. This is
where the true value of constructivist research may be
experienced. It is also why assessing authenticity is

probably the most important indicator of the impact of a
constructivist inquiry. If the inquirer cannot assess
change that resulted from the process itself, then the true
value of the inquiry may not be assessed. Strategies for
assessing authenticity, however, have not been as clearly
delineated as the strategies for assessing trustworthiness.

In this inquiry, three general strategies were used to
assess the criteria for fairness, ontological authenticity,
educative authenticity, catalytic authenticity, and tactical
authenticity. First, several stakeholder consultants were
used throughout the data collection and analysis process to
ensure a fair representation of stakeholders' perspectives.
The process was similar to the peer review process, in that
the consultants acted as objective voices when important
methodological decisions were considered. For example, a
consultant, who was also a parent of a child with a
developmental disability, was instrumental in making
sampling decisions to ensure families were fairly
represented. Contacts with all of the consultants involved
telephone conversations, face-to-face meetings, and e-mail
exchanges. Separate authenticity entries were made in the
reflexive journal to record the content of these meetings
and to provide a record for later review.

Using consultants proved to be very useful in making sense of emerging issues that led to sampling decisions and later interpretation of the data. In particular, the consultants were useful during the sampling process, though it was time consuming. These were meetings and conversations that occurred in addition to interviews with stakeholders and meetings with the peer reviewer.

The second strategy, to assess catalytic and tactical authenticity, involved review of LICC documents. The purpose was to look for evidence of change at the LICC level. For example, the LICC has a formal meeting involving all participating agencies each month to discuss issues with the service delivery system and to provide a networking opportunity. Meeting minutes provided a useful record of topics addressed at these meetings. For example, at the meeting that occurred after presentation of preliminary inquiry findings was conducted, a task force was assembled to examine child protective services and determine strategies to get physicians more involved in early intervention. Another document source was the LICC monthly newsletter.

The third strategy for assessing authenticity involved post-case study interviews with five participants. These

interviews were used to assess ontological, educative,
catalytic and tactical authenticity. Participants were
selected to represent each stakeholder group (e.g.,family,
professional, LICC staff) and the views they held prior to
engaging in this inquiry. The process involved reviewing
the data collected during the inquiry and using this
information as a baseline to judge change in awareness,
understanding and respect for other viewpoints, potential
for systems change, and the distribution of power in this
LICC. All of the participants involved in these interviews
have had to adjust to major changes in federal legislation
(i.e., Part H reauthorized as Part C), changes in state
policy guidelines, the implementation of Medicaid managed
care, changes in insurance laws, and many more changes. For
example, a family participant who was initially unaware of
early intervention was interviewed to assess change in their
knowledge and understanding of early intervention services.
These interviews provided an effective method for assessing
participants adjustment to these changes.

It was not easy to conduct these interviews.
Specifically, sampling was challenging. Several participants
felt that they did not want to participate in follow-up
interviews, because they had already been interviewed

several times or they felt that they were too far removed from the issues identified during the inquiry process. Some of the most promising candidates who were identified for participation did not want to participate. For example, family participants who had made the transition from early intervention to receiving services via public schools would have been ideal. Early intervention was a distant memory for them. In addition to the need to assess authenticity, there are implications for the individual considering the use of a constructivist methodology.

Constructivist research requires a significant commitment on the part of a researcher. The physical and emotional energy required to complete a constructivist inquiry is exhausting. Based on experience conducting research using different methods, I believe that the commitment of time and energy required exceeds that required, compared to using a different methodology. Maintaining the sharpness of the human instrument is challenging under these circumstances. The peer review process was essential for maintaining a commitment to this inquiry; the peer reviewer provided support and motivation when it was desperately needed.

Several breaks from the inquiry were also important.

There were many points during this process where I needed to forget about the inquiry so that I could come back to it refreshed and excited. The interviewing/data collection process was energizing and even fun, yet data analysis and writing the case report were extremely time consuming, tedious, and emotionally draining. Completing some of the final elements for establishing trustworthiness (e.g.,the comprehensive member check) and authenticity (e.g.,post-case study interviews) were especially difficult because they occurred after completion of the case report. It was difficult to muster the energy to complete these final tasks.

This inquiry has opened up many professional opportunities for me. The nature of constructivist research lends itself to deep immersion into the context in which an inquiry is conducted [in this case, the early intervention system in one locality]. As a result of this inquiry, relationships were formed with early intervention stakeholders at the local level and state levels. These relationships resulted in two contracts with the State Part C, Early Intervention Office: (a)a statewide needs assessment of pediatricians and family practice physicians related to early intervention training and information

dissemination, and (b) development and pilot tests of survey instruments and a process for assessing family satisfaction with early intervention services in Virginia.

There is an important lesson to be learned about the feasibility of using constructivist methods to conduct program evaluations. In my role as a Research Associate at the Virginia Institute for Developmental Disabilities, I conduct a considerable amount of evaluation research. I can see both the advantages and the challenges of applying constructivist methods to evaluation research. Committing adequate time and resources is the primary challenge evaluation researchers are often constrained by tight budgets and short-term contracts with inflexible deadlines. In this regard, constructivist research can prove difficult. Contractors who have only experienced program evaluation conducted in a positivistic paradigm often expect cost and time efficient research methods (i.e., survey research). Thus, contractors must be convinced of the need for interpretive methods, which are time consuming and expensive.

In the past two years I have conducted two evaluation studies that used many aspects of constructivist research, because I felt that some form of interpretive research was

required.   Some compromises were made because of time and
resource limitations including: using telephone interviewing
with several stakeholders because the site was one hour
away; less formal peer review was done in a less formal way
with colleagues; maintaining a self reflexive journal, but
not a separate methodology journal; and, interviewing
stopped when the time demanded, rather than when redundancy
of information was reached.   I believe that I was able to
collect valuable information from stakeholders that assisted
program planners in understanding their issues in a much
more in-depth way than our more standard quantitative
[positivist paradigm] methods could have provide.

I have also learned that, while I conduct a
considerable amount of quantitative research as an
evaluator, my interpretations of the data emanate from a
constructivist perspective.   The federal and state agencies
with whom the Virginia Institute for Developmental
Disabilities works, will continue to require quantitative
data.   However, I view all incoming data more tentatively as
a result of conducting this inquiry.   So while a particular
method used may be quantitative, my interpretations of the
data that result are tentative.   All data help us to better
understand an issue, a phenomenon or a case, but I do not

believe that any data tell us the "truth" about what is, rather, data simply provide some insight. In other words, I am not convinced that any data collected via any social science research method is truly generalizable.

This inquiry has had a profound impact on me and on the early intervention system where it was conducted. During the completion of the comprehensive member check, I found that most stakeholders who reviewed the case report found it interesting, but, felt that it was already old news. They wanted to talk more about the events that have transpired since the process began and how things have changed. To me, this was evidence that the process of conducting a constructivist inquiry does facilitate change. Change continues to reverberate in this LICC. While the process was physically and emotionally draining, the end product was worth it.

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APPENDICES

Appendix A

Unitized Code List

```
aa.   (RIC1:1:7-23)
bb.   (P7:1:28-34)
cc.   (P1:1:1-17)
dd.   (P5:1:28-35)
ee.   (P8:1:7-15)
ff.   (P11:1:12-20)

1.    (F4:9:12-14)
2.    (F4:1:29-31)
3.    (F4:9:16-17)
4.    (F4:9:4-12)
5.    (F4:9:17-18)
6.    (F4:8:29)
7.    (F4:8:32-33)
8.    (F4:1:12-17)
9.    (F4:1:22-28)
10.   (F4:3:19-23)
11.   (F4:3:23-27)
12.   (F4:3:41-44)
13.   (F4:4:6-10)
14.   (F4:4:10-14)
15.   (F4:3:28-30)
16.   (F4:5:15-18)
17.   (F4:4:23-24)
18.   (F4:4:24-26)
19.   (F4:4:27-30)
20.   (F4:4:31-35)
21.   (F4:4:35-43)
22.   (F4:4:42-43)
23.   (F4:5:3-5)
24.   (F4:5:8-11)
25.   (F4:5:12-14)
26.   (F4:5:14-18)
27.   (F4:5:26-27)
28.   (F4:5:22-23)
29.   (F4:5:24-25)
30.   (F4:11:24-32)
31.   (F4:5-6:39-3)
32.   (F4:6:7-13)
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33.  (F4:6:4-6)
34.  (F4:2:3-6)
35.  (F4:2:8-9)
36.  (F4:2:11-28)
37.  (F4:7:2-4)
38.  (F4:6:28-35)
39.  (F4:6:36-42)
40.  (F4:8:38-45)
41.  (F4:5:28-30)
42.  (E)(P1:8:4)
43.  (S)(RIC2:4:10-11)
44.  (I, R,C,B,A,H)(P1:4:29-30, RIC2:5:7; P7:6:22-
25,P2:5:23-26,F10:6:9-11,P1:4-5:37-2)
45.  (K)(F7:6:12-14)
46.  (G,A,J)(F7:6:14-15,F9:3:17-21;F3:7:9-11)
47.  (M)(F8:6:7-8)
48.  (L,D,D2)(F7:6:11-12; F13:4:36-38, F7:1:33-34)
49.  (K)(F3:3:41)
50.  (J)(P9:7:22-24)
51.  (F,I)(P1:3:6-8; F3:5:39-40)
52.  (B)(F10:1:34-37)
53.  (G,G2)(F1:2:5-8, F1:3:42-45)
54.  (T)(F3:4:24-25)
55.  (O)(P3:4:33-34)
56.  (D)(P1:2:17-19)
57.  (N)(P4:4:12-13)
58.  (C,C1,C2,C3,C4.C5,C6,C7,C8,C9,C10)(F8:2:27-28, P3:4:5-
            6, RBHA1:6:16-18, F8:3:22-23, P5:3:7, F8:4:4-6,
         F16:2:12-14, P9:4:14-15, F2:2:21-23, F3:5:17-18)
59.  (A(knowl),A2(knowl), B,B2,B3)(F8:6:21; F14:1:31-34;
            F8:6:23-25, F8:2:35-36, F3:3:21-23)
60.  (E)(F8:3:33-36)
61.  (A,A4,A5,A6,A2,A3,M(knowl),G(knowl))(F8:6:25-27,
            F13:2:13-15, RBHA1:6:23-24, F3:3:10-12; F14;2:3-5;
         F12:2:6-9;RBHA1:6:20-22, F8:2:25-26)
62.  (A7)(F14:3:33-37)
63.  (G4)(F8:2-3:35-8)
64.  (H)(P9:2:20-22
65.  (G2)(F8:2:13-20)
66.  (G3)(F8:2:21-26)
67.  (M,M2)(RIC1:5:25, F15:6:6-8)
68.  (F,F2,F4,F6,G5, CFe)(P9:4-5:26-1, P12:5:19-20,
          RIC1:2:36, RBHA1:6:22-23, RBHA2:8:9-11, RBHA1:7:1-3)
69.  (F5)(P5:3:7-10)
70.  (D)(P3:4:12)
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71.  (K,K2,K3,K4,K5,K6,N)(F12:2:16-17, P9:4:15-16, F3:3:12-
     21,      F14:2:26-27, F8:4:19-21; P9:4:15-16; P11:2:21-
     22; F7:6:29-31)
72.  (CFO)(F15:5:34-35)
73.  (G,G2,G3,G4, CFh)(DOC1:2:1-2, P5:3:26-27, DOC6:1:3-4,
             DOC6:2:6-7, F7:4:38-39)
74.  (P)(RBHA2:6:28)
75.  (F,F2,F3)(RIC1:125-27, F7:6:23-27;DOC1:1:12-13)
76.  (I, Cfp;L)(P4:4:4-6, P4:3:39-41; F8:4:11-15)
77.  (CFm)(RIC2:5:14-16)
78.  (B,I)(F5:3:30-33; DOC4:2:)
79.  (J)(DOC4:2:29-30)
80.  (H, Cfg)(F14:2:1-2, DOC4:2:15-21)
81.  (O)(F5:2:7-10)
82.  (F)(P1:6:17-19)
83.  (A)(P2:5:31)
84.  (F)(P1:6:17-19)
85.  (J)(F1:4:39-41)
86.  (O,L)(RIC1:1:37-39; P8:5:28)
87.  (O2)(P9:6:4-5)
88.  (P)(P7:6:12)
89.  (E)(P1:6:24-26)
90.  (Q)(P3:3:1-3)
91.  (B)(F4:6:28-29)
92.  (I,D)(P4:3:8-10, P1:6:36-37)
93.  (T)(F1:4:37-38)
94.  (C)(F1:4:37-39)
95.  (S)(P2:2:14-16)
96.  (N)(RIC1:1:35-37)
97.  (H,H2)(P5:6:3-5, P5:6:7-8)
98.  (K)(F1:4:42-43)
99.  (T2)(P12:3:15-16)
100. (T3)(P9:6:1-3)
101. (T4,T)(P2:2:16-19; P12:3:12-15)
102. (D)(F14:1:37-40)
103. (E, E2,P)(P2:3:21-22 & F5:5:16-17; RBHA1:6:8-12)
104. (B, B2, B3, & B4)(P1:6:7-10, P2:3:24-27, F3:5:39-43, &
     P1:6:6-7)
105. (B2)(P2:3:24-27)
106. (F)(F9:4:37-38)
107. (L & L2)( P1:1:25-28 & P1:1:22-25)
108. (AR)(F4:7:3-4)
109. (S & DR)(P8:2:36-38 & F10:1:33-34)
110. (J)(F10:4:39-41)
111. (K,A)(F10:5:5-6; P2:5:31-33)

112. (M, M3,M4,R)(P12:2:7-9, P7:2:22-24, & P7:6:10-12;
     RBHA1:2:40-41)
113. (M3)(F1:4:21-23)
114. (U)(P7:6:12-13)
115. (N,O,I)(F3:6:21-23; P7:2:13-15; F10:5:2-4)
116. (C)(F1:4:33-35)
117. (BR)(F4:10:39-40)
118. (CR, GR)(F6:3:18-19; P1:6:15-16)
119. (HR,FR & FR2)(F6:3:21-23; P1:6:12-15 & F5:5:17-20)
120. (ER)(F5:5:20-25)
121. (K)(P12:5:1)
122. (J)(F4:4:2-3)
123. (B)(P3:1:30-31)
124. (E,H)(F1:1:26; F4:6:40-42)
125. (L3,L,L2,F,G)(P12:4:34-35; P12:4:35-37 & P8:3:35-37;
     P1:2:8-10; P9:7:8-9)
126. (C)(P8:3:34-35)
127. (C2)(P1:1:29-30)
128. (I)(F16:3:3-4)
129. (D)(P9:9:3-4)
130. (J)(F10:5:8-9)
131. (C)(P1:2:19-20)
132. (H)(P2:4:13-16)
133. (M)(RIC2:3:1-2)
134. (L & L2)(RBHA1:2:5-7 & F13:2:19-20)
135. (A)(RBHA2:4:13-14)
136. (P, P1, & P2)(RBHA2:4:20-22; F4:2:27-28; F4:2:23-24)
137. (Q)(RBHA2:4:29-30)
138. (B)(P1:2:20-22)
139. (D,D1)(P1:2:33-35, P1:2:32-33)
140. (K)(P12:1:31-34)
141. (V & V1)(P7:2:37-38 & P7:2-3:38-1)
142. (G)(P1:2:25-27)
143. (F)(P1:2:27-28)
144. (E,N)(P1:2:28-30; Doc2:3:3-4)
145. (T, T1, T2, & T3)(F16:3:2-3; F4:2:12-13; P7:3:5-6; &
         F2:1:31-33)
146. (U)(F4:2:14-16)
147. (W)(P7:3:7-8)
148. (O)(RBHA2:4:27-28)
149. (A & A2)(P5:6:37-38 & F3:3:32-39)
150. (B2)(P8:5:21-22)
151. (B)(P3:2:9)
152. (E)(F1:2:28-29)
153. (H & H2)(RBHA1:3:13-16 & P8:5:22-24)

154. (L)(F4:2:11-12)
155. (G)(RIC1:5:31-32)
156. (I & I2)(F3:3:23-24 & P8:3:9-13)
157. (J,A-EI Problems)(P8;5:25-26, P5:6:25-28)
158. (K)(RBHA1:2:31-32)
159. (C, C2, & C3)(P1:9:5, P12:3:26-27, & P2:2:7-9)
160. (D & D2)(P2:3:27-28 & P3:2:6-7)
161. (F,F2)(RBHA1:7:18-20; F3:3:29-31)
162. (C-EI Problems)(P9:3:4-6)
163. (AA)(P10:2:8-10)
164. (F5,F6,F8, F13, F18, F20,A2,F4,& F19)(P9:4:20-22;
         F4:4:27-30; P10:2-3:34-1; P8:4:9-11:F14:2:24-25;
    P5:2-      3:41-1;F8:2:11-12; P12:3:1-3; F13:1:33-35)
165. (F2, F3, & F7)(P3:4:13-15; P7:5:28-32; & f10:2:32-34)
166. (L)(P9:4:17-18)
167. (B, B2, B3, B4)(F10:4:18-19, P2:5:22-23, F13:2:5-13,
         F8:3:29-30)
168. (F)(P10:2:15-16)
169. (D, E, E2)(F4:10:34-36, F4:10:24-28, F8:4:27-29)
170. (A,F)(F10:2:37-38; RBHA2:6:14-16)
171. (F14)(P10:1:34-35)
172. (F17,F16)(P10:1:35-38; P10:1-2:37-3)
173. (F15)(P10:1:33-34)
174. (F10)(P10:2:14-15)
175. (F12)(P11:2:6-7)
176. (F11)(P11:2:12-16)
177. © & C2)(P5:2:40; & P2:4:3-4)
178. (L,V,V2)(P3:3:23-24; P12:2-3:36-1 & F13:3:11-13)
179. (V3)(RIC1:4:18-19)
180. (V3,I)(F8:6:18-19; F2:2:41-43)
181. (V4)(F8:3:15-20)
182. (X)(F8:6:10-11)
183. (H2,H)(F8:6:12-15, F4:10:19-24)
184. (H3)(F6:6:22-23)
185. (HH)(F3:7:28-30)
186. (TT)(F6:2:18-20)
187. (WW)(F4:11:11-15)
188. (PP,PP2,PP4)(F16:3:8-10, F6:6:23-26, P5:4:25-27)
189. (PP3)(F2:2:37-40)
190. (R3,R,R2,R4, JJ)(RIC1:4:16-18, P7:5:27-28, P12:3:3-5,
         P10:2:34-35, RIC2:4:34-36)
191. (Q)(RIC1:4:27-28)
192. (FF, FF4,FF5,GG)(P3:3:22-23, F6:6:26-27,P7:5:2-6,
         P7:5:17-20)
193. (FF3,FF2,FF6,FF7)(F6:8:18-19, P7:5:35-26 & P7:4-5:39-2,

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          RIC1:4:29-30)
194. (Y)(P3:3:20-22)
195. (W & W2)(P12:3:34-35 & P10:2:10-12)
196. (T2 & D)(F5:4:14-15; P5:6:15-18; RIC1:4:34-40)
197. (T4)(RIC1:4:19-21)
198. (T5, T6, KK)(P10:2:18-19 & P10:2:27-28; RIC1:4:34-38)
199. (T3)(P5:3:16-18)
200. (UU)(P11:2:22-23)
201. (VV)(P10:2:6-8)
202. (OO)(P11:2:24)
203. (LL)(P11:3:1-3)
204. (C,K)(F3:2:8-9; F3:2:4-6)
205. (L)(F3:3:1-3)
206. (A, D, D2, G, I)(F3:1:39-42, F3:2:7-8, F4:5:13-14,
          DOC6:1:14-15, F13:3:29-31)
207. (H, H2)(F3:7:33-35, F8:4:21-23)
208. (B, B2, B3)(F2:5:10-12, F15:1:17-20, F9:4:21-24)
209. (E,E2,E3)(F12:1:36-38, RIC1:4-5:40-1, RBHA1:2:16-18)
210. (F)(P10:2:19-24)
211. (F2)(P10:2:25-27)
212. (F3)(P10:2:16-17)
213. (BB8,BB,BB3,BB5)(P3:3:19-20; F5:3:43-44; P1:4:15-16;
          P2:3:36-38)
214. (II, BB2, BB4, BB7)(P2:5-6:39-3; P2:3-4:38-2; P1:4:16-
          18; P5:3:29-31)
215. (BB6)(P5:3:31-33)
216. (C2, C3)(P5:4:4-6, P9:8-9:26-1)
217. (C)(F10:4:22-23)
218. (C6)(RIC1:1-2:39-1)
219. (C4)(P2:5:20-21)
220. (C5)(P2:5:17-18)
221. (O,P)(P8:2:27-28; P8:2:33-35)
222. (M6)(F7:3:14-17)
223. (M4)(F12:2:32-34)
224. (M 7 M3)(F3:7:42-42 & F4:5:24-25)
225. (G, G2, G3)(F10:4:17-18, P11:2:2-3, & P11:1:29-30)
226. (M2 & M5)(F4:5:14-17 & F7:3:17-20)
227. (Z)(F4:3:20-21)
228. (W)(F4:3:36-37)
229. (A5)(P2:4:9-11)
230. (A9)(F16:2:29-31)
231. (A6, A8, T, X)(RBHA1:7:31-32, P8:5:31, & RBHA1:7:30-31;
     F4:3:41-44)
232. (A7)(P8:5:28-31)
233. (U, U2, U3, U4)(F3:6:6-7, F2:3:17-18, F10:2:38-41,
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            F2:3:19-20)
234. (A,A2,& A4)(P2:5:34-36, P2:1:12-14, & P1:7:22-24)
235. (A3)(P2:5:36-38)
236. (I)(P1:8:23-25)
237. (Q,D2, D3, O, MM, MM2, MM3, NN)(F4:4:12-14; F4:3:34-37,
     F4:2-3:44-2; P10:3:19-20; RIC2:4:32-34; P8:5:5-7;
     P7:5:6-7; P3:3:28-31)
238. (D)(P10:3:28-30)
239. (D3,D2)(P7:4:37-39, P7:4:36-37)
240. (O,R)(P9:8:7-10, RIC2:4:36-38)
241. (S)(P9:8:10-12)
242. (SES-D)(P10:3:25-27)
243. (SES-C)(P5:4:38-40)
244. (SES-A)(P8:4:25-27)
245. (B)(RBHA1:4:17-18)
246. (B2)(F1:5:11-13)
247. (B3,E2)(F1:5:9-11; F5:4:29-31)
248. (E)(P12:4:4-6)
249. (C, C6)(P10:3:16, F1:2:32-33)
250. (C3, C8, G)(F15:2:31-32, F1:2:32; F4:3:21-22)
251. (C2)(F2:3:34-37)
252. (C4)(F15:2:29-31)
253. (C5)(F4:4:6-10)
254. (C9)(F15:4:4-6)
255. (E, E2, E3)(P3:4:6, P7:6:7; P1:7:17-18)
256. (E4)(F4:3:23-24)
257. (P)(P5:2:13-15)
258. (P3, P4, Y, L, B, J3, J, J4)(F1:2:34-36, P5:4-5:40-2,
     F4:3:19-20; F3:6:7-8; RBHA2:4:15-16, F2:3:22-24;
     F15:3:7-9, F12:3:13-16)
259. (P2)(P5:2:15-16)
260. (J5)(F15:4:19-22)
261. (J2, V)(F15:3:9-19, DOC3:1:6-7)
262. (K)(F15:3:22-27)
263. (V3, V2)(F4:3:25-27; DOC4:3:2-3)
264. (V4)(F15:4:24-29)
265. (F, F2, O,N)(F16:3:24-27, F16:3:20-23, F9:5:28;
     RBHA2:8:3-4)
266. There is no 266
267. (R, R2)(F7:3:3-4, DOC3:4:15-16)
268. (M)(F17:4:21-23)
269. (E4)(F6:4:8-11)
270. (E2, E3)(P1:2:2, P1:2:5-6)
271. (K, Cfd,CFc,CFc2)(F6:4:15-19, F6:4:20-22; F8:5:1-2,
          F8:4:38-40)
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272. (O)(F8:8:1-3)
273. (E7,E5,E,E9,N,N2)(P12:4:27-31, F10:4:32-33, F10:2:11-
        12, P12:4:23-24, P2:3:3-5, F8:6:38)
274. (C,D)(F10:2:30-35, F10:2:28-29)
275. (R,A)(F4:6:30-32;F4:5:3-4)
276. (J)(F6:4:20-25)
277. (B)(F4:4:37-43)
278. (G2,G3)(P9:5:7-8, P2:3:1-3)
279. (G)(P2:2:33-38)
280. (H)(P1:2:2-5)
281. (F)(P2:2:30-31)
282. (M,M2)(P2:3:5-6, F8:7:24-26)
283. (S,S2)(RBHA1:7:12-14, F14:4:16-19)
284. (L,L2)(F12:4:25-27, F15:5:20-23)
285. (P,P2,P3,P4)(RIC1:2:10-13, RIC1:3:14-16, RIC1:2:4-5,
        RIC1:2:5-10)
286. (Q)(P4:3:32-35)
287. (D,E)(P1:4:5-7; P8:2:16-18)
288. (A5)(RIC2:4:6-10)
289. (A3)(RIC2:2:9-12)
290. (A2)(F10:6:22-28)
291. (A)(F6:3:33-38)
292. (A4, F, F2)(RIC2:2:13-15, F9:5:16-18, F16:2:16-18)
293. (A6,B)(RIC2:2:16-18; F16:4:28-31)
294. (H)(P8:5:15-19)
295. (I)(P8:3:14-15)
296. (H2)(P8:3:13-14)
297. (J)(P8:3:15-17)
298. (A, A2,B, B2, B3, B4, B5)(P2:5:3-5, RBHA1:2:37-39;
        P3:2:38-39, RIC1:3:30-34, RIC1:3:27-28, F13:2:29-
    31,      F2:1:23-26)
299. (D)(RBHA1:5:18-20)
300. (E, E2, E3)(RBHA1:5:12-18, RBHA2:4:17-19, P7:3:6-7)
301. (C)(F15:3-4:35-1)
302. (F, F2)(P12:4:24-26, P2:7:1-3)
303. (DD,DD2, II, F, U, Y, B, EE, FF)(P2:1:14-16, P2:1:18-
    19; F8:5:38-39, F8:7:8, F7:5:29-32; P8:3:32-34;
    P2:1:25-28; P2:1:16-18; P9:7:7-8)
304. (O,I)(P2:1:23-24; P2:1:24-25)
305. (A)(F2:3:47-48)
306. (M)(F2:4:17-18)
307. (J)(P8:2:30-32)
1.   308. (I)(P9:8:14-17)
309. (B)(F5:5:13-15)
310. (Q, Q2, P, T, A, N)(P7:4:34-36, P9:8:12-13 & P4:1:36-

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     37; P9:8:12-13, F15:3:2-5; P5:4:20-21)
310a.     (J7, J5, E, J)(P5:4:36-38, P4:1:37-38, RBHA2:8:5-
          6,            P8:5:7-9)
311. (J3, J4, J8, C)(F1:5:13-15, RIC1:5:38-39, F15:4:2-4;
     F10:2:2-3)
312. (J2 & J6 & L)(P7:5:7-8 & RIC2:4:30-32 & P5:4:22-24)
313. (J9, J10)(F15:5:35-37, F15:4:13-15)
314. (F)(P4:4:26-27)
315. (G)(RBHA1:4:3-5)
316. (B, C, H)(F16:1:32-36; F10:5:9-11, F13:3:2-9)
317. (I,K)(P8:2:28-30, RIC1:2-3:41-4)
318. (D & D2 & D3)(RIC1:3:4-6 & RBHA1:3:39-40 & RIC1:2:40-
          41)
319. (L)(P8:3:22-26)
320. (F)(F1:4:11-13)
321. (A, J)(F15:5:9-10, F10:5:19-20)
322. (E,F)(P3:2:30-32, RIC1:2:27-35)
323. (C,D)(P1:5:11-13, P1:5:9-11)
324. (D2)(P3:2:29-30)
325. (B, B2, E, E2, F, I)(F9:3:26-28 & P7:6:20-22; P3:2:14-
     15;   F3:3:8-9; F5:1:36-39; F3:6:32-33)
326. (D,D2,G,C) (F2:3:49-50, F5:1:39-42, F3:6:18-20,
          F10:2:18-23)
327. (H)(F1:4:18-20)
328. (A)(P9:7:16-19)
329. (C, C2, C3, C4, C5)(P2:1:31-33, RBHA1:2:7-8,
          RBHA1:3:35-36, P1:6:38-39, F2:4:26)
330. (E, E2, E3, E4, E5)(RBHA1:2:11-13, F4:5:28-30,
          F16:4:19-21, F8:4-5:40-1, F3:4:17-18)
331. (GG)(F2:4:26-28)
332. (L)(F10:6:17-19)
333. (L2,S3)(F10:3:3-5; RIC2:2:32-34)
334. (L4)(P12:3:3)
335. (J)(P9:6:14-15)
336. (G, S, W, E, A5, A8, N, I, P, T)(P3:2:36-38, P8:4:5,
     F15:5:3-4; F10:3;7-8; P8:4:32-33, P5:5:26-28, F10:3:25-
     26, P1:5:14-17, P12:2:12-14, F10:5:19)
337. (W2)(F15:5:4-7)
338. (C, A6)(F5:3:25-28, F5:2:42-45)
339. (E2)(F10:3:11-13)
340. (A4, A9)(P8:4:35-36, F5:2:17-19)
341. (A3, A7)(P1:5:13-14, P4:2:6-7)
342. (A2)(F5:2:15-17)
343. (A,B, H)(F6:3:29-32, F9:2:27-31, F16:2:15-16)
344. (J)(F6:3:24-29)
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345.(L3, L5)(RIC1:2:20-21, P5:5:15)
346. (L)(P1:2:13-16)
347. (L2, O)(P1:2:10-12, P4:3:20-23)
348. (E)(P3:2:23-24)
349. (A2, A3, A4, A8, A9, A10, A14, A16)(P3:3:37-38,
          F5:3:20-21, P7:6:5, RBHA2:6:13, RBHA1:6:1,
     F6:7:35-37,          F14:3:3-5, P4:2:22-23)
350. (A15, B)(P5:5:10-13, F14:4:34-37)
351. (A13)(P9:4:6)
352. (A11, M, A12, C, H, H2)(F6:3:12-15, P9:9:6-8; P12:4:10-
     12; F9:2:23-25; F12:3:7-9, F16:3:18-19)
353. (A6)(P8:3:28-29)
354. (A)(F4:6:37-39)
355. (A7)(RIC2:3:6-9)
356. (F2,F3)(P7:6:6, F4:2:40-43)
357. (F)(F10:3:14-17)
358. (E,D)(F14:3:10-12; F4:12:6-8)
359. (A,A2)(F4:11:41-43, F4:11:43-45)
360. (C)(F6:5:30-34)
361. (B4)(F6:5:29-30)
362. (B3)(F6:5:35-37)
362a.      (B5)(F6:3:39-40)
363. (B2)(F6:5-6:41-1)
364. (B, B6)(F6:2-3:41-2, F6:4-5:41-2)
365. (G,G2)(RBHA2:2:37-39, RBHA2:6:1-2)
366. (L)(P4:2:15-17)
367. (K)(RBHA2:2-3:39-2)
368. (A, A2, A3)(F12:5:1-2, F13:1:25-30, F15:5:7-8)
369. (C, E)(RBHA1:4:21-23, RBHA2:6-7:30-1)
370. (B)(F9:6:34-35)
371. (K-barriers, D)(RBHA1::4-6; P8:4:21-23)
372. (A4)(F5:4:31-35)
373. (A3)(F5:4:39-40)
374. (A2)(F5:4:40-42)
375. (A)(F5:4-5:44-1)
376. (R)(P3:2:23-27)
377. (S2)(RIC2:2:35-38)
378. (T, T3, T4)(F10:3:19-21, P3:3:5-7, P3:3:8-12)
379. (H, H2, H3, X)(P5:5-6:40-2, F12:4:9, F7:2:24-27;
     F6:8:19-23)
380. (S)(P2:4:26-29)
381. (P)(F10:3:5-7)
382. (AA)(RIC2:3:24-27)
383. (Z)(P1:1:32-33)
384. (BB, CC)(RIC2:2:30-32; P12:5:18-19)

385. (A, A2)(P9:7:5-6, F6:6:19-22)
386. (A3)(P9:7:16-17)
387. (A4)(RIC2:3:37-38)
388. (H, H3)(RBHA1:4:39-41, F3:7:6)
389. (D10, E6, E8)(F2:5:14-16, F6:7:27-29, F3:6:18-21)
390. (D, D3, D15, D18)(RIC2:3:36-37, F6:5:12-14, F6:2:7-11,
          F9:4-5, 40-4)
391. (D16)(RIC2:3:39-40)
392. (D19)(F9:6:29)
393. (B, B2, B3, J2)(F6:2:36-40, F13:3:22-25, F2:3-4:50-1,
          F12:3:28-29)
394. (L)(F3:6:33-34)
395. (G2)(F3:6:35-36)
396. (G)(F5:1-2:45-2)
397. (M)(F3:6:28-31)
398. (O)(F9:6:15-17)
399. (N)(F6:5:25-28)
400. (D14, D7, J7, D4, H2,D11,D2,I4, I, I2)(F2:4:3-4,
     F14:2:18-20, F2:4:4-6; F4:3:28-30; F3:7:8-9; F9:3:8-10;
     F7:2:36-40; F7:1:32-33; F3:3:6-8, F12:3:39-40)
401. (J)(F12:3:37-39)
402. (J4)(F3:2:13-15)
403. (J5, J6)(F4:5:39-40, F2:3:41-43)
404. (J3)(F12:3:24-28)
405. (D13, E4)(F6:7:16-18, RBHA1:4:31-32)
406. (D5,E7, K, K2, K3, C3, C, C2)(RBHA2:2:36-37, F3:6:25-
     26; F12:3:23-24; F3:7:39; F4:7:3-5; F15:2:20-24;
     F6:5:14-16, F2:4:14-17)
407. (E2)(P5:5:24-26)
408. (E)(F15:5:29-32)
409. (E3, E4)(F9:3:37-40; F12:4:1-4)
410. (E5)(F2:4:18-23)
411. (H, H2)(RBHA2:5:1-3, RBHA2:4:33)
412. (E9)(RBHA1:4:28-31)
413. (E, E13, E4)(P5:5:30; F10:3:40-4; F6:2:25-31)
414. (E2)(RIC2:3:22-23)
415. (E11, E3, E10, I, I4, I2)(P4:1:27-31; RIC2:3:19-20;
     RIC1:3:17-18; RBHA2:4:35-36; RBHA2:2:21-22; RBHA2:2:21)
416. (E7, E8)(F10:3:31-37, F10:3:38-40)
417. (E14)(F7:2:28-29)
418. (E5)(F6:2:32-35)
419. (E15)(F7:2:31-35)
420. (B)(F10:2:3-6)
421. (C)(F5:2:20-21)
422. (F)(P8:4:7-9)

423. (J)(RBHA2:2:19-21)
424. (A, A3,A4)(F9:2:13-14, F6:2:18; F2:3:11-12)
425. (BPc3,BPa, Bpa2,BPa3)(F2:3:9-12; F4:11:24-27,
        RBHA1:4:24-26, RIC1:3:18-22)
426. (BPf)(F8:7:2-3)
427. (Bpd,BPd2, BPi)(P1:5:22-24, F10:4:7-9, F7:5:7-8)
428. (BPb)(F4:11:33-34)
429. (G2)(F6:2:22-24)
430. (J)(F8:7:9-11)
431. (G)(F8:7:7-8)
432. (A2)(F6:2:21-22)
433. (D)(F17:5:6-9)
434. (K)(P7:6:9-10)
435. (E2)(F2:2:9-10)
436. (E, I, G, G2, G3, G5, Cynthia, G4, D, C2, C, C, D,
     B)(RBHA2:6:7; P12:4:26-27; P7:3:23-24, F7:5:11-12,
     F7:5:12-15; P7:3:24-26; *F:: *; F2:2:10-15; P7:3:30-32;
     P2:5:8-9; P1:8:15-17; F10:6:1-4; F5:2:35-37, F13:4:10-
     13)
437. (J)(F2:2:5-7)
438. (B, B3)(P1:2:40-41; P2:4:37-38)
439. (B2)(P2:4-5:38-2)
440. (F)(P7:3:21-23)
441. (A,A2,A3,A4,A5,A6)(P1:2-3:41-2, P2:4:35-37, P9:5:14-15,
        P3:3-4:41-1, F5:3:10-11, P1:7:26-27)
442. (A)(P9:5:15-19)
443. (H, G)(RBHA2:6:4-6; P7:4:4-7)
444. (F)(P1:7:29-30)
445. (E,E2,E3)(P3:4:2, P1:7:29-30, P1:7:30-32)
446. (L)(P9:5:21-22)
447. (J)(RBHA2:6:6-7)
448. (M)(P7:4:19-21)
449.(I)(F1:4:8-10)
450. (K,K2)(RBHA1:4:17-19, P8:4:13-14)
451. (O)(F14:2:38-40)
452. (P)(P9:5:11-12)
453. (N)(P9:5:10-11)
454. (M)(P9:5:8)
455. (E)(F7:5:34-36)
456. (I)(P12:5:7-8)
457. (G)(F4:7:21-27)
458. (J)(P5:5:31-33)
459. (A, V, R)(P4:2:33-34; P4:2:28-31; RBHA1:2-3:41-3)
460. (Q)(P4:2:31-32)
461. (H,H2)(F6:6:22, P9:6:6)

462. (K,K2,K3)(F7:2:3-7, F3:6:40-42, F3:6:38-40)
463. (C)(P2:5:10-11)
464. (D)(P7:3:27-30)
465. (D, D2)(P3:4:3, P8:4:11-13)
466. (N, N2)(RIc1:2:21-24, RIC1:5:21-22)
467. (Q)(RBHA1:2:28-29)
468. (N,N2,N3, O, P, A, D, C, G,L,L2,L3, I, Q, J)(F7:2:1-3,
     F3:4:35, F2:3:6-8; F2:1:16-19; F3:5:10-11; F9:2:16-18;
     F4:5:26-27; F8:6:16-18; F17:3:2-3; F4:4:10-11, F4:2:3-
     6, F6:5:11-12; F12:4:18-19; F2:1:33-34; F17:3:21-24)
469. (H)(P1:5:18-21)
470. (H2)(P7:2:32-34)
471. (M)(F6:7:11-15)
472. (K, E)(F12:2:17-22; F17:2:26-27)
473. (F)(F17:3:3-5)
474. (H)(F17:2:27-30)
475. (A3)(F3:7:11-13)
476. (D-family)(F3:7:13-14)
477. (A,A4)(F14:4:40-41, F13:2:39-40)
478. (A2,Q)(P2:3:17-19, P9:3:17-21)
479. (F)(P2:4:12-13)
480. (P)(P5:3:35-37)
481. (B2)(F17:3:5-6)
482. (H3)(F10:5:26-27)
483. (A5)(F1:2:37-38)
484. (U)(F2:4:28-30)
485. (N)(F1:2:14-17)
486. (J, D)(F1:4:1-2; P2:4:20-22)
487. (M)(F1:2:3-5)
488. (K2)(F3:7:14-16)
489. (K)(RBHA1:3:25-27)
490. (G, I)(F5:5:11-12; F10:5:28-32)
491. (L)(F1:4:24-26)
492. (B5,B6,B7,B3, B)(F1:2:10-11, F7:4:21-24, P7:2:34-36;
     F1:4:1; F1:3:7-9)
493. (B4)(F1:2:11-13)
494. (C)(P1:3:9-12)
495. (C2)(F2:4:12-14)
496. (C3)(P7:2:30-31)
497. (C4)(F1:4:6-7)
498. (E4)(F1:3:23-26)
499. (E5)(F1:3:17-21)
500. (E2)(F1:3:13-15)
501. (E3)(F1:3:10-12)
502. (E)(P1:9:12-15)

503. (T)(F1:3:31-32)
504. (S,O)(F1:3:30-31, F1:2:8-10)
505. (O2)(F1:2:17-19)
506. (R)(P12:3:24-25)
507. (B,B4)(P1:5:28-29, F5:4:36-37)
508. (A2,A,B5)(F4:6:7-9, F16:2:2-4, RIC2:3:29-31)
509. (A3)(F17:5:5-6)
510. (A4,B3)(F17:3:13-15, F17:3:8-10)
511. (G)(F17:5:4-5)
512. (A5)(F4:6:4-6)
513. (D)(F5:3:23-24)
514. (I)(F8:6:21-23)
515. (F)(F17:5:19-21)
516. (C)(P1:5:29-32)
517. (C2)(F8:4:2-4)
518. (H)(F7:6:15-18)
519. (H2, B2, E)(DOC3:2:14; P1:8:33-34; P1:8:34-37)
520. (C)(F10:6:7-8)
521. (O)(F1:3-4:47-1)
522. (M)(P12:5:13-14)
523. (N)(RBHA2:6:10-11)

Appendix B

Epilogue Code List

```
E1      (Post2:1)
E2      (Post2:2)
E3      (Post1:1)
E4      (Post2:2-3)
E5      (Post2:3; Post2:3)
E6      (Auth4)
E6.1    (Post1:1)
E6.2    (Post2:1)
E7      (Post2:4; SR:9-10; SR:18)
E8      (Post2:2; Post2:3)
E9      (Post1:2; Post1:3)
E10     (Auth4; PostDOC2)
E11     (DOC12:3)
E12     (Post3:2; Post4:1)
E13     (Post2:1; Post5:1)
E14     (Post2:2)
E15     (PostDOC1; SR:40; PostDOC4)
E16     (Post2:2)
E17     (Auth4)
E18     (SR35)
E19     (Post4:3)
E20     (Post2:3)
E21     (Post2:2)
E21.1   (Post2:2)
E22     (Post1:1)
E22     (Post1:2)
E23     (Post3:1)
E24     (Post2:1)
E25     (Post5:2)
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Appendix C

Informed Consent

Research Participant Consent Form
for
A CONSTRUCTIVIST INQUIRY OF FAMILY INVOLVEMENT
ON EARLY INTERVENTION TEAMS SERVING INFANTS AND TODDLERS
WITH DEVELOPMENTAL DISABILITIES

## Introduction

The School of Social Work of Virginia Commonwealth University adheres to the ethical standards of protection for human subjects who participate in research. The following information is provided so that I can decide whether or not I choose to participate in the present study. If I agree to participate, I am free to withdraw at any time.

Researcher:    Patrick Shannon

█████████████

*The purposes of this project are:*

1.    To satisfy dissertation requirements for a Doctor of Philosophy in Social Work.

2.    To gain a more complete and in-depth understanding of family involvement on multidisciplinary early intervention teams.

*I understand that:*

## Benefits

1.    I will derive no personal benefits from this study. However, my participation may benefit others by enabling social scientists to learn more about involving families in the early intervention process.

## Risks

2.    There are no risks associated with participation in this study.

## Alternative Therapy

3.    This is not a therapeutic study. I have the alternative not to participate

## Costs

4.    There are no costs associated with participation.

## Confidentiality of Records

5.  My name will not be shared with other research participants
    nor used in the case study.  However, the study methodology
    involves validating information against at least one

                                                    Participant
Initials:_____

    other source, so it may be possible that my information may
    be associated with me by another study participant.

6.  The information obtained during this study will be used to
    write a case study that will constitute a major portion of
    the researcher's dissertation.  The dissertation will be
    published through microfilm, scholarly journals, monographs,
    and/or in book form.

## Withdrawal

7.  I can withdraw from the study at any time by informing the
    researcher that I wish to do so.  All data collected from me
    will be returned immediately.

8.  The initial interview will require one to two hours of my
    time.  I may be asked to participate in one or more follow
    up interviews.  Participation in follow up interviews is
    voluntary.

9.  I am entitled to review the case study before the final
    draft is written and to negotiate changes with the
    researcher.

10. I will receive a copy of the final case study, if I so
    desire.

11. I will receive a signed copy of this consent form at the
    time of the interview.

    If you have any questions concerning your rights as a
research subject, you may contact the Committee on the Conduct of
Human Research at (828-0868) for information or assistance.

*I agree to participate in this study according to the preceding
terms.*

                    Participant:     _____
_____

*I do/do not grant permission to be quoted (without attribution)
in the case study.*

                    Participant:     _____
_____

                    Date:            _____
_____

*I agree to conduct and report the research according to the preceding terms.*

Researcher: _____

Date: _____

Research Participant Consent Form
for Comprehensive Member Check for

FAMILY-CENTERED PRACTICE IN
EARLY INTERVENTION SERVICES FOR INFANTS AND TODDLERS:
THE EXPERIENCE OF FAMILIES IN ONE LOCAL INTERAGENCY
COORDINATING COUNCIL

Introduction

The School of Social Work of Virginia Commonwealth
University adheres to the ethical standards of protection
for human subjects who participate in research.  The
following information is provided so that I can decide
whether or not I choose to participate in the present study.
If I agree to participate, I am free to withdraw at any
time.

Researcher:    Patrick Shannon
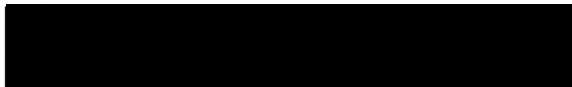
The purposes of this project are:
1.   To satisfy dissertation requirements for a Doctor of
     Philosophy in Social Work.

2.   To gain a more complete and in-depth understanding of
     family centered practice in early intervention.

3.   To conduct a comprehensive member check of the findings
     present in the case report.

I understand that:
Benefits
1.   I will derive no personal benefits from this study.
     However, my participation may benefit others by
     enabling social scientists to learn more about
     involving families in the early intervention process.

Risks
2.   There are no risks associated with participation in
     this study.

Alternative Therapy
3.   This is not a therapeutic study.  I have the alternative not
     to participate

Costs
4.   There are no costs associated with participation.

Confidentiality of Records

5. My name will not be shared with other research participants
nor used in the case study. However, the study methodology
involves validating information against at least one other
source, so it may be possible that my information may be
associated with me by
another study participant.

Participant
Initials:_____

6. The information obtained during this study will be used to
write a case study that will constitute a major portion of
the researcher's dissertation. The dissertation will be
published through microfilm, scholarly journals, monographs,
and/or in book form.

Withdrawal

7. I can withdraw from the study at any time by informing the
researcher that I wish to do so. All data collected from me
will be returned immediately.

8. The initial interview will require one to two hours of my
time. I may be asked to participate in one or more follow
up interviews. Participation in follow up interviews is
voluntary.

9. I am entitled to review the case study before the final
draft is written and to negotiate changes with the
researcher.

10. I will receive a copy of the final case study, if I so
desire.

11. I will receive a signed copy of this consent form at the
time of the interview.

If you have any questions concerning your rights as a
research subject, you may contact the Committee on the Conduct of
Human Research at (828-0868) for information or assistance.

*I agree to participate in this study according to the preceding
terms.*

Participant: _____

*I do/do not grant permission to be quoted (without attribution)
in the case study.*

Participant: _____

Date: _____

*I agree to conduct and report the research according to the preceding terms.*

                Researcher: _____

                Date: _____

Appendix D

Audit Contract and Report

Contract Between:
               Patrick Shannon (Auditee)
                         and
               Michael Crosby (Auditor)

             For the Completion of an Audit of
       *The Families Experience with Early Intervention Services*

Timeline: Audit to be completed between March 4, 2000 and
March 25, 2000.

Goals:          To complete an assessment of all elements of
                trustworthiness using Scwhandt and Halpern's
                Algorithim.  To complete an assessment of the
                process engaged in to assess all elements of
                authenticity.

Roles:          *Auditor*: The role of the auditor will be to
                apply Schwandt and Halpern's algorithm to the
                audit trail materials provided by the
                auditee.  Specific criteria for each level of
                assessment are outlined in attachment A of
                this contract.

                *Auditee:* The role of the auditee will be to
                provide all necessary audit trail materials to the
                auditor.  All materials will be transported to the
                auditors residence.  The auditee will remain
                available to the auditor throughout the audit
                process for whatever the auditor may need.  An
                attachment to this contract has been developed
                that outlines specific expectations for each
                element of trustworthiness and authenticity.

Logisitcs:      Specific times will be arranged for drop off
                of all materials as well as subsequent
                meetings.  Phone numbers will be provided so
                that the auditor can get in touch with the
                auditee at any time throughout the audit
                process.  An collegial agreement will be made
                to conduct the auditor's audit as payment for
                conducting this audit.  All expenses incurred
                by the auditor will be reimbursed by the
                auditee.

Outcomes: An audit report will be prepared by the auditor
                that includes and addresses each element of the
                audit process of trustworthiness and authenticity.
                The report should be brief: 5-10 pages.

Auditee Signature: _____        Date:_____
                          Patrick Shannon


Auditor Signature: _____        Date:_____
                          Michael Crosby

| Elements | Auditor Tasks | Guiding questions | Where to look |
|---|---|---|---|
| **Trustworthiness** | | | |
| **Confirmability** | Auditor Tasks | Guiding questions | Where to look |
| a) Are findings grounded in data | a) Sample 20 findings<br>b) Identify audit trail components linked to each finding<br>c) Verify linkages. | 1) Is the raw data linked to synthesized data in the case report?<br>2) Are categories weighted? | field notes, index cards, case report Appendix A. |
| b) Are inferences logical | A) Identify analytic strategies<br>B) Assess application of strategy<br>C) Assess accuracy of the description of concepts<br>D) Determine whether inferences are faulty or logical | 1)Has an appropriate analytic technique been selected and applied?<br>2) Do category labels accurately describe the concepts?<br>3) Do examples clearly explain the concepts?<br>4) Do examples fairly represent the data?<br>5) Are there illogical interpretations of the data?<br>6) Are there alternative explanations for inferences?<br>7) Are there unexplained data? | Methods journal, Peer reviewer notes, Self reflexive journal, data units, case report |

| c) Assess utility of category structure | A) Assess clarity of conceptual structure B) Assess explanatory power of category structure C) Assess fit between categories, definitions and examples. | 1) is there evidence of category overlap? 2) is there an unclear method of analysis? 3) have an optimal set of categories been extracted? 4) Do categories fit the emerging hypotheses? 5) do categories represent an exhaustive use of the data? | Methods journal, Peer reviewer notes, Self reflexive journal, data units, case report |
|---|---|---|---|
| d) Assess degree and incidence of inquirer bias | A) Assess incidence of undisciplined subjectivity | 1) is there an imposition of inquirer's own terminology in the data? 2) is there a sufficient description of the inquirer's tacit process? | Self reflexive journal, Methods journal, Peer reviewer notes |
| e) Assess accommodation strategies | A) Assess the design and implementation of confirmability efforts, and integration of the outcomes | 1) are there sufficient efforts to ensure confirmability? 2) does the inquirer account for negative evidence? 3) Does the inquirer include negative examples? | Comprehensive audit, Case report, Self reflexive journal |
| **Dependability** | Auditor Tasks | Guiding questions | Where to look |

| a) Assess appropriateness of inquiry decisions and methodological shifts | A) Identify an inquiry decision<br>B) Identify a working hypothesis<br>C) Locate audit trail entries describing inquiry processes, decisions, and rationale | 1) Is there evidence of purposive sampling?<br>2) Is there evidence for purposive decisions?<br>3) Is there evidence of a systematic process for changing the instrumentation?<br>4) Is there support for altering techniques? | Self reflexive journal, Methods journal, Peer reviewer notes |
|---|---|---|---|
| b) Assess degree and incidence of inquirer bias | A) Identify decisions and rationale to bound the inquiry | 1) Is there evidence of early closure?<br>2) Are there unitized, uncategorized data?<br>3) Is there insufficient or conflicting evidence disproving claim of saturation?<br>4) Are there unexplored areas that appear in the field notes?<br>5) Is there unnecessarily strict adherence to an interview schedule?<br>6) Was the study discontinued to meet a deadline?<br>7) Was the focus influenced by a sponsoring agency? | Self reflexive journal, Methods journal, Peer reviewer notes |

| | | | |
|---|---|---|---|
| | B) Identify instances that suggest cooptation | 1) Are there shifts in feelings of empathy?<br>2) Is there an identification with figures of authority in the setting?<br>3) Is there unused, conflicting evidence?<br>4) Is there unexplained neglect of potential leads? | |
| | C) Identify premature judgements | 1) Is there an overemphasis of personal notes in the analysis?<br>2) Is there an overuse of personal notes when making methodological choices? | |
| | D) Assess whether there is a Pygmalion effect | 1) Is there an unfounded convergence of personal and field notes?<br>2) Does the documentation lack a rationale for decisions?<br>3) Is there an unsubstantiated rationale for theoretical assumptions?<br>4) Is there a smooth convergence of preliminary questions and categories of outcomes? | |

| | | | |
|---|---|---|---|
| | E) Assess whether there is a Hawthorne effect<br><br>F) Determine whether the inquirer is biased through naivete | 1) Is there an unexplained similarity in language between respondents and the initial theoretical positions? | Case report, Self reflexive journal, Methods journal |
| | G) Determine appropriateness of sampling decisions | 1) Has a homogenous sample been selected?<br>2) Is there a relationship between working hypotheses and selection of sources? | Self reflexive Journal, Methods Journal, Methods chapter |
| | H) Identify the presence of triangulation | 1) Is there an unbalanced reliance on one method?<br>2) Is there a connection between working hypotheses and selection of sources? | Self reflexive journal, Methods Journal |
| c) Assess the overall design and implementation of efforts, and integration of the outcomes for dependability | A) Identify major design decisions<br><br>B) Evaluate the rationale for the design decisions | 1) Are there sufficient efforts to ensure dependability<br>2) Is there evidence of sufficient purposive/responsive flexibility | Self reflexive Journal Methods Journal Proposal/ methods chapter |
| **Credibility** | Auditor Tasks | Guiding questions | Where to look |

| | | | |
|---|---|---|---|
| a) Assess the design and implementation of the strategies, and the integration of the outcomes | A) Look for evidence of triangulation<br><br>B) Look for evidence of peer debriefing<br><br>C) Look for evidence of member checks | 1) Is there evidence of triangulation?<br>2) Is there evidence of member checking?<br>3) Is there evidence of preliminary validations? (ongoing member checks)<br>4) Is there evidence of peer debriefing?<br>5) Are the raw data isomorphic with the phenomena under investigation? | Self reflexive journal, Methods Journal, Peer review notes, Member check summaries, Field notes, Case report |
| B) Assess corroboration between descriptions of methodological choices, data sources, findings, and audit trail. | | 1) Is there evidence of responsive reflexivity? | Self reflexive journal, Methods Journal, Peer review notes, Member check summaries |
| Closure Phase | | | |
| A) Feedback and renegotiation | A) Present findings<br>B) Discuss discrepancies and determine nature of closure | | |
| B) Complete Agreement | Write final report | | |
| Authenticity | | | |
| A) Fairness | Auditor Tasks | Guiding questions | Where to look |

| | A) determine if there was a fair representation of stakeholder perspectives. | 1) Is there evidence of a process for assuring fair representation? 2) Is there evidence of sampling decisions made based on this process? | Consultant interviews<br><br>Reflexive journal Methods journal Peer review notes |
|---|---|---|---|
| B) Ontological | | | |
| | A) Determine if participants became more aware of the complexity of the social environment | 1) Did participants become more aware of the complexity of the early intervention system? | Post-case study interviews |
| C) Educative | | | |
| | A) Determine if inquiry process led to increased awareness and respect of other stakeholder perspectives | 1) Is there evidence of increased awareness and respect for the perspectives of other stakeholders in this LICC? | Post-case study interviews<br><br>Reflexive journal |
| D) Catalytic | | | |
| | A) Determine the degree to which the inquiry process facilitated change in the system. | 1) Is there evidence of actions engaged in by stakeholders? that led to change in the LICC 2) Are these actions linked to the inquiry process? | Post-case study interviews<br><br>Post-case study documents<br><br>Reflexive journal |
| E) Tactical | | | |

| | | | |
|---|---|---|---|
| | A) Determine if power has been redistributed among stakeholders leading to lasting change | 1) Is there evidence of a redistribution of power among stakeholders? 2) Has the LICC changed as a result of redistribution of power? | Post-case study interviews Post-case study documents Reflexive journal |

Appendix E

Vita