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A Qualitative Examination of the Barriers and Facilitators of Family Centered Care and Service Provision in the Natural Environment.

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UNIVERSITY OF MIAMI

A QUALITATIVE EXAMINATION OF THE BARRIERS AND FACILITATORS OF
FAMILY CENTERED CARE AND SERVICE PROVISION IN THE NATURAL
ENVIRONMENT

By

Rachel M. Fults

A DISSERTATION

Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

Coral Gables, Florida

May 2011

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A Qualitative Examination of the Barriers and
Facilitators of Family Centered Care and Service
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Although family centered care and natural environment services have been heralded as the ideal model in early childhood intervention and have been mandated by Part C of IDEA, research demonstrates that family centered principles are still not adhered to in many early childhood programs. Previous research in this area is lacking with regard to the limited diversity of participants (i.e., white, middle-class woman) and perspectives (i.e., childcare providers). This dissertation reports the results of a study that took into account perspectives of multiple stakeholders in early intervention including families, service providers, and program directors in order to understand the full range of difficulties and supports experienced when providing family centered care in the natural environment. This qualitative study used grounded theory methods to analyze information gathered through semi-structured interviews to elaborate the barriers and facilitators experienced in family centered care and natural environment services. The core theme identified in the data was the tension between the resources available to early intervention and the ideals of best practice. This core finding was supported by three themes regarding facilitators and barriers to service provision. Two of these, the need for theoretical buy-in to the model and the challenges of negotiating roles in family centered

care, emerged as either facilitators or barriers, depending on service provider roles. The third theme was common across the data and indicated that the major barrier to natural environment services was the management of scarce resources.

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Chapter 1: Introduction

In recent years, family centered care and natural environment services have been heralded as the ideal model of early intervention (e.g., Dunst, Trivette & Hamby, 2007; Sheldon & Rush, 2001; Tisot & Thurman, 2002). Family centered practice is a way of approaching service delivery for children with special needs that treats each family with dignity and respect, honors their values and choices, and provides supports to strengthen family functioning (Dunst et al., 2007). The importance of providing family centered care in the natural environment for families of young children with disabilities is underscored in Part C of the Individuals with Disabilities Education Act (IDEA). Part C of IDEA was originally established in 1986 in federal recognition of the need to enhance the development of infants and toddlers with disabilities, reduce the reliance on later special education services thus keeping educational costs at bay, and minimize institutionalization and increase opportunities for independent living for individuals with disabilities while empowering families to meet the needs of their children. This legislation stresses the importance of respectful inclusion of families into the planning of services for young children and the importance of enhancing family capabilities rather than just serving the needs of the child.

Family Centered Care

Although the concept of family centered care can be found in educational literature in earlier decades, it was not until the mid-1980s when the Association for the Care of Children's Health stepped in and provided core elements of care for children with special needs that family centeredness became a buzzword of early intervention programs (Espe-Sherwindt, 2008). All of these core elements focused on the importance of

recognizing that the family, not the practitioner, is the stable element in each child's life. Once these core elements of early childhood caregiving were disseminated, references to family centered practice became abundant. One definition that has been influential in the literature was articulated by Dunst and his colleagues, who described family centered practice as "a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing" (Dunst, Johanson, Trivette, & Hamby, 1991, p. 115). Embedded in this definition is the importance of respecting families' desires and increasing families' ability to care for their children. By including family input in determining the greatest family needs and how best to address them, families become consumers in the sense that they now have a say in service provision. Increasing a family's competence is one of the foundational tenets of family centered service posited by Dunst and Trivette (1996), who argued that the way in which support was offered to a family could have either empowering or disempowering consequences.

Although there are other definitions of family centered care throughout the literature, the majority contain two distinct aspects of involving families, coined by Dunst, Trivette and Hamby (2006) as "relational" and "participatory" practices. Relational practices are described as good clinical practices (e.g., compassion, empathy, belief in the strengths and capabilities of each family) whereas participatory practices actually include family members in the goal development and activities used to achieve set goals, the building up and expansion of current family abilities and the use of family/professional collaboration for the improvement of family capabilities. The reason that participatory practices are becoming regularly recognized issues in early intervention

is made clear when one considers the groundwork for recent legislation in special education. According to Kalyanpur and Harry (1999) the foundation for family centered care was rooted in the American cultural value ascribed to equity, choice, and individualism that is embedded within the Individuals with Disabilities Education Act (IDEA). When originally passed, IDEA contained these ideals codified from the larger American culture that placed parent participation and decision-making as integral components of choice and assurance of equity. It is these values that have made scholars like Dunst and his colleagues argue for the importance of parent participation and shared decision-making. The attitude of both researchers and policymakers in early intervention is that increasing the capacity of parents to help themselves, advocate for their children, and make meaningful decisions in the placement and services their children receive should be paramount for professionals.

In contrast, Kalyanpur and Harry (1999) explain that in special education the historically dominant perspective has been a clinical model of pathology and deviance from the norm which combined to create a reified idea of disabilities as something either with a physiological etiology (e.g., cerebral palsy) or a statistically significant deviation from the norm on measures that are assumed to be reliable indicators of ability (e.g., developmental delay in cognition). In the clinical model, the assumption is that disabilities are physical, individuals' phenomena that are chronic and require remediation or "fixing." This model has presented parents and providers alike with the idea that there is a level of expert knowledge required to make the "right" decisions for a child with special needs and led many professionals to feel that parents are not qualified to make the kind of choices needed to be full participants in the planning processes of early

intervention. Thus, Kalyanpur and Harry argue, professionals have been inculcated into the role of “expert,” and are caught between this role expectation and the law’s call for parent participation.

In addition to arguments made by professionals who have been educated in a medical model of early intervention, family centered care also has its critics in educational research. Mahoney and Bella (1998) argued that their research indicated no statistically significant differences between the degree of family centeredness of a program and the rate of development of the child or the maternal stress rating. Mahoney and Bella argued that family centered care, although based on sound principles, might require more intensity and better preparation on the part of service providers in order to realize its theoretical potential. Dunst et al. (2007) countered this point with the argument that family centered care is not expected to make significant differences in the child outcomes compared to traditional models of service, rather family centeredness is seen as an issue of quality in how these outcomes are achieved. In their words:

There is no reason to believe or expect that family- centered practices would be directly related to child development outcomes. Child focused or parent/child focused interventions are what is done and family- centered practices are how the interventions are implemented. The latter is expected to influence the ways in which the former is carried out (p. 376).

Nevertheless, Dunst et al. (2006) did find a significant mediation effect of parent self-efficacy on child outcomes, and this is the very aspect that family centered care purports to influence.

Regardless of arguments that have been made against the model, current research in the field of early childhood has substantiated the effectiveness of family centered care when rendered appropriately. Two recent meta-analyses summarize the literature, the first

of which examined 18 studies that looked at the extent to which practitioners' adherence to family centered practices influenced the participants' self-efficacy beliefs and overall parent, family and child benefits (Dunst et al., 2006). Results indicated that family centered care was directly related to parents' self-efficacy beliefs and parent perceptions of positive parent, family, and child outcomes. A second meta-analysis conducted by Dunst et al. (2007) looked at 47 studies across early intervention programs, preschool special education programs, elementary schools, family support programs, mental health programs, neonatal intensive care units, specialty clinics, and rehabilitation centers. Again, results indicated that family centered practices were related to increases in participant satisfaction, parent self-efficacy, family judgments of helpfulness of caregivers, child behavior and functioning, personal and family well-being, and positive parenting behavior.

Natural Environment Services

Whereas family centered care is seen as a way of approaching services for young children, natural environment services are seen as the ideal place to provide services while using a family centered framework. Much of the literature in these two areas overlap, and the terms are often used synonymously to indicate that when services are in the natural environment, they are family centered or when they are family centered, natural environments will be an expected option for service delivery. This can be seen in the following quote by Hanft and Pilkington (2000) who argued that family input and participation (i.e., family centered care) is the cornerstone of quality for natural environment services:

Collaboration with caregivers is the single most influential factor for providing effective therapy in natural environments, and advances three key benefits for

children, families, and therapists: (1) enhanced relationships among family members and between therapists and parents; (2) modeling and support to assist caregivers in their efforts to improve a child's performance; and (3) improved capacity to assess a child's strengths and select meaningful outcomes (p. 4).

In this quotation, the important link between family participation and providing quality services in the natural environment is made as though they are inseparable.

In recent years, several arguments against natural environment services have proliferated. The 10 most common allegations are that: a) they are not research based, b) they are not family centered, c) they do not allow for the provision of state-of-the-art care, d) care providers do not have the expertise and ability to implement care plans, e) segregated programs are a natural environment for children with disabilities, f) they do not allow for collaboration and co-treatment with multiple providers, g) therapist shortages will become more severe, h) they are not an ethical choice for service provision, and i) they place the therapist at undue risk of personal harm (Shelden & Rush, 2001). These 10 “myths” were presented and meticulously refuted by Shelden and Rush (2001) in a review of literature designed to address the primary concerns of caregivers who were opposed to a natural environment model.

Despite literature that establishes the effectiveness of family centered care and the IDEA mandate to include families while providing natural environment services, current research indicates that family centered principles are still not adhered to in early intervention for children birth to three. Campbell and Sawyer (2007) coded videos of home interventions collected from 50 service providers using the Natural Environments Rating Scale (Campbell & Sawyer, 2004) and a modified version of the Home Visit Observation Form (Wilcox & Lamorey, 2004) in order to distinguish participation-based interventions from traditional interventions. The visits were conducted in the natural

environment for each child and showed that even though the caregivers were supposed to be using a family centered, natural environment model, the majority (70%) of the interventions were “traditional” in that the primary caregiver was either not present or not actively involved. Even more disturbing were the results of a recent analysis of the 2001 National Survey of Children with Special Health Care Needs which indicated that minority and low-income families are at an increased risk of feeling like they were not treated as partners in the decisions made for their children when compared to their white, middle-class counterparts (Denboba et al., 2006). This is distressing given that an increased sense of partnership is associated with fewer absences from school, increased access to specialty care, and decreased reports of unmet needs for child and family services (Denboba et al., 2006). As mentioned previously, low-income and minority families are likely to have the greatest need for high quality culturally sensitive early intervention, but seem to be the least likely to obtain it.

Statement of the Problem

We now know that family centered care is effective when implemented properly, we also know that given comprehensive early childhood education programs we can teach pre-service educators how to work effectively in a family centered model. Murray and Mandell (2004) interviewed 22 graduates from a family centered early childhood educator training program to see how the program had influenced their application of family centered principles with diverse families of children with low-incidence disabilities. They found that 70% of the participants changed their attitudes and beliefs regarding working with diverse groups of families and those opportunities for interaction with families increased professionals’ belief in family centeredness. Murray and Mandell

also found that the linking of field experience to seminar work increased professionals' sense of self-efficacy, and allowed them to become aware of the discrepancies between theory and practice. Given our knowledge, the question then becomes, why is family centered care not practiced properly in the field of early intervention?

Given the information we have on the effectiveness and educability of family centered care along with the legislative mandates to utilize the model within the natural environment in early intervention services, why is it that the field continues to provide traditional services that center on the practitioner and the child? Previous research has cited several issues that are both organizational and personnel oriented (Bailey, Buysse, Edmondson, & Smith, 1992; Björck-Åkesson & Granlund, 1995; Hansuvadha, 2009; Murray & Mandell, 2006; Shannon, 2004). Furthermore, Campbell and Halbert (2002) argue that service providers are generally unconcerned with implementing family centered care or best practices and are more interested in alleviating the ever-increasing stress associated with their positions.

The question of why family centered care is not being provided within the natural environment is an important one for educators, researchers, and policymakers alike. Why well-known best practices are not in place despite legal mandates to assure their presence is an issue that should be at the forefront of early childhood educational research, particularly given the limited window of opportunity available with early intervention services. Within IDEA, Part C services were originally created to help alleviate the overburdened special education system; however, without an effective workforce and foundation for service provision this goal will never be realized. The purpose of this study was to research the barriers and facilitators involved in providing family centered

care and natural environment services from the perspectives of families, care providers, and program directors in a diverse urban setting. By combining a qualitative inquiry method with a broad range of families and personnel from different language, racial, and ethnic backgrounds, I have attempted to paint a detailed picture of the reasons why family centered care in a natural environment is the exception within early intervention rather than the rule.

Specifically, this study attempts to answer four questions:

1. What are the barriers and facilitators to delivering family centered care to families of children with disabilities, as perceived by the families and professionals involved in providing services to families of children birth to three?
2. What are the barriers and facilitators of providing services in the natural environment as perceived by the families and professionals involved in providing services to families of children birth to three?
3. How do native Spanish-speaking service providers perceive the barriers and facilitators to delivering services when working with families who come from English-only backgrounds?
4. How do native Spanish-speaking service providers perceive working with families of the same language background?

Chapter 2: Literature Review

In recent decades the focus of early intervention has moved towards family centered care and its underlying principles. In the 1997 amendments to IDEA, legislative changes in Part C mandated the inclusion of families into special education and early intervention procedures, thus beginning the shift towards family centered care as a foundation for early childhood programs. Family centered care is a way of approaching service delivery for children with special needs that promotes a partnership with families characterized by dignity, respect, and an inclusion of family values and choices with support intended to strengthen family functioning (Dunst et al., 2007). The basic principle underlying family centered care is that the manner in which a service is provided to a family can influence the outcome as much if not more than the type of service provided. Previous research has established the effectiveness of appropriate family centered care (Dunst et al., 2006; Dunst et al., 2007). Although family centered care is recognized as a best practice for early intervention services, research has demonstrated that the service providers within early intervention agencies are neglecting to include families into the services provided to their children in meaningful ways (Campbell & Sawyer, 2007).

Several research studies have been conducted to examine the barriers to and facilitators of family centered care; early works by Bailey et al. (1992) and Björck-Åkesson and Granlund (1995) provided broad pictures of system issues, professional issues, and testing issues using mixed quantitative and qualitative methods with large samples in the US and Sweden. Shannon (2004) conducted an in-depth qualitative study looking at interagency issues of coordinating services from social workers' perspectives

and reported problematic interpretations of Part C requirements, competition for funding across agencies, issues of mistrust experienced by minority families, and a lack of physician referrals. Later studies by Murray and Mandell (2006) and Hansuvadha (2009) used qualitative methods to examine the issue of how services were provided and why the participants found family centered care challenging; they reported a general lack of understanding and support in the work environment, a lack of established policies and procedures specific to family centered care, underpreparation, attitudinal barriers, workload issues, and language and cultural differences. Most recently, Fleming, Sawyer, and Campbell (2011) used a mixture of qualitative methods to analyze the perspectives of early intervention providers regarding participation based practices and what they felt barred them from providing optimal care to families. An examination of the main themes from Fleming et al.'s study indicated that providers demonstrated an incomplete understanding of participation-based service, the feeling that their role was to work exclusively with the child, the belief that caregivers ought not to be teaching the child, and the belief that the ability to provide optimal services was attributable to family behaviors.

Simultaneous with the development of principles of family centered care, the importance of service delivery in the child's natural setting has been increasingly recognized as one of the best practices in early intervention. When services are provided in the home or a setting where the child would be expected if he or she were not receiving any intervention services (e.g., the home, childcare center) they are termed "natural environment" services. Part C of IDEA defines the natural environment as "settings that are natural or normal for the child's age peers who have no disabilities" (34 CFR

§303.18, 1999). Part C also mandates that “to the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate” (34 CFR §303.12b, 1999). Natural environment services lend themselves to increasing opportunities for family centered care, as the caregivers should be comfortable and familiar in the environment where interventions occur.

The following literature review summarizes the published research available pertaining to the known barriers and facilitators of family centered care and service provision in the natural environment. I begin by providing an explanation of my search procedures. Following this, I reviewed the literature pertaining to barriers and facilitators of family centered care and summarized the findings of researchers. In describing the barriers and facilitators to conducting family centered care I have organized my findings chronologically, which inadvertently presents the broadest research findings to the most educationally specific findings and describes several issues with providing family centered care in early intervention. Following my description of the barriers to family centered care, I have included literature that is specific to difficulties experienced when services are provided in the natural environment. A key point that emerged is that although natural environment service is a logical extension of family centered care insofar as it is the most responsive to the needs of the families, one does not always precipitate the other. Frequently, services provided in the natural environment become the same traditional practitioner based services that have historically permeated early childhood, different from previous models only with regard to the setting (Hanft & Pilkington, 2000). Finally, following the literature review on barriers and facilitators to

family centered care and the intersection between family centered care and the natural environment, I described the results of a pilot study that I conducted on this topic. My dissertation research was ultimately informed both by the findings of the literature review and the pilot study.

Literature Search Procedures

Figure 1 offers an illustration of the search process I used in order to find literature pertinent to my research questions. In order to review the existing literature on the barriers and facilitators of providing family centered care in the natural environment, I conducted a search of journals indexed in ERIC, PsychINFO, and Academic Search Premier using the keywords *family center** (i.e., center, centered, centeredness, etc.) combined independently with *barrier* and *facilitator*. In order to address the issue of natural environment service more explicitly, I conducted a second set of searches using the same databases and the keywords *natural environment* combined independently with *barrier* and *facilitator*. Although this second search initially resulted in numerous abstracts, all of these articles were eliminated either through the application of inclusion criteria or due to overlap with the previous search; consequently, the results of this search are not reflected in the following review. Finally, I conducted a third search using the terms *family center** and *natural environment*. Several of the articles located across the searches overlapped with one another and were eliminated as I browsed the abstracts. I then read over the abstracts of all the articles and selected only those that pertained to early childhood (birth to eight years) and education. Because the literature surrounding family centered systems of care cuts across disciplines (e.g., hospital/hospice care, rehabilitation, etc.) I limited my search to educationally-related articles, although

medically-focused articles that specifically mentioned a child with a disability and educational concerns were set aside for further examination. Studies that lacked a particular focus on family centered care were also excluded (e.g., an article that described how to create a comprehensive and collaborative model for addressing emotional and behavioral disorders argued that solutions ought to be family centered, but did not focus on this issue). After this process of elimination, there were 44 abstracts that included both qualitative and quantitative early intervention studies. From these abstracts, results were further narrowed to peer-reviewed published works. The remaining articles were read in their entirety to see if the information was relevant to identifying the barriers and facilitators of family centered care, yielding the studies that are described below.

Following the acceptance of my proposal, and before completing the final draft of my dissertation for committee review, I duplicated the above search procedures to see if any new information had been published in the field. I limited this search update to the most recent works from 2010 and 2011 as previous years were covered in the previous searches. This update led to two recent articles being added to my literature review and they are included in Figure 1 below.

Barriers/Facilitators to Family Centered Care

Overall, the literature on family centered care presents several barriers that service providers and teachers have reported that range from system issues to preparation, funding, attitudes, language and culture. Studies also reported a lack of clear supports and structural organization that would help agencies communicate with one another and with providers. Not the least of these issues was the difficulty of providers' attitudes regarding families, and providers' perceived roles within early intervention.

Literature Search Flowchart

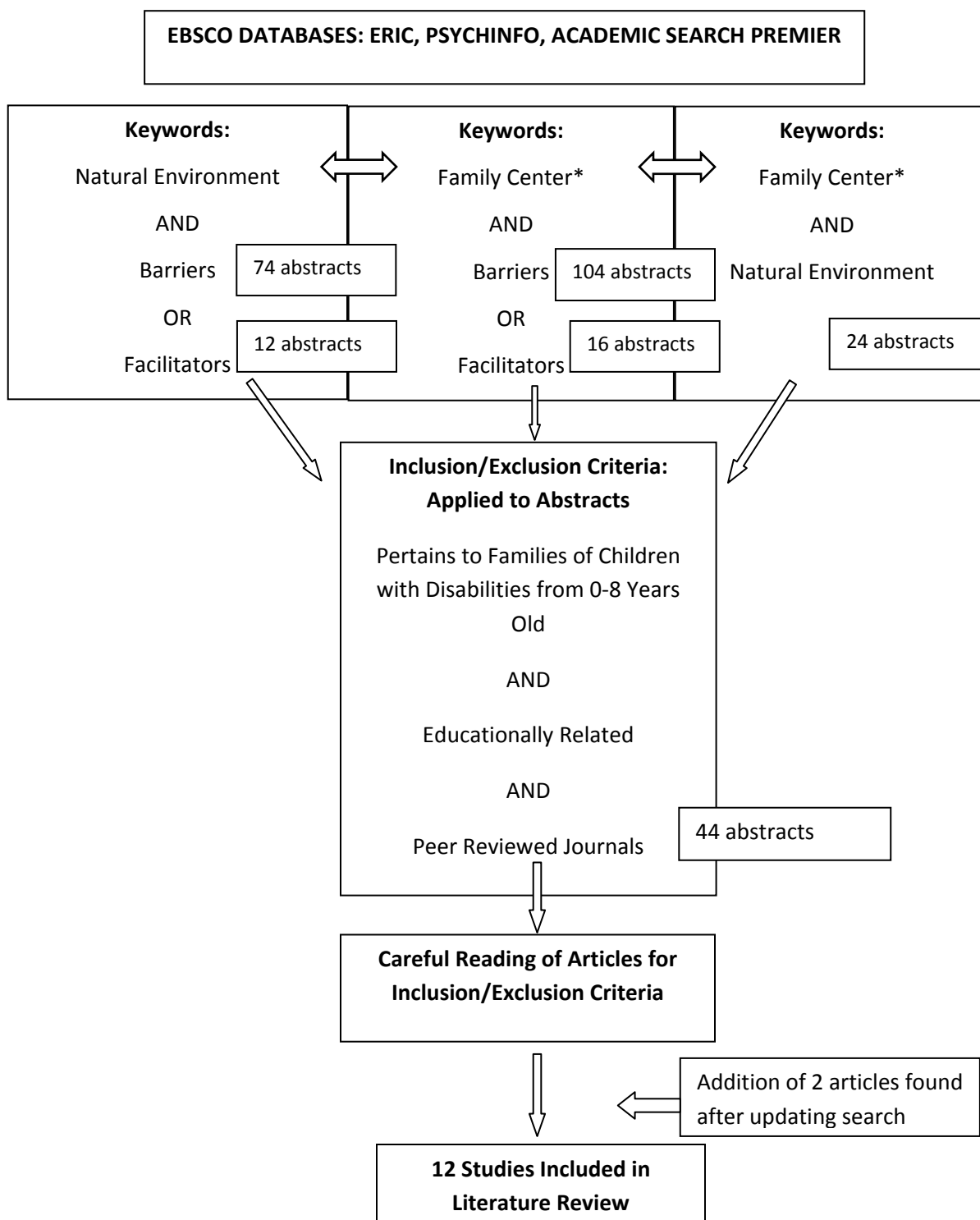


Figure 1. Literature Search. This figure presents an illustration of the search process used for the literature review.

It appears that in addition to logistical difficulties, the attitude that many providers have expressed is one that does not recognize the importance of parent participation.

Early research in family centered care: 1990-1999. Early research in family centered care and the barriers to including parents was conducted in the 1990's using large samples and surveys that provided a broad picture of the difficulties professionals were seeing with families. At the time of these studies, research and legislation were just beginning to work their way into the field of education and family centered models were a relatively new buzzword in early intervention. Many of the practitioners who were surveyed in these studies were educated exclusively within a medical model and had very little experience working in close collaboration with families. However, the difficulties they mention foreshadowed much of what was found in later studies.

In an early study of family centered services in early intervention, Bailey, Buysse, Edmondson, and Smith (1992) looked at the shifting practice in early intervention from child-focused and practitioner-oriented care to family centered care using a mixed method approach of survey items and an open-ended question that was analyzed qualitatively. Bailey and his colleagues surveyed 180 different early childhood interventionists across four states to document the perceptions of providers regarding the current state of family involvement, the ideal role for families in early intervention, and the barriers that create a discrepancy between the two. These barriers were identified as specific reasons why the shift towards family centered care was proving difficult for practitioners. The purpose of Bailey's work was to identify the state of the field at that point and report why it was so difficult to move towards a more family centered approach to care.

Results from the survey given by Bailey et al. (1992) demonstrated that the practitioner ratings of the role families play in early intervention were significantly lower than practitioner ratings of ideal roles, indicating that professionals knew there was a difference between the role families ought to play and their actual participation. The final survey item used by Bailey et al. (1992) was an open-ended question that asked professionals to identify why they felt there was a discrepancy between the ideal role of families and the families' actual role. Three independent raters identified four major barriers within the respondents' answers, including family issues (35%), system issues (35.1%), professional issues (14.8%), and testing issues (0.9%). These categories were further broken down as follows: family issues included reports of difficulties such as family attitudes towards care, family knowledge and skills, and family resources; system issues included institutional demands, resources, and difficulty changing from the status quo; and professional issues were sub-classified into knowledge/skills and attitudes of professionals. The last barrier of testing concerns represented such a small percentage of all coded responses that it was left as a general category. The remaining 13.4% of the data was identified as "uncodable" because it either lacked clarity or did not fit into any of the aforementioned categories. In quantitative research, it is common to disregard this "uncodable" data, since it does not calculate into an understandable percentage nor does it have a simple explanation. One of the benefits of qualitative research is that it allows researchers to delve into this hidden issue and bring to light things that may be significant but consistently overlooked. However since this was not the primary purpose of Bailey's work, these nuanced data were simply left unexamined.

In an extension of Bailey's work, Björck-Åkesson and Granlund (1995) conducted a mixed-method replication study in Sweden using the same instruments translated into Swedish. Björck-Åkesson and her colleague included parents of children receiving early intervention services in their sample, and compared responses of professionals with those obtained from parents. The purpose of their work was to examine any differences in perceptions of ideal family centered care and current levels of care for both parents and professionals. They also asked both parents and professionals to report what barriers they perceived as being responsible for discrepancies. Björck-Åkesson further added to the previous work by comparing answers across disciplines to see if there were differences in perceptions that occurred as a function of a particular discipline.

Results showed no significant differences between parent and professional ratings of current practices. Both parents and professionals rated parent involvement in assessment and service decisions as moderate, ranging from 4.7 to 5.7 on a scale from 1 to 10. These results were not significantly different from those obtained in Bailey's work in the United States, with the largest difference being a higher rating of parent involvement in Swedish assessment practices. Overall Björck-Åkesson and Granlund's (1995) ratings of practitioners' perspectives were very similar to those reported by Bailey and colleagues (1992). There were three areas with significant differences between practitioner ratings of ideal family involvement and family ratings of ideal family involvement where practitioners actually indicated a desire for more family involvement than families did. The three areas included decisions about child assessment, family participation in assessment, and family goals and services. The authors postulated that

these differences may have been a result of parents not knowing what was expected, since they were originally inculcated into a program where parents played a limited role. Thus, they may have felt that the best position was a passive one. The responses obtained from the open-ended question reflected somewhat different findings insofar as systems barriers were identified as the most common difficulty in providing the “ideal” levels of family involvement. Systems barriers accounted for 66% of the reported difficulties, followed by family barriers at 16%, professional barriers at 13%, and testing difficulties at 3%.

Björck-Åkesson and Granlund (1995) concluded that, in Sweden, the obvious complaint from both parents and professionals was that the system routines, resources, and status quo prevented the shift to family centered care. The authors described the program in Sweden as “family allied” rather than family centered. It is important to note that only 19% of families who filled out the survey actually answered the final open-ended question regarding barriers to family centered care. Regardless of why parents failed to provide this information, the low response rate undermined the goal of extending Bailey’s work because there were not enough data to look at parent perceptions separately from practitioner perceptions in the statistical manner the authors intended. Consequently, we cannot use Björck-Åkesson’s work to fairly represent parent opinions regarding barriers to family centered care.

Recent research in family centered care: 2000 to present. As family centered care became the model for early intervention agencies across the country, more research was conducted using detailed, qualitative methods. The following studies included participants who had several years’ experience as well as recent graduates of programs

specifically designed to increase practitioners' knowledge and adherence to principles of family centered care. The findings of these studies provided the greatest amount of information regarding difficulties experienced by service providers working in a family centered model with young children with special needs.

In a recent work, Shannon (2004) conducted a qualitative study on the barriers to providing family centered care to infants and toddlers with developmental delays. Shannon looked at this issue from the social work perspective. He interviewed 22 family members (mostly mothers) and 20 service providers and discussed their perceived barriers to implementing effective family centered care. The purpose of his work was to improve our understanding of how families and service providers experience barriers to implementation. Shannon's sample was from a Local Interagency Coordinating Council in Virginia that worked with 22 early intervention organizations from a range of disciplines. Using constructivist inquiry and a grounded theory method, Shannon found that services offered through Part C of IDEA were often interpreted differently across agencies. He also found that individual agencies within his study had a tendency to compete for funds, thus they neglected to refer children and families to centers more fitting to the family needs because they were concerned about the fiscal bottom line. Some families reported additional concerns in terms of trust; one issue parents reported was a fear that if they let professionals into their homes their children would be taken away for such things as a "dirty house." Issues with lack of referrals from physicians and lack of payment from insurance companies were reported, and complaints from professionals about a lack of familial motivation were also reported to be barriers to family centered care. Shannon's work provides a view from several perspectives to the

barriers experienced in early intervention; he concluded that social workers have the responsibility to be actively involved in helping families navigate the confusing system of services and advocate for the needs of each family at the local level and politically in professional organizations.

The question of the effectiveness of provider preparation is also prominent in the literature. Murray and Mandell (2006) interviewed 19 graduates from three separate cohorts who had completed a teacher training program called the Family Centered Preservice Model. The graduates included early childhood educators, intervention specialists, and administrators who were interviewed to see if they maintained a belief in family centered principles over time and to determine the barriers that impeded the delivery of family centered care. All participants were given a one to two hour semi-structured interview that was uniformly administered. Data were analyzed and sorted into categories and themes by three independent coders, one of whom was not affiliated with the project. The coders discussed any discrepancies until all three coders reached 100% agreement. Member checks and a well-maintained audit trail enhanced the trustworthiness of the study.

The results of Murray and Mandell's (2006) study indicated that the graduates still held family centered principles to be paramount to service delivery in early childhood several years after graduating. However, there were two major themes described as barriers to family centeredness, the first being a lack of an understanding and supportive work environment. Participants explained that they saw few opportunities to use family centered principles and very little support either from administrators or peers. This view was held by nearly all of the participants, including the three

administrators who were included in the sample of graduates. The second major barrier to family centered care was a lack of established policies and procedures that were specific to family centered care. The issues in this theme reflected a lack of participants' knowledge about existing procedures, a belief that the Individualized Family Service Plan was the only formal recognition of family centered principles and that it was insufficient, and a lack of training in the workplace regarding family centered principles. Most participants reported feeling isolated and alone in the workplace with their beliefs regarding the importance of including families, feeling as though there were no supports offered to encourage the provision of family centered care. Findings by Murray and Mandell (2006) indicate a need to understand the dynamic between administration and service providers. The authors acknowledged that study would have been strengthened if it had included information from the perspectives of the administrators and colleagues who were the source of many participants' complaints.

In a recent article that discussed the barriers and facilitators of providing family centered care, Hansuvadha (2009) conducted a qualitative study following early career special education teachers from three cohorts who worked in early childhood special education (ECSE) or preschool special education. Participants were 11 white females who graduated from an ECSE program in the Pacific Northwest between the years 2003 and 2005. The purpose of Hansuvadha's (2009) study was to capture how early-career educators felt about their ability to collaborate with families, and how this ability is shaped over time. In order to capture the perspectives of participants, Hansuvadha audio recorded semi-structured, in-depth interviews ranging from 60 to 90 minutes with each of the 11 participants. Participants were asked to describe their ability to implement family

centered practices in the beginning of the school year and again at the end. They were also asked to reflect on their personal biographies, their beliefs and experiences working with families of children with disabilities, and their instructional context. Data were analyzed using a process of coding wherein the author and a research assistant assigned open codes, categories, and themes to the data and collaborated with one another regarding each unit of analysis until 100% consensus was attained. Trustworthiness and credibility were addressed by the author through the inclusion of peer reviews, member checks, and the use of multiple data sources.

Hansuvadha (2009) found that the perceived challenges faced by ECSE teachers attempting to implement family centered care included: underpreparation, attitudinal barriers, workload issues, and language and cultural differences. Underpreparation was a concern for 82% of the teachers interviewed and included reports of issues with generalizing classroom instruction to practice, prioritizing activities and assessments in the real-world classroom environment, as well as dealing with the often emotionally-charged conversations with parents in which a child's disability was introduced or discussed. Attitudinal barriers were cited by 73% of participants and were described as parents holding unrealistic expectations for a child's progress or future. Early childhood educators in high-SES communities reported feeling belittled by parents who hired private therapists outside of school to work with their children after school. In addition to feeling undervalued, these early childhood educators reported that parents would frequently hire consultants to review their child's Individualized Education Plan (IEP) and make suggestions for improvements that were unrealistic for the early childhood educators (e.g., 50 distinct IEP goals). The negative attitude of early childhood educators

towards parents was seen with both the high-SES families who imparted heavy demands for service and for low-SES families who were seen as inefficient advocates or under-involved in their children's education.

Workload challenges were cited by 64% of participants in Hansuvadha's (2009) study, wherein the amount of time needed to work with children in groups or one-on-one needed to be balanced with the maintaining of lesson plans, IEP goals, and instructional activities. Although several participants reported a desire to work more with parents, they argued that there simply was not enough time to do so. Early childhood educators in high-SES schools also felt pressured to have perfect paperwork because they knew parents were highly educated and would object if they did not feel the early childhood educator's performance was adequate enough for their child. Cultural and linguistic differences were reportedly a challenge for 55% of the participants, all of whom were English-only speakers. Although non-English speaking families were provided translators for official school meetings, it was impossible for the early childhood educators to discuss day-to-day activities and events with these families. Translators became more difficult to obtain for early childhood educators who were in the preschool system as opposed to a childcare center. One early childhood educator described the process of obtaining a translator as "a nightmare" and another explained that she felt she was underserving these families because of a lack of clear communication.

Hansuvadha (2009) concluded that in many cases, the barriers experienced by the participants in her study served to increase the resilience of those early childhood educators who were the most committed to family centered principles. She acknowledges that her work would have been strengthened if she had a more diverse sample (100%

were white females) and more than just the early childhood educators' perspectives, however her work offers a very clear picture of the issues faced by this population.

Moving from a recent post-graduate perspective into those of service providers who have been working in-field for some time, Fleming et al. (2011) used telephone interviews with 31 providers involved in early intervention services to determine their perspectives on implementing participation based services. The participants were initially grouped into two separate categories; those who had been classified as "participation based" and those classified as "traditional practice" providers. These groups were determined according to videotapes of sessions between the provider and a child receiving services that the researchers reviewed. The researchers watched these videos and coded which providers were utilizing which practices. Providers then attended professional development training on participation based strategies and were again videotaped. Following the professional development activity only 40% of the providers who were rated "traditional" in the first set of videos were rated as moving into the "participation based" group.

Fleming et al. (2011) then interviewed these two groups using the same questions and procedures for all participants. All interviews were transcribed and coded using one of three methods; the first was a "main idea" strategy similar to thematic coding in grounded theory. Two independent raters who were not familiar with the participants' group classification read through the responses and entered them into Atlas.ti 5.0. They then identified the main idea and worked through coding disagreements until an interrater reliability greater than .80 was obtained. The second method was to utilize codes that were developed a priori based on the professional development training that was given to

providers prior to the interviews. Finally, the last two questions in the interview were analyzed quantitatively, since providers had been asked to provide a rating or percentage estimate in order to answer.

The results of this study indicated that providers held the same beliefs and experienced the same difficulties regardless of what group membership they had been assigned. The authors identified four main themes in their research including (a) incomplete understanding of participation based services on the part of providers; (b) providers feeling that their role was to enhance child development rather than participation in activities and routines; (c) caregivers roles should be involved, but not teaching the child; (d) the ability or inability to provide optimal services to families was attributed to the caregivers. The universality of responses was unexpected in the findings; the authors concluded that either their groupings were not accurate enough as they were based on only one videotaped session, or their interview questions simply were not specific enough to differentiate between the two groups. Regardless, the research of Fleming et al. (2011) provides another view of the barriers that service providers perceive in providing family centered care.

Natural Environment Services

Natural environment services are an important extension to family centered care insofar as they are supposed to be inherently considerate of the individual needs of the family. By providing care in the natural environment, service providers are bringing services to families' homes so that primary caregivers can be enabled as full participants in early intervention services. Although the ideal for natural environment services is that they would complement a family centered model of care, in reality most natural

environment services retain a traditional therapist or child centered model where the parent frequently does not participate and is rarely consulted (Campbell & Sawyer, 2007). Hanft and Pilkington (2000) argue that natural environments must be determined by team members who consult with the family and consider what the child needs to learn, which strategies would best address that need, whose expertise would be needed, and how/where services should be provided. Hanft and her colleague argue that the natural environment can be considered many different places, but should always be selected based on the needs of the family and child.

Providing therapy in natural environments using a child's play situations and daily routines does not just naturally happen: parents must share their family stories, routines, and traditions, and all early intervention specialists must find creative ways to translate their expertise to design meaningful interventions with caregivers (p.11).

Tisot and Thurman (2002) echo the sentiment that the natural environment may be a different location for each family and argue that in order to ascertain what it is, service coordinators should consult with the caregivers and review the planned placement as often as necessary to make sure it is meeting the needs of the family and child.

To truly individualize services for families, the provider should be mindful regarding the specific needs, priorities, and desires of the family; the developmental needs of the child; and the behavior settings that are defined by the family as the natural environment (p. 68).

IDEA has called for all services to be provided to young children with disabilities within the natural environment unless it is mandatory for the sake of the child to conduct them elsewhere. Unfortunately for families, practitioners often do not personally prefer natural environment services (Campbell & Halbert, 2002). For many service providers, the transportation costs and travel time required to perform services in the natural environment make this model a major challenge to providing care. Many agencies have

been forced to move to a “natural environment” model where service providers will go out to the home or childcare center because of IDEA stipulations for Part C funding. However, just because these agencies are providing service in the natural environment does not mean that they are automatically family centered. Campbell and Sawyer (2007) found that in 70% of observed home interventions the primary caregiver was either not present or not actively involved; only 30% of the 50 observed interventions were considered “participation based” or family centered by the coders.

Challenges to natural environment services. When providing natural environment services, the greatest concern that was reported in research was the difficulty of ensuring parent participation. Just because services were provided in a home did not automatically mean that parents would even be in the room during a session. Other difficulties included the need to additional training, opportunities to collaborate, staff shortages and general logistical challenges of the model. Additional difficulties in implementing natural environment services were more specific to trying to include families into the services and how these families perceived therapy that encouraged greater parent involvement.

Hanft and Pilkington (2000) identify three major challenges to providing care in the natural environment: conflicts between local program policies and legislation, therapists’ inexperience with the natural environment model, and fiscal/logistical issues and staff shortages. Program and legislation conflicts are described as the differences between the legally mandated services that reflect the best practice, and the operations that have been developing throughout the history of early childhood intervention agencies. The move away from center-based models of care was made as a result of

changing legislation rather than the therapy providers' preference. The final challenge of fiscal and logistical issues presents myriad obstacles. Billing problems for service providers who are only paid for their "hands on" time rather than time spent collaborating with families, transportation issues in rural or busy urban areas, mileage and travel expenses, and missed appointments are a few of the issues that become prominent in a natural environment model that are not a concern in the more traditional clinic based model.

In a qualitative study of practitioners' beliefs and attitudes regarding natural environment services, Campbell and Halbert (2002) ascertained the beliefs of practitioners regarding how early intervention services should be provided. In their study, Campbell and Halbert asked 241 practitioners including service coordinators, speech and language pathologists, family support coordinators, and other disciplines to make "three wishes" they felt would improve early intervention services for children and families. These three wishes can be translated as the issues that the participants felt were most problematic in service provision. All but 16 of these respondents were responsible for direct service provision. A total of 618 responses were provided and two coders conducted independent thematic analyses wherein statements that were considered related could be grouped together. A total of 16 themes were identified and a third coder was asked to independently code the responses according to the 16 themes; interrater reliability was 89%. The subsequent analyses included summaries of themes and graphic representation of the demographics of participants by themes in order to locate any patterns in responses across participants. Of the 16 themes identified, 14 were later grouped together in six broad categories and two were left out of analyses because they

were deemed irrelevant (e.g., the category “other”). The six major themes included: improvements in personal employment (20%), increases in service provision (15%), increased opportunities for teaming (15%), increased training opportunities (10%), increased parent/family participation (7%), and a return to a center-based service model (7%). Overall, Campbell and Halbert (2002) concluded that the perspectives of the service providers reflected a lack of concern with family centered care or best practices being conducted in a natural environment; rather, practitioners were concerned with the daily demands of their jobs and were interested in alleviating the increasing pressure placed on their time.

In the most recent study I could locate regarding this issue, Salisbury, Woods, and Copeland (2011) conducted an exploratory study of the perspectives providers held on using collaborative consultation (i.e., coaching) with families in natural environments. The study took place over the course of four years and followed six early intervention providers using a case study methodology. The participants in this study included five females and one male, of whom three were Caucasian, one was African American and two were Hispanic. The program used with providers was titled the Chicago Early Intervention Project (CEIP) and was based on a Family-Guided Routines-Based Intervention (FGRBI) approach. This approach emphasized the importance of both family centered care and services provided in the natural environment using family preferred activities and routines as the basis for functional outcomes.

In order to create a program to enhance the capacities of providers, organizational changes were made to the early intervention agency’s structure and curriculum, professional development activities were developed to teach the FGRBI approach, and

implementation support was maintained to help providers reflect on their practices and have a safe place to discuss challenges. Quantitative data were collected over four years using the *Stages of Concern Questionnaire* (Hall & Hord, 2001); participants were asked to fill in the 35 question measure from 2 to 6 times, depending on when they entered the study. Qualitative data were also collected over this period in the form of focus group meeting minutes and other notes of meetings. The results of the quantitative analysis indicated that after participating in the program, providers expressed less intense concerns regarding the use of consultative teaching and the FGRBI approach. In fact, positive changes in the opinions regarding FGRBI were reported for all but one participant, who happened to have been an “experienced” therapist who was well-ingrained in her philosophy of care prior to entering the program.

Results from the qualitative data collected produced three categories, specifically: *learning with support, doing it, and impact of urban culture*. The first category dealt with providers’ self-reflections and their experiences within the CEIP program. The second category described the process and experiences and difficulties providers had when actually implementing services in the natural environment in a family centered manner prescribed by the program. The difficulties they experienced in this area included learning to let caregivers take the lead, branching activities across different routines, reconciling their ideas of therapy with the expectations of the program, and dealing with the barriers of parents understanding of therapy. When parents had multiple therapists coming to the home from different agencies, the disparate way in which services were provided sometimes led parents to believe that the consultative model was in some manner a diluted form of therapy. The last category dealing with the impact of urban

culture described the issues experienced with family diversity, logistics of city environments and the density of the population leading to traffic and transportation issues, and finally the unspoken “rules” of some of the less affluent areas that dictated the safety of providers. All of these issues contributed to the experience of providers, and although they felt that the importance of the program model was great and that their perceptions had improved over time, they also acknowledged the difficulties that were seemingly unavoidable.

The authors concluded with four basic principles they felt were made clear by their research. First, they argued that integrating a model like CEIP is effective at changing the perspectives of early intervention providers towards a greater level of family centeredness. Second, they felt that the collaborative consultative approach they were advocating required providers to be outfitted with sufficient time, practice, and support in order to be effective. Third, they argued that many of these supports required by providers were present in the CEIP model. Finally, the authors argued that providers were placed in a bad position when the agencies providing early intervention services did not have a unified approach to service delivery. By having different types of therapies occurring in the home, parents were prone to making assumptions about quality of providers, based on whether they brought their own materials to the home or tried to utilize items that were available to the family during their everyday routines. Findings from this and other studies lead us to the following learned lessons in early intervention with respect to family centered care and natural environment services.

Family Centered Care in the Natural Environment: Lessons Learned

The difficulties of providing family centered care within the natural environment evident in my review of the literature include issues at the local and state levels. Difficulties interpreting the requirements of Part C, a lack of coordination between and among early childhood agencies, and a lack of clear policies and procedures for service delivery are among the list of problems at the higher levels. Moving closer towards families and service providers, barriers to family centered care include issues with testing young children, work environments where family centered care is neither understood nor promoted, organizational structures in agencies that do not promote collaboration and consultative ideals, and trust issues for low-income and minority families who see service providers as government entities that will remove their children from the home.

Although the literature provides evidence of these difficulties experienced by personnel attempting to provide family centered care, there is much to be learned. Limitations in using survey methods present one concern in the findings. Early results from Bailey et al. (1992) and Björck-Åkesson and Granlund (1995) provide broad pictures of possible barriers, but these findings are limited by the number of family respondents and the limited amount of information that can feasibly fit into a one-question survey response. More recent work using more detailed procedures and qualitative methods has its respective limitations concerning the racial diversity and occupations of participants. Studies by Murray and Mandell (2006) and Hansuvadha (2009) were both conducted primarily with white, middle-class, female early childhood educators of students with special needs. Shannon's (2004) study, although it was farther reaching in terms of the participants' occupations (e.g., early childhood educators,

families, administrators, etc.), was again limited with regard to the majority of middle-class white women that comprised his sample.

Family centeredness, by its very definition, requires consideration of the individual cultures and backgrounds of families. However, in previous qualitative research the importance of racial and ethnic diversity within special education has typically been overshadowed by the “disability as diversity” category (Pugach, 2001). That is, researchers have long argued that disability is a form of diversity, and have failed to focus on the constructs of race, culture or language within the realm of special education (Harry, 2008). The only studies reviewed that mentioned issues of cultural and linguistic diversity were Hansuvadha (2009) and Salisbury et al. (2011); again one was limited to the perspectives of white middle-class early childhood educators and the other to the views of only six participants. Research on how the race and ethnicity of service providers change the early intervention experience would represent an important contribution to current educational literature. Additional perspectives apart from those of white females are also needed to paint a full picture of the issues facing early intervention personnel. As countries around the world become increasingly diverse, research must be conducted that includes voices from those previously overlooked. A specific contribution I have made with my research is the inclusion of participants who come from racially and ethnically diverse backgrounds. The inclusion of multiple perspectives on barriers and facilitators of family centered care is also imperative if we are to understand the full range of difficulties and supports experienced within the field of early intervention. As part of my study, I have included the perspectives of service providers, program directors,

and families from different racial and ethnic backgrounds within each of the domains served under Part C programs.

Pilot Study: Young Minds

In addition to the published literature on barriers and facilitators of family centered care and natural environment services, I have also included the following summary of a pilot study I conducted on this topic prior to conducting my dissertation. This pilot study was conducted to answer the question: What are the barriers/facilitators to delivering family centered care in the natural environment to families of children with disabilities as perceived by the Young Minds program director, service coordinator, and outreach early childhood educator?

Setting and participants. The setting for my pilot study was Young Minds, a pseudonym for a grant-funded service partnership created to work with young children from birth to five years old who exhibit developmental delays that are not severe enough to qualify for services under Part C of IDEA. Services provided include occupational therapy (OT), physical therapy (PT), behavior therapy (BT), speech and language therapy, and general developmental therapy. The participants interviewed and observed for this study included the program director, a service coordinator, and an outreach early childhood educator who provided developmental services to children in their natural environment.

Method. In order to address the research question I conducted a qualitative pilot study and used grounded theory methods to analyze information gathered from two semi-structured interviews and two observations over a 16-week semester. In order to ensure the credibility of my findings, I spent four months in the field of Young Minds attending

staff meetings, research meetings, and important funding proposals/providers meetings. Although I did not collect formal data in these meetings, they did serve as a period to develop sensitizing concepts. Peer debriefing was conducted regularly and referential adequacy was maintained by audio recording interviews and writing up field notes from my observations within 24 hours. The transferability and dependability of my findings are evidenced in the thick descriptions I provide. The grounded theory procedures used for this study consisted of four general phases as described by Harry, Sturges, and Klingner (2005): open coding, conceptual coding, thematic coding and core categories.

Findings. After coding all of the data and working through the process described above, I developed a list of 91 different open codes, seven conceptual categories, two themes, and one core category. The resulting categories and themes can be seen in Figure 1 below.

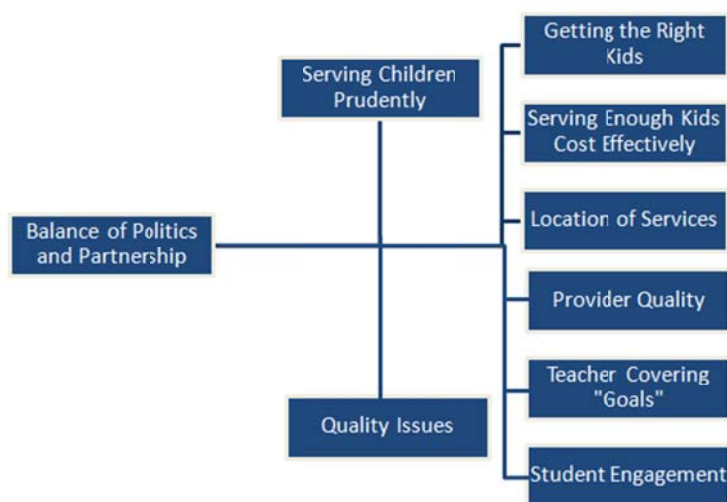


Figure 2. Conceptual Categories, Themes, and Central Category. This figure presents the underlying conceptual categories, themes and central category found in my pilot study.

Serving children prudently. The theme “serving children prudently” contained the three conceptual categories of *getting the right kids*, *serving enough kids cost effectively*, and *location of services*. Getting the right kids refers to how children were screened and determined to be eligible for the program. For Young Minds children not only had to meet a minimum delay, they could also be “too severe” to receive services. The funders instituted a new screening model in the extension, only permitting Young Minds to serve children who had been evaluated by one of the local Part C agencies and determined to fall within the mild range. This was insufficient to address the issue, as the program director explained they were still receiving referrals for children who should have qualified for special education.

Serving enough kids cost-effectively was a multifaceted issue; in order for providers to deliver services, they had to have enough children to meet overhead expenses and they had to be varied enough to meet quotas for each domain (i.e., OT, PT, and Behavior). If providers were not assigned enough cases, they would not be able to make a profit and would quit. This proved problematic in the new model when the funders required all children to have gone through time-consuming evaluations first. In addition to meeting the needs of individual subcontracted agencies, if Young Minds did not meet an overall quota of children the funding agency would pull funds for future interventions: “...when you’re giving money back to a funder then they’re saying, ‘Well, if you’re not using the money why should I give it to you’, so they cut the program.”

Location of services was the core difference between the center-based model and the natural environment model. Multiple complaints about the distractions of remaining in the classroom were made; the program director explained that “it’s incredibly noisy

and loud and the early childhood educators don't speak English and you can't communicate with them. The TV is going, um, there's children crying, it's really hard to engage that one child that you're working with." The new enrollment process added home based services and increased the overall number of centers; instead of serving 12 to 15 children in one center, providers had to go to 12 to 15 different locations. This created a substantial burden for the program director, as she explained that matching service providers to students became her biggest programmatic challenge: "Like matching up, ok this child needs behavior I need to have a behavior therapist that speaks Spanish in [the south]- and all of my behaviors providers are in the north and they speak English." Another complaint against home based care was a lack of parent collaboration: "Some parents use us like a babysitter, you know you [the parent] don't have to be there, you're gonna take care of their child for them."

Quality issues. The theme of quality issues contains the three conceptual categories of *provider quality*, *teacher covering 'goals'* and *student engagement*. This theme represents the difficulty experienced by the Young Minds program director who attempted to provide high quality services when the majority of those willing to work in the new model were lower skilled and unlicensed. The program director explained that the quality of services for speech and language therapy had decreased rapidly in the past year: "I don't know of any agency that will pay a sp- a licensed speech pathologist to go out and do community work." In response to the lack of licensed and certified therapists, many of the agencies began hiring generalist Infant and Toddler Developmental Specialists (ITDS) who were willing to travel because their salary was dependent upon individual sessions per child. As one of the complications of hiring ITDS was the

prevalence of non-English speakers, the English-speaking program director was thus forced to rely on reports of telephone consultations from the heads of service provision agencies for quality assurance.

Teacher covering ‘goals’ was subsumed by the theme of “quality issues” because of the difficulties reported by and observed with the outreach early childhood educator from Young Minds. During the two observations I made, the early childhood educator secluded herself and the child either in a corner of the room or in a separate room. Once she had settled into a private area the early childhood educator then pulled out a list of goals for the child that were derived from initial assessment results. The early childhood educator executed these goals in a sequential manner, going down the list to check off each one before moving to the next, resulting in a series of unconnected activities in which students were often uninterested. Student engagement was the final category included in this theme because the quality of service is directly related to whether or not children are engaged in the learning activities. A focus on covering student goals with a lack of consideration for the child’s level of engagement or interests characterized much of my observations. Student engagement proved to be very difficult both to attain and maintain for the outreach educator during the sessions observed.

Central category: Balancing politics and partnership. Strauss and Corbin (1998) describe a central category as one that best represents all of the themes and interactions found within a study. The balance of politics and partnership was mentioned by the program director when she talked about the difficulty of translating the mandates of funders to the service providers who did not want to hear them. Whenever an issue arose with either providers or the funders, she would work to achieve a balance that was both

cost-effective and guaranteeing of future funding. Where quality issues were concerned, she had to consider who would be willing to actually work within a natural environment and made compromises based on that information. Where providers were concerned, they had to receive enough children to cover their overhead expenses, and this sometimes meant hiring less qualified or unlicensed staff. Issues with the location of services were contentious between the funding providers and service providers, with the service providers feeling that natural environment placements were simply too impractical, and funders feeling that they were the best practice for children and families.

Conclusions. The findings for my pilot study mirror the literature discussed insofar as they provide a much broader picture of the difficulties or barriers to providing care in the natural environment than they do the facilitators. In all my observations and interviews, I got the impression that the Young Minds staff and the interventionists did not fully embrace the family centered natural environment model because of the logistical difficulties it presented. There were very few positive remarks regarding the facilitators of family centered care in the natural environment. Results from this pilot should be considered in the context of Young Minds' shifting policies, further research is needed with organizations that are not in a transition stage in order to elucidate these facilitators. It is likely that for Young Minds, the difficulty of change is overshadowing any of the positive aspects of a family centered mode. Previous research has established that this shift from the "status quo" is very difficult for providers (Bailey et al., 1992; Björck-Åkesson & Granlund, 1995).

Needed Contributions to Literature: What we Know and Where to Go

Current research on the barriers to family centered care provided in a natural environment is lacking in several respects. The most obvious is that there is virtually no information on what kinds of facilitators exist; the literature and pilot study previously reviewed evidence the general negativity surrounding this issue. Equally important, issues with the methodology of earlier studies (e.g., Bailey et al., 1992; Björck-Åkesson & Granlund, 1995) and the middle-class, white female samples seen in recent work (e.g., Hansuvadha, 2009; Murray & Mandell, 2006) leave severe gaps in the literature. With the increasing diversity of families and children as well as service providers, and the fact that children from minority and low-income backgrounds are disproportionately represented in special education services, research needs to extend beyond an all-white, mostly female, middle-class group of participants found in previous studies. As Campbell and Halbert (2002) contend:

The multiple discipline practitioners who interact daily with families and children are the essence of early intervention. The values and perspectives of these professionals come between research and practice and influence the impact of activities designed to bridge the research-to-practice gap (p. 223).

We cannot hope to bridge this gap without including multiple perspectives pertinent to early childhood intervention. We know that coming from a minority or low socio-economic background increases the risk of not feeling like a partner in the service provision for young children with special needs (Denboba et al., 2006). We also know that families from culturally and linguistically diverse backgrounds are minimally represented in research on family collaboration (Harry, 2008). In reviewing this research, Harry called for increased use of thoughtful and rigorous qualitative methods that can access the perspectives of such families. This study aimed to utilize rigorous grounded

theory methods to include the voices of diverse individuals living in an urban environment.

In her review of special education literature on collaboration with culturally and linguistically diverse students in special education, Harry (2008) asserts that the possibility of cross-cultural miscommunication is increased when service providers do not share students' cultural background. It is therefore reasonable to assume that there will be differences in the barriers to family centered care when language limitations of families and service providers vary (e.g., access to transportation, inability to speak English). For this reason, my work contributes to the literature insofar as I have conducted a study of family centered care provided in the natural environment in a culturally diverse city, with service providers who are not all native English speakers. The area in which this study occurred offers a unique opportunity to investigate the specific challenges and facilitators of family centered care faced across the dominant language groups of English and Spanish.

Chapter 3: Methods

In order to address the question of barriers and facilitators to providing family centered care in a natural environment, I conducted a qualitative research study using grounded theory methods to analyze information gathered through semi-structured interviews. There are several reasons I felt this was the most suitable format for structuring my research, the first of which is the inherent appropriateness of using qualitative research to explore in depth the knowledge and perspectives of purposefully selected individuals. A concern with process (rather than an outcome or a product) is described by Bogdan and Biklen (2003) as one of the essential features of qualitative inquiry. Patton (2002) describes qualitative inquiry as a facilitator of studying issues in depth and detail, thereby producing a wealth of detailed information about a relatively small number of people and bypassing the need for standardized measures as the researcher becomes the instrument through which a phenomenon is recorded. While standardized measures ensure that all participants are asked the same questions uniformly, they fail to access the individualized, unexpected, and nuanced information that can be obtained in a semi-structured interview.

Another reason for selecting a qualitative method is my concern for maintaining the naturalistic aspect of the environment of interest. Since the definition of “natural environment” differs from family to family (home, child care center, etc.), it is important to capture the meaning ascribed to “natural environment” by the people involved in early intervention services (i.e., both providers and families). Qualitative research involves the use of several procedures and data sources that share the commonality of the researcher as the means of measuring and reporting an issue, rather than a standardized instrument

provided to a sample large enough to estimate a statistically significant parameter.

Denzin and Lincoln (2005) describe the qualitative researcher as a “bricoleur” or quilt maker who takes details acquired from his or her research and pieces them together to form a complete and complex tapestry. It was my intention to create here a detailed picture of the barriers and facilitators of family centered care in the natural environment from the perspectives of service providers, families, and administrators.

I conducted this study using semi-structured interviews that were transcribed and analyzed using the grounded theory approach first introduced by Glaser and Strauss (1967) and later redefined by Strauss and Corbin (1998). Grounded theory provides a strong method for understanding the issues involved in providing family centered care in depth because it allows the researcher to break down the words of the people who are “in the trenches,” allowing the voices of those who know the matter intimately to be heard. The purpose of grounded theory is to build a substantive theory that is not only representative of the data and context of the particular study but is also applicable to similar situations (Glaser & Strauss, 1967). It is my ultimate intention to create information that can be useful to all early intervention agencies that work with families of young children with disabilities and that are charged with providing family centered care in a natural environment. Although some research has been done on this topic, additional qualitative research is particularly appropriate for confirming and elucidating previous research as well as filling in the blanks that may have been left by past studies (Patton, 2002). For example, Shannon (2004) conducted the most in-depth analysis of the barriers to family centered care that I could find in the literature to date; however, his work was noticeably silent with respect to the difficulty of providing care in a natural setting and to

participants' perceptions of facilitators to family centered care. As a result of the limitations of prior research, as well as the appropriateness of qualitative methods for investigating my research questions, I chose a qualitative approach to dig deeply into the issue of perceived barriers and facilitators of providing such care.

Special Considerations within Qualitative Research

Although experts in the area of qualitative research have made it clear that there are many ways to conduct a qualitative study (e.g., Denzin & Lincoln, 2005), some areas of consideration are common across approaches. Areas of concern for the qualitative researcher include: selecting a research site and sample, gaining entry into the site, deciding upon the role the researcher will play as a part of the setting, and the ability of the researcher to remain self-reflexive and not “go native” while still maintaining a sense of empathetic neutrality.

Gaining entry. The first considerations in conducting qualitative research include selecting the research site, deciding how one will gain entry into that location, and determining the position the researcher will take once he or she gains entry. The site selected must be appropriate to address the issues of interest and must be accessible to the researcher. Strauss and Corbin (1998) describe the selection of a researchable problem and research site as one of the most troublesome aspects for qualitative researchers. For my study, I chose two locations that were most likely to expose me to the everyday difficulties of providing family centered care in the natural environment and that were also accessible and welcoming. As part of the Master's program that I completed in Early Childhood Special Education four years prior to this study, I had spent eight weeks shadowing personnel at the first site, which I will refer to by the pseudonym Little Hearts

Early Intervention (LHEI), and attending weekly meetings with the site administrator. Although I had not stayed in touch with the staff since my required internship, while I was there I had established positive relationships with the administrator and staff which served to increase my accessibility to the location. When I approached the program director and attempted to gain access, I was remembered quickly and welcomed by several of the staff who recalled my internship experience. The second site I chose was the same agency where I had conducted my pilot study mentioned earlier, Young Minds. Prior to beginning my research I had spent 16 weeks shadowing personnel and attending staff meetings there. By the time I was ready to begin my research, my position as researcher was well in place and I was heartily received by the staff and providers who worked with Young Minds.

Role of researcher. The role of a researcher has been a complicated issue for qualitative research since its beginnings in ethnographic studies. The ability to balance not “going native” while simultaneously remaining empathetically neutral is a difficult task for most qualitative researchers. In his work on ethnographic research methods, Van Mannen (1988) discussed the issue of researcher perspectives and dichotomized the researcher as being either inside (emic) or outside (etic). Harry and Rippey (2009) later extended his work and discussed the importance of the position of a researcher and what it meant to be an outsider versus an insider when using ethnographic methods. Harry and Rippey (2009), citing Moustakas (1995), discussed three states of researcher presence including: “being in,” wherein the researchers acts as though they are part of their surroundings; “being with,” when the researchers commit to being a scribe or voice for

the group they observe; and “being for” in which the researchers become a political advocate for the group.

For the purpose of this study, I strove to maintain a careful balance of being a participant observer who might be described by Harry and Rippey (2009) as “being with.” I was somewhat involved with the group I researched, but I did not wish to become an advocate for whatever they felt was most important. I strove to achieve a degree of empathetic neutrality, described by Patton (2002) as one that seeks answers without judgment, with a demonstration of openness and respect. During the pilot study, I found it difficult to keep my role clear for myself, and even more difficult to be clear in explaining my role to the staff of Young Minds. Thankfully, the maintenance of researcher reflexivity was facilitated by my advisor and I found myself capable of maintaining the role of “being with” throughout the majority of the study. By generating self-reflective memos (Charmaz, 2006; Strauss & Corbin, 1998) researchers are able to remain aware of the roles they are assuming and whether or not they reflect their intentions. As part of my pilot study, I wrote several self-reflective memos that considered how I was interacting with participants, and whether or not I was becoming their “advocate.” This process ultimately helped to maintain my role of participant observer. Similar self-reflective memos were made during the process of interviewing participants for my dissertation. Overall, I felt that by the end of my research I had made conscientious efforts to maintain this position, and had been relatively successful.

Quality Indicators in Qualitative Research

Since rigor and relevance are objects of concern in all research, Lincoln and Guba (1985) provide perhaps the most widely heralded criteria for naturalistic studies that have

been established for high quality qualitative research. In their attempts to bridge a quantitatively-dominated positivist paradigm into the constructivist realm of qualitative research, they describe methods of maintaining both the trustworthiness of a study and the rigorousness of the design. The four criteria described by Lincoln and Guba (1985) include credibility, transferability, dependability, and confirmability.

Credibility. The first criterion, credibility, has several components that justify how well and how accurately the researcher has analyzed and explained the phenomena of interest. In order to increase credibility, qualitative researchers are advised to use prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy, and member checking. For this study, prolonged engagement was somewhat of a limitation as I collected data over a five month period. Although five months is hardly the multi-year study that would be sufficient in the eyes of a classic ethnographic qualitative researcher, it was a feasible amount of time in which to collect data for this dissertation. Persistent observation was not relevant because I did not conduct any observations as part of my design; rather, interviews were transcribed and analyzed. Triangulation, the process of collecting data from multiple sources, interpreting data through multiple theories, or analyzing different kinds of data, was addressed by interviewing multiple providers both within and across disciplines and families across demographic backgrounds.

Peer debriefing, as the name implies, is a process in which the researcher takes his/her data and findings to peers to check the interpretations and share ideas. For the purpose of this study, peer debriefings occurred only with my advisor and were mostly conducted following data collection and several levels of coding. Negative case analysis

takes place when a researcher examines carefully any data that seem to contradict emerging hypotheses. Any such negative cases that occurred in my data resulted in additional questions being asked to participants for clarification in order to achieve theoretical saturation (Glaser & Strauss, 1967). The referential adequacy discussed by Lincoln and Guba (1985) deals with the accuracy of the data and how well the researcher can go back and check those data. For my study, I have audio recorded all interviews and had them transcribed prior to analysis. Once transcriptions were returned to me, I listened through each recording at least once (in some cases where there was background noise I listened to audio recordings several times) and ensured that all of the typed information was accurate. The last area involved in credibility, member checks, is a process of returning to the field and sharing findings or emerging ideas with participants to see if they feel they are accurate. Member checks in my study occurred following the creation of an initial set of themes, wherein I returned the themes to several participants and asked for their input regarding my interpretations.

Transferability and dependability. The second area of concern described by Lincoln and Guba (1985) is transferability. Transferability is the degree to which the findings are applicable in a similar situation, and is closely related to the third criterion, dependability, which addresses the issue known in quantitative research as reliability, or the extent to which the findings could be duplicated in a similar scenario. Lincoln and Guba (1985) say that both of these issues must be addressed in qualitative research by providing readers with rich, thick descriptions throughout the study. By reading the contextual information involved in a given study, other researchers can determine if the situations they are studying are similar in nature, and thus the information can be

determined as either applicable or not. Lincoln and Guba also state that in order to demonstrate dependability, researchers can rely on the same thick description used to assure transferability, they can use overlap methods, or they can use the process of stepwise replication. Overlap methods are generally considered another form of triangulation (i.e., using interviews and observations and document analysis), and were not utilized for this study. The process of stepwise replication is when there are two researchers who are literally following in one another's footsteps, replicating each stage of the process; however, this is generally too cumbersome to use and was not possible given that I was the sole researcher. However, I have attempted to provide thick, rich descriptions of the data for this study evidenced through numerous quotations in my findings.

Confirmability. The last area mentioned by Lincoln and Guba (1985) is confirmability; this addresses whether or not the data and results reported by the researcher really are evidenced. This can only be demonstrated through an "audit trail" which for most studies is time consuming to complete. For my study, an audit trail is possible because I have maintained a high degree of referential adequacy (i.e., the ability to return to recordings and check the accuracy of information gathered). All information pertaining to the study was kept in a password protected computer and audio tapes were transcribed with pseudonyms. Memos, field notes, and other pertinent information were also stored with the rest of the files on my computer where they remained throughout the course of the study.

Setting

The following two research sites were chosen because they both provide early intervention services to families of children birth to three. The first site, Little Hearts Early Intervention (LHEI), provides services to children from birth to three who qualify for services under Part C of IDEA. The second, Young Minds, is a partnership that serves children birth to five who have developmental delays but did not meet the qualification requirements for LHEI or the local early childhood special education agency. The two agencies frequently subcontract with the same service providers and the access I gained through both sites yielded valuable referrals to providers with a range of backgrounds and philosophies.

Research site 1: Little Hearts Early Intervention. The primary setting for this study involved two local branches of LHEI, the lead agency for Part C services in a large county of approximately 2.5 million residents. The racial composition as estimated by the US Census Bureau is 19.5% Black, 17.8% White/Non-Hispanic, 62.4% Hispanic or Latino, 1.6% Asian, and 0.6% Other. LHEI is the lead agency responsible for the statewide provision of early childhood intervention services for children from birth to three years who have significant delays or conditions likely to cause a significant delay (e.g., Down syndrome, extreme prematurity). Services that families can receive include: assistive technology, audiology, counseling, family training, home visits, medical and medically-related services, occupational therapy, physical therapy, respite care, service coordination, sign language services, social work, speech and language pathology, translation, and transportation. These services, when not covered by private insurance, are funded through Part C of IDEA and families can apply for assistance with minimal

out-of-pocket expense. Little Hearts reports on its website that it provides options in service decisions for parents, encourages active parent partnerships and brings the services needed to the child in his/her natural environment within the context of natural learning opportunities.

Children who are referred to LHEI must be assessed using the Battelle Developmental Inventory, 2nd edition (BDI-2; Newborg, 2005). The BDI-2 assesses young children in the areas of physical, cognitive, motor, communication, social emotional and adaptive development. Children who meet or exceed a 30% delay in one area or 25% in two or more areas are eligible to receive services through LHEI, which are subsequently subcontracted through other providers. Once eligibility is determined, a team of providers meets with parents to discuss the needs of the child and develops an Individualized Family Service Plan (IFSP). Services are to be provided within the natural environment, and a central contact person is selected whom parents can call with any concerns. If a child does not meet the eligibility criteria, he/she can be referred to a private service provider or Young Minds, the second research site where I conducted my previously-reported pilot study.

Research site 2: Young Minds. The second research site where I conducted data collection was Young Minds, a grant-funded service partnership created to work with young children birth to five years old who exhibit mild to moderate delays not severe enough to qualify for services in LHEI. Children serviced through Young Minds exhibit mild to moderate delays (10 to 24% on a standardized measure) in the same areas addressed by LHEI: motor skills, behavior, speech and language, and cognition. The services provided at Young Minds mirror those available through LHEI including OT,

PT, BT, speech and language therapy, and services for general developmental delays. By including this research site in the study I was able to gain access to several therapists who explicitly refused to conduct natural environment services for LHEI because of the difficulties they had with that agency in the past.

Participants and Sampling

Participants for this study were selected according to a purposive sampling technique designed to maximize the likelihood that the issues of interest would be well covered by a range of service providers and families. My purpose was to explore the perceptions of key personnel who work in early childhood intervention and those receiving services. Key personnel interviewed included: eight Families, three Program Directors, three Service Coordinators, a Speech and Language Pathologist, an Occupational Therapist, a Physical Therapist, a Behavioral Therapist, a Parent Educator, and six Infant and Toddler Developmental Specialists (ITDS). Participants were asked to complete an interview using the guiding questions in Appendices A through F and agree to a possible follow-up discussion designed to conduct member checks and clarify any possible researcher questions. Participants who agreed to take part in the study were given a \$25 gift card as a gesture of appreciation. Gift cards were provided to participants either in the mail or directly after an interview was completed.

Program directors. Program directors from Little Hearts Early Intervention's Northern branch and Southernmost branch were asked to participate, as they are the local delivery agents for early childhood intervention services for children from birth to three years. For the purpose of this study, a program director is defined as an administrator in charge of major components of the program commonly associated with management or

director status. In addition to program directors for LHEI, I also interviewed the program director for Young Minds, the grant-funded agency described in my pilot study that was created to serve children who exhibited a 10 to 24% delay in their development, and thus were unable to qualify under the eligibility criteria established by LHEI. Program directors for the local early intervention agency were selected according to their position as head of the agency/branch. In two of the three cases, the program director was sole person in charge of the site, whereas in one of the locations there were several directors and only one was asked to participate. I was able to recruit a program director from each of the targeted areas and interviewed a total of three.

Service coordinators. Service coordinators act as the liaison between families and service providers. They ensure that families' needs are met and that families are satisfied with the care they receive. Additionally, a service coordinator is responsible to conduct intake meetings with families to explain services to them, discover what the families' concerns are for their children, and help them access resources that may be appropriate to meet their needs. A service coordinator from each site was invited to participate and share his/her experiences with families. Service coordinators were also asked to provide referrals to agency partners and families who would be interested in participating. Using this snowball technique, families were recruited into the study by first agreeing to contact/be contacted by the researcher and subsequently signing an informed consent form.

Service providers. For the purpose of this study, the term service provider is used to refer to the therapists and infant and toddler developmental specialists (ITDS). The term service provider was chosen as a more general term over "therapist" because it was the

accepted name used by those that I observed in the field and because it reflected a range of educational levels and domains. Throughout this study I refer to service providers when making a generalization about the attitudes that I found across both therapists and ITDS providers. It is important to acknowledge though that there are differences in the credentials required to be a therapist in the traditional sense, and an ITDS. Therapists are generally required to go through Masters' programs in their fields that have been accredited by professionally recognized organizations for each domain (speech, physical therapy etc.) in order to receive licensure. An ITDS on the other hand is required to hold a valid ITDS certification from a university or college and a bachelor's degree in either early childhood education or a related area.

Access to service providers was facilitated by the program directors who consented to participate in the study. During regularly scheduled meetings of providers and LHEI/Young Minds program directors, I invited the administrators of the provider agencies and their respectively-employed service providers to participate in the study. Of those who consented to participate, service providers were selected for interviews according to the snowball technique. That is, program directors who work regularly with agencies were asked to recommend service providers for each domain including a speech and language pathologist (SLP), occupational therapist (OT), physical therapist (PT), behavior therapist (BT), and an infant and toddler developmental specialist (ITDS), some of whom were willing to work with families in the home and provide care in the natural environment, and others who refused to work with families in the natural environment. It is reasonable to assume that the perception of barriers and facilitators of family centered care in the natural environment would be affected by the personal philosophy of the

providers; as such, I attempted to interview providers with a range of opinions regarding family centered care. In addition to the personal philosophy of providers, program directors and service coordinators were asked to refer service providers from Spanish-speaking backgrounds in order to focus on the third and fourth research questions. Based on previous observations in the field, the majority of the native Spanish-speaking providers were expected to come from the sample of ITDS providers. As it turned out, of the 6 ITDS providers interviewed, only three came from Spanish-speaking backgrounds. What I found was that it was difficult to find a native Spanish-speaking ITDS who understood English well enough to understand the informed consent required to participate in the study. Those who spoke fluent Spanish often spoke little or no English at all.

Families. Service coordinators were asked to provide access to families in the form of distributing invitations to parents receiving services either: a) in the home, b) at a childcare center, or c) in a clinic. For parents who agreed to participate, service coordinators were asked to provide information on the language background of the family to assist the researcher in selecting a sample representative of diverse families. Eight families were selected from those who agreed, four from the LHEI agency branch that provides services in the north end of the county and four from the south. The reason for the north/south distinction is the general difference in the ethnicity and SES between the two areas; as a whole the children served in the north end are minority children from lower SES backgrounds, and those in the south are more likely to be higher SES and White/Hispanic. Previous research suggests that there is a greater likelihood that parents who come from high-income backgrounds will be more able to “customize” their child’s

educational programming (Laurau, 2000) and are therefore more likely to obtain services in the form they desire. With this knowledge, it was reasonable to try to interview persons who would elucidate these differences. The purpose for categorizing the families on the basis of where services are provided stems from the possibility that the perceived barriers and facilitators could be different for people who are in a different economic positions to receive the services.

Data Collection

Semi-structured interviews with open-ended questions were conducted with program directors and key personnel from local service agencies to discover the perceived barriers and facilitators to conducting family centered care and natural environment services. I conducted the initial interviews with the program directors of each early intervention agency, after which I asked them to refer service coordinators and service providers whom they thought would be interested in participating. Additionally, I attended a meeting of local providers and invited several service providers from different domains to participate. Among those who agreed to participate, a variety of views regarding the benefits of family centered care were evident.

Interview guides. The interview questions used to guide initial data collection from participants are found in Appendices A through F. Questions were modified as appropriate as information was collected, and the use of targeted questions was incorporated to clear up any confusion, to “bounce” ideas from one person to another, compare ideas, and add to the saturation of emergent categories.

Program directors. The program directors of LHEI have been using the same model for several years and consequently have an established routine for conducting their

operation. It is reasonable to believe that the barriers and facilitators of providing family centered care in the natural environment are well established in the minds of these coordinators and the personnel they employ. On the other hand, Young Minds was undergoing a transformation in the manner in which their services were provided. At the time of the study, they were moving away from a center-based model (i.e., where services were provided in a group) to a family centered model where services are provided in the natural environment (i.e., home or childcare center); additionally, the screening process was completely new. The questions posed to these directors reflected the differences in programs, and thus two separate forms were created as seen for LHEI in Appendix A and for Young Minds in Appendix B. Within these interview protocols are guiding questions accompanied by possible prompts that were used during the interviews.

Service coordinators. Service coordinators were asked to share their experiences working between families and providers. Questions posited to service providers were adjusted during the interview to accommodate their unique experiences. Interview guides for service coordinators can be found in Appendix C.

Service providers. Consideration of the distinction between LHEI and Young Minds services were made on an as-needed basis; however, the service providers (i.e., the therapists or infant and toddler developmental specialists) who were interviewed were often affiliated with both of the agencies thus making the creation of a separate form redundant. Additionally, specific terms were changed to reflect the particular service provided by each individual provider. The interview guide for service providers is displayed in Appendix D.

Families. Family interviews were structured somewhat differently than coordinator/provider interviews as these participants were expected to have less knowledge of the terms used by early childhood special educators. The interview guide used with families can be found in Appendix E. Despite changes in wording, all of the questions included in the parent interview guides are based on the same core ideas regarding their experiences with family centered care, natural environment services, and the barriers and facilitators of each.

All interviews conducted with program directors were transcribed and then coded by the researcher using the grounded theory method of “constant comparison” to analyze data in an on-going process throughout data collection (Strauss & Corbin, 1998). This allowed the researcher to fine-tune questions and use previous information to elaborate on the developing categories. Although the final analyses continued past the data collection phase, in grounded theory studies it is appropriate for both to occur simultaneously in a recursive process until the end of a project (Charmaz, 2006; Strauss & Corbin, 1998). Consequently, as data came back from the transcriptionist and were checked over by the researcher for accuracy, they were coded and entered into Atlas.ti Version 5.2 qualitative software. As codes were developed, ideas for conceptual categories and themes began to form and memos for future consideration were created.

Data Analysis

All information was analyzed using the grounded theory approach of constant comparison, ultimately creating “well developed categories (themes, concepts) that are systematically related through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, nursing or other

phenomena” (Strauss & Corbin, 1998, p. 22). In other words, I have attempted to develop an explanation of the challenges to implementing family centered care and natural environment services and the specific issues that must be considered in order for either to be effective. The grounded theory procedures used for this study consisted of four general phases: open coding, axial coding, selective coding and the defining of a central category. These procedures, originally described by Glaser and Strauss (1967) have been renamed and redefined by multiple researchers, and for this paper I use three equivalent terms described by Harry, Sturges, and Klingner (2005): specifically, open coding, conceptual coding, and thematic coding. At the final “theory building” level of analysis, I have kept the use of Glaser and Strauss’ (1967) term of “central category.” While I feel that these terms have a more intuitive clarity, they still retain the meanings ascribed by Strauss and Corbin (1998). Following is an outline of the qualitative research considerations and grounded theory procedures that were used for this study.

Developing sensitizing concepts. Although it is not one of the three phases of grounded theory methodology, one of the important foundations for conducting a grounded theory study is developing what Glaser and Strauss (1967) refer to as “sensitizing concepts.” A sensitizing concept is any experience, either existential or a result of scouring literature, that provides the researcher with insight to a situation and the ability to give meaning to data; it is experience or knowledge that allows you to “see beneath the obvious and discover the new” (Strauss & Corbin, 1998). As previously discussed, before I began my research in this area I had previous experience interning over a summer at the LHEI South agency as part of my Master’s program in Early Childhood Special Education. In addition to this experience, I arranged to meet the

coordinator of Young Minds and shadow several of the service coordinators in a pilot study in order to sensitize myself to the language and environment prior to beginning research. Consequently, I felt that as I began collecting data, I was sufficiently sensitized to many of the common issues experienced and made aware of possible facilitators.

Open coding. The first step in analyzing data in a grounded theory approach is to use an “open coding” procedure, wherein all of the data are broken down into distinct incidents, ideas, acts, or events and assigned a code representative of the concept. This is the most concrete level and the most inductive stage of grounded theory methods. In this study all transcribed interviews were first broken down in this manner and then analyzed and coded per unit of meaning. As open codes were developed I continuously compared previous codes to new data, and when incidents shared characteristics of previous codes they were either given the same code or they were given a different code that was more representative of the characteristics of that data. According to Strauss and Corbin (1998), open codes should remain as close to the data as possible, for example a daisy, buttercup and rose might all be assigned to the open code “plants,” but it would be less abstract to assign them the code of “flowers” which would remain closer to the actual data.

Conceptual coding. As several open codes accumulated, I was simultaneously developing ideas for conceptual categories. Conceptual categories are created from groupings of open codes according to their similarities. This decreases the amount of raw information the researcher must juggle cognitively and should be more explanatory than open codes. A conceptual category describes a phenomenon and should answer the question, “What is going on here?” or, “What is the shared meaning within each of these codes?” Unlike quantitative analyses that have a particular order that must be adhered to

for technical adequacy, grounded theory methods incorporate several levels of analyses simultaneously. The development of categories takes place alongside the open coding process. These categories are simultaneously assigned and analyzed according to their properties and dimensions. Strauss and Corbin (1998) describe properties as the characteristics of a category that give it meaning when delineated, and dimensions as the range along which properties can vary in frequency and intensity. As categories are assigned, researchers can move from a highly inductive process of assigning open codes to a deductive process whereby inductively-produced open codes are placed in categories and these categories are then used to return to the field and “test” predictions in the form of new interviews and questions tailored to explore these predictions.

Thematic coding. Once open codes and categories have been produced, the next step is to create thematic codes. This theory-building stage of grounded theory is described by Strauss and Corbin (1998) as selective coding. Thematic codes are created to recombine the data that were disaggregated during open coding. They should tell the story of what is happening in the data along the properties and dimensions. Strauss and Corbin (1998) identify four basic procedures for conducting thematic level coding: a) lay out the properties and dimensions of each category; b) identify conditions, actions/inactions and consequences that are seen in the phenomena as a whole; c) create statements describing the relationship between categories and their subcategories; and d) identify how categories relate to one another using cues from the data. The product of thematic coding should be a collection of thematic statements, explaining how categories relate to one another along both the properties and dimensions they have. At this point it may be necessary to return to some of the participants and bring them initial relational

concepts as a kind of member checking, to see if they appear to be valid to the people who represent the “ground” on which the theory is being built. Thematic codes were developed in my study following the creation of all conceptual categories and open codes.

Central category. The final stage described in grounded theory methods is the discovery of what Strauss and Corbin (1998) refer to as a central category. Often referred to as the theory or core category, the central category should give the reader a picture of the main theme found throughout the research process. It is essentially a summation of all the findings subsumed within an abstract classification that takes into account all of the previous categories and themes and integrates them into a sensible storyline. In some cases, there can be more than one core category and multiple stories can be seen in the emerging data. This is perhaps where Denzin and Lincoln’s (2002) call for a qualitative researcher to become a “bricoleur” is most apparent, when the results from every different phase of the process come together to represent an issue. The purpose of grounded theory is to build a substantive theory that is applicable not only to the data and context of the particular study but generalizable to similar situations. I have attempted to create such a central category in my work and describe it in detail in the following chapter.

Overall, the grounded theory analysis methods used succeeded in providing clear patterns in participants’ perceptions of barriers and facilitators of family centered care and natural environment services. By utilizing the “constant comparative” approach in the level of open coding, data that originally included over 150 open codes were analyzed, reanalyzed, and collapsed into 46 different codes. In this process I began to

detail what each code meant individually, which helped to clarify which codes should be combined and which should remain distinct. The categories and themes that later emerged from these codes were reflective of previous research findings and I felt confident that a fairly robust explanation of barriers and facilitators could be made. A map displaying the process of data analysis and the resulting codes, categories, themes, and central category is included in the findings chapter.

Chapter 4: Findings

I began this study with the intent to discover why it is that best practices in early childhood intervention were not occurring as they ought to be in a diverse urban school district. In order to guide my research in this effort, four questions were formulated as a part of my proposal and became the starting point from which I developed my interview guides and study design. Specifically, these research questions were:

1. What are the barriers and facilitators to delivering family centered care to families of children with disabilities, as perceived by the families and professionals involved in providing services to families of children birth to three?
2. What are the barriers and facilitators of providing services in the natural environment as perceived by the families and professionals involved in providing services to families of children birth to three?
3. How do native Spanish-speaking service providers perceive the barriers and facilitators to delivering services when working with families who come from English-only backgrounds?
4. How do native Spanish-speaking service providers perceive working with families of the same language background?

In this chapter, I begin by addressing the findings of my first and second research questions. I have provided an explanation of the barriers and facilitators of family centered care and natural environment services discovered in my study using rich descriptions of data from interviews. I follow this with my findings for the third and fourth questions and report the unique language challenges that were described by participants. The following table summarizes both the data analysis process and results.

On the left side are the levels of the coding process and within the table the different open codes, conceptual categories, themes, and central category are listed.

Barriers and Facilitators of Care and Services

After conducting the interviews with 25 participants and utilizing Strauss and Corbin's (1998) method of grounded theory to analyze the transcriptions, I developed a list of 46 open codes that have been incorporated into one or more of the eight conceptual categories which in turn formed the foundation for three themes and one core category. This core category is titled *Limited Resources vs. Best Practice* and summarizes the underlying difficulties and compromises that were reported by the participants interviewed. Regardless of the position that the participants were in, be it parents, service providers or program directors, there was a consensus that the resources available for early intervention were increasingly scarce, and that this in turn affected the quality of service provision. Additionally, service coordinators and directors acknowledged that the limited resources created a need to compromise whatever model was in place, how many services could actually be provided in the natural environment, and how realistic it was to push an already limited group of providers to adhere to family centered principles and provide natural environment services if they were not comfortable with them. The result was a series of compromises that pitted what research and legislation hail as best practices against what providers were willing to do with the limited payment available and what agencies could accomplish when faced with an uncooperative group of therapists. Because of these issues, many of the services provided in the city where this study was conducted did not occur within the natural environment, and even fewer were conducted in a manner that could be called family centered.

Limited Resources Vs. Best Practice								
Central	Facilitators Depending on perspective/buy-in these could impede or facilitate services					Barriers Need fixing right away		
Themes	Theoretical Buy-In		Negotiating Roles in Family Centered Care			Managing Scarce Resources		
Conceptual Categories	Comfort and Buy-In to Model	Control of Environment and Scheduling	Involving Caregivers in Services	Negotiating Levels of Family Involvement	Creating and Maintaining a Productive Relationship	Economy of Natural Environment Service	Delays across all levels of service	Community Resourcing
Open Codes	Theoretical Buy-In "If Some is Good, More is Better" Family as Therapist Model Parent Understanding of Services Family Comfort with Home Services Willingness to Travel to Nat Env Description of Services	Accessibility of Materials Appointment Flexibility Limited Parent Availability Cooperation of Childcare Centers Control over Distractions in Environment Safety Concerns	Parent Agreement with Diagnosis Caregiver Willingness to Get Involved Family Concerns- Priority Integrating Parent Input Motivated by Child Progress Family as Therapist Model Cooperation of Childcare Center	Parent Tenacity Providers Limiting Parent Participation Providers as babysitters Providers Telling Parents Goals Including Family Encouraging Caregiver Involvement	Family/Provider Relationship Maintaining Open Communication Lack of Provider Follow Through Understand family system Collaborative Work Environmental Cultural Differences Language barriers	Assign Students Geographically Willingness to travel to the Natural Environment Lowered Productivity in Natural Environment Insufficient Reimbursement for Time and Travel Family no-shows Family Transportation Difficulty	Service Delays Short staffed Insurance Company Confusion Lack of Provider Follow Through Limited Providers Referral Sources	Referral Sources Initial Contact Evaluation/Eligibility Determination Connecting to Community Resources Outreach Efforts Transition to Public School System

Figure 3. Data Analysis Map. This figure presents a map of the codes, conceptual categories, themes, and central category developed.

As can be seen in the map above, I have addressed the summative answers to these first two research questions through explanations at the level of themes. It is through these themes and their underlying conceptual categories that I evidence my findings regarding the barriers and facilitators to providing family centered care and natural environment services. First, the themes that explicated facilitators of providing family centered care were found to be a) the theoretical buy-in of those involved in early intervention and b) the healthy negotiation of roles for parents and service providers. Whether a particular issue was perceived as a facilitator or barrier within these themes seemed to be affected by the role of the service provider I interviewed. Although I initially collapsed data from the therapists I interviewed (OT, PT, BT, speech) with the Infant and Toddler Developmental Specialists (ITDS), I soon realized that their views were so disparate that they often could not be collapsed into one group. Therefore, when the broad term of “service provider” failed to capture the distinct differences in opinions between the two groups I have separated views that were specific to each group by referring to either “therapists” or “ITDS providers.”

It is also important to note that the same factors within family centered care that could facilitate services became barriers in situations where they were absent or were replaced with traditional views on service provision. For example, one facilitator of family centered care was the perceived effectiveness of the relationships between parents and service providers. The absence of this facilitator was identified by participants as a barrier to service. When service providers did not foster relationships with parents and parents were left with unclear or unimportant roles in service provision, family centered care was not possible.

In the area of natural environment services, the barriers were clear and similarly reported from every source. The management of the limited resources available to early intervention programs, especially with recent cuts in funding to Part C services across the nation, made it difficult for service providers to believe that the benefit of natural environment services outweighed the costs of providing services in this model. The lowered productivity for providers and the difficulties with transportation combined with insufficient reimbursement reportedly caused many providers to drop out of providing Part C services altogether. When deciding whether or not natural environment services were worthwhile, providers often were caught up with issues of theoretical buy-in; this buy-in either barred or facilitated family centered care depending on the providers' perspective. When providers felt that the importance of the model and the benefit to the child were great enough to warrant the extra expenses, they might acquiesce to the difficulties of traveling to natural environments and navigating the distractions found there.

What became clear as I interviewed all the participants was that therapists with specialized clinical training were far less likely to buy in to the model of either family centered care or natural environment services. This reflects the argument of Kalyanpur and Harry (1999) that for many therapists, the importance of respecting the professional knowledge they held in their areas of expertise conflicted with the underlying values of choice and equity that are embedded the family centered/natural environment paradigm. Many of these therapists had dropped out of providing services for LHEI because their philosophies were more traditional and they did not see a justification for having

specialists travel to the homes when parents could bring their children in to a clinic where the environment was more controlled and convenient to the therapist.

Themes, Categories, and Open Codes

As mentioned above, the first two research questions regarding the barriers and facilitators of family centered care and natural environment services are addressed at the level of thematic codes, and it is within the underlying categories and codes that I have attempted to exemplify my findings. The following sections describe the three themes of *theoretical buy-in, negotiating roles in family centered care, and managing scarce resources*. In addition to these themes, I have broken down the individual conceptual categories contained within these themes as well as the open codes that form each conceptual category. While providing a thick, rich description of my findings (Lincoln & Guba, 1985) I have attempted to make clear which areas served as primary barriers to services, and which areas served as facilitators to services.

Theme 1: Theoretical buy-in. As mentioned earlier, the theoretical buy-in for service providers and families regarding family centered care was either a great facilitator of services or a serious barrier for everyone. Much of this buy-in was determined by how service providers felt about the tension between controlling the educational setting and serving the child in an environment where generalizations and parent participation could be maximized. The two conceptual categories that underlay this theme were *comfort and buy-in to model* and *control of environment and scheduling*.

Comfort and buy-in to model. This category attends to the comfort level experienced by families and therapists regarding the idea that parents/caregivers are to be the primary interventionist in their children's lives. It contained the open codes *if some is good, more*

is better, family as therapist model, family comfort with home services, parent understanding of services, theoretical buy-in, willingness to travel to natural environment, description of family services, and description of provider services. The comfort and buy-in to the whole idea of family centered care as well as natural environment services were essential for service providers to facilitate their efforts in this regard. In the state where the study took place, a director from one of the lead Part C agencies summarized the issue regarding service providers' attitudes towards family centered care:

You know, again it's a new philosophy. It's a new philosophy and not everybody agrees with it. Um. And you know, there are some providers who will go into the home, even if they go into the home they will tell the family, you know if the child is acting up or something, they'll tell the family "go in another room, and maybe I can calm the child down." Rather than be part of the system, you know, learn how to calm down the child. They'll say "go away and I'll fix things. I'll calm your child down." So they don't, they don't um, encompass the whole family centered issue and they don't see you know, there are a lot of people who don't see the model as such where it's family centered.

There was mixed support among the parents and providers for the idea of family centered care and integrating parent opinions and participation into services. Generally speaking, the ITDS providers who worked with children within the natural environment reported being in favor of this model. Several expressed a frustration with families who were not willing to participate in the therapy sessions and said things like, "I am only here 30 minutes a week; you are here all the time." Therapists, on the other hand, were less inclined to have the family involved in the sessions; rather they wanted parents to watch from a distance or another room, and pay attention to information given at the end of sessions. The issues salient to the comfort and buy-in to the model are evidenced in the descriptions of open codes below.

Theoretical buy-in. This code describes the attitudes of providers and childcare centers involved in early intervention regarding family centered care and natural environment services. This buy-in is described as a facilitator to providing care and an essential ingredient for success; however, directors acknowledged that among providers there existed a lack of willingness to change. Many of the service providers did not believe in the model being promulgated. As stated by one director this buy-in can be one of the greater facilitators to effective service provision: “I think the buy-in of everyone involved. Everyone has to see that this is, or believe that is a worthwhile effort and um, in order to communicate that to the families.” This director further explained:

Well I think it’s the best model. I think as far as having effective long term change it’s incredibly important, um, because if the family is not involved and engaged then they’re not likely to continue to, one, be engaged in the treatment and to continue the strategies they learned once the treatment, um, is over. So our goal is to get them involved in the planning and provision so that they will continue to stimulate their child’s development.

In early intervention, the importance of all players buying in to the model was further illustrated by a therapist who claimed that childcare centers have become an impediment to service provisions because “the director doesn’t buy into it.” A program director also stated that although the model makes good common sense, “There’s not a lot that makes it easier” and even when parents buy into the model, it is difficult to use because of the logistical barriers and the traditional providers’ philosophies. This director argued:

I truly can’t off the cuff think of a lot of advantages except that this is what the families generally want and buy into. They like the idea that you’re going to come to them. They like the idea that you’re going to empower them and give them a sense of accomplishment with their child. I mean the whole idea that the child is in a more appropriate environment and not in an artificial environment. All of those things make good common sense that the child will do better in the natural environment than in an artificial environment and he’ll be more functional where he usually is rather than being in a clinic room that’s strange with strangers.

In a situation where providers are expected to abide by the principles of family centered care and provide service in the natural environment, it was difficult to understand why the majority of providers working with LHEI were still not conforming to the model. When I asked a service coordinator what steps were taken to inform providers what the vision of LHEI was, she replied, “I have no idea.” She went on to explain that if a family made an issue of it, she would attempt to contact the service provider and reiterate the position of the agency. She was unclear regarding how providers were ever made aware of the model in the first place:

Um, I know that at some sort of administrative level those things are in a contract. Those providers I believe are informed as to how they should be providing services. All of the providers are not necessarily Part C providers so our children who we are paying for services can only go to Part C providers. Um, so those providers have to be approved by um, our program, by the state, so they should, I’m assuming on a state and local level, be informed as to how they should be providing the services, in, in, within our model.

“If some is good, more is better.” This code was an “in vivo” code that came from a statement made by a participant. The sentiment here is reflected in the attitudes of families, therapists, and ITDS alike. The idea that children were receiving too few contact hours with therapists was echoed by different specialties. A speech therapist argued that services should begin with intensive intervention and move to less intensive as a child improves:

But [LHEI] goes from the least amount to the most amount, so they want to do one time a week for 6 months and let’s see how it goes, and then if they really need more then they’ll do 2 times a week, and then if they *really* need more, I mean we’ve never gotten 3 times a week so we don’t even... but it’s, it’s, it’s contrary to what research tells us, ok? Where you need to start out with lots, bombard that kid, and then go back, you know? Train the parents, train those working with them. But you need to go in with a cavalry. No. They do it, drip, by drip, by drip.

In most of the interviews I conducted parents also felt that the amount of services they received needed to be increased and reported being happier when more time was allotted for their area of greatest concern. One parent described how she argued with her service coordinator to get her son more time per week in speech after he underwent a surgical procedure used to correct a condition commonly referred to as “tongue tied,” “she [service coordinator] said, ‘You know, we can only give out so much.’ Which I understand, but it did make a big improvement, the little bit that he did get, it did make a big improvement.” Another parent explained how she was hoping her next meeting with LHEI would result in a recommendation for increased time for her son and explained that “if they don’t recommend it I intend on asking them to recommend it, if maybe they can start doing it [speech therapy] twice a week with him instead of just the one time a week for a half an hour.”

The only groups that seemed to feel that “less is more” were the directors or service coordinators working within the early intervention agencies. One of the directors made the struggle between LHEI and service providers and families clear:

And the American model is that if some is good, more is better. So they [families] don’t want a half hour a week, they want 3 hours a week, 4 hours a week, speech therapy, occupation therapy, because if you’re going to give them some, a lot more is better. Well, that’s against the model. So there are a lot of things in dealing with families and there is a sort of, the families are pulled both ways because we deal with them initially, we explain the model to them, we tell them what we’re trying to do, what we’re trying to accomplish, what the model is and everything like that and then they go out into the community and a lot of the providers will say “you need more, your child needs more, your child is more severe than that, he really needs, you know, two half hours a week is not enough, he needs 3, 4.” So they will tell the family “you’re not getting enough, go back to [LHEI] and get more, get more.” And we don’t give more. You know, we give them for 6 months and then you have to see how they’re doing and what kind of progress they’re making and then we decide whether they need more or less or the same.

In the same vein, a service coordinator working for LHEI described parent attitudes in this way: “they feel that the more therapy they get the better it is for the child’s sake, you know, in a way kind of like, quote unquote, fix him, you know, and that’s not necessarily true.” She went on to explain that nothing is good in excess, and that children require time to be young and that with too much therapy “it’s not fair to the child, they get tired.”

Another administrator within LHEI acknowledged the decrease in services from years past, but argued that the model worked best when families were taking part in the therapy duties.

Um, now we do the evaluation and services all at a minimum of what we can provide, see how that goes for three to six months and then we can consider any increases or additions or what-have-you. So it’s definitely more stringent in a way, but we’re also just blindly recommending services now. Just saying, “Ok, so go ahead and get a speech eval, and then get an hour of speech and then we’ll see how that goes for three months and then we’ll consider increasing, adding, what-have-you.” So um, it’s just different how, how we’re recommending services now, um, but we’re recommending them based on how the model should work if it’s done correctly. [*Which is the families...*] Are involved in all of the services and they know what sort of um, strategies to use with their child throughout the week.

The idea that the amount of service is actually supposed to be reduced with the increase of parent participation in services is explored more in depth in the following code.

Family as therapist model. The “family as therapist” model is described by a director of LHEI as a model where parents should be acting as therapists. The extensive overlap between family centered care and the natural environment as understood by those in the field is also evidenced in the following quote:

Um, where you know you have one primary person who deals with the family in their home and teaches the family to be the major, uh, interventionist and you know, teaches the family how to do PT, teaches the family how to do speech. And the concept is that a family who’s with a child 24 hours a day is a much better therapist than someone who sees them three times a week for a half hour. So that’s the whole

concept of natural environment. It's more natural and it's a more appropriate place for the child to get services than going into a strange clinic or being evaluated in an artificial system. You get the child interacting with the family and you're building self-confidence in the family and that works most of the time, uh, but sometimes it doesn't.

The idea of building self-confidence in the families involved with early intervention and the importance of empowering parents to work with their own children was evident through comments of several of the administrators and service coordinators within LHEI. A parent educator explained how important it was to "make them feel like they're, you know, they're the parents, they're important, you're their first teacher, this is you, you know, you're 24/7, I'm here for half an hour or an hour." A service coordinator whose son was also enrolled in LHEI and receiving services agreed and explained the parent's role as "it's not like only the half hour that the child gets of stimulation, you have to continue that stimulation throughout the week in order for that child to reach those goals." She later explained: "You know sometimes it's not quantity, it's quality..."

This idea was echoed by several of the ITDS generalists when they described a model where the one hour a week that the provider spends with the family should teach the family skills they can use throughout their daily routines. When asked directly what a family centered approach meant to her, one ITDS answered, "It's to provide parents with tools to empower their children." She went on later to clarify: "I think the key is to empower them, empower the families with the right tools, to assist their children. And early intervention is the key, definitely. And we, we as providers um, see ourselves as guidance not as experts." Another ITDS explained her position:

Well you see the whole process of the natural environment is, at least in my theory, going once or twice a week for two hours will not hurt the child, it will benefit them. But when it comes to special needs and slow learning and motor planning issues, there's only one way and that's repetition, repetition, repetition. And we may do it 15

times in an hour, and the family can do it 45 times a day, you know, and that's what I stress to them.

Although ITDS providers generally seemed to agree with the idea behind a family-as-therapist model, they described several difficulties inherent to the work:

But, after 2006 when the natural environment took place and then there was something else that we had to train the family. But what happened is [the families are used to a different model], before we worked with the child, and they know that we are, that the ITDS but is that they know us more like a teacher, we are the teacher. So they expect the teacher to come to the home and to do their job. So this is my free time. It's my free time to go to the store, to get the milk, and to go do this and do that. So sometimes it's very difficult for the ITDS to... to... convince the family that it's part of the program that they have to be there because we are there to train them.

In contrast to the ITDS service providers, the majority of therapists expressed either disbelief in the philosophy or incredulity that they were expected to "make parents therapists" considering they underwent extensive training and education to become licensed.

I remember when [LHEI] was going to the natural environment ok? And we, this city, was probably the last city to go to the natural environment because the treatment specialists, all of us, you know therapists, it didn't matter what you were, were saying, "What do you mean?" Because Tallahassee came down, I remember, and just kept telling us because you have to teach the parent. And you have to teach, and the parent has to be involved, and the parent, and the parent, and the parent, and the parent. And I would raise my hand at all times and say, "I take offense to you telling me that I don't do this." Ok? This is how my business and my work has always been set up. So I am not sure what you are talking about that we need to do extra. But I went to school seven years to become a speech pathologist and I cannot make a parent a speech pathologist in 20 sessions, that's why they come to me.

There was only one therapist who was outwardly positive to the idea of families as therapists. She worked within the team of assessors at LHEI and acknowledged that although she understood and supported the value of the model now, she had not always in her previous years' experience when providing direct services to children.

Um, they know their child's behaviors the best, so they'll know what approaches work well with them. Um, you know, I always ask them, you know, "Is there

anything that you do that helps to calm them down?” or um, “a certain way that they like to be played with or held or what have you?” so that they’re most comfortable so that, you know, child participation is also key. So if we can get them to participate more than the more effective it will be. And also um, they come up with really great solutions, you know, uh, they know their child better than anybody and they’re providing more services to that child if they’re really following through with the model of, you know, following the home exercise program and really doing the therapies at home.

This model also relies on parent willingness to be involved and on providers including families in order to be effective. The majority of parents did not understand or make any statements indicating an understanding of the model in the first place. The only parent who expressed a clear understanding of the expectation of families being therapists expressed an intense discomfort with the idea of providing “therapy” to her children and explained that her role of “mom” was different and she felt she was more of a burden to therapists than a help.

And at that time they [LHEI] have this philosophy that they wanted the parent or a guardian or a grandma to be involved in all of the therapy sessions and that the parent should then take the other time and therapy, give therapy to the child. Which I soon realized doesn’t work with my kids because- when they’re in therapy, they want to be with me cause I’m the, the mom, they want to get loved, I feed them, I bathe them, I hug them, I love them. They don’t listen to me when I try to tell them to put the square in the box or to eat, or to you know, massage the mouth or to stretch their limbs or face, they don’t look at me in the same light that they look at a therapist. So when I would sit in therapy sessions I was more of a distraction than a help to the therapist, but [LHEI], their, their philosophy was they wanted the parent to be involved, and, and I had to show them it wasn’t working at all with me being involved and that they needed more intense therapy.

Overall, the family as therapist model was a difficult issue in both family centered care and natural environment services for families and providers. The feelings surrounding this issue varied greatly across professions, and it was generally those at the head of agencies that felt the strongest motivation to argue in favor of the model. ITDS

providers were also generally in tune with the idea, and families (when understanding of the model) and therapists were less inclined to see the validity of a coaching model.

Parent understanding of services. As mentioned earlier, the parents interviewed in this study generally did not have a clear understanding of either how the model was supposed to work, or why the issues they faced were issues in the first place. One parent actually began to work through her understanding of the model as a result of my interview with her, and from her own thinking aloud process, I was aware of her confusion regarding where and how services were supposed to be rendered. When asked if she was familiar with the term “natural environment” she replied, “Well I learned it with now through the LHEI. I had heard of that term um, a little bit other than when I worked at the United Way in talking to colleagues...” When she was asked what it meant to her she explained:

Well in the natural, for me what I understand is that if my son or daughter or both were going to school the therapy would happen in the school if we chose that, or it could happen here at the home um, like the IDTS [ITDS] did. Um, but now that I’m saying that, I never really thought of that for speech. I don’t know why. I can be honest with you and say I hadn’t; I hadn’t thought that that was an option, where speech therapy would happen in the home. I think I thought of it more for the IDTS um, because it was general, it was more, you know, they were just going to talk about speech, they were going to be doing up and down, and socializing, and interacting, but, but come to think of it I’m sitting here talking to you and my nephew’s therapy is happening in the home. I always thought that for him it was in the home and for **** and for my children it wasn’t because he was so, he’s so little.

This reaction demonstrated the importance of program presentation to parents when it came to their understanding of services. A program director explained that one of the issues providers faced was parents who did not realize they were to be a part of the service and were familiar with more traditional models of service provision.

Well one of the things that I often hear from providers is that, and not all the time, but some parents don’t understand that they are to be engaged in the sessions. You

know? Some parents may feel that we have it where families may feel that you know, you're the expert, here's my child, go ahead and fix that baby, and that's not what the program is about. Perhaps that might have been the model years ago when it was more medical in nature and you know, and because of the training that many of our therapists have received, it's not a, we take the child here and close the door, families sometimes are, that's what they're used to.

In general, the parent understanding of services seemed to be related to both the parents' education level and ability to research the program and providers' philosophy, providers' mindset (e.g., bring me your child and get away while I work), and any experience they may have had either with older children or friends/relatives in a previous medical model of service. One of the directors describes this phenomenon: "We face difficulty sometimes when parents have been in this program before, had an older child in the program before or knows someone who had been in the program, and they received a certain model [of] services."

Therapists also felt that parents did not always understand the value of the service being provided, or realize that there was a monetary component to services because they were not paying for services themselves; providers have been asked if they were "volunteers" and found this lack of value insulting. One therapist pointed out that in her experience:

The ones who are not paying don't value the service. And it doesn't matter if it's Medicaid or it's some other you know, service. Now I can't say that blanket, that's generalizing, because I have left people who you know, really do value it, and they don't have the money to continue if they had to pay out of their own pocket. But I think that they don't understand what a value that they're getting. I had a grandmother once ask me was I a volunteer. I don't think that they understand in this program

Providers did acknowledge that parent understanding is based on the presentation providers make, and parents demonstrated a lack of knowledge regarding how natural environment or family centered services ought to occur mostly because these are not

clearly explained as a part of the program. Although it was generally agreed upon and apparent that parents did not know what the model was expected to be, it remained unclear in this area whose responsibility it was to educate parents in these matters. One of the service coordinators made the attitude of providers and directors clear when she stated:

You know, if, if you don't care about your child, nobody else will, you know. They said it takes a, a village to raise a child. It is, it's true. You know, you cannot just throw it into the village and here, raise it for me, you know? (*Laughter*), you know? And give him back to me when he's all grown and knows how to do everything, you know? We all have to work together. You know, and unfortunately a lot, it takes a while for, for that to sink in to some parents, you know.

Family comfort with home services. This code represented a relatively infrequent issue that described how families felt about receiving services within the home. On the one hand when services are provided within the home it can serve to make families more comfortable because they are in a place they know and feel safe when they feel providers are not judging them. A program director reported, "I find a lot of parents like having someone come to the home and work with their family and work within the family dynamic." This sentiment was supported by a family who was perhaps the most educated and well-informed regarding LHEI and intervention services in general. This particular mother sat on the board of family centered council as a parent member in a neighboring county hospital. The mother refused to accept services anywhere except the home and explained that it was important for her son to receive services in a place where he was comfortable: "I won't take him to a center. No. That's just my personal belief and I believe that everything surrounded by the home, his home environment, his toys, his eating utensils, his high chair, his chairs, his cups, his everything."

On the other hand, directors within LHEI reported that some families feel it is an invasion of privacy to have providers in the home and that made it difficult to provide natural environment services: “Sometimes it’s the family doesn’t want it in the natural environment. They don’t want people in their home. They feel like it’s an invasion.” Another LHEI employee reported that “some families it’s easier to take them to the places because they have too many people in their home or they don’t want anybody to go to their home because for whatever x and y reasons.” The comfort of families was very important in determining whether or not a service would be provided in the home; however, it seemed to be that parents more often than not preferred home services when they knew it was an option.

Willingness to travel to natural environment. This code describes one of the biggest issues in providing natural environment services. In my study, it was rare to see providers willing to travel to the natural environment and able to juggle their own schedules productively; of course, such providers naturally facilitated the process of family centered and natural environment services. I found that the providers who were willing to travel to the home were the ITDS providers who work with children on generalized skills. These were also the providers who demonstrated the greatest level of buy-in to the theory of family centered care and natural environment service and felt that understanding the family system is important enough to travel to the home. For other providers, specifically therapists, several complaints were made in the following vein: “Sometimes you can’t get a provider who provides services in the natural environment in that particular community, in that particular zip code.” According to the LHEI parent educator, “We do have some providers in the home, um the Infant Toddler Developmental Specialist always goes to

the home.” She explained that although the model was natural environment, “generally because of the way the things are so many times it is in the clinic setting, you know, so we got kind of like a 50/50 ratio.”

Therapists who work in specialty areas are generally unwilling to travel to the natural environment. When a behavior therapist was asked why she refused to provide services for LHEI whatsoever she explained:

I think a lot of it has to do with the fact that they want us to do in-home services and a lot of the staff don't like to do it. It's really hard to hire staff members that want to go to the home or that are willing to go to a home. Um, there's lots of people that see the benefit to it, there's definitely good benefits to it, but there's a lot of negatives that go with it as well.

This was echoed by the occupational therapist, who also refused to serve LHEI cases, explaining that, “this is what I've heard is that if you don't take every child that they give you they stop calling you altogether.” This statement proved to be accurate when I later interviewed a director of LHEI. The only enticement offered to providers to conduct natural environment services is LHEI essentially blacklisting providers who refuse.

Well if, I mean it's a competition. I mean obviously in the community providers are competing for patients, you know, in order to survive. If you have two or three providers in a particular area and two of them provide in the natural environment and one doesn't, you're not going to refer to the one who doesn't. So they're either going to have to do it or they're not going to get patients.

It appeared that as a whole, this was ineffective and these providers would rather find patients elsewhere than travel to the home. The unwillingness of many specialists to travel to the natural environment was an issue for families who wanted homebound services. One mother explained what she went through to obtain a homebound therapist for her son:

Um, calling every single therapist company around and asking other people for their, uh guidance or opinions on different therapists and asking therapists for therapists

and trying to talk to different therapists, and it's a lot of layers and a lot of digging. ... And there aren't enough speech therapists and there are not enough PT therapists, I don't know why. I'm not exactly sure why if you're, if anybody's looking to go into those areas, and homebound. Um, so just digging through layers and just waiting and being patient and persistent and to give you another example of a hurdle, I finally found a company that will provide homebound speech and PT but they have to interview me as to why I want a homebound versus clinical, and I had to persuade them as to all the reasons why I wanted homebound versus clinic.

Description of services. This code contains descriptions from providers regarding the areas they cover, how that translates to child outcomes, and information from families regarding the services their children were receiving. The therapist interviewed for this study included a behavioral therapist, an occupational therapist, a speech therapist, and a physical therapist. The behavioral therapist described her service as “mental health therapy,” and explained, “It's just it looks like either a behavioral session or it looks like play therapy session or sand tray or art therapy, there's so much intertwined in there.” The occupational therapist described her work as being done “to help someone regain the ability to perform an occupation or retain the ability to perform an occupation, and occupation is anything you do.” The speech pathologist interviewed was actually a director of a speech center; she had been providing direct services to children for 20 years and had recently scaled her position back into a more supervisory and evaluative one. The physical therapist was in a similar position, as at the time of the interview she was not providing direct services to children; rather, she was serving as the specialist in the evaluative team that determined children's eligibility for LHEI.

I also interviewed a parent educator who described her position of educator as being an assistant to the ITDS providers when they brought in concerns on goal development, the creator of generic assistance packages for families that are eventually customized to specific family needs, and an unofficial “clinic manager.” Three separate service

coordinators were interviewed from each of the research sites. These coordinators were responsible for coordinating “services to provide family support in the services, the services that we provide and to serve as a, as a liaison for the family, you know, as an advocate for the family.” A total of six different ITDS providers were interviewed, and of these the majority described their positions along the lines of the following:

It’s basically I go to their, to the, the family homes and I, I teach them you know, ways of, of um, helping the child I guess increase their verbalization, um, of helping, of just basically just teaching them ways that they can um, help their child in the future.

One of the ITDS providers interviewed had the unique position of being an evaluator at an LHEI site. She described having provided services in the past for children within the natural environment, however this work had been done in a northeastern state and the experience was in stark contrast to her experiences in the city where this study took place. In her experience, she had worked within an area of primarily white, middle class families. She was unaccustomed to dealing with the multicultural nature of her current home, and said that she had a much easier time dealing with only one culture (even though it was not her own Columbian culture of reference) than she did trying to manage the multiple groups she dealt with daily in this city.

In summary, the category *comfort and buy in to model* demonstrated that the perceptions of most therapists towards family centered care are negative. Families generally demonstrated a lack of understanding, and ITDS providers often stated that they felt it was a good model that was difficult to implement. This category was significant as it was a gatekeeper for many providers; if providers were comfortable with the idea of family centered care and/or natural environment services they were willing to negotiate the difficulties they experienced. If providers did not feel comfortable with the

model overall, they were unlikely to even commit to providing services for early intervention agencies advocating this model. The following conceptual category describes some of the issues that providers had to navigate when trying to implement a family centered model of care.

Control of environment and scheduling. This category describes how the control of the environment and scheduling in the natural environment model as opposed to a clinic-based model was a huge issue for therapists when discussing service provision.

Therapists argued that there were not enough of the specialized materials they needed in the home, they had trouble finding mutually agreeable times for service with multiple families, and childcare centers often had policies that made service provision difficult or impossible. Control over the environment was an especially salient concern for providers who were asked to work in areas considered unsafe or where the distractions were intensely disturbing in nature. The open codes that comprised this category included *accessibility of materials, appointment flexibility, cooperation of childcare centers, control over distractions in environment, limited parent availability, and safety concerns.*

Accessibility of materials. Although they acknowledged a greater level of “carryover of education into their home environment” for children who worked with materials found in their homes, therapists generally complained about materials being more easily accessed within clinics. The behavioral therapist stated that whereas in the clinic all possible materials were readily available, when working in homes “you have to kind of lug all your toys with you, so we do a lot of play therapy and so when you go from place to place you have to take a lot of stuff with you.” ITDS providers and directors also held the view that using the child’s equipment in the home makes for easier generalization of

behavior. Among ITDS providers, some felt they should use their own tools while others felt that having the toys in the home is easier than having to carry around bags of toys but it is a problem when parents do not have toys. Some providers would recommend to parents where to obtain materials and purposefully use readily accessible materials. The parent educator argued for the importance of the state model which required using what is readily accessible to families, to facilitate a “family as therapist” model.

Now the state wants us to provide services in the natural environment where the child you know, lives and plays and interacts with people using the materials and toys and whatever they have accessible at home because they, and also they feel that you should not come in with a bag of toys or tricks because when you leave you take them with you and so...

Appointment flexibility. This code describes the scheduling concerns dealt with by both providers and parents. Providers said it facilitates work when parents and childcare centers are flexible. As one therapist argued:

They [parents] want you at a specific time on a specific day. I’ve had parents ask for Thursday afternoon at 4:00 and that’s the only time. I’ve had other parents ask for other specific times. So I would say that it’s parents are not very flexible.

This therapist went on to explain that when she has parents who pay for services at her clinic, she does not have the same problems with scheduling; rather, “they make themselves available when it’s convenient for me.” Other providers felt that many parents were not even working around job schedules as they were stay-at-home moms, but that they still wanted specific times that therapists could not make. Thus, when parents and providers demonstrate an unwillingness to coordinate schedules or make compromises with the other party, it creates a barrier to natural environment services.

Parents on the other hand feel that flexible providers who will work around their work schedules are wonderful. One parent described her delight as she learned the ITDS would be able to come on Saturday. Appointment flexibility was also recognized by

parents who took their children in for clinic-based services. One other parent spoke about how pleased she was that the speech center was able to schedule therapy for her twin children simultaneously.

I asked them to find me a time where I can maybe take them back-to-back, and she worked so efficiently and quickly to find me a day that I could go and take them back-to-back, so it's only one day that I have to, you know, take away from work and um, make up these hours, so they were great in that sense.

Limited parent availability. Limited parent availability was one of the major reasons parents were inflexible with their own schedules. The majority of parents in my study were employed and they often did not have the time to be at the home or centers when therapy takes place. Providers felt it is unrealistic for parents to present them with a very small window of time to conduct services, but parents felt torn by other commitments (mainly, work and other children). Some parents did not have the luxury to take time off of work. When one parent was asked what the biggest barrier was for her when it came to participating in services, she replied, "It's hard because I miss work or I might have to leave work early you know, it's one thing that I refuse to not be in there, you know, and active in whatever they're going through." Several parents discussed the difficulty in trying to juggle work and the need to be involved with their child's development.

One therapist acknowledged this and stated that one of the biggest barriers to providing services to families is "when you work with lower income people they're so busy putting food on the table that that's their number one priority. They're doing the best they can because they have two jobs."

Cooperation of childcare centers. This code describes the issues providers had with centers when attempting to provide services. The big question for this issue was whether

or not the center would allow providers to come in, and if so, with what restrictions.

These issues are summarized by an agency director:

Between 12:30 or even 11:30 and 2:30 is lunch and nap time, and centers are very protective at that time. They don't want services usually to be provided during that time. Um, and then some children get picked up early so by 3:00 they're done for the day so usually a lot of the services have to happen in the morning. Um, some centers don't want other people from the outside coming in, so that can be a challenge. Certain centers have specific requirements, like you have to get a background screening, you have to do this, this, and this, you have to put us on your insurance or we won't allow you to come in to our center which is very expensive per, for, for providers, and not usually worth doing.

Once providers are in a childcare center, other potential barriers exist, including whether the teachers are willing to work with the providers and the extent to which they are willing to listen to providers' suggestions. This is not always an issue, as one ITDS explains: "the teachers um, most of the time are on board, just because um, you know the child's not progressing and when you come in they see you as like a person that's going to help them through this process." The last aspect of childcare center cooperation is the ability and willingness of teachers to facilitate providers' services by either making a space available or making sure the other students do not interfere with sessions.

Control over distractions in environment. Distractions in the environment occur when outside of a controlled clinic setting. One ITDS provider reported preferring home environments because she felt more in control of her time and schedule; however, most of those interviewed felt that they had little to no control over the home setting.

I would have times where I would be doing therapy in a room with the child, um, and other children or the parent or the neighbor would just barge in. Um, so then you move or you do it someplace else, and I think when you're in the home that's one of the big things is you're always going to get interruptions. Sometimes you're there for one child and the parents like, well here you have them all now.

All providers acknowledged that in a home one cannot control the comings and goings of others, or the behavior of the parent (e.g., tv blaring, parents leaving to complete personal chores, etc.). In the childcare center, providers complained that they were not always able to get their own space to work with children without 30 other children vying for attention.

Safety concerns. This code represented a very concerning one for providers and directors alike. Several providers reported having experienced situations in the natural environment where they felt unsafe because of the neighborhood where the home was.

Safety is a big issue. You know, because some of the areas that our families are in here are not safe. We've had issues where providers have gone in in the middle of a drug deal, things like violence, all sorts of things. Some families will tell you "don't come to my house, it's not safe." You know, they live in a complex where there's a lot of violence and drug abuse so they'll tell you "don't come, today is not a good day." So safety is another issue.

In one case a director recalled a provider who went to a home and then called the center to tell them all four tires had been stolen off of her car. ITDS providers frequently reported meeting these children in alternate locations such as a park or McDonalds.

In summary, the issues of comfort with the model and the ability to control schedules and environments were very salient for service providers. When providers bought into the model of family centered care, the positive attitudes they carried to parents made this a facilitator to services. On the other hand, when therapists did not agree with the model, they would make arrangements that limited parent participation and parents assumed that this was always appropriate because the providers were the professionals. The ability to cut out the majority of environmental distractions was a major motivator for many therapists to steer clear of family centered natural environment models. In many ways, these issues were a gatekeeper for family centered care and if they were not resolved

successfully then service providers would often refuse to come to the natural environment, and their services simply were not family centered.

Theme 2: Negotiating roles in family centered care. The second theme in my findings represents the negotiation of roles in family centered care. This theme describes the family centered aspects that were clearest in this study as distinct from natural environment service issues. It was within this theme that the differences between “relational” and “participatory” practices that Dunst et al. (2006) referred to as essential for family centered care were reported by participants. All participants I interviewed agreed that the relational practices of providers should be positive and inviting for parents. Most providers also said they felt it was important to have parent involvement, however, when describing what that meant to them it often did not sound like the building and expansion of family capabilities or inclusion into decisions regarding goals and how to address goals that Dunst and his colleagues espoused. Most of the information in this theme is specific to family centered care, and much like the previous theme, these issues can represent barriers or facilitators to care depending on the perspectives of service providers. The conceptual categories contained in this theme are: *creating and maintaining a productive relationship, negotiating levels of family involvement, and involving caregivers in services.*

Creating and maintaining a productive relationship. Relationships between either therapists or ITDS and families were based on several factors. According to the participants, the relationship could be improved with good relational practices, such as, maintaining open communication, understanding the family system by utilizing the natural environment to conduct services, collaborating with team members across

disciplines, and being respectful of cultural and language differences. The open codes contained within this category included *family/provider relationship, maintaining open communication, lack of provider follow through, understand family system, collaborative work environment, cultural differences, and language barriers.*

Family/provider relationship. Relationships between the provider and family can develop positively when the therapist demonstrates patience, understanding of family positions, assisting family with extra needs, etc. When there is a positive relationship, parents are more likely to trust that providers are doing what they are supposed to be doing and thus support the provider: “Um, so, went to LHEI, um, met my coordinator who is fantastic um, and is just really, really kind and patient and um, very responsive to me.” As one ITDS put it, a lot of the positivity of parent/provider relationships depends on the provider’s ability to relate to a family. “Find some way to relate to them and really don’t expect them to come up to you, you come to whatever level they are.” Another ITDS explained that one of the best ways to facilitate parents’ involvement in services is “being patient and understanding, and never argue with the parents because it’s their child and you have to put yourself in their position and think that I would probably be the same way.”

Some providers felt that taking the time to form these relationships can be a waste, and that the possibility of becoming too friendly could endanger the proper therapist/family relationship and create a “dual relationship” that places the provider at risk of being taken advantage of by the parent.

Um, well with parents, God it’s hard, I mean working with parents is um, it’s challenging just because sometimes you know, like, when you talk to parents they just want to tell you, you know like, like everything about their day and how awful it is to be them, and it’s just all those things.

If the provider develops a negative relationship then parents become suspicious and may become less active participants or even consider removing their children from services. For this reason, family/provider relationships can be either a great help or a hindrance depending on how they are formed.

Maintain open communication. Maintaining open communication occurs when providers are diligent in updating parents on their children's progress and informing them about what is going on during sessions. A program director explained how this facilitates family centered care and stressed the importance of "Keeping the parents informed about their child's progress so especially at the childcare center, um, because they [childcare center] may not have that interaction with the parent on a regular basis so calling them and saying, this is where we're at."

Having open communication is essential to creating a positive family/provider relationship; providers who do not have good communication often upset parents. When asked what they wanted the most in a relationship with a provider one family replied that providers should "keep me posted on everything. You know, that they, they, if something happens they tell me, and they can't make it one time they let me know, you know, if they're going to be late they let me know." Both service coordinators and providers are expected to make regular contact with the families. One service coordinator summarized the need for open communication by explaining:

[The] program works well when there are communication and assistance from both parties, you know. The right hand needs to know what the left hand is doing, ok? So um, when there is tight, tight communication and everybody knows you know, um, what we're doing as a whole, it works best that way, you know.

One aspect of open communication that ITDS providers felt was important was for parents to communicate clearly their needs for their children; further, ITDS wanted parents to deal with the provider directly when problems did arise. She explained “some parents get um, frustrated, scared, and most of the time instead of calling the ITDS they end up calling the service coordinator, which I see its ok, you know, some ITDS may not like that.”

Lack of provider follow through. In contrast to the previous code of providers maintaining open communication, many of the families reported having either a service coordinator or a service provider tell them something and either not follow through with the recommendation or simply not call to schedule appointments or services. Parents reported calling, e-mailing, and sometimes waiting months to hear from both service coordinators and providers to no avail. One parent described her ordeal as being incredibly difficult:

I probably didn't appreciate was that her, her, she had a physical therapist who, Early um, [LHEI], and her, for some reason, ok he came one time, did the evaluation, and then didn't come back. So I called you know, [LHEI], and I was like, “Hey um,” and she was like, “Ohh he hasn't been there?” And I was like, “No he hasn't been here in like a week and a half.” And she's supposed to have her physical therapy once every week, so she was like, “Oh I'm going to call and find out what's going on.” I said, “Alright.” So like two weeks later after I keep calling her, then, I'm like, “Look, she needs her therapy, what's going on?” “Oh, well, ... when he ran her, the information, it came up that she's still under [insurance provider].” I said, “Listen, how am I supposed to know this if you people don't call and tell me? How am I supposed to know what's going on if, if you guys don't keep me posted?” And she's like, “Oh well I'm gonna go ahead and um, you know, send him the correct information.” I said, “Yea. I've already you know, had the correct information emailed, um, faxed to you by [insurance provider].” So she was like, “Alright, alright, well I'm gonna go ahead and call him.” So I said, “Alright.” Girl, like two, three weeks later passed. And I'm calling, I'm calling, you know, I harass people.

The providers also complained about the perceived lack of follow through on the part of service coordinators. One ITDS explained how she felt “like a lot of them [parents] just aren’t being led the way I’ve learned that it should happen. You know, like phone calls, you know, the service coordinator, you know, coordinating services, helping them you know.” She said this led to a lot of disillusionment amongst parents and required parents to become tenacious in their efforts to obtain quality service for their children.

Understand family system. Understanding the family system is something that some providers felt was a major benefit of natural environment services. This understanding of families allows the provider to take into account environmental factors that may be of assistance in service provision, and can lead to the connecting of needed community resources as well as an increase in positive family/provider relationships.. One ITDS provider explained how visiting the home allows providers to see “what’s going on and how people act in their natural environment cause sometimes you know, they come to you and it’s you know, a very different scene, um, than what’s really going on at home.” The behavior therapist also felt that understanding the family system was important; however, she knew this came at the expense of profitability and balancing resources in the clinic.

Collaborative work environment. Collaborative work environments develop when providers work across disciplines with one another in a positive manner and agency directors or administrators sit down together to resolve issues. The lack of collaboration between the LHEI agency and providers was an issue for agencies providing ITDS services. One agency director complained that it made her want to take her business

elsewhere, contributing further to the limited providers willing to work early intervention.

This director lamented the negative relationship with LHEI and explains:

They [LHEI] don't sit with us with the providers. Ok what do you think is the best for you? What do you think something might change to make it better? Or what are the things that you think that are the least important that we can just take it out and do something that makes something best for you in the program? No, they don't.

Cultural differences. Nearly all of the providers reported feeling that the cultural differences in the diverse city where they work are taxing to their ability to provide quality family centered care. Views on the role of parents, deference to authority, and “machismo” were all reported to be barriers for families from Latino backgrounds. One therapist expressed her difficulty with this even though she herself was Latina and “proud” of her Cuban heritage:

I think one of the barriers is probably cultural, mmkay- because every single culture views their ability to work with children differently and their role with that child differently. For example, Hispanic families, by and large, unless they've been acculturated, they are not the teachers of their children. They teach them manners, they teach them their social skills, but they are not their teachers. Their teachers are their teachers. And so this whole thing of sitting down with a child and doing homework and you know, Hispanics normally they do not play like, um, they don't play learning games [...] so what happens is this whole idea of sitting down with your child is foreign to them.

Similarly, of the service coordinators who herself was Columbian explained in detail how families from Mexican backgrounds and Latin American countries would often simply defer to whatever it was that they were told by people they perceived as being educated (e.g., doctors, therapists, service coordinators, ITDS). One ITDS stressed that the importance of keeping up with and respecting the cultural values of parents cannot be overstated because families who feel their values are not being respected are not likely to respond to services.

Language barriers. The findings related to language issues will be detailed later through this code that demonstrates the true diversity of the city in which the study was conducted. Many of the providers interviewed for this study and employed throughout the area are bilingual; however a good majority of the ITDS providers who do conduct home based services do not speak English fluently. Families and providers who speak different languages have a hard time understanding one another, and frequently in this city the provider's native language is not English. English-speaking families will often request providers who do not "have an accent" in order to better understand the people working with their children. One ITDS explains:

They [families] want fluent English, they want fluent English, they do. I mean I've had, I've, I've had cases where I have received children of other teachers, you know, providers, where they don't speak fluent, fluent English and I've had to, they've given me those children because they don't have too many ITDS who speak fluent, fluent English.

In other cases, families from Spanish-speaking backgrounds will request providers with fluent English skills to work with their children because they don't want their children to have the confusion of two languages, or they do not want to raise their child with a Spanish accent. The mix of both types of families requesting English-only ITDS providers contributes to the insufficient number of English-speaking providers.

Negotiating levels of family involvement. Creating and maintaining productive relationships between service providers and families is essential for family centered care. When providers went out of their way to foster these relationships, it would increase the parents' interest in becoming involved in service provision. The next issue of concern for these providers was negotiating how actively the parents would be involved and how much providers were willing to relinquish their professional control to enhance the

families' capabilities. Negotiating levels of family involvement describes the give and take of parents and providers working within early intervention. This conceptual category breaks down the differences between providers who simply inform parents of what they will do with children versus those who take on parents as partners in the provision of services. The six open codes in this category include: *parent tenacity*, *providers limiting parent participation*, *providers as babysitters*, *providers telling parents goals*, *providers including family*, and *encouraging caregiver involvement*.

Parent tenacity. In cases where parents were faced with providers who did not follow through with what they said they would do, tenacious parents continued to call and find ways to advocate for their child despite the lack of support. In this way, parents could negotiate stronger roles for themselves even when providers were purposefully or inadvertently limiting them due to a lack of follow through. One of the most tenacious parents interviewed in this study describes how important it is for parents to educate themselves and remain persistent in the effort to get what they need/want for their children.

So parents that I talk to that want to be involved in their children's care and want to discuss things with the doctor, the first thing you have to do is educate yourself. You don't have to go get your medical degree, of course not, but you have to talk to other moms and you have to talk to other people who have been through it, see what's going on, you know, try and find other kids that are similar to your child's cases, see what's worked for them. Go online, go find other families that have had this situation that you're in.

Therapist limiting parent participation. This code describes providers' explanations for wanting parents to give them individual time working with children. Parents describe being asked to stay out of a room or refrain from entering the clinic where the sessions take place by therapists who want to have individual time with children. Therapists may

permit parents to observe when there are two-way mirrors or windows, but only if they know the child will not see them. One speech therapist was of the opinion that having parents observe sessions through one-way mirrors could bring about a high level of parent participation: “Our families are able to come here and watch therapy because all of our obs- therapy rooms have observation rooms. Like you see mine, that little glass is a two-way mirror.” She went on to explain how she would “include” parents “when I saw patients I would go outside or I would always bring them in the last five minutes. This is what I want you to do; this is how I want you to practice this...”

ITDS providers also reported needing to purposefully limit parent participation. One ITDS provider explained her ideal: “I think it’s better to work with the child half the time, and the other half include the parent, because that child needs to become independent.” In a different line of reasoning, one ITDS explained why she felt the ideal place for the parent was out of the area:

Um, not so much in the room um, because that also affects the child’s behavior, you know, because a lot of these children they have perfect behavior with me and once they see mom or dad it just completely goes out the window. So I mean, just like in a separate room maybe, you know, if like in a glass if there’s like a glass door they can put and maybe if they want to watch, but not in, I, I, I wouldn’t say in the same room as me, I don’t think that’s a good idea.

Parent reactions to providers’ purposeful limiting of their participation ranged from initial confusion and hurt to understanding and a feeling that providers need to be left alone to just “do their thing.” One parent described her initial reaction to being asked to stay out of the room as “at first I will say I was kind of like, what? You’re going to take my son and I’m going to be in the waiting room?” She went on to explain that now she preferred it that way, so that she did not distract her son during therapy. Other families

echoed this idea: “He won’t work when I’m there. He wants me to hold him, I’ll be peeking and see what she does, but I’m not there.”

Other parents who wanted to be in the room regardless described their frustration with therapists who refused to allow them into the room: “But I went and they told me, ‘No you have to stay out there.’ I went and when they went and took him into the room, I had gone back and staring through the window.” This attitude of providers who felt the need to exclude parents contributed to the notion that a therapist can “fix” the child and parents seemed to become more entrenched with the idea that they are not qualified to help.

Providers as babysitters. The issue of providers being regarded as babysitters describes the general attitude of parents whom providers felt were treating services as a means of gaining free time to either rest or do some work that has been put off. Providers describe being frustrated by parents who do not want to stay in the room or watch the therapy session through the window. The parent educator explained that this was a major issue for many of the ITDS providers she dealt with:

Ok, what happens is the families um, see sometimes the therapists or the ITDS and somebody’s got to come in to give them a break, so instead of sitting with the ITDS to observe what they’re doing they go wash clothes, and, and I’m not saying that they don’t have a lot to do. Attend to another child, make a phone call, they have gone as far as to say, ‘I’m going, I need to go to the store.’

More extreme behaviors some of the ITDS providers complained of included parents leaving the room in order to engage in intercourse or leaving the house for several hours to run shopping errands while the providers were left with the children in the home.

Providers telling parents goals. Both therapists and ITDS service providers would often tell parents the goals or services with varying degrees of parent input. Some

providers reported trying to integrate parent input, and having to fill in the blanks from uninvolved parents or trying to translate family goals into workable benchmarks.

Well generally the parent is just concerned about the delay and that their child, most parents want to make sure that their child is at an age-appropriate level so I choose a goal by something that is reachable, I choose something that the child can reach because I'm looking for just right challenge for each child. So I choose the goals that are most reachable.

Other providers reported being incredulous at the idea that parents would know how to break down instruction and thus saw their role as telling parents how to reach a goal because that is what they as providers are trained to do. The speech therapist I interviewed replied when I asked her how parent preference was considered when developing goals:

I think most parents want you to guide them because that's why they're here, you know, and I think that sometimes and this is, this is my own personal opinion, let me preface that, I think that we give parents a lot of um, a lot of, what's the word that I'm thinking about? Like, you know, the parents need to be involved in what they want to see their child to do. I want him to speak. I want him to walk in a straight line. But how to get there, that's what we go to school for. So how do you want a child to walk in a straight line, well the first thing that he needs is this, to do this, then he needs to do this, then this is how that develops. That's what our expertise is. So for them to tell us what to work on, I think is like, it's almost demeaning, you know? And sometimes I feel like we want to empower the parents, and empower the parents, well empower the parents for what? I mean what are we talking about? We are empowering them to get services? To go to see a specialist?

When dealing with providers, parents usually acquiesce to what the provider wants to work on in terms of goals, however some parents reported arguing and developing negative relationships with providers who wanted to significantly change their child's therapy against the parent's better judgment.

Provider including family. Providers who include the family acknowledged the importance of having family members involved in sessions, and parents generally felt

that these providers were encouraging them to be present. One such provider was described by a service coordinator as being “really awesome” because “she’ll do things like in the middle of the intervention if they’re playing with a ball, she and the child are playing with the ball, she’ll throw it to mom and say, mom catch!” One parent expressed her appreciation with being included when she described a session with her son’s ITDS, who would say something and have the mom repeat it to the child “Or we would do the ring around the Rosie and I would do it with them and she, so yes, she involved me a lot. I think she’s wonderful.”

These providers will attempt to engage caregivers however often with the caveat of limiting parent participation and making sure the therapist gets sufficient one-on-one time with the child. Providers often said it is important to include the family right before or after while keeping them out of the way when needed. One therapist explained that her perspective had changed once she had children of her own, but she still felt there were legitimate reasons to limit parent participation.

How I used to look at things prior to children and how I look at them now are probably on two ends of the spectrum. Um, I have had to ask parents to step out, um, this is prior to, would I take a different approach now, probably. Um, but I guess if it’s interfering with the child’s ability to concentrate or focus then I guess that’s where you know, it’s typical to have the parents step out. I think at this point though I would still try to incorporate, I would really push through and find, find a way to make that work and just ask the parents to, to really help me be creative to find a solution to that because ultimately the goal is to teach the parents and if they’re not there observing, they’re not going to really learn.

Encouraging caregiver involvement. Providers reaching out to the parents and really encouraging them to get involved in the evaluation or the session was similar to providers including parents, however this code was distinct in that it involved more of an active role of therapists in the caregivers’ lives. This could take place with parents or

other family members, or teachers in a childcare center. The important characteristic of this code is that a service provider is actively attempting to get caregivers involved with the services being provided. One manner of encouraging involvement is by providing strategies for parents to use and explicitly teaching how to use them - modeling for parents what they should do and giving them written materials on how they can be involved. One therapist reported that one way she tried to engage parents was to recommend a book about conscious discipline to parents because “that’s how I run my therapy sessions. And I love it when the parents watch because they see that I have a different way of speaking with their child.” A service coordinator described this idea as “really trying to work with them [families] and giving them strategies, getting them to come join the sessions so that the therapists can model for the parent what they can do to stimulate their child’s development.”

Parents appreciated having tangible information on what they should do and often felt lost when this information was not presented or it was not thoroughly explained or modeled. One family made it clear that even when they were not involved in the actual session they could still feel included when therapists made an effort to do so: “They give us a lot of um, feedback and a lot of ideas, for instance with my son, um, they had recommended ... that we make some um, flashcards with pictures of, of just me, or my husband...” Another family described the current ITDS provider as being incredibly encouraging of her participation and described a typical session as him entering the house and the two conversing before he began working with the child:

Um, sometimes I follow him [ITDS] in there and let him get settled in and if I feel like he doesn’t, or he will say, “Well I need you to do this with him,” also, “I need you to, that’s why I went out and brought the puzzles, I need you to do this, I need you to have him do this, you know, because he has to learn at home too.” Which is- I

do, I read books ... with the puzzles I try to show him so I did go out and do that, so he does tell me to help him, you know, with the therapy. Like when he's gone, continue to do it.

Involving caregivers in services. Involving caregivers in services is a conceptual category that describes the issues determining whether or not providers (therapists or ITDS) attempt to involve families at any level as well as the willingness of parents to go along with diagnoses and involve themselves in services. It differs from the negotiation of roles inasmuch as without the involvement of caregivers, there are few instances of role negotiation. In a case with little involvement, services would take place either in the home or clinic with very little input from families. The same is true for childcare centers that do not welcome services; they may never get involved with the ITDS or therapist and are unlikely to conduct any supporting activities. The open codes contained within this category include: *parent agreement with diagnosis, caregiver willingness to get involved, family concerns- priority, integrating parent input, motivated by child progress, family as therapist model, and cooperation of childcare center.*

Parent agreement with diagnosis. The parents' agreement with the diagnoses given to their children, whether implicitly or explicitly, is perhaps the main gate through which any participation can occur. Some parents do not feel that their child is delayed, and therefore do not buy in to the services being provided. Parents may not accept that there is a developmentally different way in which their child must be raised and fear for their child being labeled. In cases where a referral came from a pediatrician, many families are in disagreement with the doctors' and providers' opinions and may go along reluctantly with recommendations.

Many providers say that parents struggle with diagnoses and vary from denying that there is a problem to handing the child over to a therapist and saying, “the problem is in the child, fix it.” One therapist describes parent reactions to diagnoses as sometimes “not wanting to hear the severity of what they may be facing, um, and the prognosis, you know, for a child maybe who was just recently diagnosed with cerebral palsy or, or autism.” The parent educator interviewed explained that often a family “comes in because the pediatrician referred but they don’t see, they don’t see the need to come here, they don’t see the delay because they themselves, they say they started talking when they were 4 or 5 years old.”

This difficulty was summarized by an ITDS who explained how parent responses to a diagnosis determine whether or not they will be involved in services in a meaningful way:

You know really it just depends on if the parents, one, really understand that there’s a problem, you know and they agree with, with what their pediatrician told them and they agree with the assessment and they want to help their child. You know, so it just depends, and you know I’ve worked with all levels, the socio, socio-economic across all cultures and if they really understand that there’s a problem, they really want to help the child then the services you know, make a difference.

Caregiver willingness to get involved. Caregiver’s willingness to get involved describes the parental or classroom teachers’ attitude that they ought to be speaking with and working with the provider. It is the antithesis to the “fix my child” idea that many parents hold; providers find it very helpful when parents are willing to take the recommendations seriously. One of the program directors interviewed stated that a great facilitator of family centered care was that “If they’re [parents], you know, if they feel this is worthwhile then it, um, facilitates everything. If they make the appointments, if they’re willing to participate in the sessions then it makes everything go smoother.”

Caregiver involvement is related to the provision of home activities, inasmuch as providers who recommend home activities to parents who do not do them feel that the parent is less involved with their child. Most providers agree that some families just do not wish to be involved with their children at all either for fear or lack of care. One therapist reported that “Sometimes you get parents that really have the attitude that the problem is the child and that they have nothing to do with it and that there’s nothing for them to do.” An ITDS explained that it is this willingness to get involved that determines the effectiveness of interventions, “you either have families that want to be involved or that don’t, so the ones that want to be involved, those are the ones that I see the results.” Parents often do not know what their role is and in turn describe wanting to be involved in ways that are not bothersome to providers.

Family concerns – priority. In family centered care, family concerns take precedence over the providers’ concerns and goals for the child. The idea here is to acknowledge that parents have the final say in their child’s education as well as to enhance family buy in to the goals and make them functional for the family. This aspect of care forces providers to respect that it is the family that makes the ultimate decision for what is best for the child. The parent educator made it clear that it was important to meet families where they are at and “whatever they want to work on whether it’s in your plans or not, try to um, try to include it in your plan in a way that you are kind of working at what you went there to accomplish...”

Several ITDS providers argued that this is important and difficult, that even if providers feel something is important, they must integrate it into the realm of what the family feels is most important. One program director made this position clear:

Where the family, you know, you test the child, you see the child has motor and speech and cognitive delays and that's your concern and then the family says, "But I just want to be able to take him to the park." You know, well you know, hey come on, you know; take him to the park, that's the least of his problems. But that's what the family's there for and that's what they want, that's their concern and basically that's what we deal with. That's what we're supposed to deal with. But we have people that say, "Hey, come on lady, you know, what do you mean take him to the park?" So you really have to get into a realm of being family centered and dealing with the family's concerns primarily.

Parents reported having concerns that were generally simple: "they asked me what was my overall goal in the first initial and it was more for him to be able to stretch out his arms and be like 'mommy', like you know, that's what I really wanted." One ITDS expressed the importance of listening to the family's concerns, stating, "I can't stress the importance of two ears and one mouth, and, and talking to them a lot those first few sessions so that you know the family, makes a huge thing."

Integrating parent input. This code describes how parents are asked about their concerns and then how providers may help parents translate these goals into workable objectives and integrate these concerns with their treatment plans and what their expertise leads them to consider. One ITDS described this process as "getting a clear understanding as to what their true concern is is probably, you know, and translating that into something that's developmentally relevant." One of the therapists explained how parents were made part of the process of goal development:

[Parents] have to participate in the treatment planning of it. So if the therapist goes and meets with the child several times at the school and devises a treatment plan, she has to meet with the parents and go over it with her so that it's not that it was just the therapist and the parent has to agree, but has the opportunity to change the treatment plan as well if there are things that they want to work on.

In some cases where parents are unavailable this can be as simple as looking over the Individualized Family Support Plan (IFSP) and including the priorities mentioned by

the family at the initial meeting. One of the service coordinators explained that during this process she often had to help parents make their concerns clear: “half of the time you know they need help to just creating that, because it’s like, ‘Ok I want my child to talk.’ Ok, can you be a little bit more specific. To say what?” In other cases providers will offer ideas and bounce them off parents. This input may be garnered over time, and as previous goals are reached new ones may be developed with the parents’ input. Some ITDS providers explained that parents may be too flustered in the beginning of services to offer their input however providers were adamant about including parents because they were often able to give input later on. Ultimately providers must respect the fact that family concerns are top priority if they are to be successful at integrating parent input.

Motivated by child progress. Providers enjoy seeing students make progress and reported a feeling of satisfaction with their job when they saw a child progress; likewise, parents become more enthusiastic and supportive of early intervention when they see their children begin to progress. One ITDS reported, “We have families in the beginning they don’t care, they don’t think it’s important, but when they see that the child is progressing, the child is making changes and then they say, ok, and then they pay attention more.”

This is one way a provider can begin to really encourage family participation; several instances were reported where parents who were previously unwilling to get involved suddenly became interested when they noticed the progress of their child. Conversely, providers who are emotionally removed and distant and whose students are not progressing are more likely to “lose” parents. The parent educator I interviewed explained the phenomenon:

Um, once they [parents] see that the child is making even a little progress, um, and that maybe they give him one thing to do for that week and the parents come back and see and they report a little progress is like they're, they're really get, they really get hooked into, into working with that child because they see that, "Ok you're assisting me, you're giving me strategies, now I try this with my child and it's working, I want to continue." So um, when the family sees that the child is making no progress or the therapist really is kind of cold, you know, um, they don't go back, you know, they want somebody that's energetic, fun, you know, they bring them in, you kind of have to lure them in, um, reward them.

Family as therapist model. This code was described in great detail earlier, and was double coded in the categories of *involving caregivers in service* and *comfort and buy-in to model* because of the natural overlap this issue held within family centered care. Of course those providers that bought into the family as therapist model were more likely to encourage parents and work with them to get them involved in services.

Theme 3: Managing scarce resources. The first two themes I have reported have addressed issues mostly involving family centered care, with some inevitable overlap with natural environment concerns because the model in place for LHEI utilized both in a complementary manner. The theoretical buy-in to the model was a gatekeeper for many service providers, and many therapists reported that they did not agree with the idea that parents could or should become primary therapists for their children. This issue in turn affected the negotiation of roles within services and sessions. Most providers felt that maintaining a positive relationship and having good relational skills were sufficient for providing family centered care. Parents often reported not knowing what to expect, and assuming the manner in which services were provided were appropriate because of their faith in the professionals' expert knowledge. Depending on the perspective and attitude of the participants, the individual issues reported within these first two themes could be considered barriers or facilitators of family centered care.

The last theme I present here is more specific to natural environment services and addresses issues that were reported as barriers by all participants. The management of scarce resources is a theme that encompasses the biggest barriers in terms of providing services in the natural environment. The issues in the underlying categories are things that were unequivocally problematic for providers and families and must be addressed as they inhibit services regardless of the perspectives of the individuals interviewed. The three conceptual categories that underlay this theme are *community resourcing*, *delays across all levels of service*, and *economy of natural environment service*.

Community resourcing. This category describes the community outreach and resources that were available to parents and how they were (or were not) made available to families. In several cases, parents reported not knowing about early intervention or any other options they had for their children. Providers reported doing their best to inform those parents they associated with about programs that might be of assistance, but there was very little in the way of organized dissemination of information. Open codes that form this category include *referral sources*, *initial contact*, *evaluation/eligibility determination*, *connecting to community resources*, and *transition to public school system*.

Referral sources. Referral sources come primarily from pediatricians or other professionals working with families who have children with medical needs. Few providers acknowledge doing any kind of outreach to inform families of LHEI, and families often say their doctors took too long to refer which resulted in insufficient time in the system to really help their children. The program directors at LHEI also made it clear that although referrals were allowed from “anywhere” they came primarily from

pediatricians. Some families are referred through a familial word-of-mouth reference, but even families that knew of the program were unlikely to bring their child in for an evaluation without an official letter of referral from a pediatrician. Pediatricians and other providers are legally required to make referrals; however families and providers complained that they oftentimes neglect referring until the child is older than two years.

Initial contact. An initial contact is the first attempt by service coordinators to gather information from the family after a referral is made; packets of information are provided to the family regarding the program and other possible resources they may need. The service coordinators make this initial contact and can either conduct the meeting by phone, in the office, via e-mail, or in the natural environment. Families thus learn more about the program and decide if they want to continue to the stage of child evaluations. This meeting can serve to give coordinators some understanding of the family system.

According to one service coordinator this initial contact:

Could be face to face, that could be by phone, you know. Many times it could be done in the home. You know, sometimes uh, some of us do like to a, get a feel of what the home environment is like and so we go to the home, um, to do the first contact. Now this state has allowed for us to do it over the phone, you know. And you know, in certain extreme cases you know, like if the parent cannot meet me you know, my schedule you know, because they work the same schedule that I do, you know, sometimes I have to, if the family you know requests that, it could be faxed, the paperwork can be faxed or emailed to the families or mailed to the families.

Evaluation/eligibility determination. Child evaluation is conducted on several levels. In the first level, children are evaluated at LHEI to see if they qualify for the program. Eligibility requirements for this program have been restricted in recent years and it is becoming harder for children to qualify. Children, as one director stated, “have to meet a specific criteria. It has to be an established condition, it has to be an established developmental delay, or it has to be by informed clinical opinion based on judgment of a

team.” As one service coordinator explained, as the eligibility requirements tightened “a lot of the kids that were be able to qualify before maybe there is, you know, a low score but not low enough to qualify for a program, so the parents will have to seek other means” and went on to say that parents were often recommended to try their private insurance for coverage. Children who are ineligible may be referred to community resources whereas eligible children will continue with referrals to providers.

The second level of evaluation occurs once eligibility is determined, when students are referred to providers from whom they will receive another evaluation used to establish baseline. Evaluation is conducted on-site at LHEI and parents generally feel that it is done well. Parents are asked not to assist therapists during the assessment process and reported feeling that this was reasonable in order to get a fair picture of their children’s capabilities.

Connecting to community resources. Connecting to community resources is something that is done if a family is ineligible for services or is in need of more services than the agency can provide. A family liaison or resource specialist, particularly one who has experience as a parent of a child with special needs, is ideal to fulfill this purpose.

The director at one of the LHEI agencies reported that when a family is ineligible:

We may tell the family that the child has a, you know a slight delay and we recommend that the family access, using their insurance, private therapy depending on the area. We also have, [this] county has the Young Minds program which is funded by the Children’s Trust, for children who do not qualify for early for early intervention. Prior to the criteria that we have now, we would refer children who exhibited anywhere between a 10 and 24% delay we would refer those children on to that program.

Having providers that work within a particular community facilitates their ability to become familiar with the community resources that are available to families. Several

providers and service coordinators mentioned that the ability to refer families to appropriate community resources was a benefit to working within a limited geographic region. Unfortunately, the majority of providers admitted to not being well-informed about the resources across the county, and as services were often spread out between different regions, there was oftentimes a disconnect for families.

Outreach efforts. According to the service coordinators and program directors interviewed for this study, intervention agencies rarely conduct any community outreach to inform parents and families of the Part C services to which they may be entitled. Directors report advertising and informing subcontracted providers and sending information to pediatricians, and stating that state level information is available (e.g., the LHEI webpage on the Children's Medical Services page). As one director stated, "There are state-wide efforts made. You know, advertisements and things like that to inform the general population. We don't do a lot of that in Miami to basically solicit families. Uh, we haven't done a lot of community education."

Recruiters are being hired to get providers to join LHEI and agree to provide services. Parents report not having known about LHEI, and even some who had friends and family currently enrolled in early intervention services through LHEI, did not realize their children might be eligible. One family explained:

We knew about um, that there was programs like this because my cousin's daughter was born at 5 months, um, but my, my thought was always because I was wrapped up in what was going on with my children, the helmets, the apnea, the monitors, the reflux, all of that, that well if someone hadn't said it to me it must be that they're just not preemie enough, you know, or maybe they weren't born early enough to qualify for things like this. Um because my mom, you know my cousins mom would tell my mom, "Oh what about this and this and this." Oh, well nobody has said anything to me.

One ITDS reported acting as a community outreach agent when she went about her daily routines, however on the whole there were no efforts made to reach out to the immediate community.

Transition to public school system. When families have children who are turning three, they go through a process to transition into early childhood special education services and have two choices: they can opt to share the information from LHEI with the school system and begin evaluation right away, or opt out and have none of the information from LHEI follow their child. Parents should be informed of their options and have a “transition meeting” sometime between 33-35 months of age. Only one parent I interviewed was in the process of approaching this benchmark, and she complained bitterly that they had waited until a “week” before her son turned three to tell her about the meeting. She said now she felt that she would have to scramble to make sure his information made it to the right people in the district, and she had no idea who those people were.

Overall, the level of community outreach and resources provided to parents appeared to leave parents feeling overwhelmed and under informed. Providers in turn felt that they were unable to be aware of everything that was available when faced with the sprawling community in which they worked. In cases where resources were made available, the next difficulty faced by families was the delays that were experienced at each level of service provision and transition.

Delays across all levels of service. The delays seen across all levels of service were a barrier to services across the board. The process of referral, assessment, beginning of service provision, and timely transition to the public school system were all points of

severe delays for families. This was driven by short-staffed agencies, confusion among insurance companies and providers, lack of follow through on the part of service providers, limited providers, and referral sources who did not stress the importance of early intervention to parents.

Service delays. Service delays are caused by several factors including late referrals and a failure of service coordinators or providers to follow up with parents after the initial referral and evaluation are conducted. LHEI has a limited number of days from referral to evaluate a child, and oftentimes families are not seen until the last day of that deadline. Additionally, once they are evaluated, children are often placed on the waiting lists of providers who are limited and do not want to provide natural environment services. LHEI tries to make up for service delays by hiring ITDS providers to work with children in the interim, however they are placed between a rock and a hard place inasmuch as services have a legally limited amount of time to begin, and providers are not legally required to contract their services to LHEI. As one of the service coordinators explained:

Unfortunately you know, when there is um, when there is no insurance that's where the parents have to deal with you know, and on top of that we also have waiting lists, you know, not, not [LHEI] per se, but the providers. You know, like um, let's say you know um, waiting list for Miami Children's for speech therapy might be um, um two or three months. And that's two or three months that the child might lose if he doesn't have any other choice so we can offer something in, in the meantime you know like a teacher, you know, like at least a child will be receiving some kind of stimulation from some kind of service.

The disconnect between service coordinators and providers is also a cause of delays for families. In one case a mother reported that she received an evaluation and then did not hear back from the provider for months. She said that she eventually "just got frustrated to the point where I actually emailed my whatever case worker, social

worker, and she apologized, she didn't realize that he still wasn't placed in a program."

Another parent lamented her experience with specialists: "this the bad part, it's so hard to get an appointment with some of these places. Very hard. Very, extremely hard. That's the only thing that I don't like."

Short staffed. As a result of the insufficient funding provided by the state to Part C agencies, directors reported that they are short-staffed and have increased workloads for service coordinators across the board. Caseloads are estimated by the directors and service coordinators at approximately 80 children per coordinator. The state recommendation for a reasonable caseload is only 35. A director declared at one point in an interview, "Our service coordinators have anywhere from 75 to 85 families each and that's you know, that's insane. You can't do a good job with that kind of numbers, but that's a limitation of funding." Additional changes in pay schedules for service coordinators have shifted them from being paid a salary to an hourly wage. This has cut down the amount of time service coordinators can spend flexibly managing their workloads, and has resulted in the cutting of consultation meetings between therapists and ITDS providers. One of the service coordinators described her dilemma: "unfortunately it's a lot of times, you know, like I would like to spend more time with the mother that may be you know, this early got a diagnosis for PDD [pervasive developmental delay] but I can't because my other family's waiting." The issue of understaffing contributes to the service delays experienced by families attempting to obtain services and evaluations.

Insurance company confusions. When families cannot access their own private insurance to pay for the services, LHEI becomes the payer of last resort. The issue of

insurance company confusion is often caused by insurance companies that deny claims from providers for services. In other cases, LHEI may refer a child to a provider and not communicate with the provider what insurance is held by the family. Not all providers accept all insurance policies, so in these cases providers have a difficult time even obtaining a letter of denial from insurance companies. Without this letter, they cannot apply for reimbursement from LHEI. In these cases, the issue of insufficient reimbursement becomes a problem for the providers and makes them less likely to provide services to families enrolled. An example of this kind of issue is quoted at length here from one of the therapists who had just decided to cease being a provider to LHEI at the time of the interview. When asked what kinds of issues she was experiencing with regard to financing, she explained:

They, [LHEI] for you to get paid by them because they are the payer of last resort. You must access everything else before you bill them. So once you take on an [LHEI] case, you say ok "What insurance do you have?" "Oh, [insurance A]." Perfect. You have to bill [insurance A], and when [insurance A] gives you a denial you have to attach that to your bill, ok? And then they pay you. Now, here's where it all gets murky. That seems very logical, ok? Number one, they send you clients that you do not, um, that you are not a provider for their insurance. So I would always tell them "Don't send me [insurance B], because I am not a provider for [insurance B]." Well, and, [insurance B] does not have a- a reason to talk to me, so even if I send them a bill, first of all I'm doing what I, they didn't understand is that I'm doing something that's almost illegal, because how can I send [them] a bill when I am not a provider for them? That's like, ha-ha, like me sending a bill to you for doing speech therapy. Like, we do not have a relationship. And I kept saying to them, "um, don't do this, don't send the patients over. Find out what their insurance is before you send them to me. "Because, then we would try to get that denial and of course it would never come. Ok? So that was once of the reasons, the lack of denial, but the denial was for a good reason, ok? The other thing was, they pay ok? So they would say ok, "well you don't have your paperwork." "Yes, we have our paperwork, it says there, we do not provide therapy for [alternate insurance]." "But the patient lives three blocks from our office. Now what is that you want? You want to send them to [location 25

miles south]?” “Go ahead.” But, what I’m telling you is that we can see this and we would tell them, they would say go ahead, go ahead, and then when it would get to the billing person who didn’t have communication with the other person with the case worker, they would deny it, and there would start the problems. And this happened so many times I said this is enough.

Lack of provider follow through. The lack of provider follow through that was described earlier is a significant barrier to natural environment service because it delays services and disheartens families wanting to be involved. This issue is salient in this category because providers who do not follow through with services in a timely manner often leave parents wondering if they should take further action on their own. These parents may go months awaiting providers follow up, significantly delaying services for their children.

Limited providers. The demand for providers far outweighs the number of providers available in the community. There are even fewer providers who are willing to travel to the natural environment because of the lowered productivity and high costs associated with travel. According to the parent educator interviewed, “lack of providers is the main, the main challenge.”

there are some areas that we have nobody services. I mean nobody will go into those areas. And not all of them are inner city; some of them are just areas where there are no providers. They’re too far away on Miami Beach, you know, somebody who is located in Coral Gables is not going to travel all the way to Miami Beach and back, so there are areas that are completely underserved.

One mother was insistent that all services for her children be held in the natural environment, and explained that the greatest difficulty she had experienced in early intervention was:

Find the resources, so um, like I spoke about earlier it’s very hard to find certain areas because there’s a shortage in therapists. There’s, it’s very difficult to get it

paid for, um, because when you have homebound you then have to have Medicaid or [LHEI] for the travel. The evaluation in the home and the travel, and the homebound therapists. Um, so getting it paid for, finding the therapists, and finding the um, companies that will allow homebound because I, I don't know why they're so tight on homebound. Maybe because they can't see as many patients, cause you're going to see more patients clinically based because you don't have the travel time and you don't have the distance so I think it's probably more economical to have clinic based therapies. I, I can't figure out why it has to be financially or business driven as to why most places don't offer homebound, except in severe cases, but I don't agree with it.

Referral sources. Referral sources, as previously mentioned, are a cause for delays in service because, although referrals can come from any source, generally pediatricians take a “wait and see” approach to early intervention. Several families complained that even though they spoke with their doctors about possible delays, they were not told about LHEI until their children were two years old. When considering all of the other delays that exist in terms of evaluation and the start of services, it is apparent that there are many reasons that services are riddled with delays.

Service delays like those reported above were problematic for all families and providers. They occurred at the stages of referral, assessment, service provision, and transition to the public school system. Although it appeared that issues with limited providers were often to blame for many delays, short staffing and a lack of early referral were also reported as major concerns. This is an area of service that needs to be addressed in a serious manner if early intervention is ever going to realize the goal of swift, intensive interventions that prevent the need for later, more costly special education services.

Economy of natural environment service. In order to provide natural environment services, therapists and ITDS have to travel from their offices or clinics. No

matter the provider, travel was acknowledged to be one of the greatest difficulties associated with natural environment services. When that was combined with limited parent availability and parents cancelling sessions without notice or “no-showing,” this became a deal-breaker for many of the therapists who might otherwise have considered conducting natural environment services. While ITDS providers seemed to take the costs associated with travel and the time lost to traffic in stride as part of their jobs, they did feel that it was a huge impediment. Therapists on the other hand felt that it was unreasonable for them to spend so much time on the road with the level of education and specialty they represented. The open codes that comprised this conceptual category included: *assign students geographically*, *willingness to travel to natural environment*, *lowered productivity in natural environment*, *insufficient reimbursement for time and travel*, *family no-shows*, and *family transportation difficulties*.

Assign students geographically. Assigning students to geographic areas based on zip codes helps providers juggle multiple families and allows them to become familiar with community resources. One ITDS provider explained how important she felt it was to provide services only in the geographic location where she was familiar with community resources:

I service children here in [three adjacent locations in the city], but that’s where I’m at. So if they call up and say, “You know what, I can’t do it today,” I don’t panic. “Can you do it tomorrow at 3?” And I’m 10 minutes away. Giving them an hour instead of driving down here from say [area 40+ miles north] to give that service for an hour and then driving back. I’m a lot more flexible, that’s a huge thing. And being able to know the community resources is a huge thing. If I would go service children in Hialeah or in Kendall, I don’t know the resources. And if a family says, “Oh can you do it on Friday at 2?” Well, you know what, at 1:30 I have a child, you know, be wherever, if I can’t make it, I’m sorry. And then you lose that service and the family loses that service and we can’t make it up the next day or the next week. So being in the same community is a huge thing.

Despite the incentives for making sure families are served by local providers, the lack of providers and the poor coordination of services often meant that therapists and ITDS providers were expected to travel long distances in heavy traffic in order to meet the family in its natural environment. According to the LHEI program director, “In this particular community the agencies contact us through zip codes and they tell us which zip codes they service. Some service several zip codes, some service only one, some service none.” This director went on to explain that families “obviously have a choice to go anywhere they want to go, and if they want to go outside their zip code or if they know of another agency that they’ve had service to before that’s up to them.”

Willingness to travel to natural environment. The willingness, or lack of willingness, of providers to travel to the natural environment is an obvious impediment to serving families in the natural environment. Given the limited number of providers available combined with the majority of them being unwilling to travel, the mindset that it is not a provider’s responsibility to travel makes natural environment services a lofty but unrealistic goal for program directors.

Lowered productivity in natural environment. Providers who do work in the natural environment find that they service fewer children with a much lower return than if they work from a clinic environment. When parent no-shows, travel expenses, difficulty scheduling appointments, low reimbursement rates for services, and delays in payment from insurance companies or LHEI are considered, it becomes financially unfeasible to provide home services to families. Some providers feel that with their education and expertise it is ridiculous to expect them to come to a family. As one therapist summarized:

And then there's also the timing. When you go into the home environment it's a higher cost per unit, or cost per child, because there's driving time that you have to take into account, there's the fact that you can't do back to back sessions with anybody because you have to be able to drive from one house to another house, um, and then there's the fact that you can knock on someone's door and they can show up 30 minutes later or 45 minutes later or not show up at all, or they could be there and decide not to open the door to you.

Insufficient reimbursement for service and travel. Universally, the rate paid to providers is based on the rates paid out by Medicaid, which according to the providers interviewed, has not increased in over 20 years. The rate paid for travel does not take into account distance and travel reimbursement and was recently changed from a mileage reimbursement system to a flat round trip \$15 fee. Between the distance, traffic, and low reimbursement for actual hands-on therapy time combined with instances where appointments are missed due to a family not being at the home or a child being absent from a childcare center, therapists feel this is a great barrier to natural environment services. One of the directors from LHEI acknowledged these as some of the greatest barriers to service in the natural environment in the following statement:

Distance in Miami-Dade to the-, the sort of the sprawl, the wide-spread community. Traffic obviously. Reimbursement. Reimbursement is an issue, not only at the, we follow the Medicaid rate for the most part and um, but, providers have long, long um, expressed the feeling that the reimbursement is not sufficient, and that's one of the issues. Budgetary constraints can sometimes be an issue, but we can't allow budgetary constraints to impact the services we provide, so we're almost in a quagmire with trying to figure out how to get those things regulated. But those are some of the key things.

Family no-shows. Nearly every provider and director mentioned the difficulty of providing services to families who, for one reason or another, were not present when the service was scheduled. This issue was commonly mentioned as a barrier to natural environment services; that is, providers complained that after driving to a family home and calling in advance to schedule the appointment, they would arrive to a home only to

find the parents gone or unwilling to admit entrance. One therapist explained that a reason she is reluctant to provide home services is because of difficulties in scheduling: “families don’t show up, families tell you yes I’ll be there at 10 and then they don’t—they’re not there til 10:45 or 11, so it’s really hard to schedule back to back sessions with other families.” She went on to explain that this was simply not the best use of staff time, and there was no reimbursement for missed appointments in such cases. The program director at LHEI acknowledged the legitimacy of this issue, explaining that “one of the barriers are no-shows. You would have no-shows internally, but actually driving to a parent’s house and then no one’s there, we won’t pay you for travel because there isn’t a service attached.” The issue of no-shows contributes greatly to the lowered productivity of natural environment services.

Family transportation difficulty. In the same way that providers struggle with the issue of travel, the burden of transportation is also difficult for many parents to bear. When parents are expected to come to a clinic, particularly low-income parents, they often report having a difficult time getting to and from services because of a lack of reliable transportation. The increasing gas costs and sometimes extreme distances they must travel through heavy traffic compound these issues. One mother described her struggle with trying to use public transportation when she had no money to pay the fare. As a result of unemployment and an accident that left her and her son in poor condition, she could not get him to his therapy appointments consistently. She finally called the center and just put all of his services on hold until she began receiving income through welfare; ultimately, this put off the son’s therapy for nearly two months. Another mother explained that the appointments she had to take her children to once every two weeks

were located nearly 60 miles from her home and were always scheduled during her work week. This issue of an inability to obtain reliable transportation contributes to the illusion that families are unwilling to get involved with their children.

The vast majority of the information I gathered from participants covered the issues of family centered care and natural environment services. These two issues formed the basis of my thinking when I began the data analysis phase and they are prominently featured in my data analysis map and throughout my findings. The other area I was interested in studying as part of this dissertation was the perspectives of service providers who were Native Spanish speakers and their experience with both native Spanish speaking families and families from English speaking backgrounds. The information that I did manage to collect in this vein was not included into the above framework for my findings because of the limited amount of data I was able to collect on this issue.

Barriers and Facilitators of Services from Native Spanish Speakers' Perspectives

Analyzing the 25 interviews I had conducted with participants led me to develop a list of 46 open codes, eight conceptual categories, three themes, and one core category. Within these codes, I was able to develop only one code that covered the views and perceptions of native Spanish speakers. This information was not rich enough to cover in-depth the language issues that are becoming more prominent in the area where I conducted this study, however I have included this information below in the belief that some knowledge in this matter is preferable to none.

After working through the data analysis process, it soon became clear that, although I had one code dealing with language and language issues, I was not able to collect enough information to answer the third and fourth research questions as they were originally

asked. I have included here a section discussing the unique challenges and barriers that were seen for participants who experienced issues with non-English-speaking providers; however, it does not provide a satisfactory answer to the different perspectives of Spanish-speaking providers working with families who are either native Spanish speakers or native English speakers. The open code that addressed issues unique to native Spanish-speaking providers was called *language barriers*. This open code was contained in the category *creating and maintaining a productive relationship* and is described briefly within this category in accordance with how it relates to producing productive relationships. Here I have broken down in greater detail the information that this code represented.

Perceptions of providers. The first thing that I noticed when speaking with service providers about their experiences in Miami was that it was generally believed by native English speakers, particularly those who did not speak any Spanish, that it would be a benefit to their employment if they were bilingual. A program director summarized this position:

If you're not bilingual in Miami you, it's more difficult to schedule or to fill your case load so if my staff members have to carry a case of 25, a case load of 25, it's easier and faster for me to fill one of a person that's bilingual than it is for somebody who is not. I had staff members who started seeing a child because the child speaks English very fluently and the child themselves is bilingual but the parents are not, so the treatment planning is not going to go well because typically the person, the therapist is going to write it in English and the parent can't read it. Um, and then there's also the inability to translate it to the parent, discuss it with the parent.

Although this position seemed to make sense, as I spoke with those more involved with direct service provision, a different issue began to emerge. One native English-speaking ITDS explained to me that her monolingual background had worked to her advantage because:

I have people that do not want um, a bilingual person and then request English speaking only because of the accent. So that's why I've ended up with these crazy areas because they've had problems with people that are bilingual, not understanding them [service providers] and wanting someone that only speaks English.

They [parents] request it, yes. They'll be in the middle of services and then I get a call saying we have an emergency case, we need you to take it because you, I'm the only one that speaks I think English, um, with my... The agency that only speaks English. I know there's a lot of bilingual, but mostly Spanish, you know, they have like the broken English. They do speak English but you want an English speaking only native English, you know, person then it's very different. So that's where I, it's, it's strange because it's usually the opposite, you know, but um, there's a problem, I get the call.

Other ITDS providers confirmed that this issue was a serious one for those providing general developmental services. A native Spanish speaking ITDS explained to me that in her experience:

[M]ost families they want, when it comes to Spanish, it doesn't matter the accent, they don't mind. But they want fluent English, they want fluent English, they do. I mean I've had, I've, I've had cases where I have received children of other teachers, you know, providers, where they don't speak fluent, fluent English and I've had to, they've given me those children because they don't have too many ITDS who speak fluent, fluent English. Yea. They speak English, but not fluent and the parents they always say, "Ah, you know, it's not because of me, you know I don't mind, I wouldn't mind, but it's my son or daughter that's, they're not speaking yet, and I want them to hear you know, proper English, you know, fluent." And I'm like, "ok."

Perceptions of families. Families also expressed this sentiment. Several families reported having issues with providers who were either not fluent or not English speakers whatsoever. Most of these families were from English-speaking backgrounds; however one mother who was, in her own words, a "proud Cuban" insisted that she have a fluent English-speaking provider without a Spanish accent because her husband's native language was English and he would have a difficult time discussing services otherwise. She and other families stated that if their child was going to have a delay in the area of speech, they would prefer that only one language be used at any given time, and by and large the language of choice was English. In this mother's words:

The first IDTS [ITDS] that called me- that she only spoke to me in Spanish and then sort of her response to me when I asked her if she spoke English because of my husband not speaking Spanish, she was sort of like, um, it kind of blew it off, like, it'll be fine, we'll find a way to communicate and the kids are small enough where they're not going to know the difference. I don't agree with that, I think they know the difference. And even my mom, my mom speaks English, she speaks, she can speak to a you know, um, she can communicate rather well and, and use big words for lack of a better term, but with my children I, I, and if she, she was the one who was saying, thank God because I was the one who was going to have to say it, but she doesn't even speak English to them because her English is not perfect, and neither is mine, and obviously I'm Cuban I'm sure that there's an accent there to someone Anglo, but um, I don't want her to because I want them to hear as perfect of English as they can because if there's already a delay or some issues, I want to give them the best shot that I can. So to think that there was going to be an, an IDTS coming in and teaching them, you know, it's not like she was coming to, for physical reasons or for motor skills, she was coming for speech.

Across interviews with families and native Spanish speaking providers, I heard complaints of not being able to find enough fluent English speakers to work with families. The majority of these Spanish speaking providers were the ITDS providers. All of the therapists interviewed were either English speakers or bilingual themselves, however there was such a dearth of these therapists willing to work with LHEI (in fact, only one of those interviewed for this study provided direct therapy services for LHEI and she had recently cancelled her contract) that their language backgrounds did not play into the discussion with families often. Overall, in this study the issue of language use did not play out as I had anticipated and I was not able to examine this concern as fully as I would have liked. Nevertheless, there were clear indicators that language issues in this city are present, and unlike the common issue of monolingual English providers, there appears to be an abundance of non-English speaking developmental specialists. I feel that additional research in this area is important to understanding the changing nature of language issues in early intervention, particularly in diverse urban areas.

Conclusion

With regard to my first two research questions, the barriers and facilitators that I found in both family centered care and natural environment services were contained within the core category *limited resources vs. best practice* and were explicitly reflected in the analytic themes. I felt that the core category I developed was the most appropriate extrapolation of what I was seeing take place at the ground level of service provision in early intervention. Although the question of what exactly constituted best practices in early intervention was not universally agreed upon by service providers, I feel that the case I have made in previous chapters on research and legislation has established that family centered care and natural environment services are both considered to be best practices by the majority of researchers in the field of early intervention. As such, I have used the term best practice to represent these issues and contrasted them to the unanimously acknowledged difficulties of limited resources. The need to manage the scarce resources that were in place often compromised both administrators' and service providers' ability to use these practices. The findings for my third and fourth research questions were limited due to a lack of full theoretical saturation. Regardless of the limitations, I feel that the unique issue of not having a sufficient number of English speaking providers available for services in a diverse urban setting is one that warrants further research.

In the following chapter, I present my findings in light of previous research and I attempt to clearly explain the direction that future research and policy should consider. Although there is an unusually high level of budgetary crises that have taken hold over much of the nation, the removal of resources from the lowermost rungs of our societal

infrastructure seems unwise for long term development. At the time I conducted this study, the possibility of future budget cuts or the complete elimination of Part C early intervention services was foremost in the minds of administrators and the more informed providers that I spoke with. As one director stated:

[W]e need families who have received this program, these services to speak up, to really help, because we want to do more than what we're doing right now. We want to sustain and that's an issue for [Part C services] state wide. We face a potential deficit of 12 million dollars next year, particularly with the stimulus funds ending, so we're kind of, we're a little worried. And the only way to make legislators know that this is important, this is something we need is for families to come forth and join and to come forth.

Chapter 5: Discussion

Early childhood education is an issue of great import that is becoming increasingly urgent across developed nations. As more American families find themselves with both parents involved in the workforce full-time, the number of children under the age of three who attend childcare centers has increased dramatically in the past 20 years (Children's Defense Fund, 2010). We know that a high-quality early childhood educational experience has a positive impact for children and that the benefits are great for those children coming from poor or culturally and linguistically diverse backgrounds (NICHD, 2011). Although the greatest per dollar cost-benefit ratio is highest for families from poor and diverse backgrounds, we also know that it is these families who are least likely to be able to afford and access the limited number of high-quality accredited childcare centers (Children's Defense Fund, 2010; Harry & Klingner, 2006). For most families, simply locating and affording a high quality educational center for their children is a financial burden; however, when a child has a developmental delay or a disability that causes many traditional placements to be considered inappropriate the difficulty is greatly increased.

For families who have young children with special needs, the importance of services provided by early intervention agencies cannot be overstated. According to a recent publication released by the National Institute of Health (2011): "An early education program for children from low-income families is estimated to generate \$4 to \$11 of economic benefits over a child's lifetime for every dollar spent initially on the program (p. 1)." These benefits were disproportionately helpful to the more disadvantaged groups of children living in the lowest income areas. In the state where

this study took place, a total of 67.5% of families with children fewer than six years of age had all parents employed in the labor market, so the need for high quality childcare services is greater than ever (Children's Defense Fund, 2011). For children with special needs, the importance of obtaining early intervention services is thus paramount. Part C of IDEA provides funding for lead educational agencies to provide such services free of charge for parents who are either uninsured or whose insurance will not cover the cost of early intervention. In the state where this study was conducted, an estimated 18.3% of children are uninsured by either Medicaid or a private insurer, and it is likely that many of these uninsured children are also among the 21.3% of the population estimated as living in poverty (Children's Defense Fund, 2011). Although in the current economy the very existence of early intervention programs is being threatened due to a national budgetary crisis, it is imperative that stakeholders make the importance of services for children with special needs clear to policymakers. The future quality of life for many children is at risk, and since we know that the returns from early intervention far outweigh the costs of implementation, we must make sure that early intervention services remain available to parents who truly have nowhere else to turn.

When I began this study it was my intention to create a detailed picture of the barriers and facilitators of family centered care and natural environment services according to a wide range of service providers and stakeholders in early intervention. Additionally, I sought to explore the unique experiences of service providers who came from native Spanish-speaking backgrounds, as this is an area previously unexplored in research and is a salient issue in this city. What I found regarding the barriers to services in the area of family centered care and natural environment services reflects much of

what has been published in this area. My findings support the disappointing albeit unsurprising conclusion that the same issues providers wrestled with in the early 1990s are still unsolved in the system of early intervention practiced in the state where this study was conducted.

In order to understand the disconnect between what research and legislation have called for in terms of best practices, and what professionals in the field reported, it is important to consider the foundations upon which special education laws were developed. Kalyanpur and Harry (1999) argued for a deeper understanding of the distinctly American cultural underpinnings of IDEA, and how these relate to the clash of attitudes between medical professionals and advocates of involving families and encouraging family decision making as part of therapy. According to Kalyanpur and Harry, IDEA contains several components (i.e., zero reject, nondiscriminatory assessment, individualized appropriate education, least restrictive environment, due process, parent participation) that embody implicit Western middle-class cultural values of individualism, choice, and equity. Although these values are important to American culture and are strongly embedded into the societal framework of laws and rights citizens are assured, they are not universal.

Particularly, one subculture that has developed is the special education field, which has promulgated a clinical model of pathology and deviance from the norm wherein disabilities are considered physical, individual, chronic phenomena that require remediation. This medical model has made it difficult for the ideals of parent participation and choice embedded into IDEA to realize their potential. It is the cultural emphasis on choice that has led to the creation of the family-centered models. The idea

that parents should have a participatory role in the education of their children is very much influenced by the Western ideal of individual freedom to pursue “happiness” or the greatest potential of an individual. The difficulty with this development is summarized by Kalyanpur and Harry (1999) in the following statement:

The mandate for parent participation directly contravenes the traditional notion of the professional as expert and attempts to overturn the balance of power in favor of parents by its recommendation that parent input about a child be taken in to account in the decision-making process. Professionals trained to believe that their knowledge gives them authority to make decisions about a students’ education, must now grapple with the seemingly radical idea that parents can be experts too. (p.57)

For families who come from other cultures, or subcultures that do not share the same values, early intervention and special education can be a very confusing maze in which they will quickly become lost or disenfranchised. Kalyanpur and Harry (1999) go on to explain that many of these parents have an equally difficult time understanding that the “experts” should be concerned with parent input and that parents can become active decision makers and experts in their own right. They argue that family-centered care is the right ideal for early intervention professionals to strive for; however they contend that if professionals fail to adopt a “posture of cultural reciprocity” they will likely fail to reach many culturally diverse families. Developing a greater understanding of this clash of cultural ideals would help to bridge the gap between research and practice in the area of family centered care.

Family Centered Care

Conflicts related to caregiver and professional roles were evident throughout my study. The barriers specific to family centered care that I observed included: families or caregivers who were unwilling to or uninterested in becoming involved with services,

service providers who struggled to negotiate less active roles for caregivers (whether or not they wanted to be actively involved), and the lack of positive relationships between caregivers and service providers. The theoretical buy-in to the family centered care model was also an issue for many of the services providers in early intervention. My findings reflected those of Fleming et al. (2011), which demonstrated that there was a clear lack of understanding amongst providers when it came to what it meant to involve families in care. Many of the therapists I interviewed simply did not believe that it was their job to be teaching parents how to work with children. The perceived role of caregivers from many therapists in my study mirrored the perceptions seen in service providers from Fleming et al.'s (2011) study; therapists did not feel it was the parent's role to provide therapy to children. As one of the therapist's in my study made clear, it was unreasonable to expect that she would be able to teach the parents all of the things she had learned in seven years of specialized school training. Many service providers agreed with this therapist, and had very different views on the importance of parent input and participation than either research or legislation would espouse.

The consultative approach used by Salisbury et al. (2011) was similar to the approach advocated by Campbell and Sawyer (2007), which they referred to as participation-based early intervention; this approach also mirrors Dunst et al.'s (2007) definition of participatory practices. In all of these studies, the authors reported that service providers struggled both with the importance of including families as therapists, and with the actual ability to provide opportunities for parent participation within therapy sessions. This same pattern was apparent in my study; it was the participatory part of parent involvement that providers had the most difficult time with. Therapists across

disciplines felt that they were in fact the experts in their field, and although they could help parents with strategies and suggestions for home activities, these were seen as distinctly different from the “therapy” the child would receive in a clinic.

In the case of the ITDS providers I interviewed, many of them felt that getting parents to participate and become therapy providers themselves was essential to the success of the intervention. Even so, these ITDS providers admitted to finding it very difficult to actually engage and involve families due to the various issues they encountered. Similar to the research reported by Fleming et al. (2011), the reasons for this inability to have parents participate was frequently cited as being external to the provider (e.g., the family’s education level, the parent’s interest in services, and the cultural attitudes of families). Although specialized therapists were generally less inclined to advocate for a family centered model where caregivers serve as intervention agents, other service providers, particularly the ITDS providers, felt that the model was important but attributed the lack of implementation to the families’ attitudes and system issues. Although the ITDS providers seemed to have a greater respect for the principles of family centered care in my study, they were quick to acknowledge that this kind of care was difficult and often did not occur for various reasons. Also similar to Fleming’s findings, the reasons for these difficulties were often attributed to caregivers themselves and to their lack of participation or willingness to get involved. My findings show that despite the past 20 years of attempting to promote family centered care, the system issues, professional issues, and family issues that providers rated as barriers in the past (Bailey et al., 1992; Björck-Åkesson & Granlund, 1995) are still problematic in the field today. Many of the providers claimed that under-resourcing, philosophical differences,

and families' lack of involvement were all reasons they were unable or unwilling to involve caregivers in a family centered manner.

Similar to the findings of Shannon (2004), the service providers in my study made it clear that barriers caused by a lack of payment and insurance claims being denied or ignored were a major barrier to providing early intervention services for the local Part C agency Little Hearts Early Intervention. Many therapists had in fact ceased providing services to LHEI because of these issues, compounding the problem directors already faced with limited providers. Also similar to Shannon's findings was the dearth of early referrals from physicians, either from a lack of knowledge or lack of respect for early intervention services; this finding was reported by families and providers alike. Even when families approached their doctors with developmental concerns, they were encouraged to take a wait-and-see approach rather than being recommended for further evaluation.

Natural Environment Services

In regard to providing services in the natural environment, the major issues that became apparent in my study were the buy-in of professionals and the logistical demands on providers' time, lack of profits, and a lack of sufficient resources. Natural environment services were mandated by Part C of IDEA and are expected to be the standard for care across the state; however, providers in the district where this study was conducted frequently refused to provide non-clinic-based services. With this dearth of providers willing to travel to natural environments, program directors found themselves hard pressed to meet the demands of legislation; in fact, several states have been declining to

participate in Part C services because of these demands. This dilemma is illustrated in the explanation of one director of LHEI:

There are very few instances when you can [legally] provide services for a child outside of the natural environment and if you don't have [willing providers], so it's kind of like, ok which one do I do? Do I get dinged or do I get cited for not providing the service in the natural environment or do I get cited for not being able to provide the service within 30 days, because I can wait until someone in the natural environment is available but this child may not receive services for 6 months, but if I get the child within 30 days, you know, why do I have to...? It's a bit much to have to try to explain that, well the child; it will be a detriment to the child if the child doesn't get services within 30 days as opposed to saying there were no providers out there. *Lack of providers is not an acceptable excuse from the federal IDEA. It's not a legitimate excuse to not provide services in the natural environment*, so it's a citing, so the requirement's too stringent and that's why states are dropping it (emphasis added).

The issue of provider willingness to travel is perhaps the single biggest problem early intervention agencies reported in my study. This issue is not unique to the area; a recent publication by Müller (2011) describes this as a problem throughout early intervention across the nation and attempts to provide agencies with ideas for how to recruit and retain providers of early intervention services.

In cases where providers, particularly ITDS providers, were willing to go to the home, my findings again echoed those of previous research by Campbell and Sawyer (2007). The natural environment model was designed to make caregivers' participation in services more feasible. Instead what often happens is service providers feel that they are the experts and families are part of the problem; consequently they will limit the participation of families to such an extent that it resembles what Campbell and Sawyer call a "traditional therapist centered" or "child centered" model where parents do not participate and are rarely consulted. In this sense, natural environment services are seen as nothing but a burden on many professionals, as they have taken away the ability to

control the distractions within the environment and failed to actually bring the caregivers into the services.

The model that uses caregivers as therapists is ineffective when the parent does not understand or want to participate in the model and when the provider does not wish to educate or include the parent. Research by Salisbury et al. (2011) demonstrates that parents who are unfamiliar with the caregiver as therapist model see it as being less therapeutic and therefore less efficacious. One parent made her position on this model very clear when she described exactly how the agency expected parents to work therapeutically with their own children with things learned during sessions. This mother went on to explain to me that she felt this was very inappropriate to ask of her as a mother. She felt that her role for her children was very different than a therapists' role, and in some cases she was not even emotionally capable of causing her child the kind of discomfort associated with some of the physical therapy techniques. If providers do not step up to the challenge of explaining the model to parents and demonstrating the effectiveness through child progress, parents are unlikely to support the efforts of the few providers who do attempt to include them into service provision. Additionally, if parents are not open to the idea of participating in the model, than it is very unlikely that it will be efficacious in the long term.

Unlike the findings of Hanft and Pilkington (2000), the barriers to providing service in the natural environment found in my study were less a result of therapists' inexperience with the model and more often a result of therapists refusing to take part in a model they felt was unfeasible. The fiscal and logistical issues associated with the model were very similar to those reported by Hanft and his colleague. The service providers in

my study provided very concrete examples of how the natural environment lowered their daily productivity anywhere from one half to two thirds or even all of their business.

Whereas one therapist could feasibly see eight different patients in a day at a clinic, they were limited to only two or three a day when accounting for travel, mileage, missing appointments from parents, and traffic.

Billing and payment were serious concerns for providers in my study. Travel time not being adequately reimbursed and missed appointments were also a major concern, as was the practice of only reimbursing therapists for their hands-on time with children. All of these issues have been known and documented, however early intervention agencies have yet to develop a strategy for addressing these concerns in order to encourage service providers to buy in to the model. Additionally, the issue of early intervention providers' philosophies developing in a separate arena than the philosophies guiding research and legislation was similar to that reported by Hanft and Pilkerton (2000). As one therapist explained, she was aware of the changes being made in legislation, but she was confused and insulted by them: hadn't she "always included parents" in her sessions? She argued this strongly, but defined the parents' role as being an observer, and insisted they should be watching through a two-way mirror rather than in the room creating a distraction for the therapist and the child. In her case and in some other instances with providers, the ideal for how parents can be effectively included in services was different than much of the literature surrounding family centered care. The feasibility of teaching parents advanced articulation or physical therapy techniques that required therapists to obtain masters degrees was not seen as reasonable.

Language Issues

Although I was not able to gather a great deal of information regarding the language issues experienced by those involved with my study, it seemed clear that there was a phenomena occurring here that was not apparent anywhere else in the literature.

Although it was believed by English speaking therapist that not knowing Spanish was a detriment, the ITDS providers whom I spoke to talked about being in high-demand because of their English fluency. It appeared that although there are professional requirements for a certification and a four year degree/equivalent coursework to be an ITDS, there was no control over the English language fluency of these providers.

Families reported feeling uncomfortable when they were forced to ask for “another” provider who was fluent in English to be sent to the home- and in some cases providers informed me that there are many families who just “do what they can” to communicate. The changing demographic of our country makes this issue of great concern, and the question of whether or not language requirements should be a part of the certification process ought to be raised in cities where issues like this may be a problem.

Recommendations for Practice

As the lack of providers stands as one of the most serious and limiting factors of providing either family centered care or care in the natural environment, the most important recommendation for practice that I would make is to find ways to increase the number of providers willing to work in the context of early intervention. As mentioned previously, issues of staffing shortfalls and limited providers are not unique to the early intervention agencies in this city, and several recommendations have already been made by professionals in the field as to how this can be improved. The second recommendation

I would make is to create programs in institutions for higher education and professional development programs to increase the awareness and understanding of the family centered primary care provider model that is currently espoused by research and legislation. If providers are more comfortable with the model they are expected to use, it is less likely they will outright refuse to offer services. Finally, I would recommend that all professionals trained to work within the auspices of early intervention be trained in adopting the “posture of cultural reciprocity” described by Kalyanpur and Harry (1999).

Increasing the number of service providers in early intervention. A recent publication by the National Center to Improve Recruitment and Retention of Qualified Personnel for Children with Disabilities (NIH, 2011) described a few ways that directors in early intervention can recruit providers into Part C programs. The first suggestion made was to provide financial incentives. Such incentives could take the form of loan forgiveness programs for providers who work in early intervention programs for a designated number of years after graduation, or tuition reimbursement for those currently working in early intervention. Other monetary incentives can include higher reimbursement for providers who are willing to travel to high-risk or rural areas. Safety concerns were cited by several of my providers as the reason they did not want to go to children’s homes, and although these concerns are real and should be considered, research has indicated that providers who are willing to take the time to learn the “rules” of the neighborhood can successfully provide services to children safely even in the most crime-ridden areas (Salisbury et al., 2011). Other ideas for financial incentives included increasing salary or per-service rates, covering costs for consultation services, reducing intervals between billing and payment, low- or no-interest mortgages to entice providers

to reside and work in less desirable areas, offering per-hour rates for travel, signing bonuses, and stipends for laptops or cell phones.

Another method that may be effective to increase the number of providers is to increase the media outreach from agencies to providers. Agencies can provide packets of information on early intervention for all newly licensed therapists, hold speeches at institutions for higher education, form websites that link to job opportunities and openings, direct mailings to practitioners as well as newspaper advertisements, and utilize social networking media (e.g., Facebook or Twitter) to get the word out to providers that there are opportunities for employment in early intervention. One of the therapists in my study admitted to not working for LHEI simply because she had “heard” that if she was unwilling to travel to the home, they would not refer children to her. Although the director later agreed that the agency used referrals as a form of competition and that providers would receive more referrals if they were willing to travel, the director also acknowledged that even those therapists willing to travel received many cases where parents were willing to bring children to the clinic. The therapist’s argument against providing services for LHEI did not seem warranted given that this same therapist was willing to travel to the homes of some children who were referred to her from Young Minds. The lack of information on exactly what was expected of a provider was thus a barrier to even considering the possibility of providing Part C services.

Other possible ways to increase the number of providers include hiring full-time therapists for evening, weekend, or summer positions; providing internship placements at Part C agencies so new therapists can become familiar with the system; and to hire a recruitment agency or representative. According to the parent educator whom I

interviewed, the state was currently in the process of obtaining a recruiter to increase the number of Part C providers they have; in this sense, perhaps there is a small ray of hope for directors and service coordinators. However it is accomplished, efforts need to be directed towards obtaining and retaining qualified personnel who will work with the most vulnerable of our population.

Increasing the theoretical buy-in of service providers. Increasing the buy-in of professionals in early intervention to the importance of family centered care and involving caregivers into services in meaningful ways is paramount to the program effectiveness. In the previous medical model of service provision, children were given a greater allowance of hands-on therapy time in the clinic. As research and policy combined to push the idea of including parents into the process of service provision, and indeed expecting them to act as “therapists” with their own children, the number of hours provided to each child with hands-on therapy decreased. The logic was, if parents are doing these same things 80 hours a week with their children, you would not need an occupational therapist to see the child two hours a day three days a week. The problem with this model is summarized by Hanft and Pilkington (2000); they explain how early intervention service providers were rooted in a medical model, and the push for family centered and natural environment care came from research and legislation rather than providers. In other words, therapists never agreed to the idea of natural environment services, and they do not feel that legislators or researchers who do not have hands-on experience working with these children should be able to tell them, the experts, where and how services should be provided. In essence, they have not and do not feel a need to buy in to this model. Kalyanpur and Harry (1999) corroborate this argument when they

describe how the ideals of choice and equity that are rooted in IDEA have led to a push for parent participation in legislation that does not parallel the development of the medical model of services in special education. In a summary statement of the major difficulties incurred by the medical model being so strongly entrenched in special education, Kalyanpur and Harry claim that the view of professionals in education “tends to undermine parents’ knowledge about their child. Furthermore, this hierarchy of knowledge and status directly contradicts the legal requirement for parent-professional collaboration in the education decision-making process, placing both parents and professionals in a precarious and unpleasant situation” (p. 75).

The main recommendation I would make to increase the theoretical buy in of providers is increased education and training for providers. Previous research has demonstrated that a family centered, natural environment model can be taught effectively in a comprehensive program (Salisbury et al., 2011; Murray & Mandell, 2004). Research from Bailey et al. (1992) and Björck-Åkesson and Granlund (1995) has shown that even a few days of professional development can significantly improve the attitudes of providers with regard to including parent input. A recent study by Fults and Harry (in press) also demonstrates that a graduate course designed to integrate instruction for family centered care and responsiveness to diversity can actually improve the attitudes of professionals already in the field regarding family centered care. This dissertation demonstrates the severe disconnect between what service providers in the field recognize as legitimate therapy, and what we should be espousing in our educational system. The fact that this issue has remained unresolved even though we knew it was a problem in the early 1990s is disheartening. Education programs that stress the importance of a family

centered service model and natural environment services must be made available to both current providers as well as students training to become therapists.

As a caveat to the importance of increasing the theoretical buy-in of providers towards a family centered model, I feel it is important to add that we should not forget that therapists who hold licenses and professional degrees are indeed experts in their fields. According to one director the family centered model was simply “not designed” for children with multiple disabilities and medical needs. According to B. Harry (personal communication, March 18, 2011) there must be a balance between knowing which children need intensive therapy in addition to full parent/caregiver participation. In this sense, we must make sure that in an effort to increase the willingness of providers to include families and encourage participation, we do not lose the expertise of professionals.

The posture of cultural reciprocity. The last recommendation I would make would be that practitioners and policymakers both work to ensure that professionals within early intervention are taught the importance of developing a posture of cultural reciprocity described by Kalyanpur and Harry (1999). In order to adopt this posture of cultural reciprocity, professionals first need to identify the cultural values that are implicit in their interpretations of student’s difficulties or their service recommendations. When making a goal for the IFSP or when deciding upon ways to address concerns, professionals must learn to look at their own cultural assumptions that are embedded within their recommendations. Following the identification of their own biases or assumptions, professionals must find out if the family they are serving share these values or not, and if not how they differ. By attempting to understand why a family feels a

particular way, professionals have already taken the first step towards bridging the gap between what they consider important and what the family may value. Third, professionals should acknowledge and show respect to any differences that are found and fully explain the cultural basis for the recommendations the professional has brought to the table. Finally, professionals should collaborate with families to determine the most effective way to adapt the professional recommendations into the families' value system.

This posture of cultural reciprocity, according to Kalyanpur and Harry (1999) should go beyond just noting differences. Rather, this posture should foster the professionals' sense of self-awareness, should aim for an understanding of difference at subtle levels, ensure parent and professional empowerment, avoid stereotyping, and should have universal applicability in any educational or social situation. Although this posture was developed specifically with regard to families from culturally diverse backgrounds whose values do not necessarily mirror those of the greater macro-culture, the principles contained within this approach would serve to improve the relationship between any parent and professional. As relationships with providers, or lack thereof, was one of the complaints made by parents in my study, I feel that providing ideas to foster such relationships would be beneficial

Future Research.

One of the most important findings in this study for future researchers to consider is the information that I began to see with regard to language issues but was unable to fully explore in the limited time and resources available. The changing nature of language barriers in this location with regard to early intervention will likely become an issue as the number of professionals from native Spanish-speaking/non-fluent English

backgrounds increase. It is important to note that traditionally, service providers have been middle-class women with English-speaking backgrounds, yet in this location the challenge has become finding providers who spoke English fluently. In much of the country, service providers are often still native English speakers. However, with the changing demographic of our nation and the number of citizens in large cities not fluent in English, the concern for families of children with speech delays who need providers who speak English fluently is enormous. According to the most recently available US Census statistics, people of Latino or Hispanic origin account for nearly 15% of the population, and the growth rate of this population is three times that of other groups.

Limitations.

There were several limitations to this study that should be considered when interpreting the findings. The first limitation of course was the limited time that I had in the field to study the issue of family centered care and natural environment services. This is a concern that is especially salient given that it is one of the quality considerations of qualitative research mentioned by Lincoln and Guba (1985). The fact that I was unable to saturate categories in the area of language and cultural issues demonstrates that I did not have enough time and interview opportunities to return to the field and collect additional data. Although the ideal would be to collect information until nothing new was added to my codes, categories, and themes, it is fairly evident that the few months I had of data collection left unanswered questions. Unfortunately, the time it would have taken as well as the additional interviews that had not been approved by the study's internal review board were not feasible for this study.

Another limitation that was seen in this study, and in fact is an issue in many studies where samples are not guaranteed, was the snowball sampling technique I utilized to select participants. In qualitative research, purposive sample allows researchers to seek out individuals who will best represent the phenomenon of interest. In the case of the language issues I was interested in, I found that although I had described what I wanted my sample to look like, it was really up to those who were making the referrals to provide me with information on families and providers. I asked specifically for ITDS providers who spoke both English and Spanish, and I found that this was very difficult to get using the referral sources I had. I am fairly confident there are at least six bilingual native Spanish speaking ITDS providers in the city where this study was conducted, but I was only able to meet with four. The other two ITDS providers were English only speakers and demonstrate the issues with snowballing techniques because I was essentially given what was available rather than what I really had aimed for.

The third issue of concern was a lack of triangulation using multiple methods. When I designed this study, I decided for reasons of practicality and transferability to use multiple perspectives by interviewing a range of providers. In interviewing service providers, I often noted that what they told me was happening in one sentence, was not what they supported with their examples in the very next sentence. In retrospect, I feel that were I to have observed several sessions with these service providers, I would have generated a greater understanding of how they perceived the terms “family involvement” and getting caregivers to “participate” in sessions. For example, in one case of a completely serendipitous observation, one therapist informed me that she insisted that parents observe sessions so they know what is going on and how to work with their

children. Yet when I had waited to speak to this therapist, I observed a mother come into the clinic, drop her son off with a therapist, and sit in the waiting room on her phone for several minutes. Once she had taken her call, I watched this mother leave the waiting room and go outside into the plaza where the center was located. She returned approximately 30 minutes later and again sat in the waiting room until her child was returned to her by the therapist. At no point did this mother make it past the waiting room to even glance at what was taking place in the therapy room. It is possible that the therapist I spoke to did not know this kind of thing was occurring at her center; it is also possible that she did not mean to imply that parents watched *every* session in detail, or that *all* parents were expected to make these observations. In the future, I would include observations along with interviews when trying to determine the attitudes of professionals and how they relate to actual practice.

The last limitation that I feel should be mentioned was my inexperience with navigating my “role of researcher” as a participant observer. The ability to maintain my neutrality during interviews was occasionally very difficult. When I heard the horror stories of families who underwent countless unnecessary hassles with providers, or stories of how providers had left families in desperate need hanging without follow through for months, I found myself wanting to share with parents’ information about due process and the legal rights they had to protect themselves against possible abuse. When I listened to a mother work through in her own thinking how it was indeed possible to consider a speech therapist who would come to the home, it was with a great deal of willpower that I did not tell her at that moment, “Honestly, that is what they are supposed to be doing according to IDEA and their contract with LHEI.” I felt that in many

instances, I was able to maintain my sense of neutrality and not offer words of unsolicited advice. On the other hand, when parents asked me directly to inform them of certain things, I found it very difficult to move away from the question without answering directly. I understood that the things I said would be taken as authoritative because these families knew that I was coming from a prestigious university with the intent of completing my doctoral dissertation requirements. Consequently, when one parent asked me if I agreed with a provider who had told her not to raise her voice or use physical discipline with her daughter, I found it very difficult to answer. While my motherly instincts and practices were begging to be voiced, and in fact I did answer the question with, “Well with my son, I don’t find it very effective to raise my voice or get angry...” my position as a researcher was still present in my mind. I left this interview emotionally strained because I was so consumed with my confusion regarding if I should answer, and if so what to answer, that I was not sure I said anything coherent.

Conclusion

Although there were several limitations to this study, and I was not able to answer all of my research questions to my own satisfaction, I believe this study has added to our understanding of the barriers and facilitators in family centered care and natural environment services faced by service providers, agency administrators and service coordinators, as well as families involved in early intervention. It is important that we use this information to inform policy and educational planning decisions in today’s economy. If we fail to make the needed investments for our posterity now, then we leave the future in the hands of children ill-equipped to cope with the difficulties they will inherit. The increasing unemployment and national deficit that plagues our nation will only

exacerbate the number of families living in poverty and thus the number of parents who are unable to provide high-quality childcare settings for their children. Even more importantly, the number of parents who are able to provide rich learning experiences in the home environment will evaporate as concerns with the daily stressors of putting food on the table and keeping children clothed effectively trump the importance placed on educational development.

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Appendix A

LHEI: Program director interview guide.

1. Please describe the process used to refer children in need of services.
 - a. How do parents find out about your program?
 - b. What outreach efforts are made to inform parents of services offered?
2. Once they are referred, how are children determined to be eligible for services?
 - a. Can you describe the services offered through your agency?
3. What happens to children who do not qualify?
4. Please summarize the process of referral, qualification, service provision, and transitioning as it would be experienced by a given family. Walk me through a hypothetical case.
5. For children who qualify, how are services provided?
 - a. Where?
 - b. By whom? (e.g., a SLP or ITDS?)
 - c. How many services per child? Min/Max.
 - d. Approximately how many sessions do children receive per service?
6. Tell me about the challenges you deal with when including families into the service planning and provision. (family centered service provision)
7. What kinds of things make it easier to include families into planning and service provision?
8. Tell me about the challenges you deal with when trying to provide services in the natural environment.
 - a. Parent barriers?
 - b. Provider barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
9. Tell me about the things that make services in the natural environment easier that you have found in your program
 - a. Parent facilitators?
 - b. Provider facilitators?
 - c. Legal facilitators?
 - d. Programmatic facilitators?
 - e. Physical/Logistical facilitators?
 - f. Financial facilitators?
 - g. Other facilitators?
10. Anything you would like to add? Follow up on any previous comments?

Appendix B

Young Minds: Program director interview guide.

1. Please describe the current process used to refer children in need of services.
 - a. How do parents find out about your program?
 - b. What reach-out efforts are made to inform parents of services offered?
2. How is this different from the previously-used process of referral?
3. Once they are referred, how are children determined to be eligible for services?
 - a. What services are offered through your center?
4. Has this changed from the previous model?
 - a. In what ways?
5. What happens to children who do not qualify?
 - a. What happens if they are determined to have more than a 25% delay?
6. Please summarize the process of referral, qualification, service provision, and exiting services as it would appear to a given family. Walk me through a hypothetical case.
7. For children who qualify, how are services provided?
 - a. Where?
 - b. By whom? (e.g., a SLP or ITDS?)
 - c. How many services per child? Min/Max.
8. Tell me about the challenges you deal with when including families into the service planning and provision. (family centered service provision)
9. What kinds of things make it easier to include families into planning and service provision?
10. Tell me about the challenges to providing care in the natural environment that you have run into with this new model.
 - a. Parent barriers?
 - b. Provider barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
11. Tell me about the things that make it easier to provide service in the natural environment.
 - a. Parent facilitators?
 - b. Provider facilitators?
 - c. Legal facilitators?
 - d. Programmatic facilitators?
 - e. Physical/Logistical facilitators?
 - f. Financial facilitators?
 - g. Other facilitators?
12. How does this year's model (a natural environment model) compare with the previous model used (a center-based model)?
 - a. How do you feel about the new model as compared to the old one?
13. Anything you would like to add? Follow up on any previous comments?

Appendix C

Service coordinator interview guide.

1. Can you describe your role in ES/ED?
2. How are families referred to your agency?
 - a. What happens once a family is referred?
3. Please summarize the process of service provision as it would appear to a given family. That is, walk me through a case of a family who was referred to your agency.
 - a. Where/how are services to be delivered?
4. How are families included throughout the duration of services?
 - a. How often do you speak with service providers about a child's progress?
 - b. How often do you speak with parents about their child's progress?
 - c. How is parent preference considered in the planning of goals for each child and how they will be reached?
5. Tell me about the barriers to including families in the planning and implementing of services.
 - a. Administrative barriers?
 - b. Parent barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
6. Tell me about the challenges you have noticed when providing services in the natural environment, that is, either the home or the childcare center that the child attends.
 - a. Administrative barriers?
 - b. Parent barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
7. What kinds of things make it possible and easier to provide services in the natural environment?
 - a. Administrative facilitators?
 - b. Parent facilitators?
 - c. Legal facilitators?
 - d. Programmatic facilitators?
 - e. Physical/Logistical facilitators?
 - f. Financial facilitators?
 - g. Other facilitators?
8. Anything you would like to add? Follow up on any previous comments?

Appendix D

Service coordinator interview guide.

1. Can you describe your role in ES/ED?
2. How are families referred to your agency?
 - a. What happens once a family is referred?
3. Please summarize the process of service provision as it would appear to a given family. That is, walk me through a case of a family who was referred to your agency.
 - a. Where/how are services to be delivered?
4. How are families included throughout the duration of services?
 - a. How often do you speak with service providers about a child's progress?
 - b. How often do you speak with parents about their child's progress?
 - c. How is parent preference considered in the planning of goals for each child and how they will be reached?
5. Tell me about the barriers to including families in the planning and implementing of services.
 - a. Administrative barriers?
 - b. Parent barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
6. Tell me about the challenges you have noticed when providing services in the natural environment, that is, either the home or the childcare center that the child attends.
 - a. Administrative barriers?
 - b. Parent barriers?
 - c. Legal barriers?
 - d. Programmatic barriers?
 - e. Physical/Logistical barriers?
 - f. Financial barriers?
 - g. Other?
7. What kinds of things make it possible and easier to provide services in the natural environment?
 - a. Administrative facilitators?
 - b. Parent facilitators?
 - c. Legal facilitators?
 - d. Programmatic facilitators?
 - e. Physical/Logistical facilitators?
 - f. Financial facilitators?
 - g. Other facilitators?
8. Anything you would like to add? Follow up on any previous comments?

Appendix E

Family interview guide.

1. How did you first learn about ES/ED?
 - a. How easy/difficult was it for you to enroll your child into the program?
 - b. How long was the process?
2. What services did/does your child receive?
 - a. How many sessions have they had/will they receive?
 - b. Where do they receive services? Home? Center? Clinic?
 - c. Have you ever had previous services that were done differently and/or held at another location? (if the answer to this is yes, follow up on where, when, why, and how.)
3. Please describe how involved you were in deciding what the goals would be for your child.
 - a. Were you present when they were written?
 - b. How were the goals written?
 - c. How were they decided upon?
 - d. How often are you updated about your child's progress toward these goals?
4. Can you describe a typical intervention between your child and his/her provider?
 - a. How are you involved in the actual sessions that providers have with your child?
 - b. What do you do when providers work with your child?
 - c. Have you ever attended any sessions at the center/clinic? Can you describe those?
5. What kinds of things make it difficult to participate at the center/home with your child and the service provider?
 - a. Physical/Logistical barriers?
 - b. Financial barriers?
 - c. Other?
6. What kinds of things make it easier to participate? If you wanted to be involved/more involved, what would you need?
 - a. Time in a day?
 - b. Money?
 - c. Expertise?
 - d. Other?
7. Please describe what your ideal relationship with a service provider would be.
8. Anything you would like to add? Follow up on any previous comments?