ABSTRACT

Title of Document: CASE STUDY OF A CARIBBEAN FAMILY'S PERCEPTIONS OF CULTURALLY APPROPRIATE FAMILY- CENTERED SERVICE PROVISION.

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This case study explores a Caribbean family's perceptions of the cultural appropriateness and the family-centeredness of services they received from their early intervention service providers. Families' cultural beliefs and the mandates of early intervention services under the Individuals with Disabilities Education Improvement Act are sometimes very different. These differences sometimes result in conflict.

Researchers have done well to highlight beliefs of importance to many cultural groups; however, there is no record related to Caribbean families'. This qualitative study collected data over a two-month period through interviews, observations and document analysis. The constant comparative method was used to analyze the data, resulting in the themes used to describe the phenomenon.

The number of years this family lived in the US seems to have resulted in acculturation to the point where their experiences were similar to that of an American family. They perceived the services they received to be family centered.

CASE STUDY OF A CARIBBEAN FAMILY'S PERCEPTIONS OF
CULTURALLY APPROPRIATE FAMILY- CENTERED SERVICE PROVISION.

By

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Preface

<u>*Nabel String*</u>

The blank stare from the unknown

next door neighbor, kills something inside

and the sound that pulls

is of the heartbeat, of the drum voice.

is River Sallee, is a drummer

soaring, is Victoria, is Belmont,

those places that you, I, we left

left to search, as always, for a better life.

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Merle Collins
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Chapter 1: Introduction

Providing early intervention services in a way that shows respect for each family and differences in culture has been an area of concern at least since the re-authorization of Part C of the federal legislation, The Individuals with Disabilities Education Act 1997 (IDEA), PL 105-17. The current law, Individuals with Disabilities Education Improvement Act 2004 (IDEIA), PL 180-446, demonstrates the commitment of the federal legislature to families and to respecting differences of culture. Researchers (Chamberlin, 2005; DeGangi & Wietlisbach, 1994; Harry, 2002; Lynch & Hanson, 2004; Sontag & Schacht, 1993) have sought to explore the ways IDEA 1997 affects families of various cultures. While families of several cultures represented in the United States (US) have been investigated, the experience of the Caribbean family receiving early intervention services is not represented in the professional literature. This study explores the perceptions of a Caribbean family receiving early intervention services for their child.

In making the case for the study, an attempt is made to identify the Caribbean region and report statistics on the Caribbean proportion of the US population. A discussion on culture and cultural dominance then follows. This section also contains the researcher's perspective as well as the purpose of the study and the research questions.

The Caribbean

The *Commonwealth Caribbean* is the term applied to the English- speaking islands in the Caribbean and the mainland nations of Belize and Guyana that once constituted the Caribbean portion of the British Empire (Meditz & Hanratty, 1987). The Caribbean as defined for the purposes of this study includes all the islands that extend in

the north from the tip of the Florida peninsula proceeding southward to the Northwest of Venezuela. The islands that make up the Commonwealth Caribbean are Jamaica, Trinidad and Tobago, the Windward Islands (Dominica, St. Lucia, St. Vincent and the Grenadines, and Grenada), Barbados, the Leeward Islands (Antigua and Barbuda, St. Kitts and Nevis, the British Virgin Islands, Anguilla, and Montserrat), the Bahamas, the Cayman Islands, and the Turks and Caicos Islands. The term *West Indies* is often also used to identify this region. The islands that make up the Caribbean form a long narrow chain, which is almost 2, 500 miles long and spans about 160 miles at the widest point. The archipelago, as can be seen in Figure 1, forms a sort of bridge between North and South America and divides the Caribbean Sea from the Atlantic Ocean (Rogozinski, 1999).

There was frequent migration by the indigenous peoples between the American mainland and Caribbean before colonization. The migratory practices of the indigenous Indians who inhabited the Caribbean region came to an end following colonization. Migration between the two regions redeveloped during the early twentieth century. The United Fruit Company made this development possible through the banana industry. The banana boats that operated between the Caribbean and Atlantic ports in the US encouraged passenger travel (Palmer, 1995). The United States, however, imposed restrictive immigration policies, which lasted up to the mid-twentieth century. The law that governed the policies, the McCarran-Walter Act, restricted Caribbean migrants to the United States to 100 per year. In 1965 amendments to the Act opened opportunities for greater numbers of migrants per year. While reliable data on the flow of population from the Caribbean to the US in the early years are scarce, the World Bank estimates that

between 1980 and 1988 the Caribbean lost almost 1 percent of its population (Mandle, 1998). By 1990 Caribbean-born residents in the US numbered approximately 750,000. More recent statistics show that during the period from 2003 to 2005, the number of Caribbean-born migrants (who have been granted permanent residence) is approximately 300,000 for the period. In each year, the region accounts for close to 10% of the total number of foreigners granted legal permanent residence in the US (Jefferys & Rytina, 2006). Although these statistics are not large compared to other sources of US migration, they are significant when compared to the size of the home population, estimated to be 39 million in 2005 (Population Reference Bureau, 2005).

While the major reason for migration was to improve economic and financial well-being, many migrants also came with the intention to have their children acquire a good education (Henke, 2001). These migratory trends raise questions about Caribbean families' experiences in the US education system. Of particular interest to this researcher are experiences with the early intervention system.

In the Caribbean, as in many other developing countries and regions, there is no parallel to the services provided in the US for children with disabilities. Interviews were used in the absence of literature that address' provisions for infants with special needs in the Caribbean. Interviews were conducted with the School Supervisors for Special Education, Early Childhood Education and a Developmental Pediatrician from Trinidad and Tobago.

Children with sensory and orthopedic disabilities attend free special schools that fall under the public school system. Typically, children start public school at the age of five years. Education before five years in many Caribbean islands is provided by anyone

who has the resources to do so. For the most part, therefore, on many islands providers of early childhood education services are private businesses. Children with sensory, developmental or orthopedic disabilities usually do not receive educational services before entering public school. For the most part, this is because of a lack of training, inadequate training or inappropriate training of the person operating the early childhood center. In some case where children may have presented with a unique problem at birth or soon after, a Public Health Visitor or nurse is assigned to the family. This nurse or health visitor goes to the home, charting the child's physical growth and development and monitors the child's immunization schedule. Routine developmental testing or screening is not done in the Caribbean, as it is in the US.

The United States

In the United States, federal law provides the framework and guidelines for all persons between birth and 21 years with disabilities to have equal access to educational opportunities. This law is the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, P.L. 180-446. Early intervention services fall under Part C of this act. These are public services, provided to families, designed to meet the developmental needs of a child between birth and three years with a condition or conditions identified by the state. The eligibility criteria for the state this study was conducted in is listed in Appendix A. Part C of IDEIA is unique in that it not only addresses the needs of the child, but also considers the primacy of the family for optimal child development. When originally enacted in 1986 as Part H, and revised in 1997 as Part C of IDEA, the law mandated that services be made available to all infants and toddlers with disabilities and their families (Sec. 635. (a) 2). To ensure family involvement, Section 635 (a) 3

continues, there must be "a family-directed identification of the needs of each family of such an infant or toddler to appropriately assist in the development of the infant or toddler." This family-centered philosophy has become a widely accepted component of service provision for infants and toddlers who are eligible for services. Research indicates positive developmental outcomes for the child when the family is accounted for as part of the early intervention service (Bailey et al., 1998; Dunst et al., 1991; Garrett & Thorpe, 1998; Mahoney & Bella, 1998).

With the continued influx of people from different parts of the world into the US, the percentage of children from different cultures receiving services under the umbrella of special education and early intervention is increasing. The demographics in education shows that 90% of education service providers are European-American, the dominant cultural group. One-third of the group they serve is children of color (Chamberlin, 2005). It is vital that teachers and all other service providers know about the cultural backgrounds of the students and families they serve. This is important because families' "beliefs and practices may differ in important ways from those of mainstream American families" (Harry, 1992, p. 334). Our everyday experiences are formed by our cultural understanding in ways that are not obvious, but established to be the way. It is not common for people to reflect on their experiences and values as being specific to their own culture. Therefore, when providing services to families of cultural backgrounds different from their own, professionals' perceptions will be influenced by their own understanding of the way things should be. When differences in beliefs and understandings arise, disagreements can occur that have the potential to undermine a climate of collaboration.

It may be argued that the dominant culture of the United States can only be described as a conglomerate of the many diverse cultures that contributed to the building of the nation (Harry & Kalyanpur, 1994). In an analysis of mainstream American culture, Spindler and Spindler (1990) found that the upper middle social class of the European Protestant segment of society has provided the "reference by which people have measured their success, achievement, and essentially their 'mainstreamness'" (p. 34). Though they assert this is the primary measure of "mainstreamness," the authors acknowledge that some relatively superficial features of all minority cultures in the US have been assimilated into the mainstream.

Harry and Kalyanpur (1994) concur with Spindler and Spindler (1990) in their understanding of the European Protestant segment of the US population being the "mainstream" culture. The cultural values and behaviors of this group have traditionally been emulated and preferred by minority groups of African, Asian, Hispanic, and Native (American Indian) origin and descent (Harry & Kalyanpur, 1994). While there are commonalities that can define a culture, the people who make up that culture are so different as to make each culture diverse. In this study, the term "culturally diverse" refers to minority cultures. The cultural experiences of the Caribbean minority population was explored in relation to the implementation of federal law related to early intervention.

Part C of IDEA 1997 provided a formidable task for professionals who were required to identify families' priorities, resources and concerns in a way that was non-judgmental and respectful and offer services consistent with beliefs that are personal, professional and reflective of the system they represent. This new dynamic has given rise

to the need to better understand the issues involved in implementing culturally appropriate, family-centered practices.

Researchers who have explored early intervention or special education services with families of cultures different from the dominant European-American culture highlight the importance of the families' culture as a variable in providing services. Lynch and Stein (1987) examined the way Mexican families participate in special education programs. Their findings showed that cultural barriers accounted for lack of participation by families. In an examination of Puerto Rican families' concept of disability, Harry (1992) showed that differences in definition of disability, based on the cultural orientation of families as opposed to service providers, resulted in conflict. When comparing families of White, Hispanic and American Indian ethnicity with regard to the type of service received, Sontag and Schacht (1993) found that white families accessed more services than Hispanic or American Indian families. While researchers have done well to highlight issues of importance to many cultural groups, however, there is as yet no record of the Caribbean families' experience.

Personal Perspective

As quoted by Baltutansky and Sourieau (1998) Benitez-Rojo defines the Caribbean as "a cultural meta-archipelago without center and without limits, a chaos within which there is an island that proliferates endlessly, each copy a different one, founding and refounding ethnological materials like a cloud will do with its vapor" (p. 5). This poetic characterization seems to suggest the lack of one Caribbean identity. On the contrary, it is the multicultural heritage of the Caribbean that yields a polycentric approach to our cultural identity. The mosaic cultural identity of the Caribbean is

"affirmed by idioms, languages, places, systems of thoughts, histories fertilizing one another and untying the unpredictable" (Pepin &Confiant, 1998, pp. 97-98). The culture of the Caribbean can be described as vibrant, energetic and colorful. While immigrants continue to manifest that vibrancy wherever they live, "this culture that contributes to the psychological makeup of Caribbean people-is not highly valued" (Collins, 1998, p. 121). Or at least this is the perception, since cultural debate in the region is stifled because of the pervasive perception that negative repercussions will follow, should the wrong thing be said and a politically and economically dominant country not like such behavior (Collins, 1998).

"As long as we Caribbean people keep quiet about our existence, it is easy—and perhaps even politic—for the United States to appear to do so also…" (Collins, 1998, p. 118). It is my intention to break the silence and announce that Caribbean culture extends beyond the theatrical manifestations of reggae, zook, calypso, carnival, steel pan and literature. One way that Caribbean culture resonates is in the way we care for our children. This study explores the perceptions of a Caribbean family of the cultural appropriateness and family-centeredness of the services they received while involved in early intervention services for their son. Throughout the study, I attempted to identify any variables of Caribbean culture that were significant in the way the family described their experiences.

Theoretical Understandings

The contemporary theory of Bronfenbrenner's bioecological systems model (1995) suggests that everything happening in the child's immediate environment, as well as within those systems and environments that the child may never enter, affects the

child's development. The culture of the family is one such system. It is worthwhile to explore how issues of culture impact the family and their relations with persons providing early intervention services.

Although one may claim that culture is so unique to the individual that it is not worth exploring, Ogbu (1991) reminds us that cultural models do exist and that they guide the behaviors and interpretations of the member group. According to Obgu (1991):

> The cultural model for each group—minority as well as majority—exists to provide group members with the framework for interpreting educational events, situations and experiences and to guide behavior in the schooling context and process. Since differing cultural models provoke different behaviors, the cultural model of a particular group is connected to some degree with the relative academic success or academic failure of its members. (p. 7)

Academic success or failure among minority groups is attributed therefore to the type of cultural model guiding the group. Cultural models of social realities differ, according to Ogbu (1991), because of differences in the minority groups' history.

The immigrant minorities who have moved to a society voluntarily often do so to improve economic standing, for better opportunities or for political freedom. Education for the immigrant groups is often seen as a means to an end and education of children is stressed. According to Ogbu (1991, 1978), differences in cultural assumptions cause problems affecting the relationship the immigrant group has with the school system and the actual learning process. In order to overcome these barriers to academic success that impede their long-term goals, the immigrant often uses the strategy described in sociology as "accommodation without assimilation." That is to say, while not giving up

their cultural identity, the group members make the necessary social adjustments to be successful. Ogbu (1991) states that immigrants to the United States tend to see the education available as far superior to that in their home country. They also perceive their treatment by the school system to be better. In addition, when confronted with prejudice and discrimination, they rationalize that, as "guests in a foreign land, they have no choice but to tolerate prejudice and discrimination" (Ogbu, 1991, p. 21).

Purpose And Significance Of The Study

This case study sought to understand the perspectives of a Caribbean immigrant family with a child who had received early intervention services in terms of the cultural appropriateness and family-centeredness of those services. I examined the cultural appropriateness of the family-centered services they received from service providers by conducting interviews and examining documents.

The study is significant in that it highlights the experience of a Caribbean family receiving early intervention services. The study also identifies the uniqueness of Caribbean culture, which differs from mainstream US culture and which service providers should be aware of when working with Caribbean families. The study looked at parental definition of diagnosis, parenting styles, concept of family and family identity, and ways of communicating. The research questions that follow will guide the study.

The Research Questions

The study addressed this central question: What are the perceptions of one Caribbean family of the cultural appropriateness and the family-centeredness of services they receive from their service providers? The guiding questions of the research study are:

1. How did this Caribbean family access early intervention services?

    a) Is there any relationship between leaving the Caribbean and coming to the US with the need for service?

    b) How did they make their way into the system for receiving services?

2. How is the cultural context of the family reflected through the services they receive?

    a) What are the family's goals for the child?

    b) How does the family define their child's disability?

    c) How has the child's disability impacted the family?

    d) What is a typical day like for the family?

3. What type of relationship does the family have with the service providers?

    a) Who sees the child most?

    b) Who is the most valuable to the family?

4. What assumptions or assertions can be made about the services received in the US as compared to what may have been or was received in the Caribbean?

    a) What recommendations would the family make to the Early Intervention system?

Chapter 2: Literature Review

The dynamics of providing services that are culturally sensitive and family-focused have been explored by families, professionals and researchers (Hanson et al., 2004; Harry, 2002). This review of the literature begins with an overview of concepts related to family from a Caribbean perspective. I then review federal legislation that mandates family-centered services for children who have disabilities and the theoretical underpinnings of the legislation. A presentation of literature related to family-centered service provision as highlighted by the law follows. Literature on cultural sensitivity in family-centered service provision in early intervention is then provided.

Family Structure In The Caribbean

The Caribbean society comprises a number of ethnicities, which have blended together to create a unique mixture of peoples and blend of cultures. Predominant are persons of African and East Indian descent, with Trinidad and Tobago and Guyana both having very large populations of East Indian descendants (Evans & Davies, 1997). Other ethnicities prominently represented in the Caribbean region are Spanish, British, French, Dutch, Chinese, Syrian and Lebanese (Rogozinski, 1999). Several hundred years of interregional migration, intermixing of the races and acculturation has given birth to a Caribbean cultural identity. Commenting on the Caribbean family, Barrrow (2002) said, "Caribbean family life has been uniquely shaped by an African cultural and ideological heritage, by the experience of slavery and colonialism, multi-racial and multicultural societies, and by the socio-economic context of migration, unemployment and poverty."

This blending of cultural ideologies has resulted in a Caribbean culture with values and norms not easily attributable to a particular contributing culture.

In the Caribbean, the acceptable cultural norms associated with mating and the formation of a family tend to be flexible and fluid. While a great majority of the unions are socially sanctioned, they are very often not legally recognized (Lange & Rodman, 1992). As a result, many children are born out of legal unions. Lange and Rodman (1992) report the rate to be as high as 70%. A complementary statistic, approximately 25% of children are born into a married union, is provided by Leo-Rhynie (1997). There are generally four kinds of family structures in the Caribbean. Evans and Davies (1997) and the United Nations (1995) describe: the marriage union, the common-law union (parents live together without being married), the visiting union (one or both parents still reside within their parents' home) and the single parent home, often headed by mothers. In addition to these, the United Nations Publication LC/G.1835-P (1995) reported two other types of family structures: (1) extended families, which are comprised of a man, his wife and their children, and some grandchildren, and (2) units that incorporate in-laws, stepchildren and adults not related by kinship to the other occupants.

Child-shifting, described by Evans and Davies (1997) as change in the child's residence or primary caregiver, is another phenomenon in describing Caribbean family diversity. When a child is shifted, another person (not necessarily a relative) takes care of the child. Children are very likely to be shifted if the parent is in a visiting union, has to migrate to another city or country to find work, or if the parent thinks the child would have a better life with the other person. This practice, which is commonplace in the

Caribbean, is not very common in mainstream US culture. These differences in family

structure also influence the way children are reared.

Child Rearing Practices In The Caribbean

The literature that is accessible in North American-based professional

publications related to child rearing practices in the Caribbean is very sparse. While

many authors have commented on their own experiences and observed practices, Leo-

Rhynie (1997) reports that very little systematic research has been conducted on the

topic.

Most children in the Caribbean are born into conditions of economic hardships.

Despite this, all the societies of the region highly value children and see them as

desirable. Evans and Davies (1997) quote Durant-Gonzales:

> There is much status and value placed on the "mother-role," and many beliefs
>
> propel young men and women into child bearing long before they are
>
> economically, emotionally, or developmentally ready for parental responsibilities.
>
> In the main, childbearing is linked to the emergence of a strong self-image and
>
> sense of womanhood that serves as a rite of passage. (p. 4)

Children's early experiences are largely dependant on the type of family structure

they are in. The most significant person in the early childhood years, however, is

generally the mother. The father's importance depends on his economic status and size

of financial contribution to the family (Lange & Rodman, 1992).

While parents value play, they see it as a form of social interaction, not valuing it

for educational purposes. Provision of play stimuli in the home is reported by both Leo-

Rhynie (1997) and Lange and Rodman (1992) to be limited if in existence at all. Story-

telling, though not regular or frequent, is a common practice among mothers. Success at parenting in the Caribbean is assessed by the child's obedience, good manners, ability to be clean and tidy, ability to sit quietly for long periods, and level of helpfulness and cooperation (Leo-Rhynie, 1997). These behaviors are extracted through highly authoritative and restrictive parenting strategies.

Corporal punishment is very common in the Caribbean. Although children are highly valued and desired, Caribbean families adhere to the biblical instruction not to "spare the rod and spoil the child." Beating children for misbehavior is a common disciplinary practice (Lange & Rodman, 1992). This socio cultural norm, of "the right to beat the child," is embraced by parents, teachers and parental surrogates (Sharpe, 1997).

Due to financial constraints, Caribbean children are "encouraged to be self reliant and hard working from an early age" (Lange & Rodman, 1992, p. 192). These expectations of young children are often unrealistic. When children do not meet their parents' expectations of behavior, the result is often "licks" (a beating). This cultural custom stems from any or all the following: unrealistic expectations of behavior placed on young children, parents' lack of knowledge of alternate ways to discipline, or the sheer hardship that poverty places on parents, especially single parents (Evans & Davis, 1997). In addition, these authors point out that many parents are unaware of typical child development goals.

The literature on raising a child with a disability in the Caribbean has received even less treatment than general child-rearing. Thornburn (2003) reports that there are two dominant ways in which disability is viewed in the Caribbean. One view is that the cause and responsibility for a child's disability is a result of a shortcoming of the family

or the child. This belief system often leads to shame and guilt, resulting in the hiding away of the child. The other dominant social view is that the family is not to blame, but there is a cure that can be provided by professionals.

In the Caribbean, routine screening and identification of disability are not provided at the preschool or primary school level. Problems that are not identified or obvious are not detected until the child fails to learn. While the etiology for failure to learn may not always be attributable to a disability, the lack of assessment does not allow for early diagnosis and intervention (Thornburn, 2003). Thornburn (2003) reports that the following barriers exist to service provision:

> Lack of information; misconceptions about the nature of the child's disability; lack of awareness that a disability is even present; lack of acceptance; hope in other, possibly quicker treatments (e.g., going to the United States for medical treatment, using herbal remedies, visiting an obeah woman); and poverty. (p.197)

The countries of the Caribbean "recognize that most of the children with special needs are … in the regular mainstream school system, and that this regular school system lacks the adequate provisions and support services" (Bergsma, 2000, p. 9). Countries in the Caribbean made a commitment at the World Conference on Education for All in 1990 to make the necessary changes to implement inclusive education. While the philosophy of inclusion is articulated in policy papers, early intervention policies are not noted.

Having depicted Caribbean family structure and the child-rearing practices and highlighting that early intervention services are not part of Caribbean customs. A description of the legislation for children with special needs in the US now follows.

Legislation For Children With Special Needs In The US

Pact C of the Individuals with Disabilities Education Improvement Act (IDEIA) 2004, P.L. 180-446, indicates in its findings that there is an urgent and substantial need to do the following:

(1)   to enhance the development of infants and toddlers with disabilities and, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life ;

(2)   to reduce the educational costs to our society, including our Nation' s schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;

(3)   to maximize the potential for individuals with disabilities and maximize the potential for them to live independently in society;

(4)   to enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and

(5)   to enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of all children, particularly minority, low-income, inner city, and rural populations' children, and infants and toddlers in foster care. (P.L. 180-446, IDEIA 2005, Part C Sec. 631 (a))

The policies related to these findings include financial assistance to States for the following:

a)   to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families, …

c)   to enhance State capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families; … (IDEIA 2005, Part C Sec. 631 (b)).

States receiving federal funds are required under the law to offer each infant or toddler with a disability and their family, at minimum, "family-directed assessment of the resources, priorities and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler" (P.L. 105-17, Individuals with Disabilities Education Act, 1997).

The original, early interpretation of the law, Part H of P.L. 99-457 (1986), moved federal policy away from providing services only to the child, as did the former law, Education for All Handicap Children Act. Prior to 1986, early intervention programs focused almost exclusively on the child who had a need. Rare systematic efforts were made to provide supports appropriate to the family's priorities and needs (Mahoney & Bella, 1998). According to Mahoney and Bella (1998), reauthorization of the law was influenced by theories of child development.

Theories

The contemporary theories of child development, which influenced P.L. 105-17, IDEA 1997, embraced the idea that the parent, family and socio-cultural influences play a

significant role in the development of an individual. Two key conceptualizations were that of Sameroff and Chandler (1975) and Bronfenbrenner (1979).

Sameroff and Chandler (1975) conducted an extensive review of research on early developmental predictors of poor developmental outcomes. In a study of children born medically at risk, the authors reported that positive outcomes for children were more related to the status of their parents and families than to their risk conditions. Synthesis of their findings indicated that, "the environment appears to have the potential of minimizing or maximizing . . . early developmental difficulties" (Sameroff & Chander 1975, p. 236). While the assertion may appear obvious, the research highlighted the important role of the quality of the care-taking environment in influencing later developmental outcomes. The authors hypothesized "a continuum of care taking casualty" (Sameroff & Chandler 1975, p. 236), to describe the range of outcomes attributable to different types of parenting. It was further suggested that both the child and the environment in which the child was being cared for influenced each other; Sameroff and Chandler (1975) suggested that a transactional model be used to understand these relationships.

Bronfenbrenner (1979) expanded this transactional model of understanding human development. The ecological systems theory of human development put forward by Bronfenbrenner (1979) posits that the child exists as part of a series of nested social systems. The systems, beginning with the individual, extend to the family and then to other larger systems, for example, the schools and church, which are themselves contained in an even larger system defined by culture and economics. Interactions between members within any one system and across systems affect the "ecology" in other

systems and have an impact on the development of the individual. This perspective of interactions and transactions has implications for the ways the early interventionist understands the multitude of factors that affect families and their ability to care for their members. In addition it reminds the interventionists that systems are dynamic and ever-changing, and that the system of service delivery influences families (Beckman, 1996).

Based on ecological systems theory, Carl Dunst and colleagues pioneered several studies in the mid 1980's documenting children's rate of development in relation to immediate family variables. The findings led Dunst to postulate, "that support, which is responsive to the needs of parents, is a key intervention factor that enables parents to engage in child rearing activities and routines necessary for achieving positive child outcomes" (Dunst et al., 1987). This research showed again the importance of working with families. Family involvement was cemented as a high priority in service provision in 1990 with the passage of Part H of P.L. 101-476, the IDEA. This law mandates that service providers include families in the process of planning and implementing intervention programs.

Professional Perspectives Of Family-Centered Services

Several studies have been conducted since the enactment of the P.L. 105-17 IDEA to assess the extent to which services were family-oriented. The studies that follow look at the perceptions held by professionals about family-oriented services. These perspectives, according to Dunst, Johanson, Trivette, and Hamby (1991), influence both the service delivery model and the principles of the model.

Before presenting the studies, it is important to note that under the umbrella of family-oriented services there are many models, each of which considers the family as a

unit of intervention and employs the social systems framework for understanding the family within nested ecological systems. A synthesis of the models by Dunst, et al. (1991) shows four main types that exist on a continuum, leading to greater emphasis on the families' role in decision-making about intervention services:

In the ***professional-centered model*** the professional is seen as the expert who assesses family functioning. The family is seen as in need of help to function in a healthier manner.

In the ***family-allied model*** families are identified as agents of the professionals. The families are recruited and tutored to implement interventions that the professionals deem to be important.

In a ***family-focused model*** the professionals and families collaborate about what the family's needs are. In this model families are encouraged to seek professional networks and services for advice and guidance.

Within the ***family-centered model*** the families' needs and desires determine the type of services and resources to be delivered. Professionals are seen as the agents of the family and intervene in an effort to promote family decision-making, capabilities and competencies (Dunst et al., 1991).

The gold standard for early intervention systems and services has been family-centered services (Hanson & Lynch, 2004). Within the field, programs may describe their services as "family centered" while operating according to principles belonging to another part of the continuum. Dunst, Johanson, Trivette, and Hamby (1991) conducted a study to "a) bring clarity to the meaning of family centeredness and b) assess the degree to which family-oriented early intervention program policies and practices were family

centered." The authors defined family-centeredness as "a combination of beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing" (p. 115). A multimethod, multisource approach was used to analyze the policies and practices of family-oriented early intervention programs. Three non-family-oriented and four family-oriented pieces of federal legislation were analyzed for their degree of family-centeredness. In addition, a survey was conducted to collect data on the "state adopted family-oriented support *principles*, *paradigms*, and *practices*," from state policymakers (Part H Program coordinators and Interagency Coordinating Council Chairpersons), "street-level" practitioners and consumers (members of the state ICC).

A justification for the multimethod, multisource approach adopted was not provided; however, the method appeared effective in triangulating findings towards answering the research question. While they acknowledged that the principles generated by one researcher in a previous work were but one set of standards, these were the only measures of family-support principles used for the study. The criterion for selecting the seven pieces of legislation is not provided, nor is a rationale for the groupings. The criteria for selection would have been informative and may have assisted in giving more validity to the outcomes. Although data was collected from 25 states, the number of persons in each category is not reported. The authors attempted to provide some detail about the way the surveys were conducted. This information provided a better understanding of the process used and increased understanding of the results.

In spite of these limitations, the analyses were informative, showing that P.L. 99-457 and P.L. 100-146 had greater consistency with family support principles and

therefore showed greater presumption toward being family-centered (Dunst et al., 1991).

It is interesting to note that P.L 100-294 and P.L. 100-485, which were categorized by the

authors as family-oriented, weighted similar to non-family-oriented legislation on

adoption of family-support principles. The responses from the survey showed a greater

tendency for state-level policymakers to see the adoption of family-support principles as

family–centered, compared to the views of practitioners and consumers. It was apparent

from the analysis that there is some disconnect between the way street-level practitioners

and consumers viewed the family-centeredness of the laws, as compared to their

policymaking peers. Dunst, et al. (1991) believed the findings to "represent an

'implementation lag' between establishing the parameters of a family centered program

and translating promulgated beliefs and recommended practices into actual service-

delivery efforts" (p 123).

In a study of professional perceptions, Bailey, Buysse, Edmondson and Smith

(1992) set out to investigate a) the current status of family-centered approaches in infant

intervention programs, b) professionals' perceptions of a discrepancy between current

and ideal practices in working with families and c) barriers that made it difficult to

achieve ideal levels of family involvement. This study, unlike the Dunst, et al. (1991)

research, focused more closely on professionals implementing the policies.

The study involved responses from 180 professionals working in early

intervention programs or agencies responsible for early intervention programs for infants

and toddlers in four states. The professionals were asked to complete a rating scale

before the start of an assessment workshop they voluntarily attended. The 10-point rating

scales developed by Bailey, et al. (1992) addressed four dimensions of family

involvement: "a) parent participation in decisions about the child assessment process, b) parent involvement in child assessment, c) parent participation in team meeting and decision making, and d) provision of family services" (p. 300).

Analysis of the responses showed service providers in this study perceived, "a substantial discrepancy between how they currently involve families in early intervention programs and how families should be ideally involved" (Bailey, et al., 1992, p. 307). In each of the four dimensions, current family involvement ranged from 4 to 5. The same professionals, however, considered ideal involvement to be in the range of 7 to 8. Family, systems, professionals and testing were identified as four major categories of barriers to ideal family involvement. Although this study involved a large number of respondents, data were based only on self-reports, and there were no checks to ensure that the claims were reliable and valid. This compromises the validity of the study. Bailey, et al. (1992) echo the earlier findings of Dunst, et al (1991) in stating that "the gap between typical and desired practice is substantial" (p. 307).

In an effort to better identify the factors that support and interfere with the implementation of family-centered services, Garrett and Thorpe (1998) set out to investigate the perceptions of Local Interagency Coordinating Councils (LICC) of the impact of early intervention in their communities. The researchers conducted interviews with LICC coordinators, as well as observations and review of materials using a qualitative design framework.

Twenty-six of the 40 coordinators from a state where legislation had established local councils were interviewed for the study. Based on evidence of work by Swan and Morgan (cited in Garrett and Thorpe, 1998), two extended sites were chosen. Additional

methods used to collect data included individual telephone interviews with a parent representative, a direct service provider representative, and an administrative representative from each of these expanded cites. Data were analyzed according to qualitative methods of generating categories, themes, and patterns, testing the emerging hypotheses against the data and searching for alternative explanations in the data.

The findings showed consensus among the local personnel that the legislation resulted in services that were family-centered. In making the change to a family-centered system, states and localities reported that gaining meaningful involvement was difficult to achieve. Although they reported efforts to get parents involved, it was an area with which coordinators struggled. Parents in the study agreed that parental participation was a problem. Among the factors that contributed to the low rate of parental participation, from parental perspectives, were: a) a feeling of puzzlement and intimidation with the operations of the council, which led to feelings that parents' contributions were inappropriate or insignificant and b) the time spent at ICC meetings was not paid for.

One strength of this study was the manner in which data were collected. The involvement of several members at different levels allowed for comparison and validation of data. The study, however, does not give an indication of the criteria used to assess the family-centeredness of services. While the findings indicated positive impacts in the areas of family-centered services and service coordination, the study did not describe how or what these positive impacts were.

It may be argued that the period of time between this study (1998) and that of Dunst, et al. (1991) should have been enough for implementation of policy at the local level that was in line with that of the originators. "Implementation lag" cannot stand as a

suitable argument for the continued mismatch of the family-service orientation of the law and the field practice. Garrett and Thorpe (1998) identified the need for research on collaboration and family involvement and factors that contribute to successful outcomes; they described the local implementers as "pioneers" doing their best with no guides.

The studies reviewed thus far suggest that while providers indicate a preference for greater family involvement, the actual level of involvement by families in early intervention programs is quite low. In addition, while Dunst, et al. (1991) have generated general tenets for what a family-centered program should look like, there is no standard measure for what constitutes family-centered services. In the literature on family-centeredness of services, many researchers focus on the professional perspectives. The recurring themes suggest that research should focus on the perspectives of other individuals, namely the families for whom the services are provided. Having explored the perceptions of professionals about family-centeredness of services, an exploration of perceptions related to cultural practices follows.

Family And Professional Perspectives Of Family Centered Services

McBride, Brotherson, Joanning, Whiddon and Demmitt (1993) analyzed the implementation of family-centered services from the perspectives of families and professionals. Using a combination of principles similar to those of Dunst, et al. (1991) and the four models for working with families on a continuum of family-centered services, examples of indicators for intervention practice were developed. McBride, et al. (1993) used these practice indicators to evaluate where programs fell on the continuum of family-centered services.

The qualitative inquiry was guided by three broad questions: 1) To what extent is the family considered the focus of early intervention services? 2) What roles are families taking in decision-making? and 3) To what extent are services provided to strengthen family functioning? (McBride, et al., 1993). The families and professionals were selected from four geographically dispersed Area Education Agencies (AEAs) in Iowa. A total of 15 families and 14 professionals participated in the study. Trained interviewers conducted interviews at the families' homes and, after six months of service had elapsed, followed with telephone interviews. The second interview was conducted with half the families, as a member check. A similar process was adopted to interview professionals at their work site. All interviews were tape-recorded. Recruitment and interviewing continued until saturation had been reached in the data categories.

Credibility measures for qualitative methods adopted in this study included triangulation, group debriefing and member checks. While a rich description is provided about data collection, analysis and measures of credibility, the researchers did not provide information on the way confidentiality was ensured in the study, and knowing how confidential data would be, could affect participant responses to questions. The collaborative approach used to abstract synthesis statements is a credit to the dependability of the study.

While professionals described their philosophical orientation to be family-centered, McBride, et al. (1993) found that what was articulated and what was actually practiced were sometimes incongruent. This finding was consistent with that of Dunst, et al. (1991), Bailey, et al. (1992) and Garrett and Thorpe (1998). While families in this study perceived professionals to be concerned for their families' well-being, they may not

have known that early intervention services extended to the whole family. In this study it may have been appropriate to include a question on the interview schedule to assess what parent expectations were of family-centered services. Family roles in decision-making reflected the family-allied model. While the families in the study articulated that professionals had contributed to improved family functioning, the professionals did not readily identify this as a goal. McBride, et al. (1993) found it provocative that "professionals in the study were not strongly committed to or knowledgeable about help-giving that places emphasis on building the capacity of families" (p. 428).

This study examines the perceptions of parents and professionals alongside each other and then attempts to integrate the two in order to identify where on the continuum of family-oriented services the individual program falls. While it provides valuable detailed information, the population used was reflective of the dominant culture.

Professional Perceptions Of Culturally Appropriate Practices

The issue of the family-centeredness of programs and professionals has received much attention by researchers. By contrast, the perceptions held by the same group about culturally appropriate practices has not received the same degree of attention.

In order to describe professional perceptions of cultural diversity and socio-economic status on family-professional collaboration, DeGangi and Weitisbach (1994) conducted a qualitative research study using an interview format. Twenty-six professionals from eight early intervention programs in three states volunteered to participate in the study. The professionals served families from diverse cultural, socioeconomic and educational backgrounds.

Interview questions fell into three broad categories: professional characteristics and how they affected the IFSP process, the IFSP process and family-professional collaboration. The individually administered interviews lasted approximately one hour and were conducted on site at the early intervention programs. Interviews were tape-recorded, transcribed and analyzed. The researchers formulated a categorizing system to capture a range of responses for conducting analyses. The researchers collaborated as they coded and stated that therefore reliability was not assessed.

Twenty-four of the 26 professionals reported culture to be an important variable in the IFSP process. While this finding is impressive, there was great inconsistency among the participants in the perceived impact of culture on family-professional collaboration. The professionals appeared sensitive to the need for information about the families' customs, childrearing practices and routines; however, only half of the respondents indicated "that they incorporated the family's customs and values into IFSP goals."

The sample size and self-selected nature of participants in this study prevent generalization. However, the qualitative nature of the inquiry sheds insight into how the professionals view the topic. It may have been beneficial for the researchers to examine the IFSP documents generated by the participants to ascertain the cultural sensitivity of the goals and strategies. Interviews with some of the families may have also helped to triangulate the self-reported data and give a more accurate picture of the cultural sensitivity of the professionals.

In another study addressing culturally appropriate practices, Lee, Ostrosky, Bennett and Fowler (2003) investigated issues surrounding the implementation of

culturally appropriate practices. The researchers focused on the importance early interventionists placed on cultural factors, the extent to which they implemented culturally appropriate practices and the barriers they faced in providing services to families from diverse cultural backgrounds. One hundred twenty-three early intervention professionals were asked to complete a four-part survey, containing open- and closed-ended questions. Measures used to ensure the credibility and validity of the instrument were reported. One section of the survey contained 20 suggestions of practices, weighted on a five-point scale, which may influence the provision of culturally appropriate services.

The results showed that 58% of the professionals were European-American, and more than 62% of the families served were of ethnic groups other than European-American. This finding is similar to those of Lynch & Hanson (1998) and Chamberlin (2005). Similar to the work of DeGangi and Wietlisbach (1994), the results from this study also showed that, while professionals perceived many culturally appropriate practices to be important, they did not put them into practice. Lack of time, training and materials were the most commonly cited barriers to providing culturally appropriate services. According to Lee, et al. (2003), the barriers identified are not independent of each other, and further research is needed on their interrelatedness. Based on the discrepancy between perceived importance and actual implementation of culturally appropriate services, Lee, et al. (2003) suggest that professionals may be under the misconception "that providing culturally appropriate services to families and their young children with special needs is an additional responsibility, rather than an integral part of

providing quality EI services" (p. 292). This statement echoes views held by Harry (1992), Harry and Kalyanpur (1994) and Hanson and Lynch (1998).

The sample population of this study may not be representative of the whole early intervention population, and generalizations should not be made. The self-reported nature of the survey and the fact that only professionals were included may have some implications for the validity of the responses. As the researchers noted, a study that used both qualitative and quantitative measures and involved both professionals and families might lead to a better understanding of the issues involved in implementing culturally appropriate practices.

A descriptive study addressing the perspectives of early interventionists about the multicultural practices of African-American families and the support provided to them for these families was conducted by Sexton, Lobman, Constans, Snyder and Ernest (1997). A fourteen-item questionnaire was administered to 170 early interventionists in a southern state. The instrument used a five-point Likert scale with higher scores indicating more positive perspectives of multicultural practices. The questionnaires were completed at the beginning of training workshops on multicultural issues conducted by the state. The trend of a large percentage of the professionals being European-American is also reflected in this study. Sexton, et al. (1997) reported that 67% of the early interventionists were European-American. A cultural breakdown of the population served was not provided. The early interventionists in this study had positive perceptions about the multicultural nature of interactions with African-American families. The professionals, however, had less positive reports about the administrative and systematic supports provided.

The dissertation of MacMillan Nownes (1998) set out to identify where on the continuum of family-oriented service provision put forward by Dunst, et al. (1991) parent perceptions of early childhood service provision fell. In addition, the researcher sought to identify the help-giving behaviors parents received from service coordinators and discern which ones parents found most valuable. The ecological systems theory of Bronfenbrenner (1979) forms the foundation of this dissertation. A discussion of the methods and findings comes next.

A sample of parents from Tennessee who had children receiving services was identified based on the following criteria: involvement with early intervention services for at least 12 months; had completed an initial IFSP and one IFSP review; they had a Tennessee service coordinator assigned to them on the IFSP; and they had only had one service coordinator. Two families from each of the nine districts in Tennessee were randomly selected from the sample identified by the project coordinator of each district and asked to participate in the study. Sixteen service coordinators (28% of the state's service coordinators) served the 18 families participating in the study.

The researcher contacted participants and used a combination of qualitative and quantitative methods to collect data. Interviews were conducted in person and tape-recorded, using an open-ended interview schedule. Bracketing interview design, collecting verbatim data of interviews, and peer examination of half of the parent interviews were used to ensure reliability and validity of this qualitative part of the study. The Professional Helpers Characteristics Scale (PHCS) of Trivette and Dunst (1991) cited by MacMillan Nownes (1998) was also administered, and the mean and range for this measure were computed. Qualitative data were analyzed under broad themes with

sub-domains and categories. In presenting the data, MacMillan Nownes (1998) used tables, which provided a quick and easy way to view and interpret findings. The tables were supported with rich thick descriptions and verbatim extracts from interviews. While MacMillan Nownes (1998) had the benefit of space in her dissertation, other published journal articles reviewed do not. For example, the study by Harry (1992) may have benefited from the use of tables in the analysis and presentation of the data.

There was very little variability in scores on the PHCS, which trended strongly toward the family-centered end of the continuum. The researcher could not ascertain if responses were not influenced by other factors, for example, preserving the researcher as a TEIS employee. The interview data showed that seven of the eight components of family-centered approach as described by Dunst, et al. (1994) were present in descriptions. Service coordinators were not reported to have emphasized the mothers' personal support network. The most important help-giving behavior perceived was that of "building meaningful relationships" (MacMillan Nownes, 1998).

The investigations reviewed above showed that while providers identify culture as an important factor in providing services to families, they do not incorporate family customs and values into the IFSP. The studies also provide support for the contentions of Chamberlain (2002) and Harry (1992) that service providers come from the mainstream culture.

Non-Mainstream Family Perceptions Of Family-Centered Early Intervention Services

The following studies explore the perceptions held by families of the services they receive. In particular focus are families that are from non-mainstream American cultures.

When discussing the family-centeredness of services, the perceptions of parents and families are important.

Hispanic, Black and Pan-Asian students make up the majority of the school-aged population in many areas of the United States, and many of these students are recent immigrants (Lynch and Stein, 1987). These new arriving immigrant families from the developing world face many challenges with the education system upon arrival. New arriving immigrants must grapple with an "education system that is entirely different from that in their own countries, and the special education programs, services and legislation have no parallel" (Lynch & Stein, 1987). Lynch and Lewis as cited in Lynch and Stein (1987) comment on the bureaucratic and businesslike nature of special education programs and services which often are in direct conflict with the families' cultural values and beliefs.

Lynch and Stein (1987) conducted a comparative investigation of parental participation by ethnicity. Specifically, the study was designed to examine the ways in which Mexican-American families participate in their children's special education programs and to compare their participation with Black and Anglo families. A sample of 63 Mexican-American families with children at all age levels in all special education service programs and service categories were involved in the study. Families were interviewed in their homes by trained interviewers who were native Spanish-speaking, bilingual and part of the Hispanic community. The findings from these interviews were compared to that for Black and Anglo families from previous studies.

One of the findings of the study was the low rate of participation of Mexican-American families in most research studies. Other findings included that Mexican-

American families were satisfied with the services their children were receiving, but were less knowledgeable and less involved than Anglo and Black families with children receiving services. Further analysis of the findings showed that Hispanics and Blacks appeared less involved in the assessment process and offered fewer suggestions at IEP meetings than Anglos. Hispanic parents spoke with respect about the school and programs indicating, "teacher knows best." Their comments often related to culture and in general they found "educational decision making was the school's job, and they entrusted that role to the school system and its personnel" (p. 110). This view as pointed out by Lynch and Stein (1987) is "in direct conflict with the special education system's desire for joint decision-making and for strong home/school partnerships" (p. 110).

The use of culturally competent members of the community as the interviewers was a strength of the study. The self-reporting nature of the study, however, places limits on the credibility of the results. Crosschecks could have been made with school records to validate some of the responses. Despite these limitations, the issues illuminated are of great importance. Lynch and Stein (1987) point to the disparity in the way Anglos and two minority groups, Hispanics and Blacks, assess special education services. The study raises the question of differences in cultural perceptions as they relate to special education and how service providers are addressing these differences.

In addressing the concept of disability from a cultural perspective, Harry (1992) conducted an ethnographic study of low-income Puerto-Rican families, examining parents' interpretation of their children's special education placement. Twelve families who resided in a largely low-income Hispanic community were interviewed. The selection represented 35% of the Puerto Rican students enrolled in special education

programs in the district. Hispanic social workers contacted the families and presented the researcher as a non-affiliated independent agent. Harry (1992) used an ethnographic-type qualitative research approach involving interviews and participant observations. In addition, the researcher examined students' school documents and interviewed district professionals involved in service delivery to Spanish-speaking families. These methods extended the single-interview method of Lynch and Stein (1987) and serves as a means of validating families' self-reported information. The findings of the research showed 1) parents' "parameters of 'normalcy'" in terms of children's development were much wider than those used by the education system, and 2) different designations for disability led to parents' confusion of terms like "handicapped" and "retarded" with more extreme forms of deviance. These discrepancies resulted in low parental participation and disempowerment as a result of culturally different ways of understanding.

The use of ethnography as the type of qualitative research was effective in capturing the cultural perspectives posed by the research question. Triangulation of data by examining school records and interviewing school personnel lends to the credibility of the research. The presentation of the researcher as not affiliated with the school system may have influenced parents to share information more openly and honestly. In the vein of qualitative ethnography, Harry (1992) provides thick, detailed descriptions and reports a prolonged field engagement with participants. Although the sample was much smaller than that of Lynch and Stein (1987), the methods used to collect and analyze the data increase the validity of this study.

While the results of the study should not be generalized to other populations, the results are valid. Professionals serving children with disabilities from non-mainstream

cultures need to take note of the variations in the meaning of "disability." In addition, professionals need to be sensitive when labeling children and take time to explain what the label means for that child to the family. Based on this study's findings about culturally diverse parents' understanding of disability, further research needs to be conducted with members of other culturally diverse populations to ascertain similarities and differences in definitions. Additional research could also look at the way parental interpretation of the child's disability label affects the families' involvement in special education and early intervention.

In an effort to better understand "what factors affect parents' participation in the early years of children's special education placement," Harry, Allen and McLaughlin (1995) conducted a longitudinal three-year study of African-American parents. The study took place in a school district where students and professional personnel were predominantly African-American. The researchers investigated the views of parents of 42 African-American preschool children using a combination of interviews and observations. Students were selected at random from preschool lists but were required to have a telephone contact. Eighteen children were enrolled in general education, while twenty-four were in special education programs. Parents were contacted via letters sent home with the children, and researchers then followed with a phone call. Professionals were interviewed as required by the direction of the emerging data.

Two African-American researchers collected data through taped and untaped interviews. Participant observations of special education conferences were made along with examinations of students' documents and workbooks. Interviews, which were semi-structured or unstructured, were conducted at a location preferred by the parent. Field

notes were completed after each observation. These methods were similar to those used

by Harry (1992) to collect and analyze data. The ethnography style yielded a very

detailed picture of the dynamics of the parent-professional relationship and the decline in

parent satisfaction and involvement over time.

The outcomes showed that "for the most part, parents were satisfied with their

children's preschool program, but became concerned about labeling, classroom

environment and curriculum issues by the end of the second school year" (Harry, et al.,

1995, p. 373). McBride, et al. (1993) also reported this initial feeling of satisfaction by

parents. Another finding of the study related to practices that communicated to parents

the message that their input was not important. The findings of Harry, et al. (1995)

indicate a relationship between parents' satisfaction and their level of involvement in

early intervention programs.

Sontag and Schacht (1993) explored the relation between family ethnicity, income

and age of the child with the type of early intervention service received. Although other

research questions were addressed, this literature review will focus on ethnicity. Face-to–

face, closed-item questionnaire interviews were conducted with parents of children

receiving early intervention services. Trained interviewers conducted interviews in the

parents' home; parents had a choice of their interview language. Efforts were made to

have a sample that was ethnically and economically representative of the state in which

the research was being conducted. A total of 536 families were included in the data

analysis.

Ethnic comparisons were conducted on White, Hispanic and American Indians;

according to Sontag and Schacht (1993), these are the three major ethnic groups in the

state. Generally, families were found to be satisfied with the services they were

receiving. This finding is consistent with that of Lynch and Stein (1987) and McBride, et

al. (1993).

The quantitative method used by Sontag and Schacht (1993) produced

informative data. The data pool of 536 families, however, could have gone through

further statistical analyses of the variables for each ethnic group. While the results

indicate that parents were satisfied with service provision, for example, a breakdown

according to ethnicity could have been made to report the satisfaction of each group.

This cross-analysis was a benefit of the Lynch and Stein (1987) report. In order to better

understand the data as presented, some information was needed on the statistical

procedure used to compare the data, but this was not provided. Although the sample size

was large, the data was self-reported, and there was not cross-validation with information

from the state. As with the study done by Lynch and Stein (1987), this may have affected

the validity of the results. The findings of this study are similar to that of Lynch and

Stein (1987), in that it also found that the dominant cultural group accessed more services

than Hispanics or American Indians, two culturally diverse groups in the United States.

Bailey, Skinner, Rodriguez, Gut and Correa (1999) used a combination of

quantitative and qualitative research methods to ascertain the awareness, use and

satisfaction with services for Latino parents of young children with disabilities. They

also examined parents' use of alternate treatments. In making a case for the study,

Bailey, et al. (1999) acknowledge that gaining access to needed services for a child with a

special need can be daunting for any parent. Early intervention and early childhood

special education service providers identified and recruited the families. Bailey, et al.

(1999) gathered data on one hundred Latino couples from four states (mothers and fathers separately) with children under six years who had mental retardation or some other type of disability. Trained Latino interviewers conducted the interviews, which lasted two to four hours. Interviews were usually conducted at a location chosen by the parent (usually their home) and, according to the parents' preference, either in one or two sessions.

The researchers found that only a small percentage of the sample had limited awareness and use of services, 10% and 12% respectively. Satisfaction with services received was generally low, with only 17% of the responses being mostly or entirely satisfied. Greater dissatisfaction with services was found to be associated with greater awareness and use. Parents who were less aware of services tended to be more satisfied with what they received. Again, this finding is consistent with those of Lynch and Stein (1987), McBride, et al. (1993) and Sontag and Schacht (1993).

While the literature suggests that Latino families often "seek out treatments that are alternatives to biomedical, educational and psychotherapeutic treatments and care," (Bailey, et al., 1999, p 369.) the findings of the study did not support this contention. Only 1.5% of the participants reported a use of equal amounts of biomedical and alternatives and only one used alternative treatments exclusively. The factors that had an impact on awareness, use and satisfaction included: ability to understand written and oral communications from the service provider, lack of translators, lack of information about services, being sent from agency to agency without receiving help, needing information about the child's specific condition, and feelings of discrimination. The parents who expressed satisfaction commented about a key person who was very helpful.

Although it is unknown how this sample represents the Latino population in the U. S., the variability and size of the sample were substantial. The population used for the study, however, included only parents of children who were receiving services. A true estimate of awareness is therefore limited, as is a measure of how many families rely solely on alternative treatments. The use of both qualitative and quantitative inquiry gave a rich understanding of the factors that impact the research question. This article is a good reminder of the truth in the caution given by Hanson and Lynch (2004), that culture is not monolithic; rather, within a group, differences can be as diverse as they are across cultural groups. "Although it is critical to understand the history, traditions and values of various cultures, it is probably a disservice and misrepresentation to assume that members of immigrant groups do not subscribe to what professionals consider modern approaches to services" (Bailey, et al., 1999, p 379).

The following study highlights the way cultural misunderstandings can affect parental decision-making. Rao (2000) conducted a case study of an African-American mother's perspectives on parent-professional relationships in special education. The participant, called Rose in the study, is a thirty-year-old single parent. She has two sons, the youngest of whom, John, is 4 years old and lives with her, while Mathew, who is 9 year old, lives with Rose's mother. The initial focus of the researcher was "understanding Rose's perspectives and her views on the services she was receiving … my focus changed from merely trying to describe Rose's perspectives to exploring the process through which she reached such understandings" (Rao, 2000, p. 2).

Data were collected over a nine-month period using in-depth interviews and participant observations. All interviews were conducted in the participant's home and

tape-recorded. They were initially open-ended and aimed at gaining rapport. Later, the interviews became more focused. Times for interviews were set reciprocally. Participant observations were done at the participant's home, at two parent training workshops and at a school meeting. Additional information was also gathered on three occasions at the participant's home when the service provider met with her.

Data was analyzed concurrently with data collection. One of the early findings in this case was the rejection of labels. Similar to the findings with Puerto Rican families in Harry (1992), this mother agreed that the child has a problem but rejected the label that the system attempted to place on him, seeing it as an insult to her family. Rao (2000) echoed Harry (1992) in suggesting that service providers educate parents about labels to help them better understand the child's disorder and the effects it may have. Another conflict highlighted in the study was that of parenting style. While professionals and parents may have very different styles of parenting, it is important for professionals to reflect upon and identify their own values and "address differences in this area from a posture of reciprocity and respect rather than judgment" (Harry & Kalyanpur, cited in Rao, 2000). Perceived disrespect was another area of dissonance, which leads the parent to begin withholding consent to participate in service provision. Rao (2000) cautioned that "stereotypic assumptions may be apparent not only in overt actions but also in the ways in which documents and reports are written" (p. 11). Parents read reports, and their interpretations and reactions weigh heavily on the way they perceive their involvement as being valued. The researcher recommended that professionals "steer away from unwittingly perpetuating stereotypes" (p. 11).

Many of the studies reviewed in this section used qualitative methods to capture parents' views of their experiences with the early intervention system. While population samples were small, the descriptive nature of the studies captured parents' experiences. Recurring themes in the studies were that of differences in definition of disability, and labeling. In addition to these differences, the literature indicated a frequent parental lack of knowledge of what services children were currently receiving and what was available. However, parents indicated satisfaction with the services their children were receiving.

Research Questions

This case study will explore the perceptions of an immigrant Caribbean family with a child receiving early intervention services. Based on this review of the literature, these research questions arose:

1.   How do parents from the Caribbean access early intervention services?

This question is informed by the assertion from Ogbu (1991) that one reason for voluntary immigration is often for better educational opportunities for children. The factors surrounding the migration to the US may have an impact on the way the family went about assessing services.

2.   How was the cultural context of the family reflected through the services they received?

      a) What are the family's goals for the child?

      b) What were service providers' goals for the child?

      c) How does the family define their child's special need?

      d) What is a typical day like in the family?

3.   What type of relationship did the family have with the service providers?

a) Who saw the child most?

b) Who was the most valuable to you?

These questions and their subparts are informed by the results of Bailey, et al. (1992), which highlighted family characteristics as a barrier to family-centered services.

4. What assumptions or assertions can be made about the services received in the US, as compared to what may have been or was received in the Caribbean?

a) What recommendations would you make to the early intervention system?

Summary

The literature reveals that, while family-centered services are mandated and viewed as highly desirable by legislators, providers and families alike, it is not necessarily the model in place. Dunst, et al. (1991) indicated systematic difficulties in implementing family-centered services. Hispanic, Latino and American Indian families consistently reported challenges with the education system based on differences in cultural assumptions. This trend is in keeping with the assertion of Ogbu (1991) that differences in cultural assumptions lead to conflict with the school system. Taken together, one can see that services that are not family-centered would also not be culturally sensitive. That difference in parents' definition of disability from those of services providers can lead to conflict supports the validity of these questions. The following chapter discusses the methods employed to answer these questions.

Chapter 3: Methodology

In this chapter I present the methods used to conduct this study. Presented first are my research questions as developed from the literature. A discussion of qualitative methodology, case studies and ethnographic principles then follows. Next, I present information on the setting, participants and recruitment procedures. This is followed by the methods used to collect and analyze the data. The chapter closes with a description of the methods used to verify the findings and ethical considerations while conducting the research.

The Research Questions

The study addressed this central question: What are the perceptions of one Caribbean family of the cultural appropriateness and the family-centeredness of services they receive from their service providers?

The guiding questions of the research study are:

1. How did this Caribbean family access early intervention services?

    a) Is there any relationship between leaving the Caribbean and coming to the US with the need for service?

    b) How did they make their way into the system for receiving services?

2. How is the cultural context of the family reflected through the services they receive?

    a) What are the family's goals for the child?

    b) How does the family define their child's disability?

    c) How has the child's disability impacted the family?

        d) What is a typical day like for the family?

3. What type of relationship does the family have with the service providers?

        a) Who sees the child most?

        b) Who is the most valuable to the family?

4. What assumptions or assertions can be made about the services received in the US as compared to what may have been or was received in the Caribbean?

        a) What recommendations would the family make to the Early Intervention system?

Qualitative Methodology

Creswell (1998) defines qualitative research as:

…an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

Brantlinger, et al. (2005) provides the following five descriptors of what qualitative research involves:

- Empiricism—knowledge derived from sense experience and/or careful observation.

- Knowledge production—about perspectives, settings, and techniques.

- Particular research skills and tools—systematic use of certain qualitative methods.

- Production of scientific evidence—valid information about the physical, material and social worlds.

- Coherent articulation of results—papers presenting qualitative studies establish the purpose and usefulness of findings as well as their implications for the field (pgs 195-196).

The research questions are focused on the process through which the participants come to make meaning of what is happening. Given these descriptors of the study, a qualitative rather than quantitative research methodology was adopted. This method allows for the collection of rich, descriptive and holistic accounts of the phenomenon (Merriam, 2002).

Qualitative inquiry is an appropriate method for this study, since it seeks to describe a Caribbean family's perceptions of the services they received while involved with an early intervention program. The qualitative methods used will now be presented.

Case Studies

A case study was conducted based on the definitions of Creswell (1994), Merriam (2002) and Yin (2003). The study explored a single entity (a family of Caribbean heritage) bounded by time and activity (the experience of receiving early intervention services). Yin (2003) provides a more technical definition of case studies as, "an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between the phenomenon and context are not clearly evident" (p. 13). Another component of this technical definition is that in case studies many more variables of interest than data points appear, so the case study relies on multiple sources of evidence, with data needing to converge through triangulation (Yin 2003). Detailed information was collected about the case, using a variety of informants and documents.

The theoretical assumption of this study is that a person's experiences and behaviors have a direct relation to the culture of that person (Bogdan & Biklen, 1998). The literature presented in Chapter 2 highlights the way the cultural characteristics of families influence their perceptions of the services they received. Since this case study also aimed to identify any uniqueness of Caribbean culture that impacted parental perceptions, it adopted ethnographic research principles.

Ethnography

Culture, the cornerstone of ethnography, has been studied from a number of perspectives. Some researchers look at how people use knowledge to understand experiences, others look at semiotics or signs of the language (Bogdan & Biklen, 1998; Creswell, 1998; Merriam, 2002). Another more recent approach is to look at culture, accounting for social, historical and economic situations.

This type of ethnographic tradition is referred to as "critical ethnography" (Merriam, 2002). In this approach, the ethnographer attempts to "broaden the political dimensions of cultural work while undermining existing oppressive systems" (Fontana & Frey, 1994, p. 369). This case study was approached from the critical ethnographer perspective. According to Creswell (1994), the work of the critical ethnographer is intended to aid emancipatory goals, raise consciousness, and activate social change by a call to action. The study seeks to give voice to Caribbean culture, with the hope of raising consciousness among professionals when providing services to families with Caribbean heritage.

This study is informed by what is known about Caribbean culture, as presented in Chapter 1. The fun-loving and easygoing character of many Caribbean persons demands

a more interactive and personal approach. The flexible nature of the qualitative inquiry will allow for the questions to be adapted as the research unfolds. The family was purposefully chosen to participate in the study, since they are of Caribbean heritage.

Setting

The study was conducted in an urban to suburban county in the Northeastern region of the United States. Educational services for children with disabilities are provided through the local public school system. Early intervention services are delivered under IDEIA and the State's Code of Regulations. The state uses multi-agency approach to provide services and each agency has different protocols. The local school system provides early intervention services for infants and toddlers up to thirty-six months of age. These services include special education, physical therapy, occupational therapy, speech therapy and vision services. A service coordinator is assigned to each family with a child who is receiving services. These service coordinators operate out of the county health department and the ARC. To qualify for services, children must experience a 25% delay in any area of development, present with atypical development or have a high probability diagnosed condition.

Recruitment

Purposeful sampling was used to conduct this study (Merriam, 2000). According to Creswell (2003), the goal of qualitative research is to purposefully identify participants who would best aid in understanding the phenomenon being researched. The following criteria were used to select the family for this case study:

- The family member participating in the study must have grown up in the Caribbean (birth to at least 17 years) and currently reside in the US.

- Families must have been involved with the Infants and Toddlers Program for a minimum of 9 months.

Since this study looked at how Caribbean culture might affect the family's perception of service provision, it was important that the major cultural experience of the participant in the study be living in the Caribbean.

The length of involvement with the early intervention program was designated as nine months. In previous studies, for example, McBride, et al. (1993), where parents were recruited soon after writing the initial IFSP, it was found that parental participation was very low. The researchers suggested that parents might have still been coming to terms with their child's diagnosis and relying on professional guidance. The nine-month period of involvement allows for a passage of time over which perceptions would unfold. In addition, they would have had a six-month review at which to suggest any changes. In Rao's study (2000), the parents' perspective at different phases of involvement with service provision changed.

The demographic coding system of the US does not include a category for West Indian or Caribbean. To identify families who fit the criteria, I used the following strategies. Initially, I approached two families that I know personally and asked them to participate. One family did not meet the criteria, and the other was in the process of moving to another state.

The second approach involved asking colleagues who were service providers in the local Infant and Toddler Program to identify any Caribbean families on their caseload. They were given a brief description of the study to share with the family as well as my contact information. If the family was interested, colleagues were asked to

seek permission to release the family's information to me. I also provided a contact card (Appendix B) with the title of the study and my contact information for them to leave with the parent if the parent preferred to contact me directly. Colleagues all reported that they did not think that they could speak to families about the study without clearance from the county public school administration.

I therefore sought to make contact with the directors of three local Infant and Toddler Programs that were accessible to me. I made telephone contact, shared my research objectives with the directors and asked for an opportunity to present the study to the service coordinators for the program. Wayne (2006) identified this method of presenting the study to providers as effective, since providers would be hearing about the study through personal contact with the researcher. Only one director invited me to present my study to the service coordinators of the ITP.

I made the presentation and provided the service coordinators with a contact card. Two coordinators indicated they had Caribbean families currently on their caseload, and others needed to review their caseloads. During the presentation, service coordinators asked many questions about the study centered on the way services were provided to infants and toddlers in the Caribbean. Two weeks after the presentation, I called the ITP office and spoke with both service coordinators who indicated they had Caribbean families on their caseload.

Due to issues unrelated to my study, service providers made decisions whether or not to tell families about the study. One service coordinator indicated that she had been out to visit with the family. She, however, had not shared the information with the family because she was late for another visit. The other coordinator has also been out to visit the

family. She had gone out with a trans-disciplinary team for a six-month evaluation and explained that the child's assessment showed that he was very delayed. The child's mother indicated great displeasure with the assessment results. Because of the emotional tension during the evaluation, the service coordinator did not feel comfortable sharing the information about the study with the parents.

I contacted the director of the county ITP by telephone and shared the obstacles which had been encountered. We brainstormed ideas on how to reach the families. I then sent the director a letter that briefly overviewed the study (see Appendix C). She indicated that the letter would be sent out to families. She would also personally follow up with service coordinators to contact families and get contact information to me.

Approximately two weeks after the conversation with the director, I received an email from her with the contact information for one family. During that same week, I also received a call from a service provider with the name, telephone number and address for two other families. I called all three families.

One family I was not able to contact after several telephone calls. When I contacted the other family, the mother indicated that while she would like to participate, her husband was not in agreement, and therefore the family could not be a part of the research project. When I contacted the third family, the mother agreed to participate. The parent indicated that she did shift work and was not available during the week we spoke. She did not at that time know her work schedule for the following week. She also shared that she was a single parent. We agreed that I would call the following Tuesday to schedule a date, time and venue. I called on the agreed day but was not able to get the parent and left a voice message. The mother did not return my call. I followed up with

another phone call two days later. A young man answered and after verifying who I was stated that she could not come to the phone. He shared that he was her son. I left my contact information and asked that she call me when she was available. After two days had passed, I called and left a voice message. I stopped calling the family after three weeks. Within that time, I had called on different days and at different times, and I left other voice messages, which were not returned.

During this time, I received an email from one service coordinator from the ARC. She provided information for a family with a child that had recently been discharged from early intervention services after 10 months. The family met all the criteria except being presently involved with an early intervention program. I contacted the family and left a message on the answering machine. The following day the mother returned my call. I shared the procedures involved in the study, and she indicated an interest in participating.

During this conversation, we talked about Trinidad and Tobago and where in the Republic we lived before coning to the US. We also talked about an upcoming Caribbean festival and our interest in attending. We set a date to sign the consent forms and conduct the initial interview.

Participants

The child's mother (Tamika) was born in the Republic of Trinidad and Tobago and migrated to the US when she was 17 years. His father (Kevin) was born in the US. At the time of the study they were both in their mid thirties and have been married eight years. Kevin is employed with a private firm as a Network Engineer. Tamika is a Commissions Coordinator at a medical facility where she ensures that staff receives

continuous training each year. She also attends to the overall safety and security of the facility. She is enrolled part-time in college pursuing a Bachelor of Arts in Nursing. Tamika described Tyler the dog as a member of the family and the first baby. Delante is their son and presently only child was diagnosed with torticollis (See Appendix D) at six weeks.

The family lives in a neighborhood in the northern part of the county. The neighborhood consists of single family and town-homes that appear to have been developed within the last ten years. As I drove to the house I noted how well the area was landscaped and the neatly manicured lawns. In driveways I saw cars that are considered luxury vehicles by car dealership standards. The couple owns their town home and both drive luxury vehicles.

Delante is described as a happy little boy who likes to play with his dog. At the time of the study Delante was one year and four months. Tamika said, he is trying to say, "Frank come, come Frank" and other words. She is looking forward to him combining two or three words together to say "bye-bye momma or bye-bye dada." His parents reported that he likes to play with blocks and during one interview at his house he played with a shape set. They described him as a very smart child who "picks up easily" and is "very observant."

At six-weeks-old Tamika noticed a mass on Delante's neck. He was taken to the pediatrician who recommended a MRI be done. He was diagnosed with right Torticollis at six-weeks-old and received early intervention services for nine months. Presently he walks with his head straight. His dad calls him Tornado due to the speed with which he moves, running more than walking. Sometimes he tilts his head to the right and his

parents would remind him to straighten up. His mother reported that he teases her by placing his head to his shoulder when she asks him to straighten up and laughs when she looks at him. He has met or past all the developmental milestones for his age and his parents agreed that he is progressing well.

Data Collection

The gathering of information, which could be used to answer emerging research questions, requires a series of inter-related data collection activities (Creswell, 1998). In qualitative studies, the researcher is assumed to be the primary research instrument, since the research itself flows from the researcher. Data for qualitative studies in the ethnographic tradition can be drawn from many sources. These include interviews, observations, documents, and audiovisual materials (Bogdan & Biklen, 1998; Brantlinger, et al., 2005; Merriam, 2002; Merriam, 1998; Strauss & Corbin, 1998). In this section I describe the strategies used in greater detail.

Interviews

The initial interview was conducted with the mother and father of the child (Tamika and Kevin) at their home, as suggested by Tamika. During the interview the family identified the persons involved in providing early intervention services. These persons included the grandmother of the child, the private physical therapist, the county physical therapist and the family service coordinator. I obtained telephone contact information for each of these persons from the parents.

Tamika explained that her mother was visiting with her sister, who had a new baby a few states away. When I called the house and the grandmother answered, I

identified myself, and she commented that Tamika had told her about the study. I explained the procedures to her and she agreed to participate. During this initial conversation we shared information about each other's background and interests. We also talked about the new granddaughter she was visiting. We set a date and time for me to visit in order for her to sign the consent form and be interviewed. She was very concerned about my traveling such a long distance and cautioned me to be careful.

Althea has dual citizenship between The Republic of Trinidad and Tobago and the United States. She was born in Trinidad and Tobago and before retiring worked as a nursing assistant with the Trinidad and Tobago Government Ministry of Health.   Since her retirement she visits back and forth for several months at a time. At the time of the study Althea was in her late 60's.

When I called the private physical therapist, I did not reach her, and so I left a message. The message detailed who was calling, how I got her cell phone number and the reason for the call. The following morning she returned my call. I thanked her for returning the call and shared the details of the study with her. She indicated an interest in participating and wondered about confidentiality and the release of information. We decided that I would forward her a letter about the study and ask Tamika to contact her to sign a release document. Tamika made a casual visit to the office the following week while running errands in the area and signed the release. She called me right after leaving the offices to indicate she had signed the papers and suggested I call and set a date to conduct the interview. I called, and the private physical therapist (Cheryl-Ann) and I set a date to sign consent forms and conduct the interview.

At the time of the study Cheryl-Ann was 35years old. She's first generation American her mother is from Albania and her father is Italian. Cheryl-Ann is married and has three children. Her mother lives with her family presently. She describes this arrangement as a great blessing. Cheryl-Ann has a Master of Arts Degree in Physical Therapy. She has been practicing for over ten years, for the last two and a half years she has been with this company.

I emailed the service coordinator, Liselle, at the ARC asking for an opportunity to conduct an interview. She copied me on an email to her immediate supervisor inquiring about confidentiality and whether service coordinators were allowed to do interviews such as I was requesting. In a pro-active effort, I contacted the directors of the Infant and Toddler Program and inquired about conducting the interview and reviewing the family file. She called me a few days later indicating that she had communicated with the ARC director and provided the procedures that should be followed. Following the conversation, I emailed the service coordinator, copying both the ARC director and the County director, summarizing our conversation. A few days following, I called the office of the service coordinator, her voice mail came up and I left a message. In the message I identified myself and asked about progress towards securing parental approval for the release of information so that we could conduct the interview. Liselle called me later that day indicating that she was available during the morning for the next two days. We agreed to meet the following morning to sign the consent forms and conduct the interview.

At the time of the study Liselle was in her early 30's. She is first generation American. Her father and mother are both from Jamaica. She is the only one of her

siblings born in the US. Liselle has a Master of Arts degree in Counseling Psychology. She has been a Service Coordinator for six years, the last two of which have been with the ARC of the County.

The school system operates under different protocols from the ARC, knowledgeable of these I contacted the county school system office of research in an effort to secure the documents necessary for getting approval for research. After submitting the complete document, I was informed by the assistant in the office of the director, department of research & evaluation that the county school system does not allow Masters level research to be conducted in schools. I explained that my request was only to speak with the physical therapist and that the parent would sign any relevant release documents. The assistant apologized and restated that Master's level research was not allowed in county schools except in cases where the researcher is a county employee. Thus, I was not permitted to speak with the person who provided physical therapy services through the county Infant and Toddler Program.

The informants for this case study, therefore, were the parents of the child, his grandmother, his service coordinator and his private physical therapist. Table 1 provides demographic information for all the persons interviewed. All interviews were conducted at a location identified and agreed upon by the informants. Before beginning the interviews, I reviewed consent forms, emphasizing that participants were free to indicate that they no longer wished to participate at any time, and the participants agreed to be audio-taped.

Table 1 Participants' Demographic Data

NAME	RELATION TO CHILD	PLACE BORN	ETHNICITY	EDUCATION
Tamika	Mother	Trinidad and Tobago	Mixed (African and Indian)	Pursuing BA in Nursing
Kevin	Father	United States	African American	College
Althea	Maternal Grandmother	Trinidad and Tobago	Mixed	Secondary School
Cheryl-Ann	Private Physical Therapist	United States	White	M.A., Physical Therapy
Liselle	Service Coordinator	United States	African American	M.A., Counseling Psychology

Data was collected using an open-ended interview schedule with all informants (see Appendixes E and F). Interviewing was important to this study, as it provided data related to past events and also a insight to how individuals formed interpretations of events (Merriam, 1998). An interview guide was used, since I collected data from different informants aimed at corroborating information about a phenomenon (Yin 2003). This method also helped in triangulation of the data.

With each informant, I attempted to develop some type of relationship. Agar (1996) has identified *rapport* as the official term used to describe a good relationship with an informant. Rapport was developed through initial telephone conversations by chatting casually with informants, being genuinely interested and respectful of things that they shared. Knowing that Tamika's sister recently had a baby, I asked about the baby when I called. Demonstrating reciprocity also aided in developing rapport. Knowing that Tamika was presently studying and did not have close friends or family nearby, I offered to provide child-care on the Saturdays that she needed to go to class, beginning after I had completed my paper.

Semi-structured face-to-face interviews were used. This interview method allowed specific information to be gathered from respondents while still leaving a large part of the interview for questions and issues that have no pre-specified order or wording (Merriam, 2002; Merriam, 1998). The strategy also allowed the participants to speak freely about what they experienced.

Rapport development continued during the interview. I did not hold rigidly to the interview guide, but allowed the interview to flow like a conversation. This ease in conversation was true for all of the participants except the service coordinator. Often when I called her office I got her answering machine. She was however very prompt in responding to emails our major means of communication became email. I had three telephone conversations with her, all of them very brief. While we spoke with some ease, I found that there was not sufficient rapport. While doing the transcript of this interview, I noticed several instances where I found myself having difficulty rephrasing questions without leading. On reflection, I think emailing may not have been the most effective way to communicate. Emailing does not allow the communicators to benefit from non-verbal clues such as tone of voice, inflection, emphasis and the like.

With the permission of participants, interviews were tape-recorded and transcribed. While reviewing the transcribed interviews and coding them, insights came for questions to ask in subsequent conversations or interviews (Merriam, 1998).

Observation

Since this study was conducted in retrospect, I did not have an opportunity to observe the child receiving services. However, I made an attempt to visit the locations where the family received services. This firsthand view allowed me a better

understanding of some of the things the family shared during the interview. When attempting to identify a location to conduct the interview, I offered to meet the family at their home.

When knocked on the door I hear a dog barking. I was greeted by Tamika and Delante and invited inside. Kevin was not at home when I arrived but joined us later. As I continued to hear the dog barking I enquired and Tamika shared that she put him in the basement as a courtesy to me. Since she was not sure if I was afraid of dogs or may have an allergy. I assured her I would be ok and she let Frank out of the basement.

There were two levels and a basement to the townhouse. The front door opens to the first level, which contains the kitchen, dining and living area. Bedrooms are on the second level and the basement is used as an entertainment area. I was surprised at how very clean and well organized the space was. The chairs were set to the walls leaving the floor space open except for the coffee table. Everything in the room was functional and had a specific place. There were no toys visible anywhere as would be expected in a home with a toddler. The dining table was set to the corner and I used the table to conduct the interview. During the course of the interview Delante played happily and I noticed toys emerging from a storage area beside the couch. Tamika also had a chicken in the oven set to be read when her husband got home from work. My first impressions were of how very organized Tamika appeared.

The private physical therapist offered for us to meet at a restaurant or coffee shop. I agreed and expressed a desire to see the facility. The offices were very close to the meeting place, and she suggested we conduct the interview there. The offices of this private practice occupy four suites in an office complex. The company provides

physical, occupational and speech therapy. In each suite a different type of therapy is

provided. There are two large rooms in which physical therapy is provided. While there

is a separate storage room, some pieces of equipment remain in either of the two rooms.

If needed, they are moved to the room where the client is receiving the therapy. To

access the storage room, one passes through one of the therapy rooms. This general set

up was consistent from suite to suite.

My interview with Liselle was conducted at the ARC of the county office.

Delante did not receive any services here, nor did Tamika have any cause to visit. It was

however the most convenient location for us to meet. We meet in one of the conferences

rooms as the ARC.

Document Analysis

Maxwell and Rossman (1995) indicate that researchers use documents as a means

of supplementing other data collection methods. In addition to interviews, I also

examined documents from the parents. Tamika had a neat file with all the documents she

received while Dalente was receiving services. She readily shared this file with me. The

service coordinator, after securing a release of information from the parent, shared her

contact logs with me.

The documents reviewed were the IFSP documents; these included the initial

assessment report, initial IFSP and the six-month review. The parents' copy of the Home

Follow-up Program, written by the county physical therapist, was also reviewed. These

forms were prepared at the end of each home visit and detailed observations during the

visit, suggestions of activities to try at home and reminders. Not being able to interview

the physical therapist, these forms were important, as they gave a sense of the cultural sensitivity and family-centeredness of the services provided.

Documents from private physical therapists were also reviewed. These documents included summaries of each visit, and progress assessment reports. The summary sheet contained observations made during treatment, goals for the day and treatment and home exercises. The progress/assessment reports were done once per month and detailed changes over the month, as well as short-term and long-term goals.

The service coordinator's contact logs for the period August 2005 to July 2006 were also reviewed. This contact log provided a chronology of events related to establishing and maintaining services for Delante. Included were summaries of telephone conversations with providers and the parent, fax messages, home visits, letters and so on.

These documents, along with interviews from participants other than the family, were used for triangulation of the data. I was also able to compare the documents I had from the parent with those in the service coordinator's possession. I made copies of all the documents; they were kept secured in a lock box, the key to which I had in my possession.

Field Notes

While collecting data, I took field notes. Field notes, as defined by Bogdan & Biklen (1998), are "the written account of what the researcher hears, sees, experiences and thinks in the course of collecting and reflecting…" (p.108). Field notes therefore contain two basic types of information: descriptive information about the scene and reflective information from the researcher (Gay, Mills & Airasian, 2006). To ensure proper documentation, field notes were taken in the setting and very soon after leaving

the site. In addition to the field notes, I also maintained a contact log. Each time I had a

telephone conversation with or received an email from a participant, I entered a summary

of the information into the contact log. These notes helped to recall specific details about

the participants and aided my reflection while collecting the data.

Data Analysis Procedures

Data collection and data analysis took place simultaneously (Creswell, 1994;

Merriam, 2002; Merriam, 1998). Data analyzed were the verbatim transcripts from

interviews and documents. Data were analyzed and coded for emerging concepts, themes

and categories beginning with the very first interview. Coding, as described by Maxwell

(1996) and Strauss and Corbin (1998), is an analytic process of fragmenting data so that

concepts could be identified and sorted into categories for the generation of themes or

theories. The codes are tags that assign meaning to descriptive data in the study; thus,

codes are usually attached to the word, phrase, sentence or paragraph that they refer to

(Miles and Huberman, 1994). I used colored markers to identify the word, phrase,

sentence or paragraph that a code related to.

Data were analyzed using the constant comparative method (Bogden & Biklen,

1998; Creswell 1998, Merriam, 2002). In this approach, data was coded and compared

for similarities, resulting in emerging conceptual categories. Using coding conventions

developed by Bogden & Biklen (1998), I read and coded interviews. After the initial

coding process, I re-read the interviews and was able to identify other items under the

codes. In addition to coding the interviews, I also coded the contact logs of the private

physical therapist, the service coordinator and the home follow-up sheets from the county

physical therapist.

When the coding process was completed, I made an alphabetical table of the codes with the units of data attached to them. Computer programs that allow users to cut and paste made these manipulations easy. When all the tables were generated, I printed them and laid them out side-by-side. Looking horizontally and vertically, I attempted to find similarities and differences in codes from the various sources. These were then grouped or clustered together into categories. Using these categories, I was able to confirm or disconfirm evidence.

Disconfirming evidence requires the researcher to seek out evidence inconsistent with the themes and categories that have been established. I conducted follow-up interviews with the informants to assist in clarification. This strategy is also referred to as "negative" or "discrepant" case analysis (Merriam, 2002). The process of confirming and refining categories to generate themes was ongoing. The themes established were used to write up the results section of this research project.

Reliability And Trustworthiness

In qualitative research, the researcher's interest is focused on how people construct reality. In this study, the perceptions of a Caribbean family receiving early intervention services were explored. To address issues of reliability and trustworthiness, the following strategies were used: triangulation among data sources, member checks, peer review and researcher biases or reflectivity (Brantlinger, et al., 2005 and Merriam, 2002).

Triangulation

Triangulation involved the use of many sources of data to confirm emerging findings (Bogdan & Biklen, 1998; Merriam 1998). Data came from interviews with the

both parents, the grandmother, the family service coordinator, and the private physical therapist. Documents used to assist in triangulation were service coordinator contact logs, the ITP notes, medical records, private physical therapist notes, the IFSP, and the evaluation and assessment report from the county ITP.

Member Checks

Member checks were done throughout the data collection and analysis phases of the research. Member checks were achieved by asking participants to comment on the way data were interpreted (Merriam, 2002). During interviews, I would state what I understood the informant to be staying and ask if it was correct. After reviewing documents, I gave the family an opportunity to comment on my interpretation of their perceptions and the information conveyed. The case study was provided to the family to comment on my interpretations.

Peer Review

Peer review, in accordance with Merriam's guidelines (2002), was built in to the research by having the thesis committee read and comment on the findings. In addition to the committee, the author's comment on having a colleague review the data and findings and to assess the plausibility of them. I shared details of the research with a colleague who is a graduate. This peer has been involved in several research projects using qualitative methodology and her doctoral dissertation was also qualitative. She reviewed the data as I coded and developed themes and provided feedback on the methods, analysis, interpretation and ethical considerations.

Researcher Bias

In qualitative research, the researcher is often viewed as the instrument of the research (Brantlinger, et al., 2005). I believe that our cultural orientations have a great impact on the person we are and what we hold to be normal. It is based on our cultural orientation and understanding that we make sense of our day-to-day experiences. The history of a people has a great deal to do with the shaping of their cultural orientation and each cultural group has a different historical experience. The Caribbean historical experience is different from the mainstream American experience and also of other minority groups in the US. This cultural difference, I believe, has implications for how the Caribbean immigrant family interprets their experiences with service providers in the early intervention system.

My interest in early childhood special education was sparked by my previous work on a Caribbean island in the Ministry of Education, Department of Special Education, and serving on the National Association for Early Childhood Care and Development. These experiences have afforded me firsthand knowledge of the challenges faced by parents as they seek services for their young children with special needs or those whom they think are at risk.

As a graduate student at this university, I became aware of the support systems in place for children from newborn infants all the way to adolescents with special needs. Internships at one of the county's early childhood centers which provides services to infants and toddlers through preschool-aged children made me aware of the number of children from different nationalities who were at the school. My interactions with

children, staff and parents led to a realization of the number of Caribbean nationals

receiving services there.

As an intern, I often heard providers comment about events at a home visit or

musing over what was happening in a child's home. These comments I initially

interpreted as negative, before realizing that they came from a lack of understanding of

the child's culture. In many instances, the comments were made about families from

West African nations or the Caribbean. I began offering cultural interpretations of events

each time I heard a comment. While providers were exceptionally good at what they did,

I often wondered about parents' feelings and interpretations of events. The more

Caribbean families I encountered, the greater my curiosity became about their

experiences receiving services for their children.

Ethical Issues

The nature of qualitative research provides potential for conflict (Gay, Geoffery &

Airasian, 2006). It is important that the researcher respect the rights, needs, values and

desires of the participants. In an effort not to violate the participants ethically, several

safeguards were employed. Written informed consent was acquired before proceeding

with the study. The intent of the study was presented orally and in print on the consent

form in a way that the participants could readily understand. As part of the informed

consent, the participants were made aware that participation was voluntary and that they

could choose to stop participating at any time. To protect privacy and assure anonymity

pseudonyms were used throughout the study. Verbatim transcripts, written

interpretations, and interim analyses were made available to the participants.

Chapter 4: Findings

In this chapter I present the James family. Information is provided in a chronological manner from courtship and marriage to the present. The description gives the reader a sense of who the family. Following the family description I introduce the professionals who took part in the study and provide a sketch of each. All names appearing are pseudonyms.

After the descriptions the themes generated from the data are provided as they relate to the research questions:

1. How did this Caribbean family access early intervention services?

    a) Is there any relationship between leaving the Caribbean and coming to the US with the need for service?

    b) How did they make their way into the system for receiving services?

2. How is the cultural context of the family reflected through the services they receive?

    a) What are the family's goals for the child?

    b) How does the family define their child's special need?

    c) How has the child's disability impacted the family?

    d) What is a typical day like for the family?

3. What type of relationship does the family have with the service providers?

    a) Who sees the child most?

    b) Who is the most valuable to the family?

4. What assumptions or assertions can be made about the services received in the US as compared to what may have been or was received in the Caribbean?

a) What recommendations would the family make to the Early Intervention system?

The James Family

When asked "tell me about your family?" Tamika excitedly stated, "I'll do like they do on Wheel of Fortune, I'm married to my wonderful husband for eight years, my fantastic husband for eight years." Tamika and Kevin seem to have had a fairy tale romance. They met when Kevin migrated to Trinidad and Tobago with his parents for two years. Tamika reminisced: "I lived opposite a park and they lived on the opposite side …. he saw me one day and that was it. We sat and talked …We were young fifteen…"

As in a fairy tale, the couple separated and lost contact with each other when Kevin returned to the US with his family at the end of the two-year period. At the end of high school Tamika said, "We [her siblings] each just sort of migrated up here [US]. We finished school, there was nothing really for us home so we came up here more for, like, for opportunities I would say." The opportunity that Tamika took advantage of is joining the military. "I joined the military at seventeen once I came up [to the US]."

The couple reunited four years later when they were both vacationing in Trinidad and Tobago. Tamika described the reunion in this way:

Four years later I went home to Trinidad and Tobago on vacation and he came home on vacation that same year. [He] came by to visit and asked if I lived there because in Trinidad people don't move out they just stay living there forever at the main house. He came by and I didn't recognize him when my sister said 'Tamika there is a good looking guy out here to see you.' I said, "Who, me?"

cause I don't have any friends there. I went outside, then we started talking, turns

out he only live about fifteen minutes from me in the U.S.

They exchanged numbers and about two years later, after relationships with other

people were dissolved, Tamika said,

We just sort of got together; we dated for about a year. ...His brother got married

[and] at the wedding he popped the question for me to marry him. …I said yes

and a year later we got married. We bought this house in May and then we got

married in June.

When describing the members of her family Tamika stated, "We have two boys

Frank [the family dog] and Delante. Frank was the first baby. [He] had a hard time when

Delante came." Frank, snapped at Delante twice and on one occasion in his face.

Tamika recalls with a hint of sadness having to send him away to her Aunt for a while.

Not wanting to give Frank up, she sought the advice of an animal therapist about the

behavior and was able to take him back after a month.

Tamika spoke of her extended family throughout the study. Her mother travels

between Trinidad and Tobago and the US frequently usually for six-month periods. Her

father was a jockey and worked in the US. He went to Trinidad at Christmas time and

stayed until April each year. When Tamika was 21years old, her father died in a fishing

accident in Trinidad. She comes from a family of five siblings; one boy and four girls.

All but one of her sisters lives in the US. She described her family as close knit.

Kevin made little reference to his family during the interview. While Tamika's

family is close knit he pointed out "My family is not close knit…not at all…we're the

exact opposite." He also shared that both his parents are from Trinidad and Tobago and

that he spent two years there. In a conversation subsequent to the interview, I asked Kevin to share about this experience and his family. He expressed that he did not quite understand how that information related to the study. I explained that an understanding of his cultural experiences would better help in describing the cultural context of the family. He shared that the he did not enjoy living in Trinidad and Tobago and described the economy as "backward." He did not elaborate on what he meant by "backward." Kevin said he found it difficult to cope with the demands made in education system in Trinidad. After the first year, he explained, he made friends and became quite popular. He enjoyed the second year more than the first but was happy to return to the US. When asked to share more he declined.

The Pregnancy

Tamika and Kevin were married for seven years before they got pregnant with Delante. Tamika and Kevin both shared that they planned for the pregnancy, "We planned for him and waited until we could really… we could afford him and give him all the things that we would like to give."

Tamika's family received the announcement of the pregnancy with great excitement.   She described the period in this way: "Had a fantastic pregnancy. I had no cravings. … sickness, no morning sickness. I had, it was very… as some people would say, boring … It was great."

They declined to be told the gender of the baby, selecting both boy and girl names. The birth of Delante was also an event for her whole family. Her mother, one sister and her niece were all present. Her niece came to the US from Trinidad and Tobago specifically for the birth of the baby.   On the day before she delivered, Tamika

visited a West Indian food shop for roti (see Appendix D). She recounted the proprietor commenting, "Yuh know curry does bring down baby, yuh know." She claimed to have dismissed the comment. Later that night she went into labor.

While her husband and mother suggested going to the hospital soon after the labor started, Tamika initially resisted because she had been told the birth could take awhile. After some convincing they left for the hospital. Although she was in severe labor she had not dilated sufficiently. Hours after receiving an epidural she still did not dilate. Tamika wanted to have a vaginal delivery and delayed granting permission for the doctors to perform a caesarean section for several hours. During that time of hard labor, Tamika told me, "I never did cry ... she (her mother) was holding her own little vigil in the corner praying for me." Dalente was delivered via C-section. Once they were discharged home Tamika's mother, Althea, stayed with Tamika and Kevin to help with the new baby.

At six-weeks-old Tamika noticed a mass on Delante's neck while her mother was giving him a bath. Wanting an explanation for the suspicious mass she took him to the pediatrician later that day. The pediatrician recommended a MRI be done. Delante was diagnosed with right Torticollis at six-weeks-old and received early intervention services for nine months. The questions and responses that follow describe the family's experiences during this time.

Research Question 1:How Did This Caribbean Family Access Early Intervention

Services?

a) Is there any relationship between leaving the Caribbean and coming to the US with the need for service?

b) How did they make their way into receiving services?

Each subpart of this question is addressed separately and then summarized. Table 2 shows the themes examples of codes and the data sources, which supported this question. The themes which emerged from the data were, "I needed to know," "Research shows" and "Stayed on top of it."

Sub Question A: Is There Any Relationship Between Leaving The Caribbean And Coming To The US With The Need For Service?

In this case there was no direct relation between the family coming to the US and the need for services. As stated earlier, Tamika and her siblings migrated to the US after completing high school in Trinidad and Tobago. When she migrated three of her siblings were already residing in the US. A relationship between needing services and coming to the US does not exist. The family did, however, make their way into receiving services.

Table 2   Research Question 1: Codes, Themes and Data Sources

Research Question		Codes	Themes	Data Sources
How did this Caribbean family access early intervention services?	Sub Question A Is there any relationship between leaving the Caribbean and coming to the US with the need for service?	We just migrated here For more opportunities My brother was here, two of my sisters were here	Not related to need for early intervention	Family interview
	Sub Question B How did they make their way into receiving services?	What is that I called the doctor They scheduled a MRI I found a suspicious mass	I needed to know	Family interviews Medical records
		I got online I was reading everything I was doing my own little research	Research shows	Family Interviews Service Coordinator contact logs
		I would call every week I was also calling around looking I was like your worse nightmare	Stayed on top of it	Family interviews Physical Therapist Grandmother Private PT contact log

Sub Question B: How Did They Make Their Way Into Receiving Services?

While early intervention services are available to the public at no cost, persons who are in need of the services are not always aware that they exist. The themes that emerged were: "I needed to know," "I kept on top of it," and "The research shows,"

I needed to know. The theme "I needed to know" encapsulates the codes, which reflect the families attempt to understand what the mass on Delante's neck was and effects it could have on his development. Delante was Tamika's first child, when he was six weeks old she observed a mass on his neck and sought immediately to identify it. She asked her mother if she had ever noticed the mass. She replied that she had not. Tamika next contacted the doctor. She stated, "I called the doctor. I said I need to … bring my six-week-old son in today. I said I found a suspicious mass on his neck and I want it to be looked at today." Tamika received an appointment for later the same day. She shared:

> They saw him. They told me they thought it … could be a cyst but …the doctor
> that saw him wasn't sure at the time so she wanted to have it scanned…. They
> scheduled a MRI of his neck.

Tamika was able to have the MRI of Delante's neck done the following day. When the report was prepared the doctors called her in to discuss the results. Tamika stated, "I went back and they discussed it with me and told me that it was not a cyst. They thought it was torticollis…." In addition to this explanation Tamika stated, "They told me what I would need to do in order to get that mass resolved." She was also referred to the torticollis clinic at the nearby children's hospital.

The impressions reported on the sonograph of the neck read: "Marked thickening of the right sternocleiomastoid muscle consistent with fibromatosis colli…" The report indicated there was no evidence of a malignant tumor or congenital anomaly.

One of the first steps toward getting services was Tamika's attempt to identify the mass. After she received a diagnosis she searched for more information to better understand the condition.

Research shows. Tamika's research prompted a great deal of the family's decisions as related to accessing treatment for Delante's torticollis. In a quest to better know and understand what torticollis was, Tamika conducted independent research. She stated, "I got online and I looked up torticollis and then got torticolliskids.org … I joined it online. I was reading everything I could on torticollis and …what needs to be done."

One of the first decisions the family made was changing their pediatrician. Tamika explained, "I was doing my own little research they said that they could have hip dysplasia"(see Appendix D). Tamika explained that she had been taking Delante to the pediatrician who never mentioned this or examined Delante for hip dysplasia. She stated,

> I got annoyed, I got really pissed off as a matter of fact because the doctor didn't mentioned any of that to me. This particular pediatrician didn't mention anything to me about hip dysplasia. Apparently you're supposed to have the baby checked for that as well…x-rays and whatever.

Tamika identified this lack of information to be the reason for changing pediatricians. She explained, "I mean they never mentioned anything like that to me. I found that out reading on my own."

When the James' received the referral to the Torticollis clinic at a children's hospital they immediately called to get an appointment. It was not until several months later that she received an appointment. She made the initial call for the appointment in July and was not offered an appointment until October. Tamika's research again prompted the decision to be persistent in calling to get an earlier appointment. She gave details,

> I was, like, this would not do. I was hoping that the doctors would call us in and say, no; this child needs to get in there sooner. Because everything that I've read said that the earlier you get in there and get the neck muscles stretched the better. Because when the child turns one and you have not addressed this thing you could have facial deformity.

Her actions related to the delay in receiving an appointment are discussed later under the theme "Stay on top of it."

The theme of "research shows" was also evident in Tamika's response to the question, "What did you do while you were trying to get the appointment at the children's hospital?" She stated,

> Based off on my research on the website they show what a child with torticollis would look like, how the head is tilted depending on what side. He has right torticollis…and the exercises you can do in the mean time, so we were trying to do the stretching thing.

In addition to the World Wide Web, Tamika also gained information from colleagues at work and the nurse practitioner at the children's hospital. One co-worker with a child who has Angelman's syndrome had shared their family's experience and

provided information on how services were accessed in the county where they lived. The nurse practitioner at the children's hospital provided information about the Infants and Toddlers Program in the county.

In addition to the online research being conducted, Tamika also relied on family members who she thought would be a good source of information. She shared that they called Kevin's cousin, Kendall, who is a radiologist and told him of Delante's diagnosis.

Tamika's knowledge gained from her personal research on Torticollis informed decisions made and actions taken. In each instance that action was taken, she had to be vigilant. This theme will now be explored.

Stay on top of it. The theme "staying on top of it" united the codes, which demonstrated this family's quest to access services. The theme is reflective of their vigilance. The actions taken to access services all required Tamika to "stay on top of it." In addition to trying to find another pediatrician, the James' were also attempting to get an appointment at the children's hospital. During that time, Tamika had visited her obstetrician who reinforced her vigilance. In her words he told her:

> Tamika you have to be on top this thing. You just can't just sit there and let them
> do whatever…In so many words he wasn't trying to put down …his colleagues
> but he was saying that I have to be pro-active in my own self to get things done
> and to get things moving and stuff like that.

As presented earlier Tamika had difficulty contacting and obtaining an appointment in the torticollis clinic at the children's hospital. Tamika described the process she undertook to get an earlier appointment:

I would call. Every week I would call and I told the girl 'you will hear my voice

every week or twice a week. I will call you every week to find out if somebody

cancelled, [or] if there is an opening for that Monday because I have to get my

child in there. I have to.' It ended up that I got in.

Tamika's research had reinforced the need for early intervention as early as

possible. As soon as she detected a delay in contacting the hospital, she tried another

strategy. Tamika simultaneously attempted to locate a private provider of early

intervention services that accepted the family's insurance while also trying to secure an

appointment at the hospital. She did not recall where she got the list of physical

therapists and early intervention programs. Using the list of agency names and contact

numbers she explained,

While I was waiting to get in there (referring to the torticollis clinic at the

children's hospital) I was also calling around looking for any place that did early

intervention and took our insurance …So I was calling around, calling around to

all these places cause at the time I didn't know about Infants and Toddlers

Program in the county.

Tamika stayed on top of it knowing that there must be an agency that accepted the

insurance the family had. Her calls proved fruitful when she found the Stoneville

practice. A description of the practice is made in Chapter 3. "I called them made an

appointment. They took the insurance that we had for Delante, and, … I got the physical

therapist there by the name of Cheryl-Ann Jones and she was great."

Tamika and Kevin settled on this agency since they took care of insurance billing.

Tamika explained that other agencies required the family to pay out of pocket then

submit bills to the insurance company. By 'staying on top of it' and remaining vigilant they accessed what they needed. They began receiving physical therapy at the private facility with Cheryl-Ann. Services were scheduled once weekly for sixty minutes and began on the same day.

The family had already begun to receive services when she received the appointment at the children's hospital. The torticollis clinic at the children's hospital offered physical therapy; however, Tamika declined the services. She explained why:

> They were asking if I wanted to do therapy there but I was like there is no way I'm driving here. This place is crazy. The place is like…oh my God it's just crazy. They're always doing construction [and] the parking garage is always a mess. I'm like I'm not driving down here; even my mother was a little uncomfortable… I told the nurse practitioner I won't be doing therapy here but I will continue to I will let you follow him.

In a later conversation Tamika explained what 'following' Delante involved. Taking him to the clinic where his length and weight were measured. In addition the nurse observed him and noted if his head was in midline. The nurse practitioner at the children's hospital provided Tamika with the telephone number to call the Infants and Toddlers Program in the county. Again, Tamika had to be vigilant to get this service started. She recalled,

> I called and I got a contact and faxed information over and I stayed on top of them. I mean, I was like your worse nightmare. I mean, I had to stay on top of everything and finally …

A review of Liselle's (the service coordinator) contact logs showed she collected the referral from the lead agency on August 10, 2005. In an interview with Liselle, she explained that the case assignments are made by the director and based on the geographic location of the family in the county. This arrangement facilitates having services come from a school closest to the family's residence.

The service coordinator's contact log indicates that on August 12, 2005 Liselle faxed the referral and discharge summary to the Assessment Coordinator at the school. She then made the first call to the family. The log indicated that a message was left with a female. Althea indicated when interviewed, "When they call to say they from the Infant and Toddler Program, I call Tamika one time because I know she been calling you see." Tamika received the call from her mother and immediately followed up with a call to the service coordinator on the same day (August 12, 2005).

Liselle's contact log of Tamika's call on August 12, 2005, indicated that they talked about the Infants and Toddlers Program and a home visit was scheduled for August 17, 2006. The parent's only concern was the torticollis. It was during the home visit that Liselle asked Tamika if she was from the Caribbean.

Torticollis is not one of the diagnosed conditions with high probability of developmental delay, which would automatically qualify Delante for services (see Appendix A). Therefore a developmental assessment was needed to determine eligibility status. The service coordinator's contact log showed that on August 18, 2005, she called the Assessment Coordinator at the school to schedule a date for Delante's assessment/evaluation by the school's team. September 6, 2005 at 8:45 am was agreed upon.

Tamika's staying on top of matters is also seen in the contact log. On August 25, 2005, the log entry telephone call from Tamika read, "Mom called. She left a message for me to call her regarding the evaluation date." Liselle returned the call on August 29, 2005. She told her the date of the evaluation and possible times. Liselle confirmed the date and time with the Assessment Coordinator. On August 31st Tamika was called to confirm September 6, 2005 at 8:45 for the evaluation team to visit.

The assessment and evaluation team consisted of a physical therapist and a special educator. Delante qualified for services under the criteria of Atypical Development - motor (gross and fine). Physical therapy (PT) services were scheduled once weekly for sixty minutes in the home. The IFSP dated September 6, 2005 and indicated the start date of services to be October 06, 2005.

On October 7, 2005 Liselle's contact log had an entry of a telephone call from Tamika. The entry read, "Mom called. She asked about Delante's services. I told her I will call (the school name) and call her back…." Log entries indicated that Liselle called the school and discovered from the Infants and Toddlers Program secretary that Delante had not been assigned to a physical therapist. She called Tamika back. Her log of the conversation with Tamika indicated that Delante had not been assigned and was on a pending list.

The next entry in the contact log was dated October 19, 2005 and was a telephone contact from the mother. Tamika called again to find out if Delante had been assigned. She was "staying on top" of the situation to secure services for her son. Liselle's entry indicated a call to the school, which was not answered, and a call to the mother to indicate the outcome of the call to the school. Liselle told Tamika she would continue

calling the school and would call her the next day. In the entry dated October 20, 2005 Liselle confirmed who the assigned physical therapist was and called Tamika. She provided Tamika with the information and asked her to call again if she had not heard from the therapist by Monday afternoon. Tamika continued to be vigilant. She called the following Tuesday and left a message that the PT still had not contacted her. Liselle made several calls as recorded in the contact log attempting to get information about Delante's services. Finally on November 11, 2005, Delante had his first PT visit, five weeks later than when they were scheduled to begin.

At this point he was receiving physical therapy through the private facility and the county Infants and Toddlers Program. His development was also being followed by the torticollis clinic at the children's hospital.

Summary. Delante's need was not a determining factor in this family coming to the US. This family had been living in the US for some time before Delante was born and the need for services arose. Accessing services for this family involved a great deal of diligence and independent work. As Tamika saw the mass on Delante's neck and searched to know what it was, she discovered information on the World Wide Web, which propelled her vigilance to access services for Delante as soon as possible. Information posted on the Internet served as major indicator for what should be done next.

The path to the torticollis clinic at the children's hospital was through referral from the pediatrician. However it was her persistence as she described it, "I had to get in. I just had to," that got her son an earlier appointment than offered. The information she gained along with the delay in accessing the Torticollis clinic at the children's

hospital prompted the search for private physical therapy. Tamika and Kevin searched systematically until they found a facility that would accept their insurance. Getting the service from the county ITP required her to 'stay on top of them."

The use of technology and "staying on top" of the situation by making several follow up calls were the means through which the James family came to know about and make their way into receiving services. Having described how they accessed the services, I will now look at themes emerging that addressed research question two.

Research Question 2: How Is The Cultural Context Of The Family Reflected Through The Services They Receive?

      a) What are the family's goals for the child?

      b) How does the family define their child's disability?

      c) How has the child's disability impacted the family?

      d) What is a typical day like for the family?

Several different themes emerged while analyzing the data to answer these questions. These themes, examples of codes and data sources used to answer sub questions A and B are presented in table 3.

Sub Question A: What Are The Family's Goals For The Child?

There were two themes that were clear as related to this question. The first one was "need nothing," and the second "high academic achievement. These themes will now be presented.

Table 3 Research Question 2 (A & B): Codes, Themes, and Data Sources

Research Question		Codes	Themes	Data Sources
How Is The Cultural Context Of The Family Reflected Through The Services They Receive?	Sub Question A: What Are The Family's Goals For The Child?	To give him everything he likes He's never going to need Make sure his future isn't short	Need nothing	Family interview
		Get his Bachelors… at least View him as an educated man Child is going to go to school and learn	High Academic Achievement	Family interview Physical therapist interview Grandmother
	Sub Question B: How Does The Family Define Their Child's Need?	I was not surprised To me was nothing That was miniscule	Miniscule	Family interview Physical Therapist interview
		My own little research I read Finding that website	My research	Family interview Grandmother interview Service Coordinator interview
		Could have facial deformity Trying to make sure If he did need	Fear of possible out comes	Family interview Grandmother interview Service Coordinator interview

Need nothing. This theme illustrates data associated with the thoughts, perceptions and actions related to providing for Delante. When describing their family, the James' shared that having a child was planned. A great deal of their thoughts and actions for their son related to not having him in need of anything material. The theme "need nothing" captures their thoughts.

Tamika said they waited so that they could provide for Delante, "all the things that we would like …to be able to give our child …we hope to give him, you know, everything that he likes."

Kevin, who was not present when Tamika provided her response, was asked to share his values and aspirations for Delante. He stated,

I don't really care about stuff like that… I'm concerned about his goals…about what he wants out of life and to make sure that his future isn't short…Tamika and I are both, um, come from quote un quote not necessarily affluent family and we're not affluent per say. Don't get me wrong, we're not poor people, but we want to be able to set up a system where he's never going to need anything.

Kevin explained that while he expected Delante to have wants "As far as needs is [are] concerned, he's never going to need anything because we are going to be able to provide everything that he needs." The needs the family is referring to here are material needs.

When expressing this hope for Delante never having to need anything, Tamika also voiced a desire that he be responsible. She said, "I hope that he is a responsible kid and not "quote unquote" brat and think he can just get everything and whatever… I'm hoping that he's responsible."

High academic achievement. The family's academic aspirations for Delante were evident in the data. The theme "high academic achievement," best described the codes that emerged from the data. In describing the goal of being able to provide all that Delante needs, Tamika stated that she would like for him to get his bachelors and masters degrees, at least. Kevin, in commenting about his goal for Delante said, "I guess because my parents as West Indian, and Trinidadian, more specifically…did not look out for my future and, before Delante was born, Tamika and I established a college savings fund for him." This comment reflects both the goal of high academic achievement and the goal of having Delante need nothing. Kevin went on to explain why he had this goal in mind for Delante, he said, "I have a personal goal for Delante and that is that other people view him as an educated man unlike myself. When people see my resume they don't see that Bachelors Degree or Master's Degree. They just past you by." He continued,

> It does take a piece of paper to say, 'listen I am smart.' So my thing to him is that I don't want to have that barricade. He should at least be able to get through the door with this paper after that he's on his own, you know.

> The private physical therapist, Cheryl-Ann, repeated this goal of academic achievement during the interview. When describing her feelings about Delante's present needs she commented that the parents, like many others, had academic aspirations for their child. She said, "Basically that's every parents main focus that the child is going to go to school and is going to learn." The family's goals for Delante were not described as related to his present need but his future.

Another goal that Kevin articulated for Delante was that he becomes a professional athlete. He described himself as being an athlete as a young man and his wife as possessing athlete like qualities, "I want him to become a professional athlete. I mean that's my expectations, but if he fall short of that I'm fine with that, you now I don't care, but I do think that's suppose to be natural." The private physical therapist shared knowledge of this goal of being a professional athlete when she said; "I know he was concerned he wants his son to be a football player some day."

Summary. High academic achievement and that Delante would never need for material things were the goals articulated by the parents. The perception of education in this family is as a means to an end. The family defined high academic qualifications as obtaining college degrees.

Sub Question B: How Does The Family Define Their Child's Need?

There were two themes that addressed this sub question 'miniscule" and "fear of possible out comes." The codes presented under 'my research' where separated from the theme 'fear of possible outcomes.'

Miniscule. When talking about Delante's special need Kevin stated, "If memory serves me correctly I was not surprised." He talked about it in this way,

> I understand, unlike Tamika, that there's always going to be some sort of
> formality or some kind of difficulty in our life. She and I always had issues that
> we had to address when we were dating … so it didn't surprise me… but to be
> honest with you…perfection is something that is God given and not getting on her
> but to me was nothing, that was miniscule.

Kevin said he was happy to have a baby with all its parts and felt that this case was minuscule in comparison to "what I understand it's something people would have hoped for because they have had other problems that was much more significant." The theme that united these comments is that it is minuscule or not a big thing.

Tamika said this was a condition, which if not addressed immediately, could lead to deformity. A great deal of her understanding of Torticollis came from the World Wide Web. "My research" and "fear of possible outcomes" resounded loudly as Tamika described Delante's case.

My research. As I sifted through the data I noticed that Tamika commented about Delante's need in relation to her research. Her comments were prefixed with, "I was doing my own little research and they said…" "Everything that I read said…" "Based off on my research of the website I found…" "Everything else was done on my research looking at the website, finding that website." As a researcher she commented, "The key was me finding the mass early and getting help for him early. Starting early was the key because from what I read if that mass had went undiscovered, you know, it could have been worse."

Fear of possible outcomes. When Tamika spoke of Delante's Torticollis she spoke in reference to what could happen based on her research. She commented that he "could have dysplasia, hip dysplasia" (see Appendix D). In describing her need for early intervention she explained that when the child turns one and you "have not addressed this thing, then you [the child] could have facial deformity."

Tamika learned that children with Torticollis often had flattening of the head. She began to see some flattening. She had read, "A baby's head is best shaped at seven

months." She took Delante to get an evaluation explaining that she feared he was developing plagiocephaly (see Appendix D). "I was trying to make sure that everything was done within the time so if he did need … that he would get it."

Summary. Tamika and Kevin defined Delante's special need in very different ways. Kevin found it to be a minor set back while Tamika saw it in relation to the possible future outcomes. The way that they defined his need influenced the way it impacted the family.

Sub Question C: How Has The Child's Disability Impacted The Family?

Sub questions C and D are summarized in table 4, which highlights the themes, examples of codes and the data sources used to answer those questions.

Stress versus concern. While reviewing the data to answer this question, it appeared that Tamika was stressed. This theme of being stressed shows that the sources of the stress were both directly and indirectly related to Delante's torticollis. The family had planned and waited for Delante and six weeks after their "nice symmetrical kid" arrived he became asymmetrical. This had a direct impact on Tamika, who was concerned about what torticollis meant in the long term for Delante. She recalled a recent conversation with her boss who reminded her of having been in tears when talking about Delante's torticollis. Althea (Tamika's mother) reported also being affected emotionally and commented "This was the first little baby after waiting for a baby for so long, and it's a little boy." Kevin reported that he was not surprised when Tamika called him at work with the news that Delante had been diagnosed with Torticollis. He saw this as just another challenge as he reflected on their relationship.

Table 4 Research Question 2 (C & D): Codes, Themes, and Data Sources

Research Question		Codes	Themes	Data Sources
How Is The Cultural Context Of The Family Reflected Through The Services They Receive?	Sub Question C: How Has The Child's Disability Impacted The Family?	To give him everything he likes He's never going to need Make sure his future isn't short	Stress versus concern	Family interview Private Physical therapist interview Grandmother interview
	Sub Question D: What Is A Typical Day Like For The Family?	While in high chair He had to anyway While sitting on your lap	It was part of the day	Family interview Grandmother interview Home follow-up notes
		He hated that Try to get away Always a fight.	He hated it.	Family interview Grandmother interview Home follow-up notes
		Mother being here Newly pregnant	Family support	Family interview Grandmother interview Service Coordinator interview Private physical therapist interview Home follow-up notes
		Baptized Catholic Go to church as family Granny been praying My rosary	Faith	Family interview Grandmother interview

Tamika explained the reason for the difference in impact, "I really stressed out about the whole thing. Kevin took it much easier than I did cause, you know, what was told to him was that…it would resolved with physical therapy if you catch it earlier…."

The private physical therapist commented on this difference in impact. When asked to comment on the impact that Delante's torticollis was having on the family, she remarked, "I think it ends up being more of a husband and wife, he is from Mars you're from Venus type of thing versus necessarily the fact that he had this torticollis, you know…" She explained this further by saying "Does the mother usually tend to be the more over sensitive one and much more the drill sergeant because she wants to make sure? Absolutely, and I think that was probably the case there too because she was probably much more rigorous about it than he might have been." Cheryl-Ann was quick to point out, "Although I know he was concerned, he wants his son to be a football player some day."

When asked about the way Delante's torticollis impacted the family, Liselle the family's service coordinator commented, "It sticks in my head that she said 'I feel so sorry for my baby his head is turned to the one side.'" Liselle explained that she thought the torticollis bothered Tamika to a point, but she had a lot of family support. Therefore, she thought she dealt with it well.

Tamika used the Internet to search for information to help understand the nature of torticollis. The information served as a two edged sword. While the information gained through the site informed decisions and actions, it also impacted her emotional state. One site that Tamika joined -torticolliskid.org -was particularly reported as a major source of stress. "But because I was on that website torticollis.org," Tamika

acknowledged, "I was really, really I was really upset about it and the more I read …Oh my God." Tamika's sister commented, "She was reading too much and getting paranoid"

Summary. While Kevin was concerned about what he viewed as a minuscule matter, Tamika was stressed. Her stress seems to have mainly been caused by information she read about the possible outcomes associated with Torticollis. The way Delante's special need impacted each family member influenced the way they were able to manage their daily routines.

Sub Question D: What Is A Typical Day Like For The Family?

Althea outlined what a day would be like during the time Delante was receiving services. She said, "Well he wakes up about 6 am." This is about the time both parents are getting ready for work. At about 7:00 am she would bathe him and then gave him some fruit. At about 9:00 am he went down to play. During the playtime she tried to do a few of the stretching exercises that were taught by the private PT, as well as the activities suggested by the county PT. Between noon and 1:00 pm he would get food (a bottle formula or cereal).

He would take a nap after eating. Althea indicated that the soft collar (issued by Cheryl-Ann would be placed on him when he was going to bed. This contradicted the progress report of 5/29/06 in which Cheryl-Ann writes "never use for sleeping or in a car seat." When he woke up at about 3:00 or 4:00pm he would have some fruit or cereal. When Tamika got in at about 5:00 pm he would have a bottle (formula). When Kevin got home he would hold him in one of the stretch exercises.

It was part of the day. As I attempted to address the question of the typical family day many of the responses were 'It was part of the day.' The exercises recommended

were all easily integrated into what the family did during the day with Delante. They would hold him, encourage him to feed himself, play with him and so on. Activities were incorporated into these routines to enhance the experience for Delante. Tamika and Althea both explained that the activities prescribed by both physical therapists were easy to incorporate into the daily routine since they were all done during his playtime. One activity, a way to hold Delante that stretched his neck, became Kevin's "thing to do."

One of the activities aimed at improving his inferior pincer grasp. The recommendation on January 6, 2006 by the county PT was to "work on picking up small objects like peas (cooked), goldfish, crackers, cheerios etc. while sitting in high chair." Althea explained it was "not a problem. He had to eat and it was the way to help him." Review of the home follow-up documents from the county physical therapist all showed activities that were recommended for while Delante was playing. Another example of a recommended activity was "place his toy basket on his right side so that he will have to turn to his right to play. You can then gently stretch his neck by pushing his head gently towards the left" (Home follow-up program note 12-21-05).

The home exercise program from the private physical therapist on August 29, 2005 read "practice rolling back $\longrightarrow$ to belly." This exercise Althea and Tamika reported doing during diaper changes and when tidying as a play activity. Another activity recorded on December 12, 2005, was also something the family would do naturally. For example it instructed the family to- "Sitting on your lap left leg, your arm around his trunk encourage head upright or L ear to left shoulder." The football hold, a stretch technique prescribed by Cheryl-Ann, proved difficult for both Tamika and Althea. "Kevin could do it real good," Tamika said. Kevin recalled doing the football hold

saying "That was humongous. I think more so than any other exercise the football hold was a stretch that basically it helped him a lot."   This exercise was also easy to incorporate into the daily routine. Kevin said he would hold Delante in the stretch while having a conversation or just walking with him.

　　　He hated it. While Delante was not able to share for himself how he felt about the exercises, his mother reported "he hated that first of all, he knew it was coming and if you put your hand on his head anywhere on his head, he would start try to get away." His grandmother also reported this dislike for the stretching. She said, "It was always a fight." Kevin as well knew of Delante's displeasure with the stretching. When he spoke of doing the football hold he pointed out, "Don't get me wrong he hated it, but it made sense to me to do it." The county physical therapist's Home Follow-up notes for November 18, 2005 indicated that he fussed but when left alone played appropriately with toys. In parentheses the therapist wrote, "He fooled us."

　　　Family support. Tamika went back to work three months after giving birth to Delante. With both parents working Althea cared for Delante and continued the exercises. Tamika and Kevin attributed Delante's progress to her mother being with them. Tamika stated, "My mother being here at that time …was how I think Delante did as well as he did."   She continued and Kevin concurred;

> Mother stayed on top of it. She did everything she was supposed to do. She
> stretched him constantly. They told her to stretch him every time she changed
> him [diaper change] she did it. She worked with him on the pincer grip…on
> every single thing that she was suppose to do with each therapist. She did it. All
> the amount of time that they told her to do it, she did it.

Tamika's voice cracked as she spoke of what her mother did for Delante and the family.

In addition to the support by Tamika's mother, her sister, Nicole, was also a source of support for the family. Althea returned to Trinidad and Tobago for a short time. During her absence Nicole stayed with the family to help with Delante. All the providers commented about the obvious family support that was present. Cheryl-Ann said,

> When she first came it was Tamika, her mom and her sister. Her sister was newly pregnant and that tells you a lot right there. Kevin who works here in Stoneville, would come and join in for the therapy sessions.

Tamika explained that her family is pretty much like the one she grew up in. Her family is very close and Kevin is very close to her family. He offered that his family is the "exact opposite." Family is the main unit; Tamika articulated, "The family is the core. It starts from there. One of my goals is to make sure that Delante grows up in a stable family." Tamika explained that the family is the core and if there is no core everything falls apart and is chaotic. A strong core or foundation she explained is important.

Faith. As Tamika spoke about her family she spoke about being Catholic. While both parents were baptized into the Catholic faith, Kevin no longer professed to be Catholic. Tamika's hope is for Delante to grow in the Catholic faith. She declared, "Kevin won't fight me on this because he knows where I stand …Delante was baptized Catholic." She verbalized the wish for the family to attend church together but respects her husband's choice.

When she referred to supports during her stressful times amongst other things she commented, "of course…mother [was] praying and telling me that you know things will work out. My mother is very religious."

When I interviewed Althea and asked about prayer and her reasons for praying she looked at me with shock and declared "What you asking me that?" During our telephone conversations I had share my involvement with Charismatic Renewal in the Catholic Church in Trinidad and Tobago and also my involvement with the church while at Graduate School in the US.

After explaining that I needed to hear her views she shared, "God is in charge and He made us. He is the healer I always say He is the great physician He is going to make him whole, I firmly believe that." Althea shared that she prayed the Luminous Mysteries of the Holy Rosary for each of her children and their families, each family on a different day. In addition to saying the rosary she said she called her daughter back in Trinidad and asked her to inform the network of persons who did constant adoration before the Blessed Sacrament "to pray specifically for him before the Blessed Sacrament."

Summary. Service providers took time to develop a relationship with the family. This allowed services to be provided in a way that was sensitive to the families needs. Both physical therapists suggested home exercises that would easily be incorporated into Delante's play activities at home.

Research Question 3: What Type Of Relationship Does The Family Have With The

Service Providers?

a) Who sees the child most?

b) Who is the most valuable to the family?

As I conducted interviews I realized that the providers I interviewed shared similar experiences with the James family. The theme 'ability to relate' quickly emerged as I shifted through the data. Other themes that materialized were 'genuine interest' and 'highly qualifications and experience.' These themes were verified through interviews with the providers and the family. Table 5 gives the data sources from which the themes were deduced as well as the codes that lead to them.

On the days that they took Delante to the private physical therapist Tamika and her mother would go with Delante. Kevin who worked in the area would meet them there. Cheryl-Ann would first ask for a report on how he had been doing that week. She indicated during the interview that

> Is important for me to know what is important in their lives um... and what is
> going on in their lives because I will adapt my home therapy program for them
> with regard to what is going on in their lives.

Table 5 Research Question 3: Codes, Themes, and Data Sources

Research Question		Codes	Themes	Data Sources
What Type Of Relationship Does The Family Have With The Service Providers?	Sub Question A: Who Sees The Child Most?	The response to this question was made after examination of documents.		Private Physical Therapist notes Home follow up notes Service Coordinator log.
	Sub Question B:Who Is The Most Valuable To The Family?	She explained Seem interested in family	Genuine interest	Family interview Physical therapist interview Grandmother interview
		Felt more comfortable	Ability to relate	Family interview Physical therapist interview Grandmother interview
		She qualified Quick results Cheryl-Ann was … very, very good	Highly qualifications and experience	Family interview Physical therapist interview Grandmother interview

Sub Question A: Who Sees The Child Most?

I examined documents from both physical therapists. Cheryl-Ann's notes were for the period August 16th 2005 to May 10th 2006.   These documents represent 20 visits.

The Home Follow-up notes from the county physical therapist were for the period November 11th 2005 to June 2nd 2006. These represented 13 visits the provider contact log accessed from the service coordinators case file also accounted for 13 visits.

The Service Coordinator visited the home three times. She visited on the first occasion for an initial meeting, the next visit was made as part of the assessment team and the final visit was on the occasion of Delante's six-month review.

The length of time spent with each individual influenced the family's ability to make bonds with them.

Sub Question B: Who Is The Most Valuable To The Family?

Tamika and Kevin spoke very highly of Cheryl-Ann. Kevin described her as amazing while Tamika shared that after the first meeting with her she felt more comfortable that Delante's torticollis would be resolved. Tamika shared that she knew Cheryl-Ann was not just interested in outcomes but that she really cared about Delante. She says, "Cheryl-Ann was … very, very good. Very much into how much he was doing and stuff and how we were doing exercises.

Tamika's sister accompanied her on that first visit and explains:

She was very nice, she looked at him, she explained all the exercises and everything that Tamika needed that she was gonna do…each step that she was gonna do with him.

Tamika's mother who lived with her for the first nine months of Delante's life described Cheryl-Ann as "a beautiful person." Cheryl-Ann and the family engaged in frequent 'ole talk' not always related to Delante's therapy. In recounting some of the 'ole talk' Althea commented:

> She seemed interested in family you know she will tell us about her little boy and Kevin and her would talk about games, the what do they call it here football …yeah she'd asked me about our family…she was comfortable to be with she was a nice person a beautiful person.

Ability to relate. Cheryl-Ann is first generation American. Both her parents were immigrants. She identifies working with families to be the best part of her job. She explains the importance of getting to know the family this way,

> I think it is important for me to know what is important in their lives … and what is going on in their lives because I will adapt my home therapy program for them with regard to what is going on in their lives."

She volunteered that she enjoyed working with families of different cultures. Cheryl-Ann also offered that she encounters more difficulties relating with typical American families than with immigrant families.

Cheryl-Ann describes the family's need as wanting to have their son be normal and not tilted to one side. About the family she says,

> When she first came it was Tamika her mom and her sister. Her sister was just newly pregnant…that tells you a lot right there. Kevin who works here in Stoneville would come and join in for the therapy sessions.

Cheryl-Ann shares that Tamika and Kevin had a good support system with the family and also her employers. She explains that Tamika's job "was pretty good about if she needed to leave early of if she needed to come in late they were really good about that." When asked about Tamika's friends Cheryl-Ann says, "we never really chatted about friends. We usually chatted about family and her job and that she was in school so she had a lot on her plate."

Highly qualified and experienced. Kevin indicated, "Cheryl-Ann was exceptional, she was high in my opinion, not only was she qualified but she was just so um personable." He went on to say "she's, she's tough she's, she's very, very smart girl, I mean the um the first and second meeting alone showed results."

Tamika asked specific questions about her experience with babies who have torticollis for example "I asked her straight off the break did she have any experience with torticollis."   Cheryl-Ann indicated that she had a Master of Arts in Physical Therapy and had been practicing for sixteen years.

Summary. Cheryl-Ann is the provider the family saw the most and valued the most. They comment about being able to relate to her and feeling comfortable with her. She shared a major common experience with the family that of being from an immigrant family. The fact that she shared information with the family and was interested in learning from them also influenced the relationship.

Research Question 4: What Assumptions Or Assertions Can Be Made About The Services Received In The US As Compared To What May Have Been Or Was Received In The Caribbean?

Sub Question A: What Recommendations Would You Make To The Early Intervention System?

I asked several probing questions aimed at getting a response to this question. Tamika indicated that she could not think of any services that were available at home (Trinidad and Tobago). Therefore the recommendation would just be to have services. Althea commented, "I don't see anything being done at home." She referred to a home for the mentally challenged youth and adults as the only service available.

Probing I asked Althea which of the two scenarios, private services or services in the home would work better in the Caribbean. She commented that the two were beneficial. Probing deeper I asked if there was anything that stood out in one or the other program. She shared that going to the facility was better since they had all the equipment there.

Chapter 5: Discussion

This study explored the perceptions and perspectives of a family with Caribbean heritage of the family-centeredness and cultural appropriateness of the services they obtained while their son was receiving early intervention services. To collect data, interviews with the family and professionals who provided services were conducted along with document reviews. Themes were generated based on my interpretation of data and were used to answer research questions. A range of issues emerged from the data indicating different variables, which impacted the family's perceptions of the services they received.

In this chapter I summarize the findings, and then use theoretical frameworks to link the findings. Comments on the limitations of the study, implications for future research are presented next.

The Cultural Context Of The Family Structure

Cultural Identity

The multicultural heritage of West Indian is seen in this family. Tamika born and raised in Trinidad and Tobago is a product of the intermixing of races and cultures. She is a descendant of both Indian and African parentage. Her early experiences having her father work in the US provided vicarious exposure to a foreign culture. The visits made to the US later on provided personal exposure. Kevin had the reverse of Tamika's experiences. He grew up in the US and learned of Trinidad and Tobago through stories related by his parents. He lived in Trinidad and Tobago and for two years was immersed in the culture. This blending and mixing of cultures and ideologies is reflective of

Barrow's (2002) description of the Caribbean family. This type of multicultural heritage is what Pepin & Connfiant (1998) describe as yielding a polycentric approach to Caribbean identity.

As I conducted interview and did observations, I questioned myself about what was different in this family's experience. It may be possible that the blended or multicultural nature of the West Indian makes us more adaptable to different cultures.

Family Structure

The James' conform to the marriage union model as put forward by Evans and Davies (1997) and United Nations Report (1995) outlined in the literature. While they conform to the model, fluidity of kinship described by Henke (2001) is seen in the way Tamika's mother moved between the daughters filling various needs. This family possessed characteristics that were both similar and dissimilar to characteristics noted in the literature reviewed of the immigrant West Indian. One similarity is serial migration, which describes Tamika's move to the US (Henke, 2001; Palmer, 1990; and Waters, 1999). As she shared, her siblings already lived in the US, and her father worked for part of the year in the US. The hope of finding work opportunities in the US is expressed in the literature as the longing of the West Indian immigrant, a longing Tamika also expressed. Joining the military however is not noted to be a common thing for immigrants to do.

Child Rearing

In discussing child rearing practices in the Caribbean, Evans and Davies (1997) indicate that most Caribbean children are born into economic hardships. Tamika and

Kevin both had the experience of living in Trinidad and Tobago a lesser-developed nation than the US. While they state their families were not poor, there seems to be a sense of having needs that were not meet and wanting to ensure that they were in a financial position to provide well for their son. This is captured in Kevin's statement "because my parents as West Indian, and Trinidadian, more specifically…did not look out for my future…" This perception was generalized to all West Indian families but could not be substantiated with literature or my experience as a Trinidadian. I surmise that their individual family experiences have influenced the perceptions. These individual perceptions influenced their need to be able to provide for all Delante's material needs. It explains their desire to wait until they could provide all his needs.

Tamika spoke of her nuclear type family as stable; a perception held by many Caribbean born people. While the family structure is nuclear it is apparent that Tamika's role was more significant than Kevin's in Delante's early months. Kevin during the interview shared that work kept him away for very long hours during Delante's infancy. This pattern is consistent with Lange and Rodman's (1992) description of the mother as the dominant figure in Caribbean households. This would also hold true for many American households.

This dominant sense of womanhood emerges according to Evans and Davis (1997) following childbearing, which serves as a rite of passage. In this case Tamika's family came together to provide support during this transition. The support remained in the form of her mother even after she had completed the transition to this new phase of womanhood.

Delante had several different play stimuli available to him. Both his parents and his grandmother engaged him in play with these items.   This is inconsistent with the report of Rhynie (1997) and Lange and Rodman (1992) that play stimuli in the West Indian home was limited if in existence at all. Play was seen by the therapists as very important in Delante's day as a way to imbed some the activities that would help his torticollis. His care providers were more diligent in play with him for the therapeutic outcomes. Play was therefore valued more for its therapeutic value. While there were educational benefits to be derived these were not the immediate concerns of the family. While Althea read to Delante it was not a priority built into the daily routine. A pattern noted by Rhynie (1997) and Lange and Rodman (1992) to be true of the West Indian household. While this is noted of the West Indian it is also true of many other American families.

Definition Of Delante's Need

Tamika made herself knowledgeable of Delante's needs and shared that the pediatrician provided an explanation of Torticollis.   Having professionals who educate families about a child's diagnosis was identified by Harry (1992) and Rao (2000), as an important step in helping families better understand the child's diagnosis and it's effects. Tamika was conducting her own research about Torticollis and became very upset when she realized that her pediatrician was not providing information. While I did not interview the pediatrician I surmise that the doctor's definition was not the same as Tamika's, which lead to the conflict.

It was interesting that Tamika who grew up in Trinidad feared for Delante and related his condition to possible negative possible outcomes. Kevin who spent most of

his life in the US saw it as something miniscule that would be remediable with physical therapy. These two definitions may have reflected differences in culture or differences in gender. Further studies are needed make assertions of which were the more dominant factors.

Children who have special needs are legally provided for in the US. This ideology is common to Kevin who identified himself as American. Tamika however is from a culture where children with special needs are not even identified because there are no routine screenings for diagnosis and intervention to take place (Thornburn, 2000). The cultural orientations of both parents could have influenced their views. Both parents eventually viewed torticollis as a situation that could be counteracted with physical therapy. This view Thornburn (2003) indicated to be one of two ways the Caribbean family defines special needs. That is there is a cure that can be provided by professionals as opposed to the need being a shortcoming of the family or the child.

Faith

The theme of faith spoke quietly in the data but was very integral to the family. While Tamika did not speak of praying herself she referred to her mother praying. She knew that her mother was praying.

Catholicism is very common in Trinidad and Tobago as it is in the US. The Catholic faith teaches of the Real and Divine presence of Jesus in the Eucharist. Catholics have been encouraged to seek blessings by seeking the Face of Jesus in the Eucharist. Holy Rosary is a prayer of intersession for Holy Mother Mary to plead the petitioner's case before the throne of God.

While their faith was important there is no evidence of service providers attempting to incorporate the family's faith into their recommended activities for home.

Family Service Orientation

While tempted to define the service delivery model received as Family Centered, (Dunst, et al. 1991) I refrain since it was the family who without professional collaboration sought out a network of professionals and services. The outcomes may have been different if the pediatrician had provided the family with information about Child Find efforts. The services they received would better be described as a Family Driven Model. In this model the family takes charge of accessing and coordinating services for their family.

Tamika referred Delante to the Infants and Toddlers program indicating her need for physical therapy. She collaborated with the service coordinator to secure the services needed for Delante. Tamika also initiated the process of withdrawing Delante from the Program when she assessed that his need had been met.

Perceptions Of Services

The family perceived the services as very family centered. They spoke highly of the professionalism and efficiency of the professionals providing services. As discussed in Chapter 4 Tamika found that the services also helped reduce her levels of anxiety. As found in the research by Mc Bride, et al. (1993) the professionals did not identify with having a role in alleviating parental stress. When asked how her involvement helped the family Liselle commented that she did not see her services as having been a factor in assisting the family. Opposed to her view was Cheryl-Ann who thought that her services and manner of relating with the family were helpful.

Cultural Appropriateness Of The Services Received

There was no direct question asked about the cultural appropriateness of the services received. I attempted to glean cultural appropriateness from the interviews and documents reviewed. The casual chatting or Caribbean 'ole talk' that took place between the caregivers and service providers while engaging in therapy was one method very reflective of Caribbean culture.

Professionals in this study were sensitive to the need for information about the family. Like half the professionals in the study conducted by De Gangi and Weitisbach (1994) they incorporated the family's goals into the IFSP. In the case of the private service provider this information informed the activities recommended to the family.

In this study unlike MacMillain Nownes (1998) the service coordinator emphasized and acknowledged the mother's personal support network. The personal support available to Tamika and Kevin was very obvious in the presence of her mother and sister at various points. The private physical therapist commented on family as well as job support.

The service providers in this study were different from those described by Chamberlin (2002) and Harry (1992) in that they did not come from the mainstream American culture. The professionals interviewed were both immigrant second generation Americans sharing that common experience with the family

Culture was silenced in a way by Althea not giving input form her perspective when the family was making decisions. Althea expressed that Delante was their child and they needed to make the decisions. She also commented on things being different 'up here' [in the US]. This acceptance of the way things seemed are reflective of what

Ogbu (1991) refers to as 'accommodation without assimilation.' That is to say while not in total agreement with suggestions for example the frequency of stretching needed, she complied anyway. This silence of the older generation could have implications for the transmission of culture. The family's need was provided for with the services received. My assertion is that the family was satisfied and therefore the service met the cultural needs.

Links To Theory

In this case study the family played a critical role in maximizing developmental outcomes for Delante. Tamika's parenting style of high vigilance in observing Delante resulted in her finding the mass very early. Again it was the diligence in getting a diagnosis and searching for long-term outcomes of torticollis and remedial strategies that resulted in positive developmental outcomes for Delante. On Sameroff and Chandler's (1975) 'continuum of care taking casualty' the parenting style of the James' family would be rated on the high end of positive outcomes. The transactions that took place between the environment and Delante influenced each other and contributed to his care.

The transactions within the bioecological systems theory were apparent at every level in this study. The proximal processes working in the micro system to affect Delante's development were his family. Tamika discovered the mass on Delante's neck and searched for a meaning to attach to it. The parents' quest to find services for Delante is another proximal process in the micro system, which impacted on Delante's development. Had they not searched for services as quickly as they did their son may have developed some of those negative outcomes Tamika feared.

The family is very close and the interdependent nature of their relationship was an additional proximal process that had an impact on Delante. His grandmother's presence in the home to do the recommended activities was very vital to his progress. Bi-directional interactions (Bronfenbrenner, 1995) between Delante, his parents, and grandmother impacted positively on his ability to benefit from other experiences. For example being receptive to handling from the physical therapists.

Other experiences came about through direct interaction of the parents with service providers. These mesosystem influences included the torticollis clinic, private physical therapist, the service coordinator, and the infant and toddlers program for the county. The relationships that existed between the family and each of these providers had a direct impact on the way Delante received services. In the case of the torticollis clinic, the family experienced a long wait to get an appointment and when they did receive an appointment it was scheduled for several months in the future. The physical condition of the hospital parking area also influenced perceptions of the facility. Tamika referred to it as crazy. The combined experience of long wait, late appointment and poor parking facilities influenced the parents' relations with this facility. Delante did not receive any therapy through the clinic but Tamika allowed the nurse practitioner to follow his development.

The relationship between the family members and the other providers was more positive, resulting in a positive mesosystem relation. Delante received services regularly and the service providers as well as the parents developed good relationships. These mesosystem interactions resulted in favorable developmental outcomes for Delante. The

service providers themselves reported enjoying working with families. This is another example of a mesosystem factor that had an impact on the way Delante received services.

The exosystems that were influential in this case study were Tamika's job and the administrative structure of the county infant and toddler program. Tamika job was very supportive of her having to take time off for Delante's therapy sessions. In addition her boss served as a support when she felt emotionally overwhelmed.

While Tamika was easily able to refer Delante to the county Infants and Toddlers Program, starting services proved to be difficult because of a shortage of therapists. In this case both the service coordinator and the family shared similar cultural backgrounds. This proved to be a factor, which aided communication.

I suggest that technology; in particular the Internet seemed to be a macrosystem influence. The Internet and the information his mother found there indirectly affected Delante. Another macrosystem component in this study appeared to be the culture of the immigrant. As an immigrant Tamika was aware that services were provided for children in the US. While she did not initially know where or how to access the services she searched until she found what she needed.

There were no notable changes in the chronosystem of the family except for Delante's development over time. As indicated by the physical therapist achievement of developmental milestones often result in an increase of the head tilting. There were no reports of any increase of a head tilt as a result of the maturation. Other temporal changes were not reported.

Limitations

Being a member of this culture proved to be a limitation for me in distinguishing patterns of behavior that were Caribbean from those that were not. Being from the same island as the family made it even more difficult as I shared the same cultural model of the family. As data collection progressed I found it difficult to identify practices that were Caribbean. As I reflected on this challenge I realized that my frame of reference for how things were and should be were similar to the family's frame of reference particularly Tamika's. Someone from a different cultural model may have generated different results.

Another factor that may have influenced the outcome of the study is the period of time the family lived in the US. Having lived in the US for more that fifteen years there seems to have been assimilation and acculturation to American culture. This familiarity would have influenced the family as they negotiated services for Delante.

Doing the study in retrospect prevented observations of what actually transpired while the family was receiving services. For example I was unable to observe therapy sessions with the physical therapist, initial meetings, evaluation and assessment meeting, and the six-month review. Observations may have provided a clearer picture of the cultural sensitivity and family centeredness of services.

Another limitation was not being able to interview the physical therapist for the county. Data from such an interview could have been compared with that of the private physical therapist for similarities and differences in the way they approached service provision.

Implications For Future Research

This study looked at one family, a larger sample size would give a greater indication of trends common to most immigrant Caribbean families. A study that included a greater number of Caribbean immigrant families and used a model of Caribbean culture to assess the family level of cultural identity would be useful.

Since research on Caribbean early intervention services is limited studies need to be conducted that looks at how people in the Caribbean care for children with special needs.   A future research project may look at the number of children in the Caribbean who would qualify for services using US measures and analyze the type of care the children are receiving.

Appendix A: Eligibility Criteria

Part II: Child's Developmental Status and Family Information
Section E. Eligibility Status

Check *only one* of the three boxes below designating the criteria under which the child's eligibility was determined.
Then check the appropriate box(es) under the main category selected.

If a child with a diagnosed physical or mental condition also exhibits a 25% developmental delay or atypical development, the appropriate box to check is: Diagnosed Condition With High Probability of Developmental Delay

☐ **Diagnosed Condition With High Probability of Developmental Delay**
Check *all that apply*:

- ☐ **Chromosomal disorders**
  - ☐ Down Syndrome
  - ☐ Other _____
- ☐ **Intraventricular hemorrhage** - Grades III or IV
- ☐ **Congenital infection** – symptomatic
- ☐ **Infants showing significant effects of maternal prenatal drug abuse,** such as Fetal Alcohol Syndrome
- ☐ **Prematurity** with birth weight of less than 1200 grams
- ☐ **Severe congenital malformations,** such as meningomyelocele and congenital hydrocephalus
- ☐ **Inborn errors of metabolism** where either the diagnosis is late, there is not treatment available, or inadequate treatment, such as maple syrup urine disease, urea cycle defects, galactosemia, lysosomal storage diseases, and those carbohydrate disorders associated with CNS involvement
- ☐ **Neurodegenerative disorders** that have their onset in infancy and early childhood, such as adrenoleukodystrophy and TaySachs disease.
- ☐ **Epilepsy,** where seizures are frequent or difficult to control, or the underlying condition is associated with frequent cognitive impairment e.g., infantile spasms
- ☐ **Severe encephalopathy** resulting from insult to the brain, such as trauma, drowning, poisoning, or infection.
- ☐ **Sensory impairments** where appropriate treatment still leaves significant impairment, e.g. vision not corrected to normal for age in either eye, or mild or greater hearing loss in the best ear persistent even after appropriate treatment.
  - ☐ The child is blind or visually impaired
  - ☐ The child is deaf or hard of hearing.
- ☐ **AIDS,** symptomatic or known infected.
- ☐ **Lead poisoning,** with lead level of 20 ug/dL or greater.
- ☐ **Infants affected by intrauterine drug exposure.**
- ☐ Other _____

☐ **25% Developmental Delay** Check *all that apply*:	☐ **Atypical Development** Check *all that apply*:
☐ cognitive	☐ cognitive
☐ communication	☐ communication
☐ social-emotional	☐ social-emotional
☐ adaptive	☐ adaptive
☐ motor	☐ motor

Appendix B: Contact card

A case study of Caribbean Parents'
perceptions of cultural sensitivity and
family centered service provision

Lenisa Joseph
University of Maryland, College Park

Cell: 240-593-7095
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Appendix C: Letter to Parents

14th August 2006

Dear

I am conducting a research project at the University of Maryland, College Park. The study is being conducted under the supervision of Dr. David Cooper of the University of Maryland. Procedures of the study involve interviews with a family of Caribbean heritage with a child presently receiving early intervention services.

The purpose of this research project is to look at the way Caribbean culture influences the experiences of parents who have children receiving early intervention services. The study aims to understand and describe the family's view of service providers' level of family centeredness and cultural sensitivity and the barriers and supports the family encounters within the early intervention system.

I am currently in the process of identifying families of Caribbean heritage who would be interested in taking part in this study. Your assistance would be greatly appreciated in this area. If you would like to participate or would like more information I'll be happy to share. My contact information is Lenisa Joseph at 240-593-7095 or through email at   lenisa_joseph@hotmail.com

Thank you very much for your assistance with is research project.

Best Regards

_____
Lenisa Joseph
M.A. Candidate
University of Maryland

Appendix D: Glossary of Terms

Term	Definition
Angelman's Syndrome	Mental retardation is described as a condition that is diagnosed before age 18, and includes below-average general intellectual function, accompanied by impairment in the person s ability to acquire the skills necessary for daily living.
Congenital Torticollis	Also known as Congenital Muscular Torticollis or CMT, Pseudotumor of Infancy (PSI), Sternocleidomastoid Torticollis, Sternomastoid Torticollis, or FibromatosisColli) is due to injury to the sternocleidomastoid (SCM) muscle on one side at the time of birth and its transformation into a fibrous cord which cannot lengthen with the growing neck.
Early Intervention	Program in the United States and US Territories that provides for infants and children with developmental disabilities. Some states allow torticollis to be an automatic qualifier for services but some do not.
Fibromatosis Colli	A firm, fusiform, fibrous mass in the midportion of the sternocleidomastoid muscle, occurring between two weeks and two months of age, and commonly disappearing in four to eight months; in some instances, torticollis may develop. It is believed by some to be a small hematoma due to injury to the muscle at birth.
Hip dysplasia	A condition of abnormal development of the hip, resulting in hip joint instability and potential dislocation of the thigh bone from the socket in the pelvis. This condition has been more recently termed developmental hip dysplasia, as it often develops over the first few weeks, months, or years of life.

Midline	Refers to an imaginary line down the center of the body.
Obeah	A kind of witchcraft or sorcery practiced in the Caribbean
Ol' Talk	Idle chatter, social chit chat
Plagiocephaly	Asymmetry of a newborns head caused by external pressure such as that received with constant back sleeping and little to no time spent on the tummy or due to torticollis.
Roti	East Indian dish: A flat soft bake, which enfolds a variety of curry ingredients: chicken, goat, shrimp, beef, potato, channa, baigan
Sternocleiommastoid	One of the major strap muscles of the neck that attaches in three places; origins in the ribcage (sternum) and the collarbone (clavicle) and inserts at the mastoid process of the skull (the nipple like portion of the temporal bone behind the ear). There is one muscle on each side of the neck.
Torticollis	Wryneck; a contracted state of the cervical muscles, producing twisting of the neck and an unnatural position of the head

Appendix E: Questionnaire for family interview

Use the child's name where [*your child*] appears.

Impact on family
1. Tell me about your family.
2. What was the process like moving the US?
3. Tell me about [your child].
4. How did you go about getting services for [your child]?
5. What are some of the effects [your child] has had on your family?
6. What does your family do for fun?
7. What are your dreams for your child?

Roles and Responsibilities
1. Who is [*your child's*] major caregiver?
2. How are responsibilities shared in the family?
3. Does [*your child*] have a specific role or responsibility?
4. What do you see your role as in [your child's] life?
5. What is your role/responsibility when service providers come to your home?

Culture
1. What are the most important values you wish to impart to [*your child*]?
2. Is your family much like the one you grew up in?
3. What are your feelings about [*your child's*] needs?

Needs regarding Social Services
1. Can you tell me about the services [your child] receives?
2. What do you like/dislike about the services?
3. What would you like [*your child*] to gain most from the early intervention he/she is receiving?

Advocacy
1. What is going well for [*your child*]?
2. What challenges face [*your child*] at the moment?
3. Who do you think knows what is best for [*your child*]?
4. Are there any changes that you would make to the early intervention services [*your child*] is receiving?
5. Do you feel enough is being done for families like yours?

Appendix F: Questionnaire for service providers interview

Use the child's name where [*the child*] appears.

Program

1. Tell me about your program.
2. Is there anything particularly special about your program?
3. What provisions does your program make that's helpful to families?
4. What do you think the family wants for [the child]?

Family knowledge/ Cultural Awareness

1. Tell me about [the child]?
2. How did you go about getting to know the family?
3. What are the family's strengths?
4. What are some of the effects [the child] has had on the family?
5. What support systems does the family have?
6. What are your programs goals for [the child]?
7. Tell me about the services [the child] receives
8. How well do you think the services provided are meeting the family's needs?
9. What can be done if anything to improve the services the family is receiving?

Roles and Responsibilities

1. What do you see your role as in the family's life?
2. What is your role/responsibility when you are providing a service?
3. Is your family much like the one you grew up in?
4. What are your feelings about [*the child's*] needs?

Figure 1: Map of the Caribbean

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