AN ANALYSIS OF THE PARTICIPATION OF IMMIGRANT MEXICAN MOTHERS IN THEIR CHILD'S EARLY INTERVENTION PROGRAM

by

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(Under the Direction of Zolinda Stoneman)

ABSTRACT

The demographic shift resulting from the rapid growth of the Latino population has posed challenges to systems and services necessitating a closer look at families receiving services. One specific Latino subgroup that has had little study is the Mexican immigrant family with a child with a disability who receives early intervention services. Early Intervention services advocate a family centered approach focused on the needs and priorities of the family in order to prevent long-term disability.

The purpose of this study was to explore and describe how mothers of Mexican origin who are undocumented residents in the United States participate in their child's early intervention program. Qualitative research allows close analysis of experiences that define a phenomenon. This qualitative study will promote understanding and inform ways to provide efficient and effective service through practical information that serves to increase the cultural competence of service providers.

INDEX WORDS: Families, Mexican, Immigrant, Disability, Early intervention, Undocumented status, Qualitative research, Cultural competence

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INTRODUCTION

Background and Need

One of the major trends documented by the United States 2000 census data is the growing diversity in the population of the United States as a result of immigration. Mexico is the country of origin for the greatest number of immigrants to the United States followed by China, the Philippines, India, Vietnam, and Nicaragua (Bacthel, Bohon, & Atiles, 2004). The rapid growth of the Latino population in recent years is among the most important demographic trends shaping the future of the United States, yet there are a great many questions and controversies about this population (Suro, Brodie, & de la Garza, 2002).

The Latino population includes people from diverse geographical areas with varied ethnicities, cultural backgrounds, and languages (Garrett & Bautista, 2000; Heller, Markwardt, Rowitz, & Farber, 1994). In 2003, Latinos became the largest minority group in the United States (Rodriguez, 2003). There are a number of reasons to look at these numbers with caution because of the diversity of persons who identify themselves as Latino with heritages and ethnicities that include Caucasian, Asian, and African bloodlines. The evolving terms Hispanic and Latino are often confusing due to disagreement over Latin American geographical boundaries. To further complicate matters, neither term denotes racial or ethnic categories, consequently the two terms are used interchangeably (Bacthel, Bohon, & Atiles, 2004).

Currently, the United States census (U.S. Census Bureau, 2003) lists the percentage of Hispanic/Latino individuals of any race to be 12.5 percent of the total population in the United

States. Although most growth in the Latino population has occurred in Florida, Texas, and California, recent growth in Arkansas, North Carolina, Georgia, and Tennessee is noteworthy. In Georgia alone, the Latino population nearly tripled in the last decade to almost half a million persons (Atiles & Bohon, 2002) or 5.3 percent of the total population. This number includes Hispanics or Latinos of any race. The largest Latino subgroup is Mexican accounting for 275,288 or 3.4 percent of the state's total population (U.S. Census Bureau, 2003).

Latinos have emigrated to the U.S. and concentrated in regions of the country unprepared for meeting the needs of families and children who do not fit the mainstream norm of language and culture. Recent changes in the demographics of Georgia's population show large concentrations of Latinos particularly those of Mexican origin in urban, suburban, and rural areas. These changes have found policy makers and service providers at local and state levels lacking experience with and data regarding the needs of the Latino population. Atiles and Bohon (2002) have identified significant areas of concern for Latinos through focus groups with key informants. They found that the state's "new Latino residents" indicated a need for new policies regarding employment, transportation, crime, community relations, education, child care, and health care.

Studies that have traditionally focused on the acculturating individual are inadequate for explaining how families – a central factor in the lives of Latinos are responding to adaptation to life in a new country (Landale, 1997). Furthermore, researchers (e.g., Garcia Coll & Magnuson, 1997) are critical of the extant literature using conceptual models derived from research with immigrant adults as lacking a developmental perspective and emphasizing problematic outcomes. Garcia Coll and Magnuson (1997) advocate addressing individual differences, family characteristics, and immediate and larger contextual forces that influence children, adolescents, and their families.

Searching for a Better Life

Latino immigrants come to the United States in search of a better life, to fill a labor need, or in order to find work to support families living in the United States and/or in their country of origin (Garrett, 2001; Garrett & Bautista, 2000). In terms of overall patterns of immigration, men usually come first and their families join them later, although, more and more women are immigrating alone (Castles & Miller, 1998). Persons entering the United States illegally are labeled “illegal” or “undocumented” immigrant, migrant, laborer, alien, resident, persons who “don’t have papers”, or “guest worker” for those involved in government sponsored work programs (Jones & Rhoades, 2001). These labels often lead to differential treatment or discrimination.

Regarding discrimination, the majority of all groups including whites and African Americans as well as Latinos think discrimination against Latinos is a problem. Eighty two percent of Latinos surveyed believe discrimination prevents Latinos in general from succeeding in the U. S. Seventy eight percent of Latinos believe discrimination exists in the workplace and 75% of Latinos believe such is the case in the schools. Latinos don’t just perceive discrimination coming from outside their community, they are just as likely (80%) to say that Latinos discriminating against one another is a problem primarily due to differing levels of income and education (Alvarado, 2004; Suro, Brodie, & de la Garza, 2002).

Latino immigrants may also experience isolation when they leave family and familiar surroundings to live in areas with no established Latino communities where they might encounter feelings of discrimination. Often, small communities develop and thrive when persons who have emigrated talk with others from the same regions, towns, or villages in Mexico who consequently, through word of mouth, come to find work (Garrett & Bautista, 2000). Some immigrants reunite with extended family members already living in the United States. Still, others may join existing Latino enclaves or communities, particularly in those areas where there is a large immigrant population and jobs are available (Alvarado & Stoneman, 2004). Whatever their circumstances, most immigrants follow a pattern of initially coming to a new country with the intention of returning to their home countries (Castles & Miller, 1998). For the most part, the longer immigrants live in the United States, the more their family networks expand through marriage, birth, and from continued immigration of family members (Buriel & DeMent, 1997).

Latino Children

The diversity of children in the United States is growing at a rapid pace. According to the U.S. 2000 census, one in five children was an immigrant or had at least one immigrant parent (Shields & Behrman, 2004). States with few immigrants prior to 1990 have experienced enormous influxes of immigrants during the past decade. In 2000, 62% of children in newcomer families had origins in Latin America. Mexico alone accounted for 39% of the children of newcomers (Hernandez, 2004).

In Georgia, trends show a shift from 2,263 children in 1990 to 13,363 children in 2000 in the Latino population based on the number of births by race and ethnicity of the mother. Still, there is no breakdown into Latino subgroups according to country of origin in this population. For example, the Hispanic origin status profile for Georgia from KIDS COUNT Census Data Online (2003) lists a total population of children who are under 5 years of age as 595,150. Latino children constitute 48,968 or 8.2% of this number; however, these numbers are also not broken out into Latino subgroups such as Puerto Rican, Cuban, Central American, or Mexican.

Immigrant families may have immediate and/or extended family members who might be legal residents of the U.S. or living in the U.S. under undocumented status (Garcia y Griego, 2002). Most “everyday” routines of family life in the U.S. involve interaction and participation with others. Families carry out activities such as maintaining one’s health; having a secure home; providing transportation, securing employment; being able to manage finances; educating children, and other activities aimed at sustaining the family’s well-being. Thus, situations might arise where immigrant families are expected to adapt to the mainstream culture and to modify their attitudes, beliefs, cultural norms, and behaviors (Padilla & Perez, 2003).

When disability becomes a factor in the lives of families, the organization and management of everyday family routines is disrupted with coordinating services, benefits, programs, and people involved with the family member who has a disability (Llewellyn, Thompson, & Whybrow, 2004). Services for children with disabilities in the U. S. are federally mandated and state regulated; however, these programs may vary from region to region (Bailey, Scarborough, & Hebbeler, 2003). For immigrant families unaccustomed to the U. S. laws and who might not speak or understand the English language, access to social or healthcare programs may be problematic.

Health and human services such as welfare assistance available to U.S. citizens has been curtailed for the immigrant, particularly the illegal immigrant (Garcia y Griego, 2002; Ghosh, 1998; Greenberg & Rahmanou, 2004; Takanishi, 2004). Families with heads of households who are undocumented may harbor fears regarding deportation if they call attention to themselves. They may also not understand their rights and responsibilities regarding these matters (Alvarado, 2004; Reyes-Blanes, Correa, & Bailey, 1999; Shields & Behrman, 2004). Thus, immigrant families with a young child with a disability may not be aware of available services for their child with a disability or for their family.

Disability and Children

Statistics on children born with disability in the U.S. are difficult to obtain; however, data on selected measures of healthcare access are available. The Centers for Disease Control and Prevention estimate that 1 in every 33 U.S. babies is born with a birth defect. In addition, birth defects are the fifth leading cause of potential life lost and contribute substantially to childhood morbidity and long-term disability (CDC, 2004).

The healthcare of children from poor families and children on public healthcare assistance tends to be inadequate. In 2002, children in poor and near poor families were more likely to be uninsured, to have unmet medical needs, delayed medical care, have no usual place of health care, and have high use of emergency room service than children in families who were not poor. Approximately seven million children (10%) had no health insurance; these numbers included children from families earning less than 20,000 per year (14%) and children from families earning from less than 34,000 per year (17%). Regionally, higher percentages of children were uninsured in the West (13%) and South (12%) than other regions of the country. Furthermore, children on Medicaid were less likely to be in excellent health (41%) than children with private health insurance (62%) or no health insurance (48%) (Dey, Schiller, & Tai, 2004).

In a discussion on the strengths and challenges faced by children of immigrants Shields and Behrman (2004) state that although these children are more likely to be born healthier and live in two parent families, the effects of multiple risk factors work to undermine the child’s healthy development. For instance, challenges faced by children of immigrants include: less educated parents working in low wage work with no benefits (insurance), language barriers, discrimination and racism, poverty, and lack of supports.

Families of children with disability deal with issues surrounding parental stress and relationships that include the conflicting nature of social support, the need for personal and physical space in the home, the effect of the child’s illness, and the variability of parenting styles (Esdaile, 2004; Esdaile & Greenwood, 2003). Furthermore, Esdaile found that the parents of children with disabilities aged from 2-39 years talked about emotional pain, the physical and financial burden in caregiving; and how they took control of their problems.

The cross-cultural literature on health and family practices in the United States using an ecocultural approach to analyze the impact of culture and context of different groups of families yields four key themes (Harry, 2002). First, social groups construct disability differently from one another and from [the] professionals [who serve them]. Second, differential expectations for childhood development and differential interpretations of the etiology and meaning of disabilities exist among families. Third, culture plays a role in influencing parental coping styles. Lastly, each of the foregoing factors affects parental participation in programs. These premises provide a foundational framework for the study of Latino families participating in healthcare services or programs for their children.

Early Intervention Services

Harry (2002) describes the emphasis on cultural issues affecting families of children with disabilities as quite new while viewing families in the context of how parental roles have been conceptualized by professionals over the past three decades. The literature prior to the 1970s was limited by “promotion of a pathological view of families of children with disabilities and total omissions of the impact of differential cultural beliefs and practices on family reactions” (p.

131). In the 1970s the notion of viewing the parent as teacher sought to promote positive parental involvement through behavioral training programs. With the advent of Public Law 99-457 Part H, the Early Intervention Program enacted in 1986, a new phase of the Individuals with Disabilities Act (IDEA) was introduced reflecting an ideal of parent as partner or collaborator with professionals (Dunst, Johanson, Trivette, & Hamby, 1991). This ideal has developed into a vision of family centered practice focusing on the caregiving family as a constant in the child's life and the primary unit for service delivery (Dunst, 2000).

Early intervention practice has evolved from legislative mandates initially targeted to provide services for children with disabilities in the schools to providing services for families of young children aged zero to three with a disability. Legislative changes to the Individuals with Disabilities Act (IDEA) elevated the family component of early intervention services for infants and toddlers, now called Part C. Services including family directed assessment, procedures to address family needs as well as child needs on the Individualized Family Service Plan (IFSP), recognition of the family as part of the early intervention team, and review of the IFSP every 6 months are now mandated (Bailey et al., 2004).

Currently, there is no commonly accepted or agreed upon number of children born with disability in Georgia. Furthermore, disability prevalence data for children aged 0-3 years has not be determined for states or on a national level (Stephanie Moss, personal communication, March 21, 2005). As of 2001, the total number of infants and toddlers between the ages of zero and three years receiving early intervention services in Georgia was 6,978 (Georgia Department of Human Resources, 2003). Of this number, 614 children were identified as Latino on intake interviews for early intervention services; however, data on Latino subgroups such as Mexican were not collected.

Latino families, immigrants, and diverse families have increasingly become the focus of both public policy (Ahmann, 2002; Anderson, Scrimshaw, Fullilove, Fielding, & Normand, 2003) and early intervention research (Bailey et al., 2004; Bruder, 2003). Researchers have found that Latinos living in U.S. are at risk for reduced access to health and other community support services, including services for children with disabilities (Bailey, Skinner, Correa et al., 1999; Flores, Fuentes-Afflick, Barbot, Carter-Pokras et al., 2002; Flores & Vega, 1998).

Related risk factors include: language barriers (Flores et al., 2002; Lillie-Blanton & Hudman, 2001); limited knowledge of systems and services (Sontag & Schacht, 1994); unfamiliarity with acceptable help-seeking behavior (Fadiman, 1997); distrust of the professional service system; and perceived discrimination or differential treatment by service providers (Weech-Maldonado, Morales, Spritzer, Elliot, & Hays, 2001). These issues, in combination with other risk factors, such as low education and poverty, may well contribute to increased need for, yet, reduced access to services (Shields & Behrman, 2004).

Researchers are beginning to address the needs of diverse families (e.g., Bailey, 2004; Flores et al., 2002; Flores & Vega, 1998; Garcia Coll & Magnuson, 1997). Bailey, Skinner, Correa et al. (1999) identified several key areas of need for Latino families: they frequently identified a need for information; the increased risk for lack of access to and underutilization of services; reduced participation in planning and coordinating services; and difficulties participating in parent programs. The authors note the considerable variability of reported needs across families, suggesting the need for further research to identify those particular families especially in need of services; those with reduced access to services; and those with low levels of participation in existing programs.

The United States has a long history of immigration. The issues produced by recent rapidly changing demographics in some regions of the country regarding employment, community relations, education, child care, and health care challenge existing systems, practices and policies (Atiles & Bohon, 2002). Our informed responses to these changes and challenges within our communities are key to preventing problems created by our lack of information and experience with the diversity of our neighbors. It is essential that persons interacting with immigrant families of Mexican origin recognize and develop an awareness of these families' attributes, cultural views, attitudes, beliefs, and contexts. This insight would lead to an appreciation of the factors that influence their choices, actions, and preferred lifestyles.

Problem Statement

Researchers describe studies examining the Latino population that combine Hispanics or Latinos into groups making little or no distinction between the diverse ethnic subgroups classified as Latinos (Heileman, Lee, Stinson, Koshar, & Goss, 2000; Lequericia, 1993). A limited number of studies were found focusing on the family of Mexican origin with parent or child family members who are immigrants and their health (Flores, Fuentes-Afflick, Barbot, & Carter-Pokras, 2002). Flores and Vega (1998) reviewed the extant literature to define specific barriers to health care access for Latino children. They conclude that too little is known about what parents perceive to be major barriers to healthcare, access differences among Latino subpopulations, the roles of language and culture, and the causes of obstacles resulting from the actions of healthcare providers.

There is a need to better understand the experiences of families of Mexican origin as they participate in their child's early intervention program to appropriately focus program development and interventions according to their specific needs (Bailey et al., 2004). Harry

(2002) expands on the question “What interventions are most effective for which socioeconomic groups?” by adding “and for which cultural groups?” (p. 136). Despite considerable literature on the topic, the question still lacks a clear answer; however, she acknowledges that the process of asking the question is itself the answer. She asserts that professionals should ask this question repeatedly in every situation where a previously derived set of answers proves inappropriate. Garcia Coll and Magnuson (1997) also advocate focusing on the family as the source for information on family practices when investigating the developmental trajectory of children from immigrant families.

All families of a child with a disability have specific needs dependent on many factors including how the family views the expression of these needs. Policy makers, administrators, and personnel charged with carrying out service programs according to legislative mandates ultimately influence how services are provided. Furthermore, service delivery is guided by philosophical or theoretical approaches of best practice as well as the service providers’ personal experiences, views, and biases. Families as recipients of early intervention services, have an equally important role in creating effective programs, as determined by their active participation in the program and the resultant outcome for their child (Alvarado, 2004).

Purpose

The purpose of this study is to describe how mothers of Mexican origin who have a young child with a disability and are immigrants of undocumented status participate in their child’s early intervention program. I intend to explore and interpret the perspectives of mothers pertaining to their participatory experience(s) with service providers and aspects of the early intervention program. The objective of this research is to accurately represent families of Mexican origin living within the contexts that include recent immigration under undocumented circumstances and childhood disability. An increased understanding about the participation style(s) and child healthcare preferences particular to Mexican origin immigrant families is an expected outcome of this study.

Research Questions

1. How do mothers of Mexican origin who are undocumented immigrants experience participating in their children's early intervention program?
2. What do mothers of Mexican origin identify as promoting their participation experiences in their child's early intervention program?
3. What actions on the part of service providers do mothers of Mexican origin identify as promoting their participation in their children's early intervention program?
4. What do mothers of Mexican origin identify as barriers to their participation experiences in their children's early intervention program?

Significance

In order for service providers to collaborate with families to develop and implement more effective interventions grounded in philosophical principles of family centered care, service providers must recognize the myriad influences guiding the choices and actions of immigrant families of a child with a disability. An appreciation of individual and contextual factors that influence the family's participation in the early intervention program is fundamental for fostering positive interactions. Ultimately, consideration of these factors in families' lives will help families, program planners, policy makers, and service providers effectively participate in programs and facilitate well-being in families.

Parents of children with disabilities who are members of minority ethnic groups negotiate professional services while relying on ethnic remedies and cultural practices to do what they regard as the best intervention for their child (Danseco, 1997). The collaborative transactions of parents from a different culture are influenced by the dominant culture as well as by their own cultural in-group experiences and beliefs. Service providers are challenged to appreciate the actions of families while being more aware of their own cultural backgrounds, beliefs, and practices. This form of reflective practice aids in bridging gaps created by misunderstanding due to differences in values and expectations between service providers and the families they serve.

Research on the parental beliefs regarding healthcare of families of Mexican origin that inform the provision of effective interventions is greatly needed (Flores et al., 2002). This information will aid in identifying how particular Latino groups construct disability as compared to other groups or the service providers with whom they work. It will clarify differential expectations for childhood development and interpretations of the etiology and meaning of disability. Findings from the proposed research study will also shed light on the role of culture in parental coping styles as well as the effects of contextual factors on parental participation in early intervention programs (Harry, 2002).

Finally, identifying specific areas where parents' and professionals' beliefs are convergent, divergent, and in conflict, is an initial step toward clarifying parent-professional interactions. Ways to expand areas of convergence; ways to respect areas of divergence; and ways to deal with areas of conflict can then be explored. Investigating the interface of culture, parental beliefs, professional beliefs, and childhood disability is necessary to inform what constitutes effective intervention among diverse cultural groups (Danseco, 1997).

Definitions

For the purposes of this study, I will use the following terms and definitions:

Blended households: Households of Mexican origin in which family members hold varying citizenship/immigration statuses. These include legal immigrants to the United States or someone with a work permit, someone who has received amnesty or is a naturalized citizen; children born in the United States to immigrant parents; and immigrants residing in the U.S. illegally or undocumented.

Early Intervention (EI): The provision of support and resources to families of young children between the ages 0-3 years by professionals who act as agents for addressing family concerns and desired developmental outcomes and who directly and indirectly influence child, parent, and family functioning (Dunst, 2000).

Family-centered care: beliefs and practices that define particular ways of working with families that are consumer driven and competency enhancing (Dunst, Johanson, Trivette, and Hamby, 1991)

Individuals with Disabilities Education Act (IDEA) Part 303 Early Intervention Program for Infants and Toddlers with Disabilities (Part C of the IDEA): To provide assistance to States for the purpose of: maintaining an interagency system of Early Intervention (EI) services; enhance and expand the States' capacity to provide quality EI services; and identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low income, inner-city and rural populations.

Immigrant (2 types): Legal immigrant is someone who has a *"green card"* or work permit, a term interchangeable with *permanent resident alien*. Refugees who seek asylum are also admitted legally due to documented concerns of persecution in their home country (http://uscis.gov/graphics/glossary.htm, accessed July 25, 2005). The terms “Unauthorized immigrant” and the more commonly used *Undocumented immigrant* refers to illegal immigration and includes all foreigners subject to apprehension and removal by the Immigration and Naturalization Service (INS) (Garcia y Griego, 2002) now called U. S. Citizenship and Immigration Services (USCIS) under the Department of Homeland Security (http://uscis.gov/graphics/aboutus/index.htm).

Latino/Latina or *Hispanic*: Latino is generally used to describe U.S. residents of Latin American origin regardless of their native language. Hispanic generally refers to people whose native language is Spanish. In the U.S. most Hispanics are Latino and vice-versa, consequently the two terms are used interchangeably (Bachtel, Bohon, & Atiles, 2004). Latino/Latina will be used instead of Hispanic to identify any person or group of Mexican origin.

Mexican: refers to any person of Mexican origin, born in Mexico, and who identifies themselves as Mexican.

Mexican American: The term *Mexican American* will be used for persons born in the United States with parents of Mexican origin and are U.S. citizens or persons of Mexican origin living in the United States as a legal resident.

Participation: Participatory elements of effective family centered help-giving include *family choice and action based on choice*, as well as professional or formal help giver responsiveness to and support for family decisions (Dunst, 2000, p. 100).

CHAPTER 2

REVIEW OF THE LITERATURE

Overview of the Literature

The literature reviewed for this research includes national and international journals on topics and search terms such as: health, public health, community health and human services; disability, rehabilitation, early childhood and early intervention; psychology, counseling and behavior; human development, child development; family, community health, medicine and relations; welfare, social work, nursing, occupational therapy; language, education and special education; medical and social qualitative research; human ecology; Hispanic, Latino, ethnicity, and minorities. Information was also obtained from local and regional periodicals as well as public information sources and websites.

The Latino Consortium of the American Academy of Pediatrics Center for Child Health Research identified the most important priorities and unanswered questions in Latino child health (Flores et al., 2002). Key issues include a lack of validated research instruments, frequent unjustified exclusion of Latinos from studies, and failure to analyze data from specific Latino subgroups (Zambrana & Logie, 2000). Even when Latinos are represented in study samples, their numbers have tended to be small with Latinos lumped together with no distinction made between heritage or country of origin (Flores & Vega, 1998; Hernandez, 2004; Lequerica, 1993).

Flores et al. (2002) found that culture and language have an effect on Latino children's health due to limited cultural competency training of health care professionals and demand for culturally linguistic appropriate care. These researchers also found that Latino parents reported language barriers as the single greatest barrier to health care access; specifically lack of Spanish-speaking health care staff and inadequate interpreter services.

Due to IDEA mandates, health care professionals are struggling to effectively meet the needs of individuals from diverse racial, ethnic, cultural, and linguistic groups through the provision of programs demonstrating cultural and linguistic competence (Ahmann, 2002; Anderson et al., 2003; Ayonrinde, 2003). These challenges are compounded by the unique needs of families that may not fit aggregate profiles of families based on past research or classification systems. In other words, families from diverse groups such as Latinos and Asians have very different needs according to their contextual circumstances.

Immigration Changing the Social Landscape

There is increased attention by researchers in all areas of social and related sciences to find ways to improve social and cultural understanding of ethnic groups and immigrants (Atiles & Bohon, 2002; Harry, 2002). Recent demographic shifts reflect a society that is blending to the extent that simple categorization of households by race, citizenship, or immigration status is no longer a valid measure for describing the makeup of the U.S. population (Garcia y Griego, 2002). Consequently, U.S. census data (2002) reflect changes in categorizing individuals and families according to race and ethnicity. Because race and Hispanic origin are considered two different concepts, Hispanics may choose to classify themselves as being of any race (Bachtel, Bohon, & Atiles, 2004). This classification system is one indicator of the need to closely examine the attributes of subgroups of Latino families before stereotyping them as one monolithic group. Immigrants of Mexican origin might live in blended households. Blended households can include family members who are United States-born citizens, Mexican-born or “foreign-born Mexican nationals” who are legal residents of the United States, or persons who are living as illegal residents of undocumented status.

The ethnic/racial minority populations in the U.S. have been increasing at a far greater rate than the white non-Hispanic native population. The numerical percent change in the Hispanic population in the U. S. between 1990 and 2000 was 57.9 percent. In 1990 the total Hispanic population in the U. S. numbered 22.4 million. This number increased to 35.3 million in 2000 (Bachtel, Bohon, & Atiles, 2004).

Growth of the Hispanic population has resulted equally from immigration and fertility (Padilla & Glick, 2000; Trevino, 1999). Overall, it is difficult to specifically define or categorize the Mexican origin immigrant population of undocumented status due a significant undercount in their numbers (Atiles & Bohon, 2002; O’Hare, 2001). In the year 2000 there were between 8 and 9 million Mexican immigrants residing in the U.S. including both legal and unauthorized (undocumented) immigrants (Garcia y Griego, 2002). Unfortunately, children in these families may be undercounted (O’Hare, 2001).

In the United States, immigrants of Mexican origin have been identified as being younger and undereducated when compared to other immigrants as reported by the U.S. Census Bureau (Arroyo, 1997). They are also recognized as being part of a large unskilled labor force (Atiles & Bohon, 2002), although this has been contradicted by reports that persons with higher education and skills are leaving Mexico due to low salaries and lack of opportunities in their home country (Ferris, 2001). Still, issues concerning how immigrants are perceived by their own and other cultural groups are influenced by many factors that ultimately center on how groups from different backgrounds interact. In order to improve social and cultural understanding of ethnic groups and immigrants, researchers have focused on matters such as identity and acculturation.

Identity

Flores Nieman, Romero, Arredondo, and Rodrigues (1999) contend that the examination of people's social constructions of their ethnic identities is critical for understanding their social realities. These researchers studied the social construction of ethnic identity of predominantly low-acculturated, first-and second-generation Mexicans living in the U.S. The participants of Mexican descent were categorized as first generation – not born in the U.S., 78% (Mexican); second generation – born in the U.S., 18%; third and fourth generation – parents and grandparents born in the U.S., 4% (Mexican American). For this study, focus groups (24 females, 25 males, mean age 31 years (15-57) talked about what it meant to be members of their ethnic groups.

Flores Neimann et al. (1999) based their study on Tajfel and Turner's (1986) social identity theory which conceptualized that identities are built on how individuals (a) perceive themselves to be members of the same social category, (b) share some emotional involvement, and (c) achieve some social consensus about the evaluation of their group. Tajfel and Turner's theory also included the proposition that people evaluate their own group based on their perception of how their own group compares to out-groups. In-group-outgroup comparison of this type implies the importance of appreciating how individuals understand and identify with their social groups. Flores Niemann et al. related Tajfel's notion of self-identity with Mainous (1989) who conceived of the self concept as multiple role identities through self-definitions that shape self-concept by providing expectations for role behavior consistent with a given identity.

An understanding of how people arrive at their ethnic self-images requires some knowledge of their ethnic group identities. To this end, Flores Niemann et al. (1999) relied on the work of Garcia (1982) who identified this perception as ethnic consciousness that entails socially constructing an ethnic identity. Finally, ethnic consciousness makes salient a group’s cultural model and Flores Niemann et al. utilized Ogbu’s (1990) notion that the nature of a group’s cultural model can be socially constructed from what group members say as well as from what they do.

The participants’ responses in focus groups were quantified to compare constructs within each category according to what respondents considered most important to their identity as a Mexican. The participant’s responses indicated conflict between first and second generation Mexicans and Mexican Americans and African Americans. The aspect of ethnic identity that emerged in this research regarding conflict between Mexican immigrants and Mexican Americans warrants further research according to Flores Niemann et al. (1999) Mexican respondents expressed pain at discrimination “from our own kind” (p. 57). The researchers also explained that their findings might be a function of contextual features of their geographic area where the Mexican immigrant population exceeds the Latino citizen population. Also noteworthy were the researchers’ personal observations that Mexican Americans often expressed the belief that Mexican immigrants were keeping them from advancing and often blamed negative stereotypes on Mexican immigrants. Other researchers have noted similar findings (e.g., Alvarado, 2004; Suro, Brodie, & de la Garza, 2002). These findings point to the salience of identity and self perceived differences between persons assumed to be in the same social category.

Differences within ethnic groups might also be attributed to acculturation. The notion of acculturation is often used to understand the process through which immigrants respond or adapt to the mainstream societies of settlement in which they find themselves (Berry, 1997, 2001; Berry, Poortinga, Segall, & Dasen, 2002). When one considers that an individual’s ethnic identity is a personal construction as well as a social construction, it becomes imperative to investigate how groups with differing backgrounds interact. The study of immigrants to the United States has evolved within acculturation research in several spheres including language, culture, and healthcare.

Acculturation

Acculturation is a complex process wrought with matters concerning interaction between individuals or groups with differing backgrounds. The relationship between the process of acculturation and Latino issues such as language (Marin & Gamba, 1996); biculturalism and changes in value systems (Smart & Smart, 1993); culturally based norms and behavior (Arcia, Skinner, Bailey, & Correa, 2001); health (Blacher, Lopez, Shapiro, & Fusco, 1997; Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997) and health decision-making (Anderson, Wood, & Sherbourne, 1997) and healthcare (Flores et al., 2002) is confounded by the complexity of acculturation itself. Researchers also advocate the use of methodologies that address these complexities and explore the emic perspective through qualitative, longitudinal, and cross-sectional research (Bond, Jones, Cason, Campbell, & Hall, 2002).

Marin and Gamba (1996) argue that acculturation is a long-term, fluid process in which individuals simultaneously move along at least two cultural dimensions. In this process, individuals learn and/or modify certain aspects of the new culture and of their culture of origin. Language and acculturation are associated using a scale developed by Marin and Gamba called the Bidimensional Short Acculturation Scale for Hispanics (BAS). This scale is based on their hypothesis of acculturative changes that Hispanics experience.

The BAS and other acculturation scales share the limitation of being unable to measure acculturation at a more basic level in terms of changes in individuals’ values and norms. Marin and Gamba (1996) attribute this limitation to the lack of culturally appropriate emic and etic instruments to measure basic Hispanic values. Furthermore, they advocate a proper understanding of acculturation and that future research use longitudinal designs and qualitative as well as quantitative data to investigate the reasons for the strong relationship between language-related questions and measures of acculturation.

A basic premise of much of the health research conducted with immigrant groups is that culturally based behaviors change over time as a result of acculturation due to ongoing interaction with the mainstream United States culture. Models of acculturation; however, have not taken into account how group-specific characteristics and varying social and political contexts faced by a given immigrant group may impact the acculturation process (Arcia, Skinner, Bailey, & Correa, 2001).

Arcia et al. studied 150 families examining the inter-relationship of acculturation indicators such as language use and proficiency, current environment, ethnic identity, and length of residence in the U.S. between two Latino groups-Mexican and Puerto Rican. Findings indicated that increased years of residence in the United States had the predictable impact of increased competence in English language proficiency and use of the English language for both groups. Possible reasons given for these disparities are the use of English language instruction in Puerto Rican schools and the freedom Puerto Ricans have in traveling from their country to the U.S. mainland. Duration of residence in the U. S. was associated with the cultural orientation of current and desired environments (e.g., friends, food, music) and with ethnic identity among Mexicans. This was not the case among Puerto Ricans; however both groups desired Latino “service providers”. Length of residence or generation status was also found to function differently for Mexican Americans than for Puerto Ricans. This finding was purported due to the Puerto Ricans being more bicultural from the outset than Mexicans.

Mothers of both groups used less English language, expressed less perceived social marginalization than fathers, and of those with very young children, most were not employed outside the home. Arcia et al. speculated that gender, or the more proximal variable-labor force participation, as the reason fathers spoke more English and reported experiencing more discrimination. The respondents in this study understood discrimination as resulting from being visibly identified as Latino not from behaving differently. Arcia et al. advocate for the use of more complex models to study acculturation focusing on perceived acceptance, gender, and country of origin.

Acculturation has also been associated with the physical and psychological well being of immigrants; however, Berry (1997) purported that cross cultural research findings regarding the health of immigrants are inconclusive. Inconsistencies surround time at which the health status of the immigrant is measured e.g. before or after migration. Unfamiliarity with health systems and language may also be confounding factors.

Anderson, Wood, and Sherbourne (1997) investigated the incidence of childhood immunizations and maternal acculturation in Latino families from Los Angeles. In their sample of 688 mothers and their children, 76% of the mothers were born in Mexico and were predominantly Spanish speaking (75%). Additionally, more than half of the maternal sample scored 1 on an acculturation scale ranging from 1 to 5, indicating less acculturation. Most mothers in this study were currently married or living with a partner. It is noteworthy that few women reported having close family networks. Most women reported two or fewer close relatives with almost 40% of the women reporting no close friends. Furthermore, findings indicated that the less acculturated mothers had better immunized children suggesting that being less acculturated is tied to better child health.

Health outcomes were the focus of a study by Flores et al. (2002). Although these researchers discovered that excellent health outcomes in immigrants deteriorate with greater acculturation and each successive generation, they acknowledged researchers share little understanding of what factors are responsible for the "healthy immigrant" effect. Another outcome of this study indicated that language barriers cited by Latino parents were the single greatest barriers to health care access. The parents specifically identified lack of Spanish-speaking health care staff and inadequate interpreter services. Flores et al. also recommended that researchers abandon the traditional deficit view of Latino culture that focuses on problems and its impact on health and adopt a more balanced perspective that emphasizes appreciation and understanding of the salutary components of Latino culture.

In a study focusing on acculturation of Hispanics and how they make decisions regarding their health, Bond et al. (2002) noted that health protective factors erode among Hispanics who migrate to the United States. The objective of their study was to identify health promoting lifestyles and how they differ with increased acculturation to the mainstream culture in the U.S. They noted that the literature suggests that less acculturated Hispanic women have healthier outcomes than women who have become acculturated to life in U.S. Their research also indicated that poorer health outcomes are associated with the moderately acculturated group when compared to groups with a strong association to either Mexican or American cultures.

Blacher, Shapiro et al. (1997) studied the incidence of depression in Latino mothers with and without a child with mental retardation. More than half of the mothers (66.9%) were born in Mexico. They found that stressors for all mothers included low socioeconomic status, decreased socialization e.g. lack of interaction with friends and/or spousal abandonment, and unemployment. The depressed mothers did not differ from the non depressed sample on forms of media used daily; coping styles; strength of religion; positive perceptions of their child; or demographic variables of income, education, age, language use, employment, or country of origin. Predictors of depression were identified as having more family problems, poor health, fewer interactions with English-speaking persons e.g. teachers or case managers in their daily lives, and more negative feelings about parenting a child with mental retardation. Blacher et al. recommended that researchers and health professionals should collaborate to improve prediction of depression in the most vulnerable mothers. They also suggested work with Latino families to access services to meet mothers' own health needs, programs to reduce stress directly or indirectly related to a child with mental retardation, and less isolation from family and personal social networks may be protective measures against depression

The relationship between the acculturation process and Latino issues such as identity, length of residency in the U.S., health, and healthcare choices is confounded by the complexity of acculturation itself. Complex models that address specific relationships between acculturation and identified Latino concerns using appropriate emic instruments with specific Latino subgroups are lacking (Flores & Vega, 1998; Hernandez, 2004). This situation undermines research supported by sound etic foundations based on a balanced perspective and understanding of Latino subgroups. Studies that address these complexities using qualitative methodologies to permit the development of the Latino's (emic) perspective and cross sectional sampling from participants of varying acculturation levels are also advocated by researchers (Bond, et al. 2002).

Latino Families and Healthcare

Many barriers have been identified regarding the Latino family’s access to health care, satisfaction with services, communication with service providers as well as support and resources for families (Bailey, Skinner, Correa et al., 1999; Weech-Maldonado et al., 2001). These barriers are attributed to language, social status, poverty, acculturation, lack of knowledge regarding available services; cultural practices, and lack of culturally competent personnel (Atiles & Bohon, 2002; Flores et al., 2002; Flores & Vega, 1998; Lequerica, 1993; Miranda, Estrada, Firpo-Jimenez, 2000; Miranda & Matheny, 2000).

The family with undocumented, immigrant members faces more barriers having to do with legal residency and misconceptions regarding their heritage, beliefs, and customs that encourage discrimination (Alvarado & Stoneman, 2004; Suro et al., 2002). Weech-Maldonado et al. (2001) studied the effect of managed care on racial/ethnic minorities finding that assessments of care received show minorities are less satisfied with health care than whites. Furthermore, these authors found that Hispanics are twice as likely as other groups to report experiencing long waits and to perceive that their healthcare provider failed to listen and provide information.

Non-English speakers are particularly dissatisfied with overall care, courtesy and respect, as well as discharge instructions (Weech-Maldonado et al., 2001). As previously mentioned, language is identified as a barrier to care especially for Spanish-speaking Latinos. In a review of the health care of Latino children, Latino parents cited language barriers as the single greatest barrier to health care access. Lack of Spanish-speaking health care staff and inadequate interpreter services were specifically identified as a barrier (Flores et al., 2002).

Individuals with Disabilities Education Act (IDEA) Mandates

Dreger and Tremback (2002) recognized that language barriers complicate health teaching. The authors addressed optimizing patient health outcomes through the treatment of literacy and language barriers for health teaching. This included understanding written information received during health care visits such as using food exchange lists, reading a thermometer, complying with childhood immunization schedules, and medication administration.

Due to the growth of the Spanish speaking population in the U.S., the authors focused on the rapidly growing Hispanic population, although they acknowledged similar statistics for the Asian population. Hispanics were reported to be one of the adult minority groups with a disproportionate representation of low literacy skills; however, Dreger and Tremback did not break out subgroups of Latinos. Additionally, the authors did not distinguish whether they were referring to the English or Spanish literacy skills of Hispanics.

Dreger and Trembeck (2002) developed several steps for nurses to ensure effective communication that commenced with understanding standards and regulations guiding health care professions and facilities. The authors also cited the Department of Health and Human Services, Office for Civil rights regulations on the rights of patients with language barriers (LB). Title VI of the Civil Rights Act of 1964 prohibits discrimination by all medical providers on the basis of national origin for all patients who receive Medicaid, Medicare Part A, or other government funds. If a patient does not speak English well, health care facilities are required by law to use a bilingual staff member or an interpreter so the patient can explain the medical problem, ask questions, and understand treatment just as well as patients who speak English as their primary language. Furthermore, care may not be denied or unduly delayed because of a patient's need for an interpreter. Federal guidelines are also available regarding maintaining patient confidentiality; ways to provide interpreter services, assessing an interpreter’s qualifications and competencies and specific interventions for patients with limited English proficiency.

Three other steps outlined by Dreger and Trembeck incorporate ways to accomplish each task. These included: providing interpreter services, using teaching and communication theory in practice, and documentation of assessments and interventions. Finally, the authors emphasized that caring, knowledge, and imagination are often the only tools a healthcare provider has available for teaching. That said, they asserted that effective communication is one way to advocate for patients by empowering them with clear explanations regarding their condition and care.

It is difficult to measure if heathcare facilities follow the aforementioned recommendations. Anderson et al. (2003) explain that presently there are too few comparative studies on the effectiveness of interventions to improve cultural competence in healthcare settings. *Healthy People 2010* (U. S. Department of Health and Human Services, 2000) objectives relate to culturally competent care interventions that address the overarching goal of increasing quality and years of healthy life and eliminating health disparities.

Cultural Competence

The cultural and linguistic competence of health care practitioners is a concern for health care programs struggling with the challenge to effectively meet the needs of individuals from different racial, ethnic, culture, and linguistic groups (Anderson et al., 2003). The National Center for Cultural Competence has identified six prominent reasons for promoting cultural competence. They include (1) to respond to current and projected demographic changes in the

United States; (2) to eliminate long standing disparities in the health status of people with diverse racial, ethnic, and cultural backgrounds; (3) to improve the quality of services and health outcomes; (4) to meet legislative, regulatory, and accreditation mandates; (5) to gain a competitive edge in the market place; and (6) to decrease the likelihood of liability/malpractice claims (Ahmann, 2002).

When it amended the IDEA, Part H of Public Law 109 –119, Congress recognized the high incidence of disability and developmental delay among children from racial minority groups. Legislation stressed the importance of providing early intervention services in a culturally competent manner. Health care professionals are challenged to develop culturally competent practice skills in order to work effectively with families of young children (Hanft, 2001; Hanson & Lynch, 1990; Rounds, Weil, & Kirk Bishop, 1994).

Lynch and Hanson (1992) discussed essential components of training in providing early intervention personnel with the objective of improving interactions with families whose culture differs from one's own. On a primary level, values clarification, culture specific knowledge, application of self-knowledge, and culture-specific information are recommended to practice at the interpersonal level. Secondarily, information is used at the systems and organizational level to review program practices to determine cross-cultural appropriateness and effectiveness.

Legislation such as the Individuals with Disabilities Act (IDEA) mandates practices such as providing information in a person's native language (Hanson & Lynch, 1990). Nonetheless, there is substantial variation in awareness, use and satisfaction with health care services among diverse parents. Many factors contribute to this variation. Characteristics of the child, family, and community can all have an effect. Additionally, as previously mentioned, parents may experience difficulties due to language barriers and lack of familiarity with cultural variations in values, goals, and behaviors.

The literature consistently reports that parents are generally satisfied with early intervention programs; however, there are few studies addressing early intervention services, program efficacy and families in the context of ethnicity. Limited research has been conducted in regard to Latino families' awareness and use of special and related services, a matter that is particularly important during the early childhood years when disabilities are likely to be identified (Bailey, Jr., Skinner, Rodriguez, Gut, & Correa, 1999).

Early Intervention

Early intervention (EI) programs can be conceptualized as an entry point for services provided to young children between the ages of 0 and 3 years and their families. Dunst (2000) defined early intervention as the “provision of support (and resources) to families of young children from members of informal and formal social support networks that impact both directly and indirectly upon parent, family and child functioning” (p. 95).

Early intervention services focus on the child with a diagnosed disability or the child at risk for experiencing significant delays in their development and their family’s related needs. Services are coordinated to provide evaluation; determine the scope of services needed; provide intervention; measure progress, and provide a mechanism for transition to other services as the child develops. Early intervention practice in the places where children live, learn, and play are part of the child’s natural environment. More often, the home is where EI services are provided (Campbell, 2000).

Several influences have led to the incorporation of the concept of family centered care in early intervention. According to Harry (2002), the passage of Public Law 99-457 in 1986 introduced the current phase in early intervention that reflects an ideal of the parent as partner or collaborator with professionals. This evolving ideal focuses on recognizing the beliefs and practices of diverse families as crucial for family centered practice. Bruder (2000) challenged service providers to move beyond the rhetoric of family centered care by providing early intervention services and supports that are “respectful, evidence-based, and appropriate to each family’s situation” (p. 112).

Aspects of family centered practice are depicted in a model proposed by Dunst (2000) (Figure 1) and derived from family systems theory. Family –centered practices in the early intervention model emphasize social systems and environmental variables associated with child development enhancing and family strengthening consequences. The model conceptualizes Early Intervention as including children’s learning opportunities (intentionally planned or naturally occurring), parenting supports, and family/community supports provided in a family centered manner. Learning opportunites are interesting, engaging, and competency producing. Parent supports include information, advice, and guidance. Lastly, family/community supports include any number of intrafamily, informal, community and formal resources needed by parents.

Family-centered practices support and strengthen family functioning and promote competence for acquiring desired resources and outcomes. In other words, early intervention practice is based on the intersecting components of the model that pertain to *what is done* and *how interventions are done*. Key elements within the model overlap at intersections to highlight the use of parenting styles and instructional practices, family and community activity settings, and participatory opportunites to promote child competence and positively influence parenting attitudes and behaviors. Dunst (2000) advocates the use of this model for guiding early intervention research investigating different environmental factors that function as interventions.

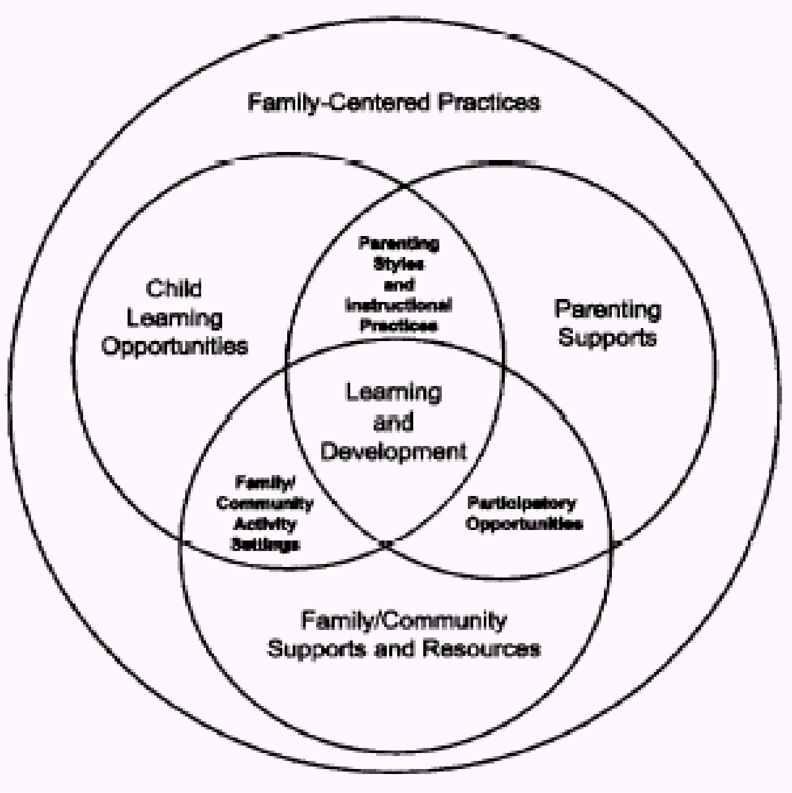

Figure 1. *From "Revisiting Rethinking Early Intervention" by C. J. Dunst, 2000, Topics in Early Childhood Special Education, 20, p. 101 by Pro-ed. Reprinted with permission.*

Theoretical Foundations of Early Intervention

Early intervention services are based on family systems and ecological perspectives (Guralnick, 2000; Hanson & Bruder, 2001; Mahoney & Bella, 1998; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993). Contemporary practice in early intervention involves the widely accepted family focused Model of Early Intervention and Family Supports. The family focused model is based on a social systems framework for understanding the influences of social support and other factors on child, parent, and family functioning (Dunst, 2000). Other names for this approach include family friendly, family driven, family directed, and family-centered care or practice (McWilliam, Tocci, & Harbin, 1998). Central to this framework are the concepts of collaboration with parents and the support of parents (Mahoney & Bella, 1998). Furthermore, the integration of theoretical formulations and empirical evidence from social network theory, ecological psychology, help seeking theory, and adaptation theory contributes to the development of the current EI model as previously described.

Bruder (2000) advocated for a participatory approach that presumes knowledge is socially constructed, contextually grounded, and experience based. These influences support the premise of family centered care as being focused on ecocultural theory. The ecocultural perspective recognizes the expertise of families as most knowledgeable about their local contexts and conditions. Families are also considered most optimally situated to design, implement, and evaluate solutions most appropriate to their situations. According to Bailey, Skinner, Correa, et al. (1999) the child with a disability is part of an ecology that includes parents, siblings, extended family members, friends, neighbors, and community agencies.

The theoretical foundations of early intervention practice center on the family and the child’s environment. Several researchers recognize the need to examine the processes involved in family focused early intervention and family outcomes (Hinojosa, Bedell, Bucholz, Charles, Shigaki, & Bicchieri, 2001; McBride, Brotherson, Joanning, Whidding, & Demmitt, 1993; Spiker, Hebbeler, Wagner, Cameto, & McKenna, 2000). In light of globalization and rapid cultural change, other researchers advocate studies that address within culture studies and measures of cultural process (Garcia Coll, Akerman, & Cicchetti, 2000). These perspectives are key to examining the influence of family centered early intervention practice and culture on child and family outcomes.

Latino Families Participating in Their Child’s Early Intervention Program

Latino families who receive early intervention services share common concerns with all families regarding affordability, availability, and information. These families also share within-group variation with respect to sociocultural and migrational histories, social class, education, occupation, familiarity with majority culture, and place of origin (Bailey, Skinner, Correa et al., 1999). Each family’s unique circumstances influence related risk factors such as language barriers; limited knowledge of systems and services; unfamiliarity with acceptable help-seeking behavior; possible distrust of the professional service system; and perceived discrimination by service providers. Low education and poverty, may also contribute to increased need and reduced access to services.

Bailey, Skinner, Rodriguez et al. (1999) asserted that limited research has been conducted with regard to Latino families' awareness and use of special and related services. These matters are particularly important during the early childhood years when disabilities are likely to be identified. Regarding satisfaction with early intervention services, these authors hypothesized that it is not the family characteristics alone that predict dissatisfaction with services. Dissatisfaction is more likely to occur when EI program characteristics do not match the needs of the family, as in the case where a Spanish-speaking family does not have access to materials in Spanish or a translator, or when service providers are not perceived to be accepting or willing to be helpful.

Family focused early intervention emphasizes collaboration and partnership between families and service providers. The concept of participation is defined in terms of how a family makes choices. The family’s actions based on these choices are part of an effective family centered service program. Consequently, the family’s participatory actions are seen as facilitated by responsive service providers who support family decisions (Dunst, 2000).

Dunst, Trivette, and Snyder (2000) found no operational definition of collaboration or partnership in their review of the literature on parent and professional relationships. These authors asserted that a relationship exists between partnerships and effective help-giving and empowerment of families by service providers. Partnerships are defined as enabling people by creating opportunities to become competent in areas of life that partners deem important. Thus, in the case of providing early invention services, partnerships would be expected to strengthen the functioning of family members and service providers as a result of collaborative experiences.

Gaps in the Literature

Harry (2002) addresses the trends and issues in providing health care services for culturally diverse families noting that the question of effective interventions for certain cultural groups still lacks a clear answer. Her appraisal of the question “What constitutes appropriate intervention for particular families?” as the probable answer captures its complexity. That is, if we repeatedly ask this question in every situation where a previously derived set of answers proves inappropriate, we may be best able to address the specific needs of the families we serve while also improving our cultural competence.

Researchers (e.g., Flores & Vega, 1998; Flores et al., 2002; Hernandez, 2004) call for the use of methodologies that address the unique yet complex circumstances of immigrant families using emic perspectives through qualitative research (Bond et al., 2002). In order to investigate the participation of families of Mexican origin who are undocumented in their child's early intervention program it is necessary to focus on their perspectives regarding their participation in an early intervention program.

Preliminary Studies

Pilot Study

A pilot study (Alvarado, 2004) of two mothers of children with special needs was conducted to describe how mothers of Mexican origin who are immigrants living under undocumented status participate in their child's early intervention program. In-depth interviews, examination of archival data, and participant observation were conducted to provide data for this study. A phenomenological analytical approach and qualitative data analysis (QDA) software were employed to examine salient details particular to each family's experience.

The findings of the pilot study indicated that these families shared similar experiences and interactions as any family who has a child with a disabling condition and participate in their child's early intervention program. Four core themes emerged concerning aspects of the mother and family participating in the early intervention service program. These included the *mother acting as an active participant*, her *understanding of her child*, *mother's communication with service providers*, and the mothers' description of *family life affected by their undocumented status*.

This preliminary examination allowed an appreciation of how families of Mexican origin described their participation in their child's early intervention program while being influenced by the circumstances related to their undocumented status. The knowledge gained from this study provided healthcare professionals with information on how the participants use their own experiences, information, and judgment to understand their child. Findings also illustrated how immigrant mothers of young children with disability describe how others perceive them, their child, or situation. Examples of communication with service providers and others as well as examples of communication within family decision-making were employed to illustrate those perceptions. This research was published in the American Journal of Occupational Therapy, September/October, 2004 (Alvarado, 2004).

Two other immigrant mothers of Mexican origin were also recruited and interviewed for a follow up study. One woman was an undocumented immigrant and the other emigrated from Mexico after her father obtained U. S. amnesty for his family; however, her husband was an undocumented immigrant. A core theme from the preliminary study concerning family life as immigrants was selected for examination as an experience particular to the study participants.

Narrative inquiry was chosen to explore the participants' descriptions of family life as immigrants. This method commits the researcher to *describe* the phenomenon by telling a story rather than *explaining* it. The subject of the research is not the object of observation, but becomes the narrator or the storyteller (Kramp, 2004). Narrative analysis, one of two types of narrative inquiry was used in the retelling of the participant's life stories regarding family life as immigrants. Narrative analysis involves constructing a story in which the data is integrated rather than separated.

The participant's stories were then probed using analysis of narratives. This other form of narrative inquiry is used to separate data in order to discover themes (Kramp, 2004). Four themes emerged from the women's stories about their family life as immigrants. The themes illustrated examples of *family ties* that played an important part in their immigration; the establishment and management of their lives in the United States; circumstances about their *border crossing*, and the *services accessed for family members*. These stories of the four immigrant women were then compiled and published as a booklet (Alvarado & Stoneman, 2004) for service providers and the lay community to provide a glimpse into these families' immigration experiences and lives in the United States.

In order to focus on the phenomenon of *participation in an early intervention program* it was necessary to specifically ask about this experience. Conducting the preliminary pilot study and subjecting the pilot data and the additional data from newly recruited participants to narrative inquiry led to reframing of the interview questions for this study. The interview questions were also revised to capture related or influential aspects of the family's life as part of their description of how they participate in their child's early intervention program.

Additionally, examination of the transcripts of initial interviews with participants from the pilot study using conversational analysis was instrumental in recognizing methodological flaws in my interviewing technique. This led to the redesign of interview questions focusing on specific aspects of participation in an early intervention program and the pacing and phrasing of interview questions. Other qualitative methods used with the data included critical analysis of an early intervention team in which I observed the evaluation of a child, the subsequent team meeting to determine the child's eligibility for entry into the early intervention program, and consultation with the child's mother regarding the evaluation results.

The pilot study, the narrative inquiry, and use of other qualitative methods to explore data and generate themes yielded many insights that have supported the veracity of this inquiry.

Conducting this preliminary research also helped refine the research questions, study design, and methodology for further research.

Chapter Summary

There is increased attention by researchers in all areas of social and related sciences to find ways to improve social and cultural understanding of immigrants (Atiles & Bohon, 2002; Harry, 2002). Due to rapid demographic changes and the diversity of the Latino population (Martin & Midgley, 2003), research targeting specific ethnic subgroups is relevant to understanding attributes and influences particular to groups. For instance, immigrants of Mexican origin may live in the U. S. as members of blended households that include family members who are U. S. born citizens, Mexican born or foreign-born Mexican nationals who are legal residents of the U. S. or persons living as illegal residents in the U. S. under undocumented status (Garcia y Griego, 2002).

The study of persons who are immigrants encompasses myriad factors; however, the concepts of identity and acculturation are prevalent among researchers. The study of acculturation and Latino issues includes language (Marin & Gamba, 1996); biculturalism and value systems (Smart & Smart, 1993); culturally based norms and behavior (Arcia et al., 2001); health (Blacher, Lopez et al., 1997; Blacher, Shapiro et al., 1997); health decision-making (Anderson, Wood, & Sherbourne, 1997) and healthcare (Flores, 2003). All in all, researchers advocate the use of methodologies that address complex interactions between groups and explore the emic perspective through qualitative, longitudinal, and cross-sectional research (Bond, et al. 2002).

The demographic diversity of the population in the U.S. has challenged existing systems and practices (Atiles & Bohon, 2002). Legislation now mandates cultural and linguistic competence from systems and organizations that are federally funded (e.g., Public Law 99-142; Title VI of the Civil Rights Act of 1964). In spite of these mandates, researchers have identified many barriers to healthcare access for Latino families. Barriers include access to care, satisfaction with services, communication with service providers as well as support and resources for families (Bailey, Skinner, Correa et al., 1999; Weech-Maldonado et al., 2001).

Effective access to healthcare is also limited by language and literacy barriers, social status, poverty, acculturation, lack of knowledge regarding available services; cultural practices, and lack of culturally competent personnel (Atiles & Bohon, 2002; Dreger & Tremback, 2002; Fadiman, 1997; Flores et al., 2002; Flores & Vega 1998; Lequerica, 1993; Miranda & Matheny, 2000; Shields & Behrman, 2004). Key issues in Latino child health include a lack of validated research instruments, frequent unjustified exclusion of Latinos from studies, and failure to analyze data from vital Latino subgroups (Flores et al., 2002).

My area of interest involves the participation of families of Mexican origin who are undocumented residents of the U.S. in early intervention services for their child with a disability. Research with particular subgroups of Latinos becomes imperative when studying participation in an early intervention program based on the philosophy of family-centered care. This philosophy emphasizes acknowledging and using the family’s strengths, competency to care for their child; and ability to seek and use community resources. Understanding of how families of Mexican origin who are living in contexts that include undocumented immigration status and disability may aid service providers in planning and carrying out intervention programs that facilitate active participation on the part of these families.

CHAPTER 3

METHODOLOGY

Methods

The objective of this research was to investigate how mothers of Mexican origin living under undocumented immigrant status in the United States participate in an early intervention program. I intended to explore and interpret mothers' perspectives on how they and their family experience participating in their children's early intervention program. In this chapter I describe the design of the study and the methods used to conduct this research including sampling, data collection; validity and reliability strategies; data analysis; time line and budget. Additionally, the Early Intervention (EI) program, the Individualized Family Service Plan that serves to document EI services, and the transportation system available to Medicaid recipients are described based on 63nterviews with EI personnel and an early childhood expert. Finally, my researcher biases and assumptions are described in a subjectivity statement.

Design of the Study

Schwandt (2001) described a quality as an inherent or phenomenal property or essential characteristic of some experience. Qualitative research is broadly defined as a research activity aiming at understanding the meaning of human action. The design of this study involved qualitative analysis of the phenomenon of a mother's participation in her child's Early Intervention Program. This multiple case study research was exploratory and descriptive. Data was gathered from unstructured, open-ended interviews, participant observation, and data in the form of written documents or artifacts.

This study also investigated the impact of contextual conditions on families involved in an early intervention service program. The case study was chosen because it is the preferred strategy when “how” and “why” questions are being posed and the investigator has little control over events. Additionally, it is used when the focus is on a contemporary phenomenon within some real-life context (Yin, 1994).

Technical aspects of case study inquiry support distinguishing between the phenomenon and context in real life situations. Yin (1994) described the case study as a research strategy comprising an all-encompassing method – with the logic of design incorporating specific approaches to data collection and to data analysis. Yin asserted:

> Case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion, and as another result benefits from the prior development of theoretical propositions to guide data collection and analysis. (p. 12)

A case study approach was the preferred method for this research because the case study added two sources of evidence besides a historical account: direct observation and systematic interviewing. Evidence was also available in many forms, such as documents, artifacts, interviews, observations, field notes, the participant, and the researcher who becomes a participant at each stage of the research process.

Participant Selection

Purposive sampling was used in this research. This method was selected because it involved choosing participants based on the sample’s relevance to the research questions, analytical framework, and explanation of the phenomenon – *participation,* being developed in this research. There was good reason to believe that the question of “what goes on here” was critical to understanding the process of participation. Relevance in this type of sampling was also facilitated by choosing multiple cases (i.e. families) that might yield predictable contrasts in understanding the definition of participation or choosing those likely to show the same or similar definition of participation within this particular group of study participants (Schwandt, 2001).

In order to gain entry into the field, the program director for the Children with Special Needs (CWSN) Early Intervention (EI) program in a mid-sized city in the southeastern United States was contacted and given a copy of the Institutional Review Board approval for this research. The EI program office sent a letter (Appendix A) to families with Spanish surnames receiving early intervention services. The letter provided a brief introduction to the researcher, the study, and invited the family to participate in this research.

Inclusion criteria for the study was: families of a child between the age of 1 and 3 years currently enrolled in a state and federally funded Early Intervention program and who have an Individualized Family Service Plan. This document is developed in accordance with the family’s priorities and needs, and guides early intervention service delivery. Only mothers who self-identified as being an immigrant of Mexican origin and also living as an undocumented resident in the United States were included in this study. The early intervention personnel do not ask about United States citizenship during the gathering of intake information, therefore I asked this question in person when explaining this study to potential participants. Interview transcripts were transcribed in Spanish and discussed in Spanish if the participant’s primary language was Spanish in order to member check their own transcripts for accuracy of meaning.

Because of the indepth nature of this study a sample of six mothers of children receiving early intervention services was targeted. They were contacted when they either expressed an interest in participating in this study to another service provider who contacted me or they contacted me directly by telephone. I telephoned or visited the family to schedule a time to explain the study and gain consent for participation in the study (Appendices B & C). The initial meeting included explaining the study, describing procedures to safeguard confidentiality, obtaining consent to participate, and an initial interview which included gathering demographic data to ascertain if the mothers were undocumented immigrants to the U.S. This process was repeated until six participants were recruited for the study.

The Early Intervention Program

Georgia's statewide interagency service delivery system for infants and toddlers with developmental delays or disabilities and their families is the Babies Can't Wait (BCW) program. The Georgia Department of Human Resources, Division of Public Health is the lead agency administering this program. Early Intervention services in Georgia consist of 19 Health Districts throughout the state to ensure access to residents of every county to early intervention services (Georgia Division of Public Health, 2005). The participants' early intervention program was located in one of the 19 Health Districts in Georgia. This district was identified as District 20 and the actual names of all participants and informants in this study have been changed in order to maintain confidentiality.

The service coordinator who primarily works with the Latino population in District 20 and an early childhood expert who provides technical assistance to the state early intervention system were interviewed In order to describe the EI process and practices. The service coordinator has eight years experience working in the EI program. She provided information regarding the EI process and practices with Latino families. The early childhood specialist has 20 years experience in the area of early childhood and early intervention. She has worked on revising the Individualized Family Service Plan (IFSP) document for the purpose of engaging families in their child's EI program. I formally interviewed each of these individuals on several occasions and followed up with telephone conversations and emails to member check and verify the interview data. I also relied on personal experience as an occupational therapy service provider in the District 20 EI program.

Data Collection

In order answer the research questions, I used the following qualitative data collection methods: interview, participant observation, document analysis or examination of archival data, and participation in or inquiry into activities either generated by the families or related to the parent's participation in the early intervention service program. I conducted an interview at the time of initial contact with the mothers if they agreed to participate in the study. Each participant chose pseudonyms for herself and family members. Following the initial interview, a $10.00 gift card was given to the parent informant(s). Overall, at least three contacts were be made with participants to conduct interviews, gather data, and member check their transcripts for accuracy. Follow-up telephone calls and interviews were scheduled as needed in order to verify information or return original archival documents or artifacts.

Demographic data was collected using a structured interview format (Appendix D). An interview guide (Appendix E) was used during the initial and subsequent interview sessions as needed. All interviews were audio recorded, conducted in Spanish, transcribed in Spanish by the researcher, and later translated to English for reporting purposes.

Data collection also involved gathering archival data, participant observations, and journaling that was transcribed as supporting or refuting data. Archival data included copies of each family's Individualized Family Service Plan (IFSP), minutes of IFSP meetings, EI service program informational brochures, EI intervention program instructions, or any materials related to the early intervention program. Data pertaining to home and family life was gleaned from archival data such as home utility bills, family photographs, and other items deemed important by and shared by the informants. I also observed naturally occuring interactions between parent(s) or other family members with the child with a disability whenever possible.

Other participant experiences included any meetings, seminars, social events, or related activities such as team evaluations of a child and family. I also selected key informants from early intervention personnel who administer or provide services in early intervention programs for interview regarding policies and practices surrounding EI services for Latino families with undocumented family members, but not specific to families in this study.

Data Management and Analysis

The method I used was an inductive, context-sensitive scheme that began with working with the actual language of the respondents to generate codes and categories. Then I worked back and forth between the data segments and the codes and categories to refine the meaning of categories as they emerged through the data. The coding procedure involved disaggregating the data, breaking it down into manageable segments for the purposes of explaining or developing an understanding of ‘what’s going on here’ (Schwandt, 2001).

The coding process was compatible with the qualitative data analysis software NUD*IST, an acronym for the accurate description of Non-numerical Unstructured Data Indexing Searching and Theorizing N6 (Richards, 2002). This software was used to code and categorize data segments in a systematic way. A file for each participant was created when their interview transcripts were imported as documents into an N6 project pad. As each document was analyzed, data segments were coded or categorized within a node system. The software allowed for editing, annotating, making memos and building searches using the data segments. Coding procedures were used to organize the data generated by the participants from transcripts or field notes, documents, photographs and other archival data and artifacts.

A descriptive analytic strategy was employed; however, I also analyzed the data while relying on theoretical frameworks used to conceptualize social identity theory and the acculturation process, the Model for Early Intervention and Parent Support (Dunst, 2000), findings from research described in the literature, and findings from the preliminary research conducted with four participants. Cross case comparison was used to code participant responses, not as a measure for comparing and contrasting cases.

Veracity/Validity and Reliability

Merriam (1998) indicated that it is imperative to recognize that “all research is concerned with producing valid and reliable knowledge in an ethical manner” (p. 198). She contended that it is through accounting for validity and reliability that research can be considered trustworthy. Questions related to the construction of the interviews, the process of analysis of the data, and interpretative methods are critical questions that need to be answered in qualitative research. Silverman (2001) argued that some social researchers believe that concerns related to validity and reliability only arise in quantitative research and that these terms take different meanings in naturalistic or qualitative research. It is therefore important to distinguish the meaning for each of these terms and how to account for them in order to produce quality, trustworthy research.

Strategies to ensure veracity in the data collection phase involved triangulation of multiple sources of data including observation, interview, member checks, clarification of responses, and review of archival data. Triangulation is a procedure used to establish if the criterion of validity is being met and is a means of checking the integrity of the inferences made by the researcher (Schwandt, 2001). Triangulation is also described as a way to strengthen a study design with a combination of methodologies to confirm findings (Patton, 1990).

Janesick (2000) claimed that the cornerstone of qualitative research is description and explanation of persons, place, and events. Thus, validity in qualitative research has to do with description and explanation and whether the researcher's explanation fits the description or is credible. Lincoln and Guba (1985) suggested that the member check is "the most crucial technique for establishing credibility" (p. 314). There are several ways that qualitative researchers can cross check their work. Using member checks, the researcher asks the participants to indicate if the derived conclusions are plausible. Another form of member checking is having an outsider read field notes and interview transcripts (Janesick, 2000).

In this study, after each interview was transcribed, the transcripts were checked with each informant by reviewing the transcript in Spanish for accuracy. I also used this time to seek clarification from the informant as needed. Additionally, I checked my interpretations of the participant's data with a Spanish-speaking peer not associated with this study. The peer reviewer examined the transcript(s) and the codes generated and interpretations made from the data. Furthermore, in peer examination, colleagues are asked to comment on the findings as they emerge. Peer review also provided a check on researcher bias. Participant observation opportunities also served as data sources and were used to validate interview questions to assure a well-rounded picture of the early intervention services provided for the study participants.

Reliability as described by Gall, Borg, and Gall (1996) is "the extent to which other researchers would arrive at similar results if they studied the same case using exactly the same procedures as the first researcher" (p. 572). Nevertheless, the isolation of the laws of human behavior is not a goal in qualitative research. Reliability should indicate whether the results are dependable and consistent with the data collected.

Merriam (1998) recommended that the researcher provide his or her position about the group being studied, the criteria for selecting the participants; a description of participants; and the social context from which data was collected. A subjectivity statement clearly outlining my assumptions, worldview, and theoretical orientation as suggested by Merriam (1998) was included to explain my position relative to this research. Triangulation of multiple methods of data collection and analysis, as well as a detailed explanation of how the researcher arrived at the results included detailed descriptions of procedures and explanations of how the data is interpreted and conclusions drawn. Journal notations regarding the systematic and idiosyncratic aspects of qualitative research were also used to aid in providing a reliable audit trail.

Finally, the concept of instrumentation can be applied to qualitative research similarly as in quantitative research (Lincoln & Guba, 1985). The researcher as a human instrument can be refined and become more reliable through training and practice (Merriam, 1998). To improve my skills as a qualitative researcher, I have taken six doctoral level courses on qualitative methods, attended several intensive workshops on the use of qualitative data analysis software, conducted a pilot study, and applied several methods of analysis to the data including phenomenological analysis, narrative analysis, analysis of narratives, conversation analysis, and critical analysis. I have also published findings from the pilot study in a national journal (Alvarado, 2004) and immigrant stories (Alvarado & Stoneman, 2004). These experiences have helped me develop skills as a qualitative researcher; however, I realize I will sustain and hone my skills through continual use of qualitative research methods and continuing education.

Subjectivity Statement/Research Bias and Assumptions

My research interests involve a family’s ability to successfully, on their terms, inform and access those services that will benefit or advance their personal, families, and their children’s success. Of particular interest are the experiences of immigrant families of Mexican origin who have a child with a disability.

I decided to undertake research concerning this topic because I am interested in researching the experiences of the family who lives with challenges imposed by disability and living under undocumented status in the United States. Of particular interest is how the family responds to these challenges. In some ways I am conflicted in making a distinction or assuming that the experiences of families of Mexican origin are different from any other family experiencing living with a child with a disability. However, I am moved to researching their experiences because of existing misconceptions about their identity. Wide variations exist in individual and group characteristics of Latino families such as, acculturation processes, immigrant status, and generational status. I have come to know the impact to these families due to inaccurate perceptions about them and their lifestyles. The media, personal communication, first hand experience as a service provider communicating with other service providers as well as lay persons regarding the “Hispanic, Latino, illegal alien” family, or other labels has provided insight into how these families are often stigmatized, categorized, and misrepresented.

My personal experience includes being a Latina woman of Mexican heritage growing up in a large family with parents who immigrated to the United States from Mexico. My family continues to be primarily Spanish speaking depending on which family members are communicating. Another major influence on my research interests includes twenty-nine years of professional experience working with families as an occupational therapist in healthcare systems in Texas and Georgia which has provided valuable insight into some of these issues. My education in occupational therapy, the behavioral sciences, my experiences as the rehabilitation services manager in a major research center; and my professional practice as a service provider in hospitals, clinics, school systems, and in the homes of families has helped me develop an understanding of some issues faced by families living with disability. Additionally, my experience as an assistant professor in the Department of Occupational Therapy at Brenau University provides opportunities and challenges to promote cultural competence in teaching students about children and families.

The events and persons in my life, that include labels such as “immigrant”, “resident alien”; family life and events affected by alcoholism; congenital anomaly; AIDS; post traumatic stress disorder; cancer; and “ordinary” childhood and adult illnesses and injury bring me to this point. Everyday life events such as watching my mother, father and others in our neighborhood as they raised their children; as they worked, sent their children to school while being constrained by language barriers in doing something as simple as attending “open house” at their child’s school were part of my upbringing. Other life events included socializing within and between cultures, brothers going to war, and family intermarrying among and between other ethnic groups. All the while I am shaped by observing and being affected by or in some cases, I consciously chose not to be affected by the prevailing historical, social, political, economic ideologies and actions directed at being part of a blended family of Mexican immigrants and United States born children.

Regarding my particular framework of knowledge, I feel that my viewpoint agrees with post structuralism and constructivist thinking. This approach appears to be one way I would feel comfortable in researching the reality that people construct. It is also a way to explore dominant social constructions of reality that promote inequities. Schwandt (1997) writes, “Our world knowledge is not a simple reflection of what there is, but a set of social artifacts; a reflection of what we make of what is there” (p. 20).

I believe reality is constructed through human interaction and that multiple realities coexist. Since reality is a social construction, we can attempt to understand how particular individuals represent their reality symbolically through language; especially by exploring how it has been used to indicate differences. I believe this is directly related to how systems develop and are maintained by the views of individuals who control and are controlled by them. In other words, the culture of a system is influenced by the perceptions of those within the system and determines the quality of interactions that occur between those managing the system and those who seek services from the system. This process might actually determine actions or choices to access the system.

In order to accurately understand and describe the experiences of families of Mexican origin, it is necessary to work as a co-participant to structure the inquiry; discuss the emergent design; discover the use of symbolic representation; and uncover and critique the ideology of the participants. This process involves using qualitative methodology and raising questions to heighten my awareness of their experience and to understand other perspectives. I have two traits that will either be a help or hindrance. I tend to take things at face value and I also strive to be objective. I have to use caution because although I respect the truths that people hold, I would want to critically analyze their reasons for holding these “truths” while conducting trustworthy research.

Personal experience tells me that I can achieve my goals and I am in a position to realize and take advantage of opportunities to learn. These experiences have also shown me that some barriers exist, whether they exist in systems or obstacles due to socially constructed perceptions or contextual situations. These experiences have been influential and have provided the insight that motivates me to research the experiences of families. They stem from experiences with persons in my life who were not judgmental as well as those who were. My parents, who showed me that work, acceptance of others, and love of fellow human beings does make a difference. My experiences and those of others I have known have also revealed the impact of non-acceptance and the damage it causes. I hope to provide insight as well as information about these issues for discovery and positive change for families, service providers, and systems.

The issue is not that we must always be culturally aware and espouse cultural sensitivity in all we do - this is an impossible task. Rather it is to understand and respect other perspectives. In so doing, we can provide services and information to families who seek to make choices they feel will help their families. We cannot do this without inquiry into and discovery of their experiences.

Timeline and Budget

Key dates for the dissertation research are as follows:

- 3rdst week in March, 2005 - Complete Oral Examination
- April 8 -Turn in prospectus to advisory committee
- April 19 –Prospectus defense
- April 25 through July 9 - Data collection & Ongoing Data Analysis
- July 9 through September 18 - write up findings and implications
- September 30 - Dissertation Defense
- December 5 – Submit Defense Approval Form & corrected copy of dissertation

Budgetting for this research involved accounting for the following expenses. Each participant received a $10.00 dollar gift certificate to a local retail store, which meant that incentives cost approximately $80.00 dollars (in cases where both parents were interviewed). I photographed generic communities like those of the participants. I used a digital camera and had access to an audio recorder and transcriber. The cost of photographic processing, audio tapes was not expected to exceed $100.00 dollars. Although I transcribed the interviews, I also hired a transcriber who is Latino in order to expedite the process of member checking. His fee was .03 cents per word. In summary, the costs for completing this research, including mileage and paper for drafts of the dissertation was estimated at $500.00.

Chapter Summary

The objective of this research was to investigate how mothers of Mexican origin living under undocumented immigrant status in the United States participate in an early intervention program. Qualitative methodology was used to explore, describe, and interpret mothers' perspectives on how they and their family experienced participating in their children's early intervention program. The research design was phenomenological analysis of multiple cases for the purposes of coding participant responses to generate and refine codes and categories for describing the phenomenon of participating in an early intervention program.

Data management included the use of software to systematically organize data segments. The validity and reliability of multiple data sources was maintained through several procedures including triangulation, member checking, peer examination, and accounting for the researcher's subjectivity as a co-participant in this research. It is hoped that the use of sound qualitative methodology enhanced the quality of this research and will contribute to the literature regarding families of Mexican origin living in contexts that include disability, immigration, and healthcare.

CHAPTER 4

FINDINGS

The purpose of this study was to describe how mothers of Mexican origin who have a young child with a disability and are immigrants of undocumented status in the United States participate in their child’s early intervention (EI) program. The research questions were designed to explore how mothers of Mexican origin participate in their child’s EI program and what they identified as promoting participation, particularly actions on the part of service providers as well as obstacles to their participation. The objective of this research was to accurately represent families of Mexican origin living within the contexts that include immigration under undocumented circumstances and childhood disability. The procedures described in Chapter 3 were used to formulate these findings.

Data from 18 in-depth interviews and informal follow-up telephone interviews with 6 participants, interviews with early intervention personnel and an early childhood expert, observations, and document analyses comprise this summary of findings. The participants chose pseudonyms for themselves and their immediate family members. Names of places, persons, and organizations have been changed to preserve the anonymity of individuals and the community.

Data collection methods occurred concurrently. For example, observations were interspersed with interviews of participants and informants. Using a phenomenological approach in data analysis, review of the data was accomplished by using qualitative software for the purposes of coding and categorizing participant responses. Data segments were systematically organized in order to generate and refine categories of themes for describing the phenomenon of participating in a particular early intervention program. Themes were continually revised throughout the data collection, categorization process, and analysis of data.

During the analysis of the data, member checks continued with the participants. Member checks served to clarify each participant's statements, verify facts on documents or from interview data, and account for the researcher's subjectivity as a co-participant in this research. I also verified my interpretation of the participants' use of phrases or language when data was transcribed from Spanish to English in order to avoid losing their meaning in translation. Peer review by a colleague who is fluent in English and Spanish was also employed by email to check a sampling of transcripts and the themes that were generated from the transcript data.

This chapter provides findings concerning the participants' communities. The participation of Mexican immigrant families in the EI program is portrayed based on descriptions provided by the EI case coordinator who works with Latino families. Findings primarily concern the contextual descriptions of the participants and their experiences participating in their child's EI program. Findings are presented regarding the research questions as themes generated regarding the participatory experiences of mothers in their child's early intervention program. The study members' perspectives on factors that promote participation or act as barriers to their participation as well as actions of service providers that promote participation are also presented.

Description of the Participants' Communities

In order to maintain anonymity regarding the place of residence of the participants, information regarding the particular county in which they resided will be presented under a pseudonym for the county. Names of other people, places, and organizations that may specifically locate the participants will also be changed. The participants and their families lived in 2 neighboring counties in the Southeastern United States. The larger of the two counties is

Corridor County. Its county seat is a thriving city with a long history of economic growth now based in the production and processing of poultry. All the participants originally lived in Corridor County, except one participant who recently moved from Corridor County to a smaller, more rural county.

Corridor County has undergone rapid growth in the Latino immigrant population, particularly the Mexican immigrant population. This county has one of the highest percentages of Latino residents reported to be between 20 and 22 percent of the total state population (Atiles & Bohon, 2002; Georgia Hispanic Chamber of Commerce, 2005). The number of Hispanics classified as Mexican in Corridor County is 22,826 out of a total of 156,101 inhabitants or 14.6% of the population and 2,224 out of a total 38,446 inhabitants or .5% of the population in the smaller county (Georgia County Guide, 2005).

The demographic profile of Corridor County illustrates its income, public assistance, health, education, and transportation characteristics as compared to the average county in Georgia. Statistics compiled for some of the categories represent data for the years of 1999 through 2003. The average weekly wage in all industries within Corridor County was $596 compared to $495 in an average Georgia county. The median household income was $45,091 compared to $34,990 in the average county in Georgia. Slightly more than eight percent of households in Corridor County earned less than $10,000 and 11.0% earned over $100,000 compared to 14.3% earning less than $10,000 and 6.9% earning more than $100,000 in the state. Additionally, a significant number of persons were classified as living below the poverty level in Corridor County (15,238) compared to the average county in Georgia (6,329). These numbers represent a wide range in income per household within a large, growing county.

Corridor County also had more practicing physicians (295) than the average Georgia County (104). The percentage of citizens in Corridor County with disabilities between the ages of 21 and 64 years was comparable to the average county in Georgia (22.3% versus 23.8% respectively). Statistics for children with disabilities under the age of 5 years were not available. The percentage of the population that received public assistance in Corridor County was: Medicaid assistance (17.6%), Supplemental Security Income (1.5%), and Food Stamps (5.0). These population percentages were lower than the average county in Georgia where residents received: Medicaid (23.8%), Supplemental Security Income (3.4%), and Food Stamps (11.4%).

Education statistics for the public schools in Corridor County show the percentage of Hispanics in the total enrollment to be 27.6% compared with 3.7% in the average Georgia county. The percentage of students in Corridor County with limited English proficiency was 15.36% compared to 2.6% of students in the entire state. These percentages did not specify the language that the students spoke. Finally, transportation in terms of total motor vehicle registration in Corridor County was 155,594 compared with 48,624 in the average Georgia county (http://www.georgiastats.uga.edu).

Description of the Early Intervention Program

Georgia’s statewide interagency service delivery system for infants and toddlers with developmental delays or disabilities and their families is the Babies Can’t Wait (BCW) program. Early Intervention services in Georgia consist of 19 Health Districts throughout the state to ensure access to residents of every county to early intervention services (Georgia Division of Public Health, 2005). The participants’ early intervention (EI) program was located in one of the 19 Health Districts in Georgia. This district was identified as District 20 and the actual names of all participants and informants in this study have been changed in order to maintain confidentiality.

The service coordinator who primarily works with the Latino population in District 20 and an early childhood expert were interviewed in order to describe the EI process and practices. Information offered by these individuals and my personal experience as an occupational therapy service provider in the District 20 EI program was used to describe EI services. The early intervention process from intake to termination of EI services is described as follows. Additionally, details of components of the IFSP that reflect family centered care are provided. For the purposes of this study the terms professional, service provider, therapist, or EI personnel may be used interchangeably to denote anyone who provides EI services.

Early intervention services are provided to any child from birth to three years of age. There is no criterion for services besides the child having a disability or being at risk for developmental delay. Anyone can refer a child for services. When a referral is received, it is assigned to an intake worker who contacts the family to tell them that their child has been referred to the EI program. The intake worker informs the family that they have the option of having their child's development evaluated and that they have a right to decline services (Early Intervention Case Coordinator, personal communication, June 27, 2005).

If the family is interested in receiving EI services, the intake interview, that is part of Individualized Family Service Plan (IFSP) and the initial eligibility evaluation is scheduled. Two service providers are required to go to the family's home to do an intake interview and evaluate the child's development. Usually EI personnel such as an EI Specialist, Social worker, or Case coordinator, and a provider from any appropriate discipline, depending on the child's needs, evaluate the child. In some instances, the family might come into the EI program's office for intake and evaluation. In either circumstance, the family is informed of the results of the developmental testing of their child and has the option of accepting EI services or not.

If the family chooses services, it is given the notice of eligibility for EI services and then the family and EI personnel complete the IFSP. The case coordinator contacts a provider chosen from a list of persons who contract their services to the EI program. If the provider agrees to work with the family the coordinator sends the IFSP to the provider who than contacts the family. EI services continue as per the IFSP and are reviewed every 6-months thereafter. Children are eligible to receive EI services until they are 3 years old. If the family is satisfied with their service providers, they do not have to choose new providers each time an annual review is conducted. Nonetheless, the family has the option to change therapists at any time if they are not satisfied with their service. EI services terminate one day before the child's 3rd birthday.

Sometimes, the child will continue to require services after they are 3 years old and preparations are made to ensure ongoing services. The family has several options that are usually presented to them by the service coordinator. These options are formally addressed according to family preference through transition procedures when the child is 30 months old. If the family chooses to have therapy provided by the school system, school system personnel contact the family and service coordinator to schedule a meeting. The school system staff evaluates the child and prepares to begin providing services for that child if needed. The family may choose to continue services with the therapist(s) who provided EI services, select another therapist, or any combination of services in order to meet their child's needs.

District 20 has undergone several changes that reflect a shift to the family centered care model advocated by Dunst (2000) and Shelden and Rush (2004). Changes include revisions to the IFSP and the introduction of a transdisciplinary model of EI service provision called the Coach Model (Shelden & Rush, 2000) that is being piloted in District 20. Several EI districts, including District 20 are using and systematically evaluating the revised IFSP as a means to make the intake process the initial point of engaging families (Early Childhood Specialist, personal communication, April 25, 2005).

The Individualized Family Service Plan

The Individualized Family Service Plan (IFSP) includes the intake information gathered during the initial visit(s) with families. The IFSP has been revised to highlight and incorporate the family's strengths, participation, and interactive abilities into the EI intake process. The IFSP documents the structural components of the EI process. It is also used to engage the family in the EI process from the very beginning and to establish that the EI program will help the family support their child. The IFSP revisions are the result of extensive strategic planning to improve family participation in the EI process within 17 of the 19 Health Districts providing EI services (Early Childhood Specialist, personal communication, April 25, 2005).

The first 3 pages of the IFSP document identifying information (Section 1) such as: where the family lives, contact information, and service coordinator information (Section 2). Section 3 contains information about the child and family such as family strengths and resources, topics of interest related to the child, and a description of the assistance or information that the family seeks from the EI program and providers. Section 4 includes information about the child's natural environment such as involvement in the family's routine, the child's likes or dislikes, and activities the family is not currently doing, but would like to do now or in the future.

Section 5 of the IFSP summarizes information gathered during intake, evaluation, and assessment activities. It documents the child's development in areas such as communication, cognition, social/emotional skills, motor skills, and adaptive skills including vision, hearing, and general health status. Section 6 of the IFSP is referred to as the “transition page” that is used for planning services in another program. The transition segment of the IFSP is followed by Section 7, which contains outcomes identified by the family that are expected to result from early intervention services. This section also includes documentation of any changes made at the six-month review of EI services. It lists strategies to be used to embed intervention into the family’s routines or activities, suggests resources and support tools, and reflects the efforts to engage the family in the EI process.

If the outcome statement set for the child cannot be achieved in the child’s natural environment, Section 8 of the IFSP is used to document justification for services to be provided elsewhere such as a clinic or hospital setting. The scope of EI services including which service will be provided, where services will be provided, how these services are funded, who will provide services, and when the services will be provided are detailed in Section 9. The IFSP team that includes the family as well as other services is identified in Sections 10 and 11. Finally, documentation of meetings to review the IFSP as well as meeting minutes kept of each review or change in the IFSP are entered in Section 12.

Throughout a child’s enrollment in the EI program, the service coordinator checks with the families and the providers to monitor progress on a monthly basis. If the child has met his or her developmental outcome as stated on the IFSP, a new outcome statement is made in consultation with the child’s family. At a minimum, the IFSP is reviewed every six months. Every year the family has an IFSP review and goes through the eligibility evaluation again. The purpose of this review is to update services, the child’s medical history, consent forms, and to review the family’s financial statement. When EI services are terminated, the service coordinator interviews the family in order to review and rate how their child's outcome statements were being met.

The EI process and the changes in the IFSP procedures intended to follow the spirit of family centered care have been described as they pertain to families in District 20. Furthermore, the service coordinator described specific aspects of EI service delivery related to her experiences with families of Mexican origin in District 20 who are undocumented residents of the U.S. Some EI practices concerned the pragmatics of matching providers with families that speak primarily Spanish while other observations dealt with helping the families navigate the EI system, healthcare systems, and transportation systems. For instance, Latino families who are enrolled in the EI program and are Medicaid recipients were described as relying heavily on transportation provided by public assistance such as the Non-Emergency Transportation Program available to Medicaid enrollees and public transportation such as taxis.

Medical Non-Emergency Transportation

The Non-Emergency Transportation Program (NET) is statewide transportation system administered through the Georgia Department of Human Resource (DHR) Office of Facilities and Support Services, Transportation and Services Section. The program provides non-emergency transportation for individuals enrolled in the Medicaid program. Transportation services are provided to clients served by the Division of Aging Services, Developmental Disabilities and Addictive Diseases, the Division of Family and Children Services, and the Division of Public Health. The stated goal of this program is to provide safe, efficient, and cost-effective transportation in order to link people with services and opportunities.

The transportation system provides contracted services and/or oversight. Non-emergency transportation is provided through contracted services by vendors in each region of the state.

These vendors may come from government entities, the private sector or from not for profit organizations. A transportation broker can be contacted via a toll-free telephone number in each region of the state. Services are available Monday through Friday from 7 a.m. through 6 p.m. Medicaid recipients must call and schedule transportation three days in advance. Families and children enrolled the Early Intervention program who have children who are Medicaid recipients are given information on the NET program. The EI program provides a one-page information sheet in the English and Spanish language to families. This form explains how to access non-emergency transportation, how to schedule an appointment, and how to report problems with a Medicaid transportation provider (EI Social Worker, personal communication, September 9, 2005).

Families of Mexican Origin and Early Intervention Services in District 20

The following illustrated the perspectives of the EI service coordinator on her work with Latino families. The service coordinator was asked what EI personnel do with information that a family is undocumented if this is the case during the intake process. She answered,

> “We don’t find out that information. They [families] don’t have to give us a social security number or anything. The main information taken is where they live and what is going on with the child. Every child is entitled to EI services, so we don’t have to screen out documented from undocumented. We take all kids who have a suspicion of developmental delay and do the evaluations.”

In order to choose a service provider, the case coordinator explained that she telephones providers who are bilingual ahead of time to check on their availability. Although, technically, any provider can be contacted, the service coordinator finds that the Latino families appreciate being able to communicate with the provider in Spanish. The service coordinator also related that it is difficult to find therapists who are bilingual. For example, because the EI program has few speech therapists fluent in Spanish, the Latino families usually receive the services of a special instructor who is bilingual. This usually happens when the child's developmental problems are more likely attributed to environmental factors such as not getting enough stimulation at home to promote the development of speech. In these cases some bilingual special instructors can address the child's developmental problems.

If the child needs a therapist of a particular discipline and the EI program cannot provide a therapist who can speak Spanish, an English-speaking therapist serves the family. Still, the service coordinator conceded, this situation is very difficult for Latino families who primarily speak Spanish. She explained, "Many times the family doesn't exactly know what the therapist has told them. They think [they know], they can tell pretty much by the gestures and what the therapist did with the child, but I have to be more involved."

In practice, the service coordinator working with Latino families stated she attempts to meet with each family during times when the therapist is present to review and discuss progress with the provider and family. Regardless, the service coordinator reported that often the English speaking therapists cannot give her a detailed description of what the child can do when she asks for a progress report on the child. The service coordinator felt it is more difficult to provide services with a speech therapist who is not fluent in the family's primary language, than with other service providers.

The service coordinator made several other observations particular to families of Mexican origin in addition to having to explain and re-explain how the EI system works. When describing her perspective on the families' understanding about how to navigate the EI system as it related to the amount of time the families were in the United States, she asserted "… people who have been here a lot longer, even the ones from Mexico and undocumented. If they've been here for a while, they seem to understand a little more, or have been exposed, or something…to the system".

The service coordinator related another aspect of her work with families of Mexican origin concerning their understanding of their rights. She described having to explain to families that they have the right to choose or decline services and that she sometimes sensed the families feared speaking up. When asked why she thought families responded this way, she explained

> Well, my guess would be because they are undocumented. In the first place, they are scared. I sense that the families are frustrated particularly with providers who can't speak their language. I'll address it sometimes and it is almost that they feel that they have to tell me everything is ok. That they can't say "No, I don't like this" it takes a while, usually I say, "Look, I'm sensing this. Would you just tell me if you're not happy with this situation?"

The service coordinator felt she could usually tell when the families with whom she works were having problems. These feelings were often conveyed verbally and non-verbally, for example by the questions they ask.

Two other issues were brought to light by the service coordinator that related to accepting a child with a disability and the timing of referral for EI services for children. The coordinator commented, "Some of my Hispanic families seem to have a more difficult time accepting a child with a disability." She elaborated noting that it mostly happened with children diagnosed with Down's syndrome and she gave the following examples.

> A child's father attended the evaluation and said the child's mother could not come, because if the child needed therapy, the mother would think that the child was damaged.

> Another family with a child with Down’s syndrome is having a hard time even thinking that the child will be delayed [in developing]. I [service coordinator] take a long time in explaining what developmental delay and Down’s syndrome is, and that it is not a disease. That kind of thing, it’s almost like a dreaded disease, a bad word.

The service coordinator also observed differences in the timing of EI referrals for Latino children from primarily Spanish-speaking families. She noted that these children were usually older than children from English speaking familes when referred for EI services. Although she acknowledged that particular medical providers are overloaded with Mexican immigrant patients, she also felt that Latino children might not be referred earlier because some families do not know their rights, do not know what to ask for, and do not usually sue physicians. She claimed that some professionals are not as careful as they would be with the middle class American family stating “[American families] …who know their rights, will say, “You better tell me what I need to do with my child or else I’m taking you to court”.

The service coordinator noted that many families that are undocumented will tell her they have been to the pediatrician and expressed concerns about their child’s development. Still, she finds some children are not referred for EI services until they are 32 or 33 months old. This creates a situation where many families enter the EI program late. In these cases, the EI staff frequently has to refer these children to other specialists (e.g. hearing, vision, neurologists, and orthopedists) for unmet needs. The coordinator acknowledged, “That is a big difference with the Mexican family. Probably a good 90% of my families get referred to CMS [Children’s Medical Services program] because there is a medical need that has not been addressed.”

For the most part, the service coordinator felt Latino families are similar to any family served by the EI program as they are all very concerned about their children and they want what is best for their child. Furthermore, she noted that most of the Latino families with whom she works attend a parent support group for Spanish speaking families. Although, this group is not part of the District 20 EI program, it is considered a resource for families. Information regarding the parent support group is also routinely given to families.

The EI program in District 20 has been described to illustrate how services are organized and administered. Working with Latino families who are primarily Spanish speaking included other aspects of EI service delivery as described by the service coordinator. Although she described families as being similar to other families regarding the families' priorities about the health of their children, she noted several differences particular to Latino families who receive EI services.

Mothers of Mexican Origin Who Have a Child with a Disability

The findings of this study include contextual descriptions for each of the six participants in this study based on interviews with the participants and observations in their homes. The participants are introduced in order to provide relevant information regarding their pregnancy, delivery, and living situations and to orient the reader to the participants' circumstances surrounding having a child with a disability and family life. The demographic information was gathered from a structured questionnaire, Appendix D. Each participant chose pseudonyms for herself and her immediate family members. The participants also provided information about their immigration or their undocumented status voluntarily or as related to their life story or circumstances in the United States (See Appendices F & G). Additionally, Appendix H shows the EI services and other public assistance received by the children and families in this study. Figures 2 through 4 illustrate housing, neighborhoods, and communities similar to those in which the participants live.

Figure 2. *Apartments like those of the participants*.

Figure 3. *Housing subdivision similar to that of the participants*.

Figure 4. *Advertising in the participants' local community*.

Participant's Contextual Descriptions

Nidia

Nidia is 43 years old, the third eldest of 10 children who live in the United States (Texas, Florida, and Georgia) and Mexico. Nidia was born in Tamuin, San Luis Potosi, México. She has two children, one adult (24 year old) daughter who is married and lives in the same town as Nidia and a young child, Ruth who is now 1year and 10 months old. One of her children died in 1999. Nidia has been in the United States for approximately 5 years. Her husband has been coming and going to the U. S. for about 26 years. Nidia is not employed; however, she currently keeps one young child (4 year old) of a relative and has been an elder caretaker in the past for about a year. Nidia's husband is a laborer.

Nidia stated that she did not know she was pregnant as her menstruation periods were always late. She began to feel ill, was unable to sleep, and could not breathe when she was taken to a clinic, then admitted to a hospital for a cardiac catheterization. A blood test and an ultrasound revealed she was 6 months pregnant and that her baby would be born premature. Nidia thought the medications she took while ill, tests, and radiographs might have contributed to the baby's problems. Initially she was told the baby needed to be born naturally (vaginally) due to Nidia's heart condition then later that she must have a Caesarian section procedure because the baby needed to be born.

When Ruth was born, Nidia said she heard her cry once and has not heard her voice since. Ruth weighed 1 pound, 8 ounces. Nidia remained hospitalized for 6 days and Ruth was transferred to a larger children's hospital in another city to have a tracheotomy and remained in intensive care for 3 months. Nidia told her doctor she did not accept blood due to her religious beliefs, but would accept blood substitutes. Nidia felt the doctor was angry with her and that he changed his affect toward her explaining that he gave her "mal cara" or a bad face. They did give Ruth blood and Nidia felt that in order to justify their actions, they claimed that she did not want Ruth. The family was referred to Child Protective Services/Division of Family and Children's Services (DFCS) (http://dfcs.dhr.georgia.gov/portal/site accessed July 24, 2005) and a court case ensued. All turned out well when the judge ruled that Nidia's family could take Ruth home after her hospitalization.

Nidia explained Ruth has a problem with her respiratory tract. Ruth's documented diagnosis is respiratory failure, bronchopulmonary dysplasia, gastroesophageal reflux, and prematurity. Ruth currently has a tracheosotomy and a feeding tube and pump through which she is fed approximately 14 hours a day. Ruth also has a nurse 5 days a week, 8 hours a day, during waking hours. She qualifies for nursing services 7 days a week, but weekend staffing is a problem. Ruth has received EI services since she was about 6 months old. Early Intervention services include speech therapy, occupational therapy, and case coordination. Ruth walks around freely in the apartment and plays with the other child whom Nidia babysits.

The family includes 5 persons, Nidia, her husband Jorge, Ruth, Nidia's younger brother, and a friend all of whom currently live in a 3-bedroom apartment in a neatly manicured complex. Before Ruth was born they lived in what Nidia described as a 2-room "basement apartment" adequate for just one person that was very damp. In order to keep Ruth, they had to rent this apartment so as to prove to the DFACS that they could provide an adequate home for Ruth.

Andrea

Andrea is 21 years old and she is 3rd eldest of 5 children who live in the United States (Tennessee and Georgia) and Mexico. Andrea and Luis, her husband, were both born in Escobia, Oaxaca, México. They have two children, Angel, their five-year-old son and daughter, Gabi who is 2 years old. Both children were born in the U.S. Andrea and her husband, Luis, have lived in the U. S. for about 4 years. Andrea works in a restaurant kitchen 4 days a week and pays 10 dollars a day or 40 to 60 dollars a week for child care when she is working. Andrea drives, but does not have a driver's license. Her husband, Luis works in construction and takes English classes 2 nights a week.

The family (Andrea, Luis, Andrea's brother, Angel, and Gabi) recently moved from a small house with a living room, kitchen, bathroom, and bedroom. They now live in the back, lower level of a house that has been converted into apartments. Their apartment has 2 bedrooms, a kitchen, living room, and 1 bath. This home is near a busy intersection of town that was once mostly residential but is now commercialized.

When I arrived at Andrea's new home, Angel, who was playing in the yard ran up and asked who I was looking for. He then showed me around the side of the house to their front door.

As I was leaving we spied a raccoon crawling around the trashcans about 20 yards from the back door. Andrea asked me what raccoons were called in English and we discussed different names for them in Spanish. Angel was very interested in the raccoon and was warned to stay away from them.

When Andrea described her pregnancy with Gabi she became tearful. After Angel was born, Andrea stated she was taking injections to prevent pregnancy. She found she was pregnant after taking a free pregnancy test. Andrea went to the Public Health Department, but was turned away because she did not have a “matricula” or a picture identification card. She did have a paper called an “Acta” stating where she lived in Mexico, but this was not accepted. Andrea sent for her papers from Mexico. Meanwhile she received no prenatal care.

Andrea described having a “rapid” delivery that was uneventful until she and Luis were told Gabi was born with Spina Bifida. Gabi was immediately transferred by ambulance to a larger hospital in another city for surgery. They were told in Spanish that Gabi would need surgery to push the spinal sac back into her spine and close the hole in her spine. Gabi was hospitalized for about a week or so then discharged to her family.

When Gabi was discharged from the hospital, Andrea was told that Gabi’s spine was closed, everything would be fine, and to be careful with Gabi around her active brother who was around 3 years old at the time. Andrea described Gabi as doing everything normally except not being able to walk. Gabi can crawl and was observed crawling actively across the floor. She likes to paint, write, and talk. Gabi receives early intervention (EI) services such as physical therapy one time a week at home and case coordination. She has received therapy since she entered the EI program when she was about two months old.

During subsequent interviews Andrea expressed her frustration about not getting prenatal care. Andrea described how Luis helps with Gabi. “My husband helps too. Well, he acts strong (se pone fuerte), like he is not sensitive. When she was born he cried (*era lágrimas, no?*). We despaired thinking we did something [to cause this], because no one wants this, but he was strong. He is by my side and Gabi’s. He helps her walk, standing in front of her when she walks, moves her feet and gives her massages.” When Andrea described how Luis helps her, she laughed softly.

Karina

Karina is 28 years old and was born in Durango, Durango, México. She is the eldest of 8 children who all live in Albuquerque, New Mexico. She has been living in the U.S. for 4 years and lived with her in-laws in Albuquerque when she first arrived in the U.S. Her husband’s name is Miguel, he is 28 years old and was also born in Durango. They have 2 daughters, Carla is 8 years old and was born in Mexico and Rubi is 2 and a-half years old and was born in the U.S. Karina used to work in a poultry plant as a packer for about one year and presently is not employed. She takes care of a small child at times. Miguel works in a poultry plant.

Our inteviews usually took place in the morning. The apartment complex where the family lives is tucked away off of a busy street. It is older, but the apratments look well kept. At the times I visited, I usually saw women watching their children and talking at the front doors to their apartments. One morning when I arrived, a woman had just dropped off a young child who looked to be about 3 years old at Karina’s apartment. Karina told Carla, who was in the living room watching cartoons to take Rubi and the girl into her bedroom to play. The girls played quietly, softly talking, and playing during the interview.

Karina, her husband, and two children live in this apartment. Their apartment has a small kitchen that opens from the front door and is separated from the living room by a low bar. Their dining table is placed next to one side of the bar so only two sides of the table are available for sitting to dine. There is one bedroom and one bathroom. Karina does not have a washer or dryer and goes to the laundromat to do her laundry. Their apartment was usually quiet, dark, and cool as we talked.

When Karina was in her 3rd month of pregnancy with Rubi, she received an ultrasound at a clinic where she was receiving prenatal care. She was told that something was noted in the baby’s heart, but they did not know what it was, but that it was a small problem (*problemita*). She was sent to a specialist who did some tests and told her Rubi had Down’s syndrome. Another 3 months passed before she got a definitive diagnosis over the telephone that Rubi indeed had Down’s syndrome.

Karina said that moment was difficult and that she and her husband cried for that moment, but it seemed liked a transient event (*como algo pasajero*). She said they accepted it, and live well, accepting Rubi without reproach or protest. Karina felt the clinic staff prepared them through discussion (*platica*) about Down’s syndrome, problems Rubi could have, and complications that might occur. She felt she and her husband were well prepared for Rubi’s birth. When Rubi was born, people came to visit at the hospital, to help them understand Down’s syndrome, and accept their child without worrying. Karina was discharged to her home after 3 days. Rubi remained in the hospital for 2 and a-half weeks because she had a hole in her heart and had difficulty breathing; however, she responded to medication and needed no surgery. Karina imparts that Rubi is fine now and that she feels the family has received much help.

Karina said she initially did not know what to expect or how different their lives would be compared to others; however, she feels Rubi is no different from any other child. She described life with Rubi as beautiful, even easy. They love her and treat her equally as their other child. Karina described Rubi as a loving, playful child who walks, runs, and is restless. She said Rubi fights, but is very loving.

Initially, Rubi was slow in her movement, could not raise her head, and when she was a year old she was not sitting by herself, holding toys, or crawling. Karina had to care for Rubi's every need and be vigilant about everything in Rubi's life. Rubi has received EI services for approximately 2 and one half years. She presently receives EI services including occupational therapy, physical therapy, speech therapy, special instruction, and case coordination. Karina credited Rubi's therapy for helping her attempt to talk, walk, run and jump and feels that she is meeting her goals. Rubi is also going to preschool in the fall and Karina is choosing which school would be best for Rubi.

Odalis

Odalis is 35 years old and was born in Irapuato, Guanajuato, México. She is the 7th of 9 children; all live in México except Odalis and her sister. Odalis is married to Eberado who is 22 years old and works in a local retail store. They have one child, Soyla who is now 10 months old. Odalis worked in a poultry plant for about one and a-half years as a cutter. Odalis' family and her sister's family share this houshold. Her sister is married and has a 5 month-old child. The couples and their children live in an apartment that has 4 bedrooms, 2 bathrooms, and a combined kitchen and living area. The living area is a large, open room with furniture placed against the walls and bright artificial flowers atop the furniture. Odalis commented that she is a meticulous housekeeper then laughed when she said "…at least in all the areas people can see."

Odalis and her family, live in a rural town approximately 30 minutes north of the town where the other participants live. It is an old, small town undergoing many changes. Their apartments are fairly new, and appear to be meeting a need for housing newcomers to this area. All are identical except for the satellite dishes, small gardens, car bench-seats for sitting outside, and working refrigerators on concrete porch slabs, outside some apartments. The apartment dwellers appeared to be mostly Latino and music could be heard coming from somewhere in the apartment complex. There is no shade for parking and now that school was out some children could be seen playing in the sun-drenched asphalt parking lot. Although no adults seemed to be watching, one got the sense the children were being supervised.

Odalis worked at a poultry plant until she could not withstand the dizzy spells caused by her pregancy. She received prenatal care and when she was five months pregnant, she was told that her blood test was “poquito mal” and was sent to a specialist in a large city nearby. She explained that the specialist told her not to be afraid, that her child would be born with something normal that would be fixed and that is all she was told. She would have to return every week for a checkup until her baby was born. Odalis decided to move in with her sister because she felt she would need the support after birthing her baby.

Odalis also knew she would have a Caesarian section procedure because Soyla’s intestines were outside her body and this condition was seen on ultrasound. Soyla was born after 9 months gestation. Immediately after she was born, Soyla was taken to surgery to replace her intestines inside her body and close the repair. Odalis was in the hospital for 4 days and Soyla remained hospitalized for 2 months before coming home. Odalis described the time Soyla was hospitalized as feeling like the world was closing in on her (*se me cerraba el mundo*). She and her husband were trained in how to care for Soyla at home. Odalis said she appreciated the care and advice she was given while Soyla was hospitalized.

Soyla's condition at birth is documented as oomphalocele and her diagnosis as listed on her Early Intervention Individualized Family Service Plan is significant developmental delay. Soyla, has a tracheostomy to help with breathing and a nasogastric tube for feeding. Odalis stated Soyla will probably have surgery when she is 2 years old to remove the tracheostomy and repair the hernia-like bubble on her belly. Odalis described Soyla as a child who likes to be mischievous, playful, likes music and "dances", and she points her finger at things to express her needs. Soyla is not eating food by mouth or talking at this time. Odalis is afraid Soyla will not be able to do these things, although she said her doctors and therapists constantly reassure her that she will. Currently, Soyla receives approximately 3 days of in-home nursing a week, day and night. Soyla has received EI services for approximately 6 months and currently services include: occupational therapy, assistive technology, and case coordination.

Additionally, Odalis recounted one incident when she was surprised to be investigated by personnel from the Child Protective Services/Division of Family and Children's Services (DFCS). Although Odalis explained that she did not know who initiated the complaint against her. She could not believe someone would say that she would hurt her child. Nonetheless, one morning, personnel from DFCS knocked on her door and asked to check her apartment. After they observed her care-giving skills, they seemed satisfied and withdrew the complaint.

Jaime

Jaime is 26 years old and her husband is 35 years old. Jaime was born in Zihuatenejo, Guerrero, México and is the eldest of 6 children all of whom live in Mexico. Her husband Jesus was also born in the state of Guerrero, Mexico. She has been in the U.S. for about 10 years. She and her husband have four children whose ages are 9, 6, 3 years and 1 year and 3 months. All of the children were born in the U.S. except her 6 year old child. Jaime also has 6 uncles who live in the U.S. (Washington and Texas) although she says she does not see them. Her husband has 2 sisters and 2 brothers who also live in the same town as Jaime.

Jaime and her family live in a new subdivision off a busy side street in an area of town that was primarily residential; however, businesses such as a fire station, a school serving primarily the Latino population, churches and a day care center are also located there. The subdivision is well maintained, with middle income-type housing consisting of one and two story homes with small lawns. Their home has 4 bedrooms, 2 baths, a living room, kitchen, and dining room. Nine persons live in this home, Jamie's family (6 persons) and her husband's sister who has 2 children whose ages are 8 years and 3 months.

When I arrived for our initial interview, two adults, a woman and an older man were in the kitchen and dining area. I was not introduced to them. Jamie's children were also at home as school was out, they were usually playing outside with dolls or on the trampoline in the back yard. If they were indoors, Jaime would shoo them out to play when we had our interviews. We would go into Jamie's bedroom where her child's crib was placed next to the full sized bed and have our interviews. Alex, Jaime's youngest child was with her throughout our interviews.

Alex was due in May and Jaime received prenatal care at the Public Health Department. Jaime reported that she went for her regular checkup in February and was unaware that Alex might be born premature or with Down's syndrome. Jaime's labor pains began at about 6 in the afternoon and she went to the hospital about 9 or 10 that evening. There she was told that Alex would be premature and he was born on that evening, March 1, at 6 months gestation. Jaime said

Alex was given oxygen and placed in an incubator. He remained hospitalized in intensive care for approximately 3 months and was discharged to his home in May.

Jaime recalled expecting a normal delivery and that her husband initially felt bad when Alex was born. She remembered telling him that these things happen and that they have to accept it. Now, she said they are fine and that they love Alex very much. When Jaime was discharged from the hospital after 3 days, she and her husband, visited their son daily. At times she would take a taxi to the hospital or go with her husband after his workday. Her sister-in-law cared for her children during this time.

When Jamie described Alex she said he can crawl, get off of the sofa alone when he is placed on it, and that he drinks from a bottle. Alex goes to doctors for his vision, hearing, pediatric, and pulmonary needs. Jaime said Alex gets sick often, has been hospitalized several times, and that they initially thought he was having problems getting oxygen, however tests have shown no further problems in this area. She also stated his eyes tear up and move too much and that he is also not able to hear because of liquid in his ears or possibly due to problems in his inner ear. She said Alex's condition is very complicated and showed me a diagram of the ear given to her at the hearing clinic to point out Alex's potential problem areas as explained to her. Alex's doctors are also trying to coordinate surgeries to correct his vision and hearing problems. Alex wears hearing aids and when Jaime placed them in his ears he tugged at his ears until he dislodged them.

Alex has received EI services for approximately 9 months including services for his hearing deficit, occupational therapy to address developmental delays, and case coordination. Currently, Jaime stated his goals are to use his hands more, play, and talk. Therapists come to her home one time a week and Jaime felt Alex is making progress with crawling and playing. Alex's sisters also were observed playfully picking him up and playing with him as he crawled about the floor.

Janeth

Janeth is 21 years old and her husband Miguel is 30 years old. Janeth is the eldest of 5 children all of whom live in Mexico. Janeth and Miguel were born in Durango, Durango, Mexico. Janeth has been in the U.S. for about 6 years. Janeth and her siblings were orphaned when their mother died shortly before Janeth entered middle school in the U.S. She and her younger brother came to the U. S. to live with relatives in the town where she now lives. Janeth attended elementary school in Mexico and middle and high school until the 10th grade in Georgia. Family life for Janeth and her brother in the U.S. was unstable and her brother has since returned to Mexico. Miguel has 3 brothers who also live in this town and 1 sister who lives in Kansas.

Janeth and Miguel have been married for about four years. They waited for over two years before deciding to have a child. Janeth was three months pregnant when she went for a check up. Her pregnancy was uneventful and she and Miguel were happy awaiting their first child never anticipating that there could be problems. Her delivery went well and after Brigette was born, she stayed in their hospital room for about 4 hours. Janeth noted something in Brigette's face and told herself "*Que sea lo que Dios quiera*" or "It will be God's will" as she held her. During this time Miguel left to buy a camera, after he returned they were told that Brigette had respiratory problems and she was placed in an incubator. Janeth remembered that it seemed strange that Brigette would have respiratory problems after being in the room with them for about 4 hours and they wondered if this were true. Later a doctor and an interpreter entered Janeth's hospital room and told her and Miguel that Brigette had Down's syndrome.

Janeth was discharged after 3 days and described this time a "*duro*" or difficult. She would take a taxi to visit Brigette every 3 hours since she did not drive. She would also go to the hospital early in the morning with Miguel who would go to work from there. Brigette was hospitalized for 6 days and has not been hospitalized since. Janeth recalled that she and Miguel awaited Brigette's birth with much love and continue to love her very much. They decided to learn as much as they could about Down's syndrome and to raise Brigette as normally as possible. When Brigette was about 2 months old, Janeth took her to be evaluated as her diagnosis qualified her for early intervention services. Janeth and Miguel decided to postpone EI services because Brigette was developing typically. Brigette began receiving physical therapy and case coordination when she was about 6 months old. Currently, Janeth describes Brigette as "*hermosa*" and "*bonita*" (lovely and beautiful) saying she and Miguel feel Brigette can do anything. Brigette is able to sit, crawl, play with toys, and make vocal sounds.

Janeth and her family live in a quiet residential neighborhood where homes line the street as the street slopes away toward the busy streets of their town. When I arrived for our first interview, the physical therapist was leaving and Brigette was happily playing on a blanket on a carpeted floor surrounded by toys. The room had no other furniture except a computer and appeared to be used as a playroom. This home originally belonged to Janeth's sister-in-law (husband's sister). Initially Janeth and Miguel lived here then moved to a trailer. After Brigette was born, her sister-in-law moved and tried to sell the home. Janeth and Miguel moved in saying they would rather rent a home that was familiar to them and a good place to raise Brigette than rent the trailer. Four people live in this home, Janeth, MIguel, Brigette, and Miguel's brother. Miguel works in construction from morning until 8 or 9 in evening 5 days a week and some

Saturdays until about 3 in the afternoon. Her brother-in-law also works. Janeth currently is a homemaker; she also worked as a packer and checker at a poultry plant for about a year.

Each participant was very forthcoming with information describing her feelings regarding the circumstances surrounding her pregnancy, the birth of her child with a disability, describing her personal and her family's responses, as well as her hopes and dreams for her child. In all cases, and in 2 cases when the participant's husband was present, he contributed his viewpoint regarding his child and the early intervention program. The personal nature of this information at times was difficult for the mothers and fathers to relate and required a sensitive attitude on my part.

We now turn to the participants' responses to the four research questions posed in this study. Their responses are summarized in Tables 1 through 4. Findings were sorted into categories that are presented in this chapter highlighting specific responses made by the mothers that generated themes in response to each of the research questions. The Spanish words used by the mothers were incorporated into the categorization of their responses to each question. These words were selected for categorizing the findings of each question because the mothers (and in some cases, fathers) frequently used certain words to convey their responses to particular research questions. Each Spanish word used to categorize findings is defined in order to relate it to the content of the responses to each question. Furthermore, the Spanish words might hold relevance to interchanges between persons of different cultures. Findings for each research question are presented individually; however, several questions interrelate and will be discussed in Chapter 5.

How do Mothers of Mexican Origin Participate?

In order to answer the first research question “How do mothers of Mexican origin (MMO) participate in their child’s early intervention program?” it was necessary to ascertain what participating meant to the members of this study. The mothers’ definitions of participation provided insight into the meaning of the term for them and established what might guide their actions when they participate in their child’s EI program. The mothers had little difficulty describing what they do in their child’s EI program when they described participating in therapy or activities pertaining to their child’s development or wellbeing. Three Spanish words *significar, hacer*, and *conviver* denote significance or meaning, doing, and living together. These words represent the mothers’ descriptions of how they participated in their child’s EI program. Table 1 represents thematic categories and subcategories that comprise findings regarding the mother’s definitions of the term participation as well as specific ways in which they participate.

Significar (Meaning)

During the first interview with the mothers, I observed that I had to explain what I meant by participation when I asked the question “Describe how you participate in your child’s early intervention program.” The mothers usually asked what I meant and then I would reply with a specific example such as “Well, how do you participate or what do you do to participate when the therapist works with your child?” I found that the mothers grasped the meaning of the question “How do you participate?” when I introduced the question with “What does the word participate mean or signify to you?”

The Spanish word “significar” or “significarse” denotes to mean (National Textbook Company, 1994). When the mothers defined the word participate in their own words, then followed with their descriptions of how they participate, their responses took on clarity and left

Table 1

Participating in an Early Intervention Program

Research Question	Findings
How do MMO who are undocumented immigrants participate in their child's Early Intervention program?	*Significar* (Meaning) • Defining participation • Helping • Paying attention • Being present • Being clear • Informing • Being prepared *Hacer* (Doing) • Learning techniques • Practicing • Answering questions • Asking questions *Conviver* (Co-existing) • Acceptance

little doubt that they were describing how they participate in their child’s EI program. It no longer appeared that they were relying on my examples of participation. I began every initial interview with the question “How do you define or what does the word participation mean or signify for you?” in order to establish what participation signified to the members of this study.

The participants’ and the service coordinator’s definitions of the term participation illustrate how the participants described what participation meant to them. At times, the participants’ Spanish words are used to convey thoughts that signify particular meanings that emerged as themes regarding participation. When the participant’s husband was present, questions were addressed to him as well and his responses are also presented.

Several of the other subcategories included under the category *significar* represent specific examples of participating. The subcategories include helping, paying attention, being present, being clear, informing and being prepared. Some of these sub themes are embedded in the mothers’ definitions of participating; however, specific examples of participating that reflect these subcategories are also provided.

Defining Participation

Karina stated

> *…¿participación en intervención temprana? Bueno para mi es un….como dice la palabra participación en ayudar a las niños, poner atención en sus terapias. Compartir con las terapistas, compartir con otros papas – tipo de terapia, tipo de….sera enfermedades*
>
> … participation in early intervention? Well, for me it is… say participation in helping the children, paying attention to their therapy. Sharing with therapists, sharing with other parents – about therapy or illnesses/diseases

Odalis responded

> *pues participar para mi se entiende que pues, ayi me aclara todo de que yo tengo que hacer, todo con mi niña.*
>
> I understand participation to mean being clear on everything I have to do with my child.

Jaime

> *…yo participo ayudarle a el; darle terapias tambien. …para que sepan mas sobre los niños, que son las necesidades que tenien. … si me gusta participar. …decirles lo que el niño tiene. Este, como esta desde que nacio hasta ahorita.*
>
> I participate by helping him, giving him therapy too. …so that they [providers] know more about the children, what they need …I like to participate. …to tell them about the child, how he has been from the time he was born until now.

Janeth

> *'participar' para mi es ayudar, …estar preparado para sequir con qualquier cosa que se le necesite, estar allí. O sea no nada dejarle las cosas a las personas… Tiene que estar uno allí para participar, para ayudar, para ver como va avanzando la niña y todo. O sea no estar atenidos a que las personas que les estan ayudando tiene que hacer lo todo. Uno tiene que ayudarla tambien*
>
> Participation means helping, …being prepared and present. Not leaving things to others… One has to be present to participate, to help, to see how the child is improving. Not rely on others who are helping to do it all. We have to help her too.

Janeth's husband Miguel responded by saying

> *Yo pienso que estar participando en lo de la niña. Estar adelantose uno con la niña tambien antes de que ellos llegen. ...Por eso es que, que nosotros hamos estado con todos*

> *los libros que hay sobre de eso; estamos leendo para no estar esperando que llege otra persona que nos diga…no, para cuando llege ya la otra persona ya estar nosotros adelantados…*
>
> I think participation also means participating in everything pertaining to the child. Getting ahead along with the child before they [providers] arrive. That's why we read about it so we don't have to wait for someone to come and tell us…no, so when they arrive we can be ahead…

The EI service coordinator who primarily works with Latino families was also asked to define participation. She responded by stating

> First of all, the service coordinator's responsibility is to make sure the family is informed of what things mean and what their choices are because it's kinda hard to participate if you don't know those things. And then they [the family] participate by making choices about what they want. Whether that be choice of providers or the outcomes, what it is the family really wants the child to accomplish and that they have their say in what we do. We go according to what the family sees as their need. I guess that's what it means to me. To be really involved every step of the way and make any choices.

How the respondents defined participation provided insight into the meaning or significance of the term for the participants. Their definitions of participating helped to establish what guided their actions or what they did when they took part in their child's EI program. Several specific examples of the significance of participating for the mothers were also mentioned in the other subcategories of doing and co-existing. Each finding will be related to a particular emergent theme.

Helping

Most of the mothers and some fathers described helping on several levels of the EI process and service delivery in terms of participating. For example, they talked of their participation upon entry to the EI program and during the evaluation phase, when identifying problems and making goals, critiquing treatment, and determining the effectiveness of the treatment their child received. Their descriptions included helping the child, helping each other, helping the service providers, helping other parents, and the family members who help. Most often descriptions of helping interacted with the other subcategories generated in response to this question or with doing (*hacer*) as will be described later; however, the basis for participating involved helping the child.

For instance, Jamie described how she helps her son Alex by participating. "I participated by helping him [Alex], giving him the therapy they have taught me – how to crawl, identify things for him, and following their recommendations". Andrea illustrated how her husband helps with their daughter's (Gabi) care.

> *"Mi esposo tambien el le ayuda…asi ayuda con cateter y todo. Por que esta a lado de mi y de Gabi (laughs). …a que le ayuda caminar, se pone adelante para ayudarle a caminar, le mueve los pies asi o le da masajes tambien*
>
> "My husband helps her too. …helps with the catheter and everything. He is by my side and Gabi's. …helps her walk, stands in front of her to help her walk, he moves her feet or gives her massages"

Miguel, Janeth's husband talked about wanting to help other parents who are new to the experience of having a child with Down's syndrome.

> *…ir a ayudarle, calmarla, porque para saber esto al principio es difícil. Estar ayi para dar le el apoyo pues para que siente mejor y para que mire que no es la unica persona que esta en esto*
>
> … help them [parents], calm them, to know this is difficult at first. To be present to support them to feel better and help them see they are not the only person in this (situation).

Paying attention. The mothers described several circumstances where paying attention was a necessary part of participating. Andrea and Odalis used the term "*dejado*" to denote a person who is negligent or does not take a situation seriously. They usually used this term to mean a negative characteristic that would jeopardize the health of a mother or her child. The term was also used to describe a parent who did not adequately attend to her home, family, or to mean someone who did not follow instructions or recommendations, instead doing things his or her own way consequently impeding the progress of the child. All the parents stressed the importance of paying attention to their child's needs in order to help him or her develop and make progress. They consistently used the term "*salier adelante*" to mean their child would progress or come out ahead as a result of their attention.

Odalis commented

> *… para hacerlo una cosa bien. Por que ya ve muchas veces no hacemos los que los doctores nos dicen y uno lo esta haciendo de su manera y cuando va salir uno adelante? Pues, hecharle ganas con la creatura como Dios nos la dio"*
>
> ….to do something well. Because you see, many times we don't do what the doctors tell us to do and one does things their way then when will one come out ahead? Well, we have to put forth the effort [work] with the child the way God gave her to us

Andrea jokingly inferred that Mexican people always seem to be *dejados* or don't take a situation seriously. She recommended that it is best to take on a situation as one would take a bull by its horns, so that one could agree with and follow a program designed to help the child and family.

Being present. Every mother described being present during the therapy sessions or any EI service. Most talked about it being their role as a mother and how being present helped them know what to do when they carried out therapy with their child throughout the week. The act of being present was described throughout every situation the mothers described from the time the child was born to the present-day.

When the children had to remain hospitalized after they were born, the mothers spoke of their despair on leaving their child in hospital. Being present took on another dimension as it related to learning how to care for their child while having to either commute long distance to the hospital or spend weeks learning the care their child needed before the child was discharged to their care. They also imparted the importance of being present in order to learn, to explain, and to teach family members and professionals who provide home care or professionals in the hospital how to care for the child.

Being clear. This subcategory related to having a clear idea of what the specific responsibilities the mother (and father) had in the care of their child. Odalis explained that being clear meant understanding everything she had to do for her child. She included housework such as cleaning, cooking, and even doing therapy with her child as her responsibility as a mother. Odalis explained

> *pero mientras mi niña esté así con muchos problemas, no me puedo yo mover porque no hay como la madre, no me siento confiada a dejársela a una persona que no pueda estar*

> *ahí todo el tiempo. Aunque estén aquí las enfermeras, yo me salgo solo un rato pero luego entro, no por desconfianza de la enfermera, porque ya las conozco, pero sí quiero estar por si se les ofrece algo, y también para ver que todo esté bien, y si me preguntan "¿que dónde tienes eso, dónde está lo otro?*"
>
> While my child is like this, with many problems, I can't be away because there is nothing like a mother, I don't trust leaving her with someone who can't be here all the time. Even if the nurses are here, I go outside for a while and return quickly, not because I don't have confidence in the nurse, because I know them, but I want to be here in case they need anything, and to see if everything is alright, and if they ask me "Where do you have this or where is the other?"

Being clear on one's responsibilities also related to the mothers' comments on being accountable for their child's health. The mother's role and responsibility for her child were linked to references about her ability to care for her child. For example, Odalis commented, "If I, and my husband, do not participate, then my child will become ill from the "*cochinero*" filth as they say in Mexico. Can you imagine? If I did not do my part, what would they [professionals] say?" Some participants associated the concept of being clear with the importance of knowing what to do with their child or their ability to care for their children. Nidia, Odalis, Janeth, and Jamie stressed that their responsibilities included keeping the child's environment clean, managing feeding and breathing tubes, knowing how to use machines and equipment such as hearing aids, and managing medications. The mothers also dealt with several professionals who either work in their home on an extended basis (8 hour shifts) or come into their home on a weekly basis. These situations appear to necessitate being clear about responsibilities and roles.

Informing. Every situation dealing with the EI process contained an element of informing whether it was the mothers informing the providers or receiving information. Karina spoke of feeling like both a student and a participant when she stated

> *Yo me siento como estudiante y participante también, porque aprendo de ella, y también trato de decirles lo que la niña ha hecho, lo que ha aprendido en el transcurso de la semana. Por eso yo me siento como participante y que tenemos un intercambio de información.*
>
> I feel like a student and a participant too because I learn from her [therapist] and also I tell them what the child has done, what she has learned during the week. I feel like a participant when we have an exchange of information.

Informing concerned all aspects of participating in the EI process. All the mothers spoke of being informed of their rights concerning EI services, specifically the right to choose providers and refuse services they deemed inadequate. Providing information to service providers during evaluation, during weekly or monthly monitoring, and during formal review meetings was also frequently mentioned. The act of informing was also associated with the mothers' capabilities especially in terms of their competence in carrying out procedures and therapy with their children.

Being prepared. Most of the mothers spoke of some aspect of being prepared. For example Janeth and her husband, emphasized learning about Down's syndrome. They gave several reasons why they thought being prepared was important including not relying on others although they acknowledged that having the providers' help was beneficial. Other reasons included, knowing what do in addition to therapy, being prepared before therapists arrive in order to ask questions, and knowing what is best for teaching their child. Being prepared also held significance for the mothers in terms of knowing what to expect from therapy and from EI services in the long run.

The category labeled *significar* addressed the first research question – How do mothers of Mexican origin participate in their child's early intervention program? It included the sub categories of defining participation, helping, paying attention, being present, being clear, informing, and being prepared. The participants' responses illustrated the significance of their participation for them. The significance of what the mothers do when they participate influenced how they *do* participating.

Hacer (Doing)

The next category entitled *hacer* and its subcategories represent what mothers do when they described how they participate. The word *hacer* is emphasized because it means to do (National Textbook Company, 1994) and will orient one to what the mothers do when they participate. These actions involved learning therapy techniques, practicing the techniques with their children, and asking or answering questions.

Learning techniques. When describing what they do when they participate in their child's EI program, the mothers referred to aspects of learning what to do. The relevance of learning what to do was also associated with the previously mentioned themes; however it was also related to the mother's role and social identity. Nidia referred to her responsibility as a mother when she described her role in her child's Early Intervention program.

> *¿Mi responsabilidad? Pues, yo digo es grande, la mia, o que… pues yo soy la mama. Tengo que, tengo que estar; pues viendo como la ayudan para*

> *yo ayudarla cuando yo estoy sola. … Después, por ejemplo me enseñan que le diga a la niña para que ella diga "quiero comer" por señas, entonces yo estoy aprendiendo para yo enseñarle a la niña.*
>
> My responsibility? Well I say, is great because I am the mother. I have to be there, watching how they help her, so that I can help her when I am alone.
>
> For example, they show me what to say to my child so that she can sign [use sign language] to say "I want to eat", then I learn so that I can show her.

Odalis referred to initially being overwhelmed with all the care Soyla would require. Initially, she did not feel capable and was afraid she would hurt Soyla if she inserted the tube too deeply when she was giving her medication. Odalis recounted how she and her husband learned the techniques necessary for caring for Soyla at home and how everything now seems easy.

> *de primero si, se me cerraba el mundo. Ya ahora ya no. …ya todo para mi es, facil pero de primero si, se complica uno.*
>
> At first I felt my world would close in. Now, everything is easy, but at first it was complicated.

Karina recounted how the occupational therapist always taught her how to teach Rubi. "*Por ejemplo, la terapista ocupacional siempre me dice cómo enseñarle*". She described how the therapist gives her advice and information on such things as how to teach Rubi to grasp her spoon, to dress or undress herself, to not throw her toys, to use the bathroom, what toys and games to use to teach Rubi, and ways to get Rubi to move her body like dancing, singing while moving her arms, and learning her body parts.

Jamie described how she follows the therapists' instructions and ideas on how to teach Alex how to crawl, grasp toys and say words that relate to the things she is showing or describing to him. Even though she has received some written instructions in English, Jamie explained she could tell what they mean by looking at the illustrations on the instruction sheets. She related that it is uncertain how much Alex is able to see and hear (he wears hearing aids) and that his doctors are evaluating him for vision and hearing surgery.

Janeth explained that Brigette at three months of age was not having any developmental problems before entering the EI program, so she felt it was best to wait until Brigette was 6 months old to have her formally evaluated. After Brigette began receiving EI services Janeth felt that she progressed more because the EI services helped her learn what to do to help Brigette.

Practicing. All of the mothers referred to practicing the techniques they learned from the providers at home in order to carry out therapy with their child. Even though Gabi's physical therapist came one time per week, Andrea would practice walking with Gabi the other days of the week. Andrea recognized the developmental significance of walking for Gabi. She claimed that Gabi understood its significance too stating "*ya entiende el significado de que es caminar*." She found practicing with Gabi motivating because initially the doctors said Gabi would not move from her waist down. She also described practicing wheelchair techniques with her daughter: "*Suponemos con la wheelchair* [Andrea's word] *tiene ella que abrocharse, ponerle frenos, y bajarse.*" "Suppose with the wheelchair, she has to fasten the seatbelt, put on the brakes, and get off herself." When Gabi got tired of practicing using her wheelchair, Andrea would tell her to unfasten her seatbelt and put on the brakes herself. Then Gabi would be expected to get out of the wheelchair and onto the bed herself.

Odalis explained that often she has no time to practice with Soyla during the week because she is busy with housework. She says that the nurses take time to practice teaching Soyla how to sit and play and that she will take the time to play with Soyla after the therapist leaves. Odalis' and Nidia's children have feeding tubes and their current goals are to eat. Consequently, both are following instructions about how to present food to the children, how to teach them to use a spoon, and the importance of including them in mealtime by having them sit in their high chairs at the table during meals. Nidia also said she appreciated practice because watching is not enough, it is the practice that helped her most and that has made her confident in caring for Ruth at home.

At this time all the mothers but one stay at home with their children. They all practice with their children in order to help them progress and all use the techniques the service providers have demonstrated. They also described "*platicando*" or having chats with their therapists about their children and rely on their advice and the sharing of information. Most of the mothers say that they answer and ask questions during these chats and appreciate having assistance with their children's development.

Answering questions. The next two sub categories of *hacer* or doing deal with answering and asking questions. Overall, all the mothers described doing this when they participated in all phases of the EI process. The EI process entails answering questions during intake, evaluation, service provision, review, and when parents critique intervention or when they are asked to determine the efficacy of EI therapeutic activities. For example, Odalis stated

> *Si, me preguntaron como, pues que problemas era lo de la nina, y pues yo las estuve explicando lo que me vean dicho allá en el hospital. Luego ya me dijieron que como le estoy dando cuidados yo a la nina y ya les estuve diciendo de… cosa por cosa lo que tenia que hacerle a la nina*

> Yes, they asked me about my child's problems, I explained what they said at the hospital. Then they asked how I was caring for my child and I explained everything I was doing for my child

All the participants felt they were able to answer any questions posed regarding their child's development. They were also able to describe their child's strengths as easily and thoughtfully as they described the things their children could not do. The mothers also stated they were comfortable with imparting information about their children to others. Nidia and Karina related that during their child's evaluation, they were asked questions about what their child did and if she was progressing in terms of her development. The evaluators then asked to observe the child doing the task. For instance, Nidia recounted

> *Pues si me preguntan que hace, en que esta progresando mas Por ejemplo, en esta última vez me preguntaron qué hace la niña, y entonces la pusieron en práctica los que vinieron y así vieron cómo trabaja ella, y este… no, pues está bien todo.*
>
> Well yes they ask me what she does, where the most progress is seen. For example, the last time they asked me what the child does, and then they had her demonstrate that way they could see how she works, and …well, it is all good.

Janeth described how she participated during Brigette's intake evaluation,

> *Si participe por que yo estaba ayi con ella. Y mire como la evaluaban, le enseñaron jugetes, y ella los queira. Todo estuve ayi con ella durante de toda la evaluacion. Y me gusto mucho como la trataron. Este, como jugaron con ella. Pues todo que me preguntaron, me preguntaron en punto de vista mia o si todo…pues estuvo bien para mi eso.*

> Yes, I participated because I was with her. I saw how they evaluated her, they showed her toys and she wanted them. I was with her during the whole evaluation. I liked how she was treated, how they played with her. Well they wanted my point of view in everything they asked, well that was fine for me.

Andrea described Gabi's behavior when she is evaluated, "They asked if I had any questions, something to add, and because Gabi gets embarrassed when she is evaluated and won't show them what she can do, they asked how Gabi does things. At home she does everything." Andrea, like all the mothers also answered questions about what her child did during the week when the provider(s) or coordinator came to her home to make a progress report.

Asking questions. The mothers all reported feeling comfortable asking questions of their service providers. They asked questions regarding the treatment their children received. For example, Andrea stated that she asks either her service coordinator or the therapist when she wants information about a particular treatment Gabi is receiving. Odalis also stated that when she is in doubt she asks questions.

All of the mothers reiterated that they understood their responsibilities and rights regarding early intervention. This underscored the role their service coordinator played as their advocate. For example, Karina stated "The coordinator gave me a form, explaining all my rights about what I can say is good or bad [about the EI program]. Odalis also reiterated, "It's clear, that if there is anything I don't like I have the right to say so, to let them know I don't like how it is done." Overall, the mother's descriptions of asking questions were associated with their descriptions of their relationships with their providers. This aspect of participating is expanded by the participants' responses to the research questions dealing with what phenomenon or actions on the part of the service providers promote participation.

Conviver (Co-existing). The final category concerning how mothers participate in their child's EI program dealt with the mother's (and father's) views about their child, their child's development, and their hopes for their child's future. This category is labeled *conviver* and means to live together or figuratively, to co-exist (National Textbook Company, 1994). The participants' perspectives are represented here as findings pertinent to describing how the participants view their child living with others.

Five of the six mothers did not anticipate having a child with a disability. Jamie, Janeth, and Andrea were unaware that their child would be born with Down's syndrome or Spina Bifida. Karina was informed that her baby had Down's syndrome late in her pregnancy. Nadia was unaware that she was pregnant and Odalis was aware that something was wrong with her baby and had to be closely monitored from the time she was four months pregnant. All received prenatal care with the exception of Nidia and Andrea.

The mothers described the uncertainty they initially felt regarding raising a child with a disability. All the mothers imagined a life very different and difficult upon having a child with a disability, but now they depicted a life that is enriched by having their child with special needs. Karina echoed the sentiments the other mother's expressed

> *Bueno, yo pensaba que iba a ser otra cosa muy diferente. Yo me había imaginado un cambio de vida total, tanto para mi esposo, mi otra niña como para mí. Pero no, ha sido muy bonito, muy fácil por decirlo*
>
> Well I thought it would be different. I imagined a total change of life for my husband, other daughter, and for myself. But no, it has been beautiful, very easy so to speak.

Several of the mothers and fathers mentioned acceptance of a child with a disability in the family as well as by the child’s community and by others. All of the participants spoke of accepting their child as God had sent him or her. Karina and Jamie also stated that Rubi and Alex are considered the same as their other children except for having to go to the hospital more and needing therapy. Jamie also made a point that Alex should not be compared with typically developing children by commenting “He will do what he is capable of doing” and that he should be treated like any other child.” Odalis said she viewed Soyla as being just like any other child, because “…if her feeding tube were removed from her nose she looks completely normal.” This was why she said she puts all her effort into helping Soyla eat by mouth and do whatever else she might need so the feeding tube can be removed.

Janeth and Miguel talked more about Brigette’s acceptance by others and how they would teach her to be strong and not be hurt by people who would make fun of her and might not understand her. Miguel stated “*Central relaciónarla con toda la gente*” meaning they would make sure others get to know Brigette. They also said they would raise her to be independent. Jamie, Odalis, and Karina also echoed these sentiments. All the parents described themselves as overprotective, but they also said their goal was for their child not to depend on others. Being independent or being able to take care of oneself was mentioned by all the participants as something they desired for their children.

Although the parents expressed sadness about their child’s condition, they all expressed the desire to “*sacar el nino adelante*” which means to help their child get ahead or succeed. Nidia acknowledged, “I would like for my child to be well, not to be connected to the tubes. At night she needs oxygen, and with all the equipment she becomes agitated. I just put it [oxygen hose] on and she cannot tolerate it and takes it off. I would like for all this to end.”

On the other hand, the participants also expressed a willingness to help their children overcome any disability and had faith in their children's abilities. Karina mused on living with Rubi "Yes, I did not know how different [Rubi] would be compared with other children, I didn't know about Down's syndrome, what type of care we would have to give her, but it turns out that she is no different." She also related her feelings when she sees other children noting a difference between them and Rubi, *"Me da tristeza pero yo sé que lo puede hacer,"* " I am saddened but I know she can do it."

Jamie asserted that the best way for professionals to help the child and family is to accept the children as they come and help them come out ahead (*salir adelante)*. She felt professionals who convey this attitude help parents teach their children. Finally, Andrea expressed faith in her self, as did most parents. She reported getting excited about Gabi's future, said their lives were straightening out, that she is learning more about how to care for Gabi, that there is much work to do and many things to consider, and that it will be possible. "*Me emociona por que es como un recto, como aprender mas, como tendra cuidarle, mucho trabajo, muchas cosas, pero vamos a poder…."*

The category labeled *Conviver* represents how these parents view their child living with others. It also represents their hopes and dreams regarding how others would view their child. This category is linked with what it means (*significar*) to the mothers to participate and how they do (*hacer*) participation. These themes convey the participant's attitudes and feelings about participating in their child's early intervention program.

Phenomenon that Promote Participation

Themes generated from the second research question concerning what mothers of Mexican origin identify as promoting their participation in their child's early intervention program are represented in Table 2. The mothers' responses indicated perceived interactions, observed events, and feelings involving communicating, receiving recommendations and support. Sub categories are also represented under each category according to specific examples given by the participants.

Comunicar (Communicate)

Due to having providers come into their homes on a weekly basis to provide EI services communication was frequently mentioned by the mothers. The participants described several forms of communicating as promoting their participation in their child's EI program. Two subcategories: *platicar* or chatting and language such as use of written, verbal, or demonstration for instructing were forms of communicating described by the mothers. Although the forms of communicating are categorized separately, there was considerable overlap in how the mothers described communicating.

Platicar (Chat). The Spanish word *platicar* describes the first subcategory and is meant to convey chatting with someone. The mothers often described *platicando* or a verbal exchange with providers about their child, the intervention or treatment, and EI procedures. When they described their communication with their providers, most depicted a very relaxed and informal interaction. The tone of the communication was also personal and involved *confianza* or trust, a theme discussed later as actions on the part of service providers that promote participation. The comunication usually took place during interactions with providers in the participants' homes and involved teaching.

Table 2

Phenomenon that Promote Participation

Research Question	Findings
What do MMO identify as promoting their participation in their child's Early Intervention program?	*Comunicar* (Communicate) • *Platicar* (chat) • Language – Spanish, written, verbal, demonstrate *Surgerir* (Suggest) • Teaching • Informing • Advising *Sostener* (Support) • Husband, children, family • Faith/Religion • Parent group

Language

The mothers were primarily Spanish-speaking even Janeth who attended middle and high school in the U. S. preferred speaking Spanish. Janeth said she was comfortable speaking English; however, there were words that she had to look up in a dictionary. Her husband also said he would often come home from work and look up the meaning of words that he had heard during his work day, but did not understand. Andrea's husband was taking English language classes twice a week after work. Andrea had attended these classes also, but stopped because of her work schedule. Nevertheless, she plans to go back and practices "a word a day." Even though, the mothers stated they preferred to receive information in Spanish, all of them said they were learning English on some level.

Nidia and Odalis received large amounts of information pertaining to medications and procedures for their children. Both have had several providers with varying levels of Spanish language proficiency come and go in a short period of time (approximately a year). Nidia described her Spanish-speaking service providers as "good". When communicating with her providers who did not speak Spanish, Nidia used signs, she used the four-year-old child who she babysits to translate at times, or the dictionary. For instance she declared *"Pues me han tocado buenas y me hablan en Español. Una de las enfermeras lo hablaba más o menos pero ya se fue. Con las demás medio por señas y un poquito me ayuda la niña, y el diccionario."* Nidia stated she is reassured when instructions are given in Spanish and in English so that she and providers understand what is to be done with Ruth and in case she forgets. Although Nidia and Odalis had no complaints about having some providers who do not speak Spanish; they stated they appreciated and preferred Spanish-speaking providers.

For the most part, all the mothers reported receiving written information in Spanish from their EI service coordinator. They preferred receiving written and oral instruction in Spanish, demonstration when instructed, and having a translator present when their children were evaluated. Jaime said she referred to the pictures on the forms with given written instructions in English because they are easier to follow. The mothers acknowledged they understood that having a translator was not always possible. Still, all the mothers expressed appreciation for their provider's efforts at communicating with them. Karina stated:

> *Tratamos de comunicarnos cuando no hay nadie más que nos pueda ayudar, y él trata de entender español, son pocas las palabras que dice pero veo que él sí trata de hablar, y sí nos podemos comunicar, de una manera o de otra.*
>
> We try to communicate when there is no one to help us. He [service provider] tries to understand Spanish, he speaks a few words but I can see he tries to talk, and yes, we can communicate one way or another.

Surgerir (Suggestion). When the mothers talked about communicating with professionals the content of their conversations consisted of receiving recommendations or suggestions from the service providers. The scope of the providers' suggestions corresponded to the goals the mothers would articulate; however, the mothers did not always state the goal as written on their child's IFSP. They described their children's goals in more global terms such as "sacarla adelante" meaning to help the child get ahead or progress. For example Karina explains

> *Bueno, (sighs) para lograr las [metas] en questión de la niña, Rubi, para lograr que…si o sea, para logra sacarla adelante. De yo se de un modo o de otro, si de una manera o de otra, pero, de hacer todo los….um obstaculos. O sea, a lograr las metas.*

> Well, (sighs) in order to achieve Rubi's goals, that is, in order to get her ahead (make gains). For me, be it one way or another, if on her own or by other, obstacles are met in order to achieve the goals.

All the mothers and Miguel, Janeth's husband described receiving suggestions or recommendations about how to help their child develop as motivating them to participate.

Teaching. The mothers described the suggestions they received from providers as occurring in the course of being taught what to do with their child. Nidia described how therapists addressed Ruth's developmental needs when she explained:

> *O si, si, por dicer de las metas. Que primero pues una de las metas hera que caminara, ya camino. Ya una terapista ya no viene. Ahorita estamos en la de que coma. De comer y el habla pues no se puede todovia pero hay poquito poquito les enseña con, con señas, con juegos...*
>
> Oh yes, yes, speaking of the goals. Initially, one of the goals was that she [Ruth] walk and she walked. So one therapist doesn't come [to her home]. Now, we are about getting her to eat. To eat and talk because she can't yet, but little, by little we teach her, with signs, and games…

Karina related that she expects the best for her child. She stated that she considered the therapists to be "… very good, like teachers, because they taught me how to help her and how to teach her too." Brigette's father Miguel commented on his role as teacher modeled after the therapists *"…de saber lo que ellos sepan - porque en eso se tiene que fijar uno tambien, que movimientos hace. Todo. Nos lo informen lo que estan haciendo mal los niños"*. His words indicated the importance of knowing all that the therapists know and being watchful of his child's reactions and movements. Furthermore, he wanted to be be informed of what his child is not doing well.

These examples illustrated that the parents viewed the professionals as teachers. Moreover, their implied role as students indicated a willingness to be a participant in their child's care. Many of the parents' comments regarding being taught how to care for or provide therapy for their child echoed the significance that participating carries for them.

Informing. The next category, informing, might be closely related to receiving suggestions or being taught; however, the participants' responses had more to do with being informed. The parents indicated the importance of knowing about resources, how to access a service, and knowing about the positive and negative aspects regarding their child's development. Being informed was also closely tied to their preferred ways of receiving information. For the most part, the mothers indicated that they knew about the EI program when they left the hospitial after delivering their babies. For example Andrea described being informed

> *Siempre en el hospital, cuando te alivias y saben que tu hijo esta malo, te dan unas tarjetas donde trae las direcciónes, telefono donde tu puedes hablar o comunicar tu pregunta. Eso es bueno, por que ya sabes desde el hospital.*
>
> Always, at the hospital, when you give birth and they know that your child is sick, they give you cards with addresses, telephone numbers your can call to ask questions. This is good because it helps you know before you leave the hospital.

Andrea also said "This was done for me. I was also telephoned at home and visited at home."

The mothers were also very clear about their rights in the EI process; however, some aspects of the EI program such as the evaluation process, establishing goals, and program termination were less clear. Being informed also appeared to carry a different meaning for some of the parents than for others. For example, Jamie viewed being informed as promoting her participation stating that if she received helpful information then she would not feel bad. Janeth and her husband, MIguel viewed being informed as promoting their participation when information was directly related to the child's problem and was provided as quickly as possible. It should be remembered that they did not know their child would be born with Down's syndrome, nor were they immediately informed that Brigette had Down's syndrome when she was born.

Miguel, Janeth's husband, stressed the importance of being informed so that parents could be prepared to care for their child at home, to know how to gauge their child's development, and to carry out therapy. He also said that he valued being an informed parent because it ultimately benefited Brigette. Lastly, Odalis viewed being informed as a motivator for participating when she explained that receiving positive information or feedback about the quality of her care for Soyla served to give her a purpose and to cheer her, "When doctors tell me my child is doing well, it motivates me *(me da ánimo)*. It would be bad if they told me instead of going forward she is regressing."

Advising. Most of the mothers distinguished the difference between receiving advice and being taught, receiving suggestions, and being informed. The mothers referred to being advised in the sense of "*consejo*". A *consejo* denotes advice that is based on trust or is solicited from a trusted person. Just like the informal chat, a *consejo* is more personal such as being counseled. Several mothers referred to being advised and being free to solicit advice as promoting their participation. This was largely based on an element of trust that is discussed later as a service provider action that promotes participation.

When Karina described her experience with EI providers, seeking advice became the key to her feeling comfortable about Rubi's impending transition out of the EI program. Karina explained the following concerning choosing a preschool for Rubi.

> *…tambien pido consejos a las terapistas, y les comento, bueno platico. No quiero decider sola que es mejor para ella. Yo quiero las terapistas que me den su opinion*
>
> I ask for the therapist's advice, I comment, well I chat with them. I don't want to decide on what is best for her by my self. I want the therapists to give their opinion

Karina's example of asking for advice illustrated the important personal nature consejos play in facilitating participation.

Sostener (support)

The third category of themes generated concerned support. *Sostener* is a word that denotes to endure or to support oneself (*mantenerse*) (National Textbook Company, 1994). The word *sostener* was used to label this category because it represents things that the participants described as helping them participate in an EI program. Each interview with the mothers and fathers in some cases contained sensitive information that was often difficult for the participants to discuss. In the course of the interviews, several of the participants referred to family members or to circumstances and events that helped them initially endure long hospitalizations and uncertain outcomes for their children. Furthermore, the mothers identified their supports as being instrumental in carrying out day- to-day routines that also involve participating in their child's EI program.

Husband, children, family. The participants identified different family members as supports when they talked about their pregnancies, when their child was diagnosed with a condition, the circumstances surrounding the birth, hospitalization, and the present day care of their child. Additionally, the mothers' contextual stories provided some insight into how some mothers described being supported. Still, the mothers specifically described the kind of support they received and from whom they received it when they discussed how they managed or maintained family life.

All of the mothers said that their husbands were supportive during their pregnancies and the birth of their child. The mothers' discussions with their husbands involved accepting their child as they accepted their other children and a resolve to do what they could to "*sacarlo adelante*" or to help their child get ahead or to make progress. They also said their husbands continued to be supportive but they found that their husbands' work schedules constrained their participation in the EI program. For instance Jaime commented *"Pues, el si le gusta pero es que tiene mucho trabajo. Pues tiene que trabajar. Pero si le gusta.",* "Well, he would like to [participate] but he has too much work. Well he has to work. But he likes it [participating]." Janeth's husband also echoed this sentiment and stated that he wanted to change jobs in order to spend more time with Brigette.

Other family members were also identified as supports. Odalis said she decided to move in with her sister's family for the support and care she felt she would need after her complicated pregnancy. She commented*"Yo sabia bien que como quiera iba necesitar yo de mi hermana."* Nidia relied on help from her adult daughter to maintain the household, provide meals, and lunches for her husband to take to work while she was with Ruth during her long hospitalization. She commented *"Ella [Nidia's daughter] copero de esa manera en la casa, ella me preparaba las comidas por que yo tenia que estar en [city] por la nina. Pues imaginase para ir y venir, no podia pues ellos trabajan."* Nidia lamented that she could not come and go to the hospital at will because her family had to work.

Andrea recognized her children *"mis hijos"* as being her supports. Although some of the mothers reported not having extended family members in the U.S. they spoke of family members on their husband's side of the family who were supportive. They also said that they kept regular contact with family members in Mexico. These family members were described as concerned, supportive, informative, and routinely providing advice on caring for the child.

Faith. All of the mothers made references to the will of God when describing what sustains them. They also said they accepted their child as God gave the child to them. They referred to God as the one who provided the support they needed to carry out the work required to help their child develop to their potential. Some mothers' references to God extended to being able to go back to work and contribute financially to the family once their child was able to care more for her self. Usually the mothers' wishes for the future were prefaced by the words "*Si Dios quiere*" or "God willing".

Nidia spoke of Jehovah and her brothers in faith when describing Ruth's hospitalization and the ordeal of going to court for gaining custody of Ruth. Moreover, she added that her family and most especially her husband was her source of support because he was there for her. She commented, "*Mas que nada la confienza en Jehova. Verdad, pues es El me da la fuerza, personas - hermanos espirituales, mi familia, pues mas que nada la de mi esposo, pues el es el que estaba aqui"*. "More than anything my trust in Jehovah. True, it is He who gives me strength, persons- spiritual brothers, my family, well more than anything my husband, because he was always here." Nidia reported attending Jehovah's Witness services three times a week and Karina said she attended the Catholic Church on a weekly basis. Andrea and Janeth reported being Catholic and attending several times a year and Jamie and Odalis reported no religious affiliation. Nevertheless, all the mothers referred to God's will as a factor in realizing outcomes for themselves and their children.

Parent group. Parent to Parent of Georgia is a support group that provides information and support to parents of children with disabilities (http://www.parenttoparentofga.org/ accessed July 26, 2005). Jamie, Andrea, and Karina described attending this parent group as a source of support. Odalis and Janeth said they had been informed about the group, but had not attended. Nidia said she had not heard of the group even though her case coordinator stated she told all the families with whom she works about the parent group. The mothers who had attended the group said that the group met on a monthly basis at a local school. Reimbursement for transportation was also provided if needed. Parents and their children attend the group and parents usually bring food or refreshments are provided.

Andrea described the group as therapy for families. She said that the content of the meetings sometimes involved the emotional stresses, demands, and feelings of guilt and blame that parents have about disability. Andrea described the meetings as a place where parents can celebrate the joys and triumphs of their children meeting their goals.

> *O! yo iba a Padres a Padres de Georgia y ayi me dan como clases, de todo, y tuve aprendiendo. A veces hablan de que los papas cuando uno tiene un nino asi, se hechan la culpa de unos a otros, y se divorcian or se dejan, … hay como terapia de padres tambien para que los urge a esas problemas. Hablan de que tienes un nino con descapacidad, cuando hace algo te sientes mas feliz, por que, tienes algo especial.*
>
> Oh! I went to Parent to Parent of Georgia [groups] and there they give classes about everything and I learned. Sometimes they talk about parents who have a child like this, they blame each other, or they divorce or leave, it's like therapy for parents, for those of

> us who have those problems. They talk about having a special child, when he does something you feel happy because you have something special.

Jamie also described the group as a resource for getting information about certain diagnoses, social programs such as Medicaid, and schools with beneficial programs for her son Alex. Futhermore, she said that the group was a distraction from boredom. Overall, the mothers who attended the parent group felt it was a beneficial resource.

The phenomenon identified by the participants as promoting their participation included communicating with providers, receiving suggestions from providers in the context of teaching, being informed, and getting advice. These forms of interacting were also described as sharing experiences to which the mothers felt invited and valued. Finally, the mothers identified their husbands, children and family, religion, and the parent support group as things that served to sustain them throughout their pregnancy, birth of their child, and the present.

Actions that Promote Participation

Findings generated from the participants' responses to the question concerning specific actions on the part of professionals that promote participation (See Table 3) were categorized as three components. The word *nacer* meaning to originate conveys the notion of service providers who were creative and committed to their work with the children. The term *apoyar* or to support was used by the mothers to connote the service providers' actions that invited their participation. It also encompassed the actions of the service providers that signaled they valued the mother's participation and the service providers' supportive attitudes. Finally the term, *confianza* or trust included mutual trust, providing options to the mothers, and communicating. Sub categories of these themes provided specific examples given by the respondants of actions that promote their participation.

Table 3

Actions that Promote Participation

Research Question	Findings
What actions on the part of service providers do MMO identify as promoting participation in their child's Early Intervention program?	*Nacer* (Originate) • Creative providers • Committed providers *Apoyar* (Support) • Inviting • Valuing participation • Supportive attitudes *Confianza* (Trust) • Mutual trust • Providing options • Communicating

Nacer

Nacer is a word that means to be born or originate (National Textbook Company, 1994). It is used here to denote descriptions of actions originating from the therapists that helped the child and thus motivated the mothers to participate. Subcategories of *nacer* were the creativity of the providers and the commitment that they showed in providing services.

Creative providers. When Nidia described what Ruth's therapist does to help her eat she got excited and said

> *… por ejemplo, (names occupational therapist) ya ve ella viene, le trae de todo a ver que, con que la anima. O sea le busca bastante. Y yo se, el niño, que es como un yo digo vocación, verdad? Que tienen para los babes. O sea que trabajan en eso, y les nace por que los tratan bien, verdad?*
>
> …for example, (names occupational therapist) she comes, brings things that will motivate the child. That is she looks for ways or will try anything. And I know a child is like a vocation, true? That they have for babies. That is they work at it, it is inborn because they treat them well, true?

Nidia's words described the therapist as creative and one who will try anything to help Ruth meet her goals. Furthermore, Nidia said she felt ideas originated or "*le nace*" with the therapist because she is committed to working with children as a vocation.

Karina described Rubi's speech therapist:

> *Ella es muy buena terapista, ella juega con la niña, canta, baila. El baile es para ayudarle que mueva sus manos, que brinque, que mueva su cuerpo, que conozca las partes de su cara, su nariz, sus ojos, su boca, sus oídos, sus manos. Que aprenda movimientos con su cuerpo, que aprenda de qué manera va el ritmo de la canción. La*

> *idea con esta terapia es que así la niña no puede hablar las cosas, que por lo menos sí las entiende y que enseñe con el dedo las cosas.*
>
> She is a good therapist. She plays with the child, sings, and dances. The dancing helps Rubi move her hands, to jump, move her body, to recognize the parts of her face, nose, eyes, mouth, ears, hands. So that she can learn how to move her body with the rhythm of the song. The idea with this therapy is that if the child can't speak, she can at least understand and learn to point at things.

It is important to note that Karina was also able to describe why this type of activity is used in therapy and how it will benefit Rubi.

Committed providers. The commitment shown by providers was illustrated in Andrea's comments regarding what the therapist did and how the therapist's actions motivated her to participate. During an interview Andrea pointed to Gabi's walker and commented, "it [walker] doesn't work for Gabi because she does not have enough arm strength to hold on to it and support her weight. The physical therapist is looking for something that will work and that Gabi will like." Andrea described Gabi's physical therapy session in the following manner

> *O, por que siempre cuando ellas vienen pues ayuda mucho por que cuando ellas hacen los ejercicios ella le da gusto saber que dar los pasos y luego cuando uno le pone los zapatos ella quiere caminar; que dice que quiere caminar. Y cuando uno le ayuda para que valla caminando y que mire sus pies. Y eso es que me motive que ella tambien le gusta. Le gusta aprender algo nuevo.*
>
> Everytime they [therapists] come it's very helpful because when they do exercises Gabi is happy knowing that she can take steps and when we put her shoes on, she wants to

> walk, she says she wants to walk. And when we help her walk she can see her feet. This is what motivates me and she likes it [therapy]. She likes learning new things.

Andrea’s comments indicated she was also aware of the reasons why the walker was not working for Gabi. More importantly, her description of Gabi’s therapy session and Gabi’s responses to therapy indicated that she felt the therapist was committed to helping Gabi reach her goal of walking.

Apoyar (Support)

The next category describes actions on the part of providers that were viewed as supporting the mothers to participate. *Apoyar* is the Spanish word meaning to support or give support (National Textbook Company, 1994). This category involved the notion of *conviver* presented earlier and is used in the spirit of sharing or to *compartir* as in sharing an experience. Subcategories include actions such as inviting and valuing the mother’s participation through supportive attitudes.

Inviting. The subcategories of inviting and valuing the parents’ participation in EI services have different yet associated meanings conveyed by the mothers’ responses. The mothers used the words “*me invitaron*” or “they invited me” when identifying actions that promote their participation in their child’s EI program. Some mothers, Karina in particular, were very articulate in describing what being invited meant to her in terms of being valued. When asked to identify what promotes her participation in Rubi’s EI program, Karina answered

> *Bueno, nos estan invitando. Siempre. Me siento importante, pues de que nos tomen en cuenta de que no nos hagan a un lado. Esas son, mis experencias por dicerlo asi. Siempre nos estan comunicando de que esi estamos de acuerdo en, por decirlo asi*

> *"Cierta persona va venir a visitar a Ruby para entrevista". Entonces a mi, me preguntaron, me tomaron en cuenta y eso aunque no nos hecho a un lado.*
>
> Well they invite us. Always. I feel important because they take us into account and don't push us aside. These are my experiences. They are always communicating with us to see if we agree. They say "So and so is coming to see Rubi, for an interview". But they asked me, they took me into account, and haven't pushed us aside.

Karina's description of being invited also conveyed elements of occurances previously described that promote participation such as communicating and being informed.

All the mothers referred to being regularly invited to participate in most of the EI process. The concept of being invited to participate was associated with their comments regarding providing information about their child's progress. Being invited fit with the mothers' role of having the responsibility for the well being of their child. Consequently, the mothers spoke of being valued by professionals when they were invited to collaborate with providers.

Valuing mother's participation. Overall, when the mothers described their participation in the EI process of assessment, problem identification, goal setting, and critiquing treatment options, they all indicated that their participation was valued. They felt their comments were solicited and that their input was used to coordinate their child's care. Karina commented, "They [providers] always ask my opinion in making Rubi's goals. My participation involves putting forth the effort. She [Rubi] can do it." She also described her experience with EI service provision

> *yo siento que mi participación vale. … yo no ha sentido…los malos tratos, para no dicer racismo* (uttered in a lower tone of voice)*, o por ejemplo, mala cara? Hasta ahorita no, muy amables, al llamarme "Buenos dias, como estas, buenas tardes, como has estado."*

> *Al ir tambien, por ejemplo ayi a Babies son muy amables, o sea muy bien atendidas la niña, y muy sonrientes.*
>
> I feel my participation is valued. I haven't been treated badly, or felt racism (said in a lower tone) so to speak, or been given a bad face. Until now, everyone is kind when they call they say "Good morning, how are you? Good afternoon, or how have you been?" When I go to the EI program offices, they are kind, attentive to my child, and smile. Personally, my experience has been good."

Karina's comments were relevant to knowing how she described racism in her own words. Her words illustrated the feelings that some of the mothers and one father conveyed earlier regarding living and working within a convivial context. These feelings concerned accepting and understanding the child with a disability and by association accepting the family of a child with a disability.

Supportive attitude. Providers who demonstrated a supportive attitude in their actions was another factor identified as promoting participation. A supportive attitude on the part of providers was evident in some of the preceding examples particularly those actions of the committed therapist. The following illustrates the range of views the participants have regarding how providers with a supportive attitude help them. For instance, Odalis stated that she gets motivated and feels good when her providers praise her work with Soyla. She proudly announced that she is often told "*Esta haciendo las cosas bien señora*" or "You are doing everything well, ma'm." She also said she would feel badly if she were told her child was doing worse instead of better.

Odalis provided another example where the actions of her therapist promote her participation

> *Pues cada vez que viene la terapista ocupacional, ve la niña y a ver si está progresando, y me deja como tarea "sigue haciendo más esto", y viene y a checa y dice "bien, bien", porque está bien, "sí trabajaste mucho en la semana" y esto y lo otro. Ella habla poquito español pero ahí le entiendo. y la terapista me revisa las tareas para ver si trabajé con la niña o no, entre más rápido progrese la niña, pues mejor...*
>
> Every time the occupational therapist comes, she checks if the child is making progress, and she gives me homework such as "continue doing more of this or that". She speaks a little Spanish but I understand her. She checks and says, "Good, good, yes, you worked hard this week…" and the therapist reviews my homework to see if I worked with the child or not, the faster Soyla progresses, the better.

All mothers expressed that they relied on supportive attitudes from providers in order to care for and carry out procedures that promote their child's well being. Andrea and Karina voiced a sentiment conveyed by all the mothers when they stated that the support they felt from their providers helps them feel less isolated and able to carry out therapy at home. Karina related

> *Yo siento no estoy sola. Por decir tengo el apoyo de, de las personas que han estado con Rubi desde de que ella nacio. O sea, ellos me dicen "Esto te ayuda". Aungue sea todo con palabras, con consejos, pero, es muy bueno, muy bien para mi niña. Me gusta. Que puedo pedirles por decir, un… un apoyo. Por dicerlo asi, el apoyo en ciertas cosas, si en cierta cosa es; de que ellos me ayuden a elegir que es lo que ella necesita un poco mas.*
>
> I feel I am not alone. I have the support of people who have been with Rubi since she was born. They say "This will help." Though if only with words, advice, it's good for my child. I like it. I can ask for their support in certain things, they help me decide if Rubi needs a little more.

The supportive attitude on the part of providers appeared to be placed on a personal level indicative of relationships that are formed between the mothers and their service providers. The mothers also expressed the feeling that providers who demonstrate a supportive attitude promote participation through acceptance. The notion of accepting the child was mentioned by several mothers and Janeth's husband as key to helping their child come out ahead or *adelante*. Jamie asserted that the best way for professionals to help the child and family is to accept the children as they come and help them come out ahead. She also stated that a supportive attitude helps parents teach their children. The majority of the participants' responses were in accordance with this feeling.

Confianza (Trust)

The last category representing actions that promote participation concerns mutual trust or *confianza* between the participants and their service providers. The Spanish meaning of the word *confianza* is to trust, to be secure or to have confidence (National Textbook Company, 1994). Mutual trust was also associated with a supportive attitude previously described by the participants as promoting participation.

Mutual trus. All of the participants expressed that they had *confianza* or trusted their providers in aspects of the EI process such as being able to discuss evaluations of their children, identify problems for their child, express dissatisfaction with providers or services, set goals, and critique treatment or interventions. They all expressed that they felt their input about participating in the EI program was taken into account and acted upon. Some of the participants provided examples of how they trusted their providers in regarding specific aspects of their child's care.

Odalis used these words "*Me siento pues confiada con ella*." to express being secure and confident in Soyla's case coordinator's explanation of Soyla's condition. Odalis stated that her case coordinator explained Soyla's condition and why Soyla would eventually be well, be able to eat, to talk, and have surgery to repair her stomach. Janeth expressed confidence in her providers,

> *Pero tuviera algo que a mi no qustaria yo si [tengo] confianza en dicirle. Si, es hacer falta expressar sus opiniones tambien. Y si, hasta ahorita todo lo que ha hecho con la niña me ha gustado por que no ha cido nada brusca con ella. Pero si hubiera algo que no me gusta de plano …me siento comoda en dicierles si. Pero hasta ahorita todo ha estado bien.*
>
> If there was something I don't like, I trust I can tell them. It would be remiss not to express one's opinions. I have liked that my child is not treated roughly (*brusca*) they always have treated us well. If there were something wrong… I feel comfortable telling them, yes. Until now, everything has been fine.

These statements corresponded with the mothers' comments that indicated they were informed of their rights and that they felt comfortable exercising their rights. The mutual trust evident in the participants' descriptions of their relationships with their providers also supported the service providers' role as family advocates.

Providing options. Having confianza or trust in a service provider was illustrated in the mothers' comments regarding the care, therapy, and plans for their child. One aspect of this relationship involved being presented with options. Although the mothers previously described being made aware of their rights in the EI process, having options was something they associated with their relationship(s) with their providers. The mothers' decisions on exercising their options are described as part of this relationship. For example Karina described choosing the most appropriate preschool for Rubi

> *Me gusta porque me dan opciones, puedo elejir, pero luego tambien pido consejos a las terapistas, a las personas que venien, y les comento, bueno platico, no se yo extactamente. No quiero decider sola que es mejor para ella. Yo quiero por ejemplo las terapistas que me den su opinion. De como ven a Ruby, o sea de que mejoria ha tenido pues en que avances para ella…que escuela es mejor para ella, que cosas son mejor para ella. Si o sea, que ofrece una escuela, y que ofrece otra escuela, y que es mejor para ella. Entonces este, tengo esa…por dicer ese privilegio.*
>
> I like it because they give me options, I can choose, I consult with the therapists and others, they comment, and we chat. I don't know exactly what to do. I don't want to decide alone what is best for her [Rubi]. I want their opinion, how they see Rubi, her progress, and which school is best for her. I have, so to speak, that privilege.

Karina's comment illustrated the mutual trust between herself and Rubi's providers. She also viewed having choices as a privilege.

Several other mothers talked about having options related to the timing of entry into the EI program, setting goals, and treatment options. Most of the participants stated that they consulted with the providers and that mutual decision-making had occurred.

Again, Karina's statement "*Yo creo que si tengo la decición, la ultima palabra*." illustrates beautifully how the actions of the service providers promote participation. She said "The persons who came [to my home] made me aware of my role as a decision-maker. I understand that I decide, [I] have the last word."

The participants' statements regarding decision making illustrated the mutual trust formed in relationships with their providers and indicated a collaborative effort between the participants and providers. The mothers were specifically asked if they felt the providers collaborated with them during all phases of the program in order to verify if EI service was family centered. All the participants except one (Jaime) felt strongly that they were collaborators in their child's early intervention program.

*Communicating.*Communication has been discussed in terms of ways in which the participants prefer to exchange information with providers. It is discussed here in terms of the actions on the part of providers identified as promoting participation. For example, several mothers mentioned observing how their providers make an effort to speak Spanish. Nidia described several of her providers as making the effort to get her any information pertaining to her child in Spanish.

Karina described what happened with one of Rubi's providers who did not speak Spanish.

> *tratamos de comunicarnos cuando no hay nadie más que nos pueda ayudar. Y él trata de entender español, son pocas las palabras que dice pero veo que él sí trata de hablar, y sí nos podemos comunicar, de una manera o de otra.*
>
> [We] try to communicate when there is no one to help us. He tries to understand Spanish, he speaks a few words, but I can see he tries to speak, and yes, we can communicate one way or another.

Odalis and Jaime also recounted instances of how they communicated with their providers who did not speak Spanish. For example, each woman described a situation when an interpreter was not present and how their providers sensed that they did not understand what was being said. One provider called another Spanish speaking professional to explain Soyla's problem to Odalis and her husband, Miguel. Most of the participants described similar situations.

Although all the participants said they appreciated their providers' efforts to speak Spanish or the efforts at making sure an interpreter was available; some problems occurred with providers in other agencies that are discussed in the next section concerning barriers to participating. Overall, communicating as described by the participants was usually in terms of how they felt they were attended to and treated by others. Manuel made a point of saying *"Si hasta ahorita con las personas que hemos conocido, por cierto, no las hemos tocado asi afuera de donde trabajan y los saludan y todo"*. "We are always greeted when we see persons [healthcare personnel] outside of their workplace." His comments illustrate the importance of others' acceptance of and understanding of a child with a disability that the mothers also voiced.

The participants described other instances where communicating reflected mutual respect and collaboration. For example, Karina described how she and Rubi's providers communicate about changes in goals and appointments

> *Por que como en lo mio o sea algun cambio en las terapias, algun cambio primero me lo hacen saber. Algun cambio, por decir "La niña ya logro esto, vamos hacer, vamos a ponerle otra meta." A lo mismo, puedo ir, me llaman. Y lo mismo yo tambien, [digo] "Hoy no puedo, la Rubi esta enferma, o voy a la clinica con Rubi, o no voy a estar aqui tengo otra cosa que hacer asi." Pero es muy poco que yo cancelo, siempre estoy aqui.*
> If there are any changes, in therapies, any change, first they let me know. Any change, such as "The child achieved this [goal], so we will make another goal. They call me or I call them to say "I can't keep an appointment, Rubi is sick, or I'm going to the clinic with Rubi, or I will be here or I have something else to do." I rarely cancel…

Overall, these descriptions of communicating illustrate the variety of circumstances in which communication was used to promote participation. It was evident that the participants appreciated the efforts made by providers who did not speak Spanish to communicate with them. The mothers also acknowledged the providers’ attempts to make them feel comfortable and impart information.

This section described actions on the part of service providers that promote participation. Findings indicated that the participants’ responses correspond to the aforementioned themes that emerged from the data regarding how mothers of Mexican origin participate and phenomenon that promote participating. The themes that emerged from responses to this question interrelate with the previous two research questions concerning how mothers participate and what phenomenon promotes participation. Still, they are distinguished as being the actions that stem from the provider instead of from the participant, the persons in their lives, or their life circumstances. These findings specifically illustrate what providers do or the actions of providers that promote participation.

Barriers to Participation in the Early Intervention Program

The final research question concerned barriers to participation as identified by the participants. Table 4 represents the participant’s responses to this question. Barriers to participation involved transportation, healthcare, and social systems or *sistemas.* Subcategories entailed time, cost, problems with access to the transportation system, communicating with non-Spanish speakers, and receiving mixed messages from professionals. These subcategories were interrelated such that language barriers posed problems in accessing and using the Medicaid Non-emergency Transport (NET) system yet the cost of public transportation with Spanish-speaking taxi drivers was prohibitive for the participants.

Table 4

Barriers to Participation in the Early Intervention Program

Research Question	Findings
What do MMO identify as barriers to their participation in their child's early intervention program?	*Sistemas* (Systems) • Transportation/Healthcare/*S*ocial • Accessing transportation • Time • Cost • Non-Spanish speakers • Mixed messages

Sistema (System). The word *sistema* was used to label this category because obstacles were associated with problems the participants encountered when they interacted with persons associated with various systems. All of the mothers except one described barriers to participation dealing with the Non-Emergency Transport system and public transportation. These barriers constrained participation in various community activities and access to resources within the community. Still, one participant, Jamie experienced problems communicating with Early Intervention service providers. Nonetheless, two participants, Nidia and Odalis, identified communication barriers with persons in the healthcare and social service systems not associated with the Early Intervention program. These interactions jeopardized their trust in these systems.

Transportation. The problems the mothers reported were primarily related to the time, service rendered, and the associated cost involved with accessing and using the Medicaid Non-Emergency Transportation (NET) system or public transportation. Associated problems included language barriers between the participants and non-Spanish speaking NET dispatchers and drivers. Every mother except Andrea identified transportation as a problem that limited her ability to fully participate in her child’s Early Intervention program or access her community. Andrea reported driving her own car; however, she did not have a driver’s license. Nonetheless, Andrea drove to work, drove her other child to school, and drove Gabi to appointments. Andrea’s situation posed a barrier to participating in her child’s Early Intervention program as it placed her and her family at risk for legal problems such fines and being an uninsured driver.

Other problems described by the participants were associated with transportation and involved lost unpaid time from work for the participants’ husbands or other family members when they had to take time off to drive them to appointments. For instance, Nidia expressed that she worried when her daughter took time off from work to drive her to appointments. She stated that her daughter was starting a new family and that they needed the money. Consequently, Nidia was reluctant to ask her daughter to take time off from work to drive her to Ruth's appointments.

Time. When the participants described using the NET system, they reported problems concerning the time involved in using the system. Problems ranged from scheduling pickup, inconsistent schedules, and the long commute when traveling to a major metropolitan hospital that specializes in children's healthcare. The mothers reported that they were often late for appointments or worried about being late. Nidia commented

> *Aunque es dificil, pues le digo por que a veces no llegamos (chuckles) a tiempo. A veces llega uno tarde por que van a recojer otras personas y esi no saben el luegar, se pierden. Ya me ha pasado, que me ha hido y se han perdido, y llegamos tarde. Y para mi la cita de Lunes, es bien importante…*
>
> Though it is difficult, well I tell you because at times we do not arrive on time. At times we arrive late because they pick up other persons and if they can't find the place, they get lost. It has happened to me, that I've gone [used the NET] and they got lost and we arrived late. And for me my appointment on Monday is very important…

Even though Nidia acknowledged that it is difficult to use the Medicaid transport she said there is no alternative, "*ni modo*" and that she must make Ruth's appointments. Nidia said the appointments are important because Ruth's doctors are coordinating surgeries to remove Ruth's tracheostomy and feeding tube. She described her experience with the system as not arriving on time, or arriving late due to picking up other passengers and even getting lost. Jamie also described times when she would call for transportation and the van would not arrive on time. In those instances she would have to call a taxi.

Cost. Nidia calculated the cost of using public transportation to get to several places such as the public health clinic for one appointment and the doctors' offices for another appointment on a particular day. The cost of taking a taxi from her apartment to the public health clinic in the morning was 12 dollars, after which another trip to Ruth's pediatrician by taxi was 14 dollars round trip. Nidia recounted that later that evening she talked with her husband about spending 26 dollars for local transportation. They decided that she had better arrange for the non-emergency transport to the large children's medical center located an hour away. Nidia was resigned commenting "*pero ni modo*" or "there is no other way".

Several of the mothers, Nidia, Jamie, and Karina reported being unable to fully participate in their child's EI program. One barrier concerned the fact that the participants' husbands were the sole breadwinners in their households. The family's income prohibited the participants' ability to bear the expense of a taxi. For instance, Karina shared why she was unable to fully participate in Rubi's EI program.

> *Bueno, barreras para mi son es que no puedo yo, o sea por dicer tener*
> *una participación muy abierta por dicer lo asi. Eh, mire, solo mi esposo trabaja, yo no trabajo, (sighs) entonces, solo estamos con el sueldo que el gana. Entonces yo no puedo participar [como] yo quisera, aunque yo guiera, no puedo participar por que solo el trabaja entonces estamos ah, em…por dicerlo, solo al sueldo de el. A lo que el gana, entonces yo al moverme, yo uso puro taxi.*
>
> Well, barriers for me are that, so to speak, I can't fully participate. Eh, look, my husband is the only worker, I don't work, (sighs) and we live on what he earns. So I can't participate in the manner that I would like, even though I want to, I can't participate

> because he is the only worker and we are, em…so to speak, living on his salary. On what he earns, so if I have to get around, I use the taxi.

Furthermore, Karina was not aware of the public bus system operating in her city; however, this system is fairly new and has limited routes. Additionally,Odalis lived in a rural area with no public transportation system except for taxis. She said she wished to return to work as soon as possible since her family was also having trouble making ends meet, but that her first concern was Soyla's well being.

The mothers described many problems related to navigating the Non-Emergency Transport system. For instance Jamie reported

> *Pues es que a veces llamaba la de la parte de Medicaid pero no pues no venian …y yo tenia que estar en la cita… y a veces no venian por mi y pues …lo mejor el taxi*
>
> Well at times I would call the Medicaid [transport system] but they would not come [were late]…and I would have to make my appointment…and at times they would not come for me and well … a taxi is better

Most of the other mothers also reported experiencing similar problems. Nidia related another experience when the non-emergency transport van driver told her that she had to sit in the front seat of the van while Ruth was placed in back of the van. Nidia asked another passenger to change seats with her because she was afraid Ruth might need to be suctioned or choke and she had to be by Ruth's side to care for her.

> *Una ves me llevaban en un van y me hechan a mi adelante, y la nina atras. Y la nina necesitaba succion y como la hacia yo? Separado de dos asientos, la chauffeur persona que no habla Espanol. Entonces digo yo como le hago? Tuve que pidierle favor a la que*

> *iba al lado y ella sin saber. Ah ha eso mas me preocupaba tambien. Y ni modo pues ya illevamos alli. Entonces ahora que me toco esta ultima cita, le dije a mi hija. Dijo yo les dejo mi caro para que mi apa se valla que no pida ride al trabajo. Y que mi primo las lleve; el esta de vacacion…*
>
> One time we took the van and they put me in [the] front [of van] and the child [Ruth] in back. And the child needed suctioning and how would I do it? Separated by two seats. The chauffeur spoke no Spanish. Then I said, 'How will I do this?' I had to ask a favor of a woman sitting next to Ruth [to change seats]. Ah ha that worried me too. But there was no other way; we were on our way. Now that I have another appointment, I told my daughter about it and she left her car so that her father would not have to ask for a ride to work and my cousin could drive us [to the appointment], since he is on vacation…

Access to transportation was a barrier that extended to other aspects of the mothers' lives such as bearing the cost of public transportation, budgeting for a family on one person's salary, and bearing the consequences of lost time from work to drive to appointments. Other barriers involved problems communicating with the Non-Emergency Transport dispatchers and drivers. These problems have led some of the mothers to use the NET system as little as possible.

Most of the participants described communication barriers specific to accessing the Non-Emergency Transport system. The participants with the exception of Jamie did not mention communicating with EI providers as a barrier; however, some participants identified communication combined with other factors as barriers to potential barriers to participating. For example, Andrea said

> *A veces, si, por que la gente no se puede informar por que no sabe Ingles, y como que le da pena; ir a preguntar or hacer preguntas. O a veces el obstaculo es no tener caro, no puede uno ir o saber donde estan las oficinas. Eso los obstaculos.*
>
> At times, yes, people can't get information because they can't speak English, it's as if they are embarrassed; to ask questions. Or sometimes the obstacle is not having a car, not being able to go or not knowing where offices are located. Those are obstacles.

Non-Spanish speakers

The participants spoke of the problems they encountered when they telephoned the Non-Emergency Transport system due to dispatchers who did not speak Spanish. These difficulties involved scheduling a pickup and providing the dispatchers with directions to their homes. Overall the mothers did not find communicating with non-Spanish speaking providers problematic when participating in the EI system. Still, the mothers speculated that communicating could be problematic if instructions were provided in English. For instance Nidia was asked what barriers impeded her family's ability to feel like participants in Ruth's development. She commented "*Como barreras? Por ejemplo vamos a dicer que me dan informacion, em me la manden. Y esi me la mandan en Ingles, pues como quien dice (laughs) no se entiende nada. Pues es una barrera, si*". "Barriers? For example let's say that they give me information, let's say they send it. If it is in English, well like they say (laughs) [I] will not understand anything. Well, that's one barrier, yes". Jaime also commented that she relied on pictures to understand the content of information provided on English Language handouts. One handout was a diagram of the ear and hearing mechanism that Jamie used when explaining Alex's hearing and pending surgery.

For the most part, the mothers commonly identified language barriers when they referred to access and use of the Medicaid Non-Emergency Transport system. Although this service is not administered by the EI system its relevance to the participants' lives was high in terms of access to their communities. Lack of transportation access appeared to impact several aspects of the participants' lives that affect the well being of the child and family.

Mixed messages from professionals. One participant identified receiving mixed messages from EI providers as a barrier to her ability to fully participate in her child's EI program. For example, Jaime described being confused by conflicting information she received from therapists and other providers in the EI system regarding Alex's progress. Jamie related that a provider would say Alex's development was delayed while another would say Alex's development was on track and he was doing well. She stated "*Si pues las de [names one service] me dice que esta muy atrasado. Y este, pues las otras, pues que esta bien.*" When Jamie was asked how she dealt with receiving conflicting information on Alex's development she replied "Well, I didn't think anything of it because he will, how shall I tell you? Well, he will do what he can …". Additionally Jaime said that she asks questions when she is confused.

Nidia and Odalis reported interactions with personnel from other healthcare and social systems that were complicated by communication barriers. These incidents concerned the mothers' ability to care for their children and the adequacy of their homes for raising their children. Nidia recounted a situation that she described as greatly impacting her physical, emotional, and spiritual well being. After Ruth was born Ruth received a blood transfusion. Nidia felt that because she had voiced her religious convictions about not receiving blood for herself, the doctors were angry with her because they began to give her "*mal cara*" or a bad face.

She also felt that they began to say that she did not want Ruth so that they would not be liable for deciding to give Ruth blood.

Nidia stated she had a difficult time comprehending that the healthcare providers would think she did not want her child. She also felt this situation negatively affected the professionals' attitude toward her. The problems created by this miscommunication led to a court case in which Nidia eventually won custody of Ruth. Furthermore, before the family was allowed to take Ruth home, they had to move into another apartment that had to pass inspecton by personnel from the Division of Family and Childrens Services (DFCS). Nidia stated she and her family had to prove that they could care for Ruth.

Odalis reported experiencing a similar situation that led to an investigation of her ability to care for Soyla at home. She suspected she was being "investigated" (Odalis' words) after she complained about a professional who was not associated with the EI program who was providing health care for Soyla in their apartment. Odalis said she was surprised by a knock at her door early one morning soon after she issued her complaint; personnel from DFCS came to ask her questions about Soyla's care and to look at her apartment. Although nothing came of the complaint, Odalis reported that she could not believe that someone would say that she could not care for or hurt her child.

The aforementioned examples were identified as barriers to participation and are provided as examples of instances where the capabilities of the mothers as caregivers for their children were challenged. Nidia and Odalis stated that they felt bad thinking that others would question their ability to be good mothers and were threatened by the situations where custody was an issue. The experiences of Nidia and Odalis were not directly related to communicating with early intervention service providers as was the case with Jaime. Nonetheless, these experiences serve as examples of barriers to participating that are created by miscommunication. The seriousness of these incidents warrants an awareness of the importance of clear communication in order to understand the situation of another person. Futhermore, the consequences of miscommunication posed threats to the mutual trust or *confianza* between the mothers and their providers.

Chapter Summary

To summarize, background information related to the participants' communities and descriptions of their individual and family experiences as parents were presented in order to situate the families' environments and introduce the participants. Furthermore, each participant identified herself as an undocumented immigrant living in the United States. The participants lived in a thriving city in a county that continues to experience changes due to immigration, business, and urban sprawl. The participants were drawn to this community for several reasons that included being with family and employment opportunities.

The participants' demographic data (See Appendices F& G) was gathered from interviews with the participants. All were mothers of Mexican Origin (MMO) who identified themselves as born in Mexico and residing in the U.S. under undocumented status. The age range of the MMO was 21 years to 43 years and their husband's ages ranged from 21 to 61 years. The time the MMO have been in the U. S. ranged from 3 to 10 years. Their level of education varied from 2nd grade through 10th grade, and all MMO attended school in Mexico with the exception of one participant who attended a U. S. middle and high school until the 10th grade. Three of the MMO were formerly employed in the poultry industry, one was employed in a restaurant, and five were homemakers. The husbands were employed as laborers in concrete, construction, heating and air conditioning (4), in the poultry industry (1), and in a large retail store (1).

The participants' young children in EI (identified as target children) were all born in the U. S. Their ages ranged from 8 months to 2 years and 6 months. These children had been enrolled in the EI program for a period from 5 months to 2 years and 4 months. The EI services they received included case coordination, hearing, speech, physical, and occupational therapy. They also received other services including in-home nursing and public assistance in the form of Medicaid, Supplemental Security Income (SSI), and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The target children were the only children in 3 families; 2 families had another child who was born in Mexico, and 1 family had 2 other children born in the U.S. and 1 other child born in Mexico.

A contextual description introduced each study participant in order to provide relevant information regarding the circumstances surrounding her child with a disability and her family life. Each participant was very forthcoming with information describing her feelings regarding the circumstances surrounding her pregnancy, the birth of her child with a disability, describing her personal and her family's responses, as well as her hopes and dreams for her child. In two cases, the participant's husband was present and he too contributed his viewpoint regarding his child and his participation in the early intervention program.

The personal nature of the information at times was difficult for the mothers and fathers to impart and required sensitivity on my part. For example, Andrea described the despair, frustration, and the anger she felt when denied pre-natal care because she did not have the papers required by the Public Health Clinic. Nidia also expressed worry over a letter received by her family and other families stating that driver's licenses would not be renewed for persons who could not provide proof of legal residence in the United States. Andrea and Odalis' husband also are unable to obtain drivers' licenses due to their undocumented status. Odalis and her husband also recounted that they were unable to make ends meet with his salary. They had applied for public assistance but were told that they were ineligible because they were not legal residents in the U. S.

The Early Intervention (EI) program was described in order to depict how services were organized and administered. Changes involving intake procedures using the Individualized Family Service Plan within the EI program were described in order to illustrate efforts to provide family centered care, engage families in the intake process and involve families in their child's EI program. Furthermore, the participants continued to navigate various other associated healthcare systems such as in home nursing care, public health programs, social and public assistance programs, private physician offices, clinics, hospitals, and transportation systems.

Additionally, the needs of some of the participants point to changes needed to modify the EI process for Mexican immigrant families. These include matching bilingual providers with families, increasing efforts to guide families through the EI procedures, improving early entry into the EI program, and referring children and families for other services. Nevertheless, despite differences attributed to the families' unfamiliarity with the U.S. healthcare system and language barriers, immigrant families of Mexican origin were described as being similar to most families regarding making the health of their child a priority.

The research questions posed in this study concerned how mothers of Mexican origin participate in their child's EI program, what phenomenon and actions on the part of providers promote participation, and the identification of barriers to participating. The researcher used Spanish words as labels for the themes generated from the participants' responses because the mothers used the terms frequently, thus providing an emic perspective on concepts relevant to the research questions.

In order to answer the first research question, each participant’s definition of the term “participation” was solicited to establish the meaning (*significar*) of the term. Additionally, their definitions provided insight into what guides their actions or what they do when they take part in their child’s EI program. The examples of participation given by the mothers interrelated with the other research questions. In short, the respondents said that participation meant helping, paying attention, being present, being clear, informing, and being prepared. Within the course of providing information about participating, the mothers referred to words that described characteristics of their cultural group. For instance several participants used the word “*dejado*” to describe a trait they attributed to some Mexican people or to an irresponsible parent meaning one who is negligent or does not take a situation seriously.

A second category of themes regarding how the mothers participated involved the word *hacer* that denotes doing and represents the actions of the mothers while participating in their child’s EI program. Participating involved learning therapy techniques, practicing the techniques with their children, and answering and asking questions. Finally, the category labeled *conviver* represented how the parents viewed their child living with others. This word denotes co-exising and conveyed the parents’ attitudes and feelings about accepting their child and their child’s place with others now and in the future. This category was linked with what it meant (*significar*) to the mothers to participate and how to do (*hacer*) participating.

The second research question focused on phenomenon that promotes participation in the Early Intervention program. The mothers’ responses represented incidents, events, occurrences, or objects that promoted their participation. Three categories of phenomenon were found that promote participation. The first category labeled *comunicar* or communicating, involved two subcategories *platicar* or chatting and language. Most of the participants used the term platicar to denote the informal conversations or the chat each would have with providers about the child. The second category related to communicating included language and represented the language the mothers preferred for communicating and learning. The mothers' first language was Spanish. Although they were learning English and had differing levels of proficiency, all preferred communicating in Spanish. Participating in their child's EI program included multiple forms of communicating such as receiving instructions in Spanish, receiving written and verbal instructions, and receiving instruction through demonstration.

All of the participants described *surgerir* or receiving suggestions from providers. Recommendations were made in the context of teaching, being informed, and getting advice on how to help their child develop, provide therapy, or care for the medical needs of their child. These interactions were also described as sharing experiences to which the mothers felt invited and valued; however, these themes appeared more as actions on the part of service providers that promote participation.

Finally, the mothers identified what served to *sostener* or support them throughout their pregnancy, childbirth, and their present-day circumstances. Family members, religious affiliation or ideology, and a parent support group were most often identified. These sources of support revealed that some of the participants utilized several personal and external resources to help them cope with circumstances associated with caring for a child with a disability.

Actions on the part of providers that promote participation were identified in response to the third research question. Three themes illustrating the actions of providers were described. The first, *nacer* was used to label a category of responses that described providers who were creative and committed and tried creative techniques to help the child develop. The providers also were described as being dedicated to helping the child enjoy therapy and these actions in turn were motivating for the parent(s). Several participants were able to describe details of therapeutic activities and the benefit to their children indicating close collaboration with providers.

The second set of actions involved the notion of *apoyar* or support for the participants by the providers. The participants described instances of being invited to participate in their child's EI program. Consequently, the participants felt that their participation was valued through the providers' supportive attitudes. Lastly, *confianza* or trust described the mutual trust the participants felt with their providers. The participants appreciated having options presented to them yet relied on providers for advice. Lastly, the mothers acknowledged the providers' attempts at communicating important details about their child's care with them as making them feel comfortable and capable. These findings specifically illustrated the actions of providers (what they do) that promote participation.

The final research question concerned barriers to participation as identified by the participants. Themes dealing with the *sistema* or system involved transportation, time, cost, and navigating other healthcare systems. All of the participants identified access to transportation as a barrier to participating in their child's EI program. This barrier extended to other aspects of the families' lives. Additionally, barriers were identified concerning *comunicar* or communicating with non-Spanish speakers and receiving mixed messages from professionals. Two mothers related serious incidents concerning their ability to care for and provide for their children that stemmed from miscommunication. Although these incidents were unrelated to communication with EI personnel, the consequences of miscommunication warrant careful attention as they jeopardized building trusting relationships between the participants and service providers.

Many of these factors were interrelated; however, the study participants provided insight into several important aspects of participation by families of Mexican origin who are undocumented immigrants in their child’s early intervention program. These included insight into the meaning of participating, descriptions of what mothers do in the course or participating, and descriptions of specific actions and factors that promote and hinder participating. These findings will be discussed further in Chapter 5 in terms of conclusions regarding the participation of mothers of Mexican origin in their child’s early intervention program, the implications for service provision, theory, and research.

CHAPTER 5

CONCLUSIONS AND DISCUSSION

The purpose of this study was to describe how mothers of Mexican origin (MMO) who have a young child with a disability and are immigrants of undocumented status in the United States participate in their child's early intervention (EI) program. In order for service providers to collaborate with families to develop and implement more effective interventions grounded in the philosophical principles of family centered care, service providers must recognize the myriad influences guiding the choices and actions of immigrant families of a child with a disability. The study and findings from this study will be summarized. Findings will be discussed and conclusions drawn regarding the participation of mothers of Mexican origin in their child's early intervention program. The implications for service provision, theory, and research will also be presented.

A qualitative phenomenological multiple case study approach was taken in order to explore, describe, and interpret the perspectives of mothers of Mexican origin pertaining to their participatory experience(s) in their child's early intervention program. The case study is the preferred strategy when "how" questions are being posed; when the investigator has little control over events; and when the focus is on a contemporary phenomenon within some real-life context (Yin, 1994).

An increased understanding about the participation of mothers of Mexican origin who are immigrants was an expected outcome of this study. The research questions were designed to explore how these women participated in their child's EI program and to examine what phenomenon or actions they identified as promoting their participation, as well as what they identified as barriers to their participation. Exploring the phenomenon of participation initially required asking the study participants to define participation in their own words then asking them *how* they participated. This study was guided by the following questions:

1. How do mothers of Mexican origin who are undocumented immigrants experience participating in their child's early intervention program?
2. What do mothers of Mexican origin identify as promoting their participation experiences in their child's early intervention program?
3. What actions on the part of service providers do mothers of Mexican origin identify as promoting their participation in their child's early intervention program?
4. What do mothers of Mexican origin identify as barriers to their participation in their child's early intervention program?

In order to answer the research questions, purposive sampling was used because it involved selecting participants based on the sample's relevance to the research questions, analytical framework, and explanation of the phenomenon – *participation,* being developed in this research. Early Intervention personnel do not ask about the immigration status of families. The sensitive nature of recruiting study participants who met the inclusion criteria of being immigrants from Mexico who are undocumented in the U.S. necessitated initially inviting families with Spanish surnames enrolled in the Early Intervention (EI) program to participate in this study by letter. Recruiting involved meeting with a potential participant and explaining the study. If the woman agreed to participate in study, demographic data gathering also included asking about her immigration status.

The participants’ community was described in order to situate the participants and illustrated the characteristics of the county in which they reside. The community profile illustrated trends such as a growing population of individuals of Mexican origin in the county. The participants’ contextual descriptions provided evidence of family ties and employment opportunities that initially drew the participants to this geographical area. Furthermore, the participants’ contextual descriptions provided an account of the circumstances surrounding having a young child with a disability and family life.

In order to describe the EI processes, practices, and services provided to Latino families, several forms of data collection were utilized. Interviews were conducted with participants, an expert in early childhood, EI social worker, and an EI case coordinator who primarily works with Latino families. Documents such as each family’s Individualized Family Service Plan (IFSP), artifacts shared by the families, and field notes were examined. Observations were also made in the participants’ communities and homes and my personal experience as a service provider were used in data collection.

Demographic data for each participant and her family was also collected and included each participant’s age, birthplace, education, employment, and time in U.S. for the mother. Child information included age, birthplace, diagnosis, time in EI program for the child, and EI services provided. This data was collected from interviews and from examination of the family’s IFSP.

Data management included audiotaping interviews conducted in Spanish, the primary language of the participants. Audiotapes were then transcribed in Spanish and member checked with each participant. Interviews with other key participants were also transcribed and member checked. Data was coded and categorized using qualitative software in order to capture recurring themes across cases. Ongoing review and the revision of codes and categories continued throughout the data collection and data analysis phases. Emergent themes were categorized and labeled using the participants’ Spanish words in order to represent the meaning conveyed by their responses to the research questions.

Summary of Findings

Findings from this study are organized according to demographic data describing the participants, the four research questions that guided this research, and associated information regarding EI service delivery. Six mothers of Mexican origin (MMO) were primary participants and some of their husbands’ comments were also included as data responses to certain questions. Demographic data for the participants (See Appendices F & G) were presented in chapter 4 and are summarized here.

All of the MMO were born in Mexico and were residing in the U.S. under undocumented status; time in U. S. ranged from 3 to 10 years. There was a wide variation in the mothers’ ages (21 years - 43 years) and fathers’ ages (22 years – 61years). Three of the participants had at least a 9th grade education in years, two completed the 6th grade, and one had a second grade education. All of the MMO were homemakers and one mother was also employed. The families were all blended families as described by Garcia y Griego (2002) with family members who were undocumented immigrants and U. S. born children. The participants’ young children in EI were all born in the U. S. and their ages ranged from 8 months to 2 years and 6 months. These children were enrolled in the EI program for periods from 5 months to 2 years and 4 months. The children and families also received other services such as in-home nursing and public assistance (See Appendix H).

The study’s participants provided insight into several important aspects of a parent’s participation in their child’s EI program. These include insights into the meaning of participating for families of Mexican origin, a description of what families do in the course of participating, and the specific actions and factors that promote or hinder participating. Findings for each research question were categorized according to themes that emerged from the participants' responses.

The first research question concerning how the MMO participated in their child's EI program generated the participants' definition of the term participation. According to the respondents, participation means helping, paying attention, being present, being clear, informing, and being prepared. These themes interrelated with a second category of themes that represented what the mothers do when they participate. Participating involved learning therapy techniques, practicing the techniques with their children, and answering and asking questions. A third theme represented the parents' attitudes and feelings about accepting their child and their child's relationships with others now and in the future.

Findings for the second research question concerned phenomenon that promotes participation in the early intervention program. This question generated three themes focusing on communication, receiving suggestions from providers, and supports. Communication involved informal conversations with providers about the child or the EI program and forms of communicating for learning. All of the participants described receiving suggestions from providers made in the context of teaching, being informed, and getting advice from providers. Some participants also identified personal and external resources and supports such as family members, religious affiliation or ideology, and a parent support group.

Three themes illustrating the actions of providers that promote participation were identified in response to the third research question. In contrast to experiences that promote participation, these findings specifically illustrated the actions of providers (what providers do) that promote participation. The Spanish word, *Nacer* labeled the category describing creative and committed providers. The second set of actions involved the notion of *apoyar* or support for the participants such as being invited to participate in their child's EI program and feeling valued through the providers' supportive attitudes. Lastly, *confianza* or trust represented the mutual trust the participants described in their relationships with their providers. These interactions involved having options while relying on providers for advice and communicating important details about their child's care with providers and were described as making the participants feel comfortable and capable about caring for their child.

The final research question concerned barriers to participation. The majority of the participants identified access barriers to transportation systems involving cost, time, and language. These barriers extended to other aspects of the family's lives such as budgeting on one person's salary, and bearing the consequences of lost time from work to drive to appointments. Additionally, barriers were identified concerning communicating with non-Spanish speakers associated with the transportation system and receiving mixed messages from professionals in related healthcare systems. Finally, miscommunication was implicated as a barrier to establishing and maintaining collaborative relationships between the mothers of Mexican origin and service providers.

Conclusions and Discussion

Two main conclusions are derived from this study. First, combinations of factors interact to influence the participation of mothers of Mexican origin in their child's Early Intervention program on an individual and systems level. Second, collaborative partnerships between mothers of Mexican origin and service providers reflect family centered early intervention practices.

Conclusion One: A combination of factors interacts to influence the participation of mothers of Mexican origin in their child’s EI program.

The participants of this study described and exemplified individual and system issues that interact and impact their involvement in their child’s EI Program. When the participants described their emigration to the U.S. family ties were key in their decisions to move to their present place of residence. Researchers have identified family factors as a major force driving immigration (Castles & Miller, 1998; Garrett, 2002; Garrett & Bautista, 2000). The participants also identified families as supports to participating; however, most of the mothers did not have extended family living in the immediate geographical area. Andrea, Karina, Jamie, and Janeth had their husband’s extended families living the U.S., and Odalis’ famiy was living with her sister’s family. Still, the participants reported frequent telephone contact with families in Mexico as a source of support.

In the United States, healthcare systems are challenged with providing culturally competent and appropriate services to diverse populations (Anderson et al., 2003). The rapid growth of the Mexican immigrant population in Georgia is a contemporary issue that has challenged unprepared policy makers and healthcare providers who lack both experience with this population and data on their needs in areas such as transportation and healthcare (Atiles & Bohon, 2002). On a system level, the participants identified transportation as a major barrier to participating in the EI program. Observations of the transportation system in the participants’ community indicated a lack of public transportation and a proliferation of taxis that cater to the Latino population. A city public transportation system has recently been initiated but it has a limited route. Public bus service from the participants’ communities to the major children’s medical center does not exist at this time. Still, the existing public transportation systems cannot accommodate the special needs of some children requiring wheelchairs and medical equipment.

Individual and system level factors interact regarding transportation. Access to the transportation system funded by public assistance/Medicaid was problematic for the participants on several levels. For instance, communication with English-speaking dispatchers and drivers was difficult for the Spanish-speaking participants. The participants also reported problems with scheduling transport, being separated from their children on the transport vans, not getting picked up, being late for appointments, and even getting lost. Furthermore, this publicly funded transportation system did not appear to be responsive to national mandates requiring culturally competent healthcare systems. Agencies receiving federal and state funding are required to provide non-English language resources to their consumers as per their needs (Anderson et al. 2003; Lynch & Hanson, 1990). These problems caused the mothers to underutilize the transportation service.

Other transportation related issues involved one of the participants, Andrea, who drives but has no driver’s license. This problem is an individual and system problem since persons of undocumented immigration status in Georgia currently are unable to acquire or renew a driver’s license (Southern Regional Council, Coalition for Safe Roads, 2005). Similarly, two other participants voiced concern about their husbands being unable to acquire or renew a lost driver’s license. Finally, the participants described the consequences of limited access to transportation. Limited access to adequate transportation limited the mothers’ participation in EI activities, constrained access to community resources such as parent support groups, burdened the family finances, and even jeopardized the employment of family members who lose wages and time from work when they drive them to appointments.

Findings of this study also correspond with the literature regarding multiple risk factors that challenge children of immigrants and their families. These are identified as less educated parents working in low wage work with little or no benefits, language barriers, discrimination, and lack of supports (Shields & Behrman, 2004). Other issues that families of children with disability deal with involved parental stress, relationships that included conflicting social support, personal and physical space in the home, and the effect of the child's illness on the family (Esdaile, 2004). For the most part, the participants described dealing with the aforementioned factors to varying degrees.

On an individual level, the educational level of the participants was less than a high school education in the U. S. The primary language of the mothers was Spanish. Although communication was reported to pose no problems with EI participation for all participants except Jaime, communicating with non-Spanish speakers was identified as problematic in circumstances where mixed messages were received and miscommunication occurred in other systems such as hospitals or with healthcare providers from other agencies. These findings are consistent with the literature that identifies language as a barrier to care for Spanish speaking Latinos (Bailey, Skinner, Correa et al., 1999; Weech-Maldonado et al., 2001).

Findings regarding the effect of the child's illness on the family indicated that the mothers reported stress that was related to initial worries about having a child with a disability. Two mothers of children with more health problems stated they were concerned about their child's health outcomes. Overall, all the study participants described a loving and accepting attitude toward their children. They also spoke of efforts on the part of the family directed toward helping their child progress and to be independent.

The parents also emphasized the ideal of living together (*conviver*) and the importance of others outside the family accepting the child. All the participants made references to God in terms of making the best of a God-sent situation, putting forth an effort to accept and help their child as a gift from God, and relying on God's support for caregiving and their hopes such as returning to work. These individual level findings corresponded with current literature that advocates the need for addressing individual differences, family characteristics, and the contextual forces that influence children and their families (Garcia Coll & Magnuson, 1997).

Issues of discrimination are considered a phenomenon occuring on both an individual and system level. Although the participants did not report experiences of discrimination while participating in the EI program, Nidia and Odalis recounted problems related to miscommuniciation that led to misperceptions about their ability to care for their child. All of the participants expressed their profound sense of the importance of others' perceptions of them as responsible parents who are committed to helping their child progress.

Andrea did not attribute being denied pre-natal care by the public health system in her community to discrimination; however, her experience implicated discrimination as a factor. When discussing her pregnancy, Andrea related that she was turned away from the Public Health Department because she did not have a "matricula" or a picture identification card. She did have a paper called an "Acta" stating where she lived in Mexico, but this was not accepted. Andrea sent for her papers from Mexico meanwhile she received no prenatal care and Gabi was later born with Spina Bifida. Andrea expressed sadness, frustration, and anger about this situation.

The experiences the mothers related illustrate the effects of miscommunication and disparities in health care that most likely stem from miscommunication, misconceptions about others, and discrimination. These interactions are experienced on an individual level yet they are located on a systems level. For example, prevailing attitudes about immigrants, particularly undocumented immigrants influence the way persons in these situations are treated. They also lead to distrust of healthcare systems on the part of immigrants as reported in the literature (Weech-Maldonado et al., 2001).

Finally, other systems issues included concerns over family finances, even though all the participants' husbands were employed. It can be concluded that the husband's jobs are primarily low wage with poor benefits since all the participants' children received Medicaid health benefits and other forms of public assistance. Several of the participants also expressed concerns related to providing adequate housing for their children. For instance, Nidia and Odalis had to prove that they could provide adequate housing for their children who required equipment such as ventilators, oxygen monitiors for breathing and feeding pumps. Janeth and Andrea also moved from rented dwellings they described as inadequate for raising their children.

Overall, the interaction between individual and system level issues affected every aspect of the participants' lives. Systems issues cannot be separated from individual issues when families deal with managing their everyday lives within the context of disability. The findings from this study regarding the combination of factors that interact to influence participation correspond to some aspects of the literature on immigrants and healthcare concerning access to services and supports, communication, and health coverage for children (Bailey, Skinner, Correa et al., 1999; Dey, Schiller, & Tai, 2004; Shields & Behrman, 2003; Weech-Maldonado et al., 2001). Nonetheless, each participant's response to individual and system issues is uniquely personal and ultimately influenced the quality or level of their participation.

Conclusion Two: The actions of mothers of Mexican origin and service providers reflect some components of family centered early intervention practices.

A limited number of studies focus on the family of Mexican origin with parent or child family members who are immigrants and their health (Flores et al., 2002). Specifically, no research was found describing the actions of mothers of Mexican origin who are undocumented immigrants and providers that promote their participation in their child's EI program. Nevertheless, the cross-cultural literature on health and family practices in the U. S. has identified factors that influence parental participation in programs. These involve the construction of disability by families and providers; differential expectations for childhood development, interpretations, and meaning of disability among families; and culture's role in influencing parenting styles (Harry, 2002).

Additionally, early intervention practice has evolved to reflect family–centered practices that emphasize the family's social systems and environmental variables associated with child development enhancing and family strengthening consequences. Dunst's (2000) Model of Early Intervention and Family Supports (Figure 1) conceptualizes early intervention as intersecting interactions between children's learning opportunities (intentionally planned or naturally occurring), parenting supports, and family/community supports. Learning opportunites are interesting, engaging, and competency producing. Parent supports include information, advice, and guidance aimed at strengthening existing parenting knowledge that promotes the acquisition of new competencies. Lastly, family/community supports include any number of intrafamily, informal, community, and formal resources needed by parents.

The findings of this research provided insights on what participating means to the mothers of Mexican origin and how they participate. The examples of participating given by the study participants elucidated their preferences for receiving information, their strengths, and aspects about their caregiving. The participants described phenomenon, the characteristics of service providers, and service delivery factors that promote their participation. All of the mothers described aspects of their relationships with providers that influenced their level of participation. They also described their perceptions of the benefits they and their family received from participating in EI services. These findings correspond with components of Dunst's model as described below.

In responding to the first research question, the mothers' description of the meaning of participating conveyed actions that influenced how they participated. For instance, the participants described helping, paying attention, being present, being clear, informing, and being prepared as participating. These actions were associated with what they described as doing when they participated such as learning techniques from providers, practicing techniques with their children, and answering or asking questions of their providers. Additionally, the notion of *conviver* or to co-exist conveyed the mothers' and fathers' views about their child, their child's development, and their hopes for their child's future. For example, each participant expressed that they accepted their child, desired for others to accept their child, desired for their child to progress or be independent (*salir adelante*), and expressed confidence in their child's abilities. These findings relate to the instructional practices and parenting styles components of Dunst's model of early intervention and family support.

The participants' descriptions of phenomenon and actions on the part of providers that promote participation illustrated the collaborative interaction that occurred when the mothers participated. For instance, *platica* or chatting was one way the mothers described receiving suggestions from the providers in the context of being taught, being informed, and being advised by the providers. The mothers also identified their supports as family members, their religion, and religious or parenting groups. These findings correspond with the instructional practices and family community supports and resources components within Dunst’s early intervention model. Furthermore, attending parent groups was compatible with the participatory component of the EI model in which social support networks influence parenting attitudes and behaviors.

The actions of the providers as described by the mothers illustrated what providers do that promotes the mothers’ participation. Being creative denoted a therapist who utilized many strategies to help the child reach his or her goal. Being committed was associated with a provider who used techniques, equipment, and developmentally appropriate approaches that motivate the child, and most importantly were fun for the child. Consequently, these actions were identified as motivating the mothers to participate. The mothers also described their relationships with providers as stemming from the providers’ supportive attitudes (*apoyo*) that made them feel invited and valued. The providers’ actions that promote participation fit the child learning opportunities and parenting supports components of the EI model.

Another aspect of the participant provider relationship was mutual trust or *confianza* representing actions on the part of the provider such as offering options, choices, and communicating with the participants. Communicating here is distinguished from the preferred methods for learning that the mothers described as receiving written, verbal, and demonstrated information in Spanish. In the participant-provider relationship described by the mothers, communicating referred to how the mothers were attended to and treated by the providers. Communicating also included cordial greetings and respectful, collaborative, yet informal two-way information exchanges. For example, one mother described being called by providers or calling the providers when appointments changed or were cancelled because the mother had other commitments. These findings specifically illustrated what providers do or the actions of providers that promote participation and are compatible with the parenting supports component of Dunst’s model.

In summary, the findings of this study provided insight into particular aspects of participation for a specific subgroup of Latinas. Family centered early intervention practice is based on the intersecting components of an early intervention model that pertain to *what is done* and *how interventions are done*. The collaborative relationships formed between the providers and the mothers through their participation in the child’s EI program reflected some components within the Model of Early Intervention and Family Support as conceptualized by Dunst (2000).

The components of the EI model most compatible with the findings of this study included child learning opportunities, parenting supports, and instructional practices. Family/community supports and resources, family/community activity settings, and participatory opportunities appeared to be mediated by barriers to participation. These barriers included the combination of factors that influenced participation such as lack of access to the Non-Emergency Transport system and miscommunication that might lead to underutilization of services or supports and distrust of professionals.

Implications for Practice

Results from this study inform parents of children with disabilities, child and family professionals, healthcare professionals, personnel, and students, early intervention personnel and service providers, early childhood specialists, educators, policymakers, and the general public. It is my hope that these findings will encourage service providers and others to recognize and utilize the family as primary in promoting their children’s and family’s development. The findings of this study illustrate the importance of considering the perspectives and backgrounds of the families that are served in mutual learning experiences that promote competence. Consequently, providers can collaborate with families to implement effective programs using culturally competent practices that are responsive to their needs.

Currently, policymakers are grappling with issues related to systems and services concerning healthcare, transportation, education, housing, and other systems in order to address the needs of diverse populations. The issues faced by the participants of this study that are identified as barriers to participation deal with many of these systems. Policy makers and administrators must begin to address the needs of immigrants in several areas. For instance, a major barrier to participation for the members of this study concerned transportation. The transportation system in the county in which the participants live is not adequate to meet their needs. A small bus system was recently introduced; however the routes are limited and it is questionable whether the buses accommodate the needs of persons with disabilities. Although, taxis catering to the Latino population have proliferated, the cost of transportation is prohibitive for some families. Furthermore, taxi systems that cater to Latinos are often reported to be unresponsive to the needs of families with young children. For instance taxi drivers often do not allow the use of carseats in order to accommodate more passengers (EI Social Worker, personal communicaton, September 9, 2005).

The issuance of driver’s licenses to undocumented immigrants is also a topic before legislators that calls for a solution (Campos, 2003). Advocates for issuing drivers licenses to undocumented immigrants contend that denying drivers licenses to undocumented immigrants hampers accountability for driving and insurance coverage, proliferates identify theft, impedes law enforcement, undermines trust between immigrant communities and law enforcement, and is an ineffective means of immigration enforcement (Southern Regional Council, 2005).

Unlicensed drivers are jeopardizing their lives and the lives of others; however, they are also constrained by the lack of alternative transportation.

These overarching transportation system problems affect the families of the study participants who must drive in order to work and provide for the healthcare needs of their families. Problems associated with lack of transportation extended to other realms of the participants' lives including budgeting and employment. The participants of this study underutilized transportation systems for the previously mentioned reasons that also included language barriers and services that were unresponsive to their needs. Lack of culturally competent personnel in agencies increases disparities in healthcare (Anderson et al. 2003). These problems call for policy makers to insure that publically funded agencies adhere to federal and state mandates in order to provide culturally competent services and decrease healthcare disparities.

The need for adopting culturally competent practices was evident throughout some examples of systems within which the participants navigate. Educators and healthcare providers and personnel must educate themselves; model culturally competent practices, and educate their students and others regarding the needs of diverse populations. It is imperative that pre-service education includes foundational theory, practice, and research that address individual difference, family characteristics, and contextual forces that influence children and their families as advocated by Garcia Coll and Magnuson (1997).

Furthermore, policy makers, program administrators, educators, healthcare personnel and providers, students, and others who communicate with persons who primarily speak Spanish must seek opportunities to improve communication with Spanish language speakers. Levels of communication proficiency include having a working knowledge of the Spanish language or having access to resources such as interpreters, online dictionaries, pocket dictionaries, publications and handouts. These resources will aid in decreasing disparities in healthcare and improve cultural competence in service provision as well as foster good community relations.

The Early Intervention program in which the participants are enrolled could serve as a template for service provision. The EI program has evolved to support a family centered philosophy. The participants' responses to questions about the EI process indicated that collaboration was taking place during several phases of the EI process: at intake, when the child was evaluated, when problems were identified, and when treatments/interventions or service provision was critiqued. Findings from this study also provided evidence that several aspects of Dunst's model for early intervention and family support were present in service provision with the exception of participatory activities in family and community settings for the majority of the study participants.

Even though most aspects of a family centered EI model were demonstrated by the findings of this study, EI service providers and healthcare educators must focus on goal setting with families. Family priorities are fundamental to effective service provision and all of the participants of this study were able to generally describe their child's goals. Still, in order for child outcomes and developmental trajectories to be accurately measured for diverse groups, parents and providers must concur on articulating the child's goals and carrying out activities that foster the child's and family's goals within their homes and communities. These actions are imperative for identifying cultural variations in goals; communicating clearly with families; understanding the perceived or implied responsibilities of families and providers, and implementing relevant services for families.

Finally, the findings of this study provided practical knowledge regarding collaborative practice with families of Mexican origin. Establishing how families define participation, identifying how participation occurs, practicing actions that promote participation, and identifying barriers to participation are ways to facilitate family centered care. Educators must teach Dunst’s Model of Early Intervention and Family Support. Service, providers must practice using the model, and all involved (including parents) must gather evidence to support family centered Early Intervention practice. These are some ways to expand the literature on child and family development concerning families of Mexican origin and other diverse groups.

Implications for Theory

The results of this study inform the theoretical foundations of early intervention. Early intervention services are based on family systems, ecological, and ecocultural perspectives (Bruder, 2000; Guralnick, 2000; Hanson & Bruder, 2001; Mahoney & Bella, 1998; McBride et al., 1993). Contemporary practice in early intervention involves the widely accepted family focused Model of Early Intervention and Family Support (Dunst, 2000). The family focused model is based on a social systems framework for understanding the influences of social support and other factors on child, parent, and family functioning. Central to this framework are the concepts of collaboration with parents and the support of parents (Mahoney & Bella, 1998).

The ecocultural perspective presumes knowledge is socially constructed, contextually grounded, experience based, and recognizes the expertise of families as most knowledgeable about their local contexts and conditions (Bruder, 2000). Families are also considered most optimally situated to design, implement, and evaluate solutions most appropriate to their situations. Ecological theory suggests that the family is a social institution embedded within broader cultural contexts. According to Bailey, Skinner, Correa, et al. (1999) the child with a disability is part of an ecology that includes parents, siblings, extended family members, friends, neighbors, and community agencies.

As previously concluded, findings of this study inform understanding of what participation means or signifies for mothers of Mexican origin. The significance of participating for the mothers influenced their participation in their child's EI program. Additionally, the phenomenon and actions that promote the mothers' participation rely on the significance participation holds for the mother and by extension, other family members.

These factors are considered socially constructed as evidenced by the words and phrases expressed by the mothers concerning cultural characteristics and philosophies. For instance, within the course of providing information on participating, the mothers referred to words that described characteristics of their cultural group. Three participants used the word "*dejado*" to describe a trait they attributed to some Mexican people or in reference to an irresponsible parent meaning one who is negligent or does not take a situation seriously. The participants usually used this term to mean a negative characteristic that would jeopardize the health of a mother or her child. It was also used to describe a parent who did not adequately attend to her home, family, or to mean someone who did not follow instructions or recommendations, instead doing things their own way consequently impeding the progress of the child.

Additionally, all the parents described the importance of providing the attention they felt their child needed and their desire for their child to be independent. They all used the words "*salier adelante*" or "*sacar adalente*" to denote to come out ahead. The consistent use of this word in their speech illustrated a philosophy that appeared to influence their lives. The words *dejado* and *adelante* exemplified the social construction of roles and responsibilities assumed by the participants. These findings correspond to social identity theory as used by Flores Neiman et al. (1999) who contend that examination of people's social constructions of their ethnic identities is critical for understanding their social realites.

The findings of this study regarding the phenomenon and actions of providers that promoted participation also inform theoretical concepts of early intervention dealing with ecological and ecocultural perspectives. The mothers described relationships with their providers that demonstrated supportive attitudes, trust, and collaboration. These relationships stemmed from the mothers feeling that they were included and valued thus exemplifying that service providers recognized the mothers' expertise and knowledge about their child and family. The mothers' responses to research questions indicated their collaborative involvement in EI processes (See Tables 1 through 4).

Lastly, findings representing the notion of *conviver* or to live together and the supports identified by the mothers corresponded with ecological theory. These findings exemplified the family's philosophy of acceptance for their child as well as their hopes that others accept, relate to, and include their child in everyday activities or their communities. Similarly, the participants identified supports that included intrafamily and community resources such as their husbands, children, family members in the U. S. and Mexico, religion/religious groups, and parent support groups. Although, some participants identified certain community resources as supports, other individual and system level factors interacted to constrain their access to child and family learning opportunities and resources within their communities.

Implications for Research

As I have noted, findings from this study provide information on the participation of a subgroup of Latinos-mothers of Mexican origin in their child's EI program. Future research might focus on replicating this research within cultures and cross culturally to explore parental participation among other groups. Researchers advocate examining processes involved in family focused early intervention and family outcomes (Hinojosa et al., 2001; McBride et al., 1993; Spiker et al. 2000). The findings from this study corresponded to some aspects of the widely accepted model of early intervention (Dunst, 2000). Family focused Early Intervention processes and practices adhering to this model could also be examined with other cultural and ethnic groups.

Future research might also include: conducting a study using the four research questions posed in this study with Black, white, and Asian groups and their subgroups. These research questions might be posed to EI providers controlling for years of practice and work with diverse populations. The study could be replicated with mothers of Mexican origin who are undocumented immigrants in the Northern, Southern, Eastern, and Western regions of the United States. A component of this research might also explore disparities in EI programs nationally as reported by Spiker et al. (2000).

This study might also be replicated with matched samples of Latino subgroups that are United States citizens and undocumented residents in the United States. Longitudinal study using the research questions from this study might be used to explore family participation in the EI system over a three-year period from intake to transition to the pre-school system. Other variables might be added to measure developmental outcomes over time. Finally, the use/utility of the Model of Early Intervention and Family Supports (Dunst, 2000) in Early Intervention practice could be examined to gather data on the variables that corresponded with the model and those found lacking. These variables concern access to child learning opportunities and participatory opportunities for supporting parents through family and community supports and resources. Research findings would support Evidence Based Practice in the Early Intervention field and contribute to the pre-service education of service providers.

Limitations and Strengths

Limitations of this research include the small study sample. Although the mothers shared common characteristics such as being undocumented immigrants from Mexico, they are unique individuals. Several personal characteristics such as age, education, personal experiences, and resources ranging from family support to religion are unique to each participant. Furthermore, the ages of their children were not matched and their time participating in the Early Intervention program varied from almost two and half years to five months. Nonetheless, this study examined the ongoing participation of an underrepresented group - mothers of Mexican origin who are undocumented in one specific Early Intervention program. This study also offers the potential for focused research targeted at examining the practices of a particular group of families and practioners utilizing an accepted model of Early Intervention practice.

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APPENDIX A

LETTER TO LATINO FAMILIES

May 23, 2005

Estimada familia en el pograma Intervencion Temprana Babies Can't Wait:

Mi nombre es M. Irma Alvarado. Soy un estudiante en el programa doctoral en el Departamento de el Desarrollo del Niño y Familia en la Universidad de Georgia. Realizo investigación en las experiencias de madres del origen Mexicano que toma parte en su programa temprano de la intervención de niño. El propósito de esta investigación deberá investigar en detalla esas experiencias de una familia que vive con un niño con una incapacidad diagnosticada entre las edades de uno y de tres años.

Yo le invito a tomar parte en este estudio. Si usted es interesado a hablar conmigo acerca de la unión de este estudio, yo arreglaré un tiempo con usted decirle más acerca de yo mismo y le dice más acerca de esta investigación. Contácteme por favor en 404 862-0838.

Gracias

M. Irma Alvarado
404 862-0838

****

To Latino Families in the Babies Can't Wait Program:

My name is M. Irma Alvarado. I am a student in the doctoral program in the Department of Child and Family at the University of Georgia. I am conducting research on the experiences of mothers of Mexican origin who participate in their child's early intervention program. The purpose of this research is to investigate in detail those experiences of families who live with a child with a diagnosed disability between the ages of one and three years.

I invite you to participate in this study. If you are interested in talking with me about joining this study, I will arrange a time with you to tell you more about myself and tell you more about this research. Please contact me at 404 862-0838.

Thank you.

APPENDIX B

CONSENT FORM (ENGLISH VERSION)

Dear Participant,

You are invited to participate in a research project entitled *Living with a child with a disabling condition* conducted by M. Irma Alvarado from the Department of Child and Family Development at the University of Georgia. For this project I will be investigating experiences of Mexican origin families living with a child with a disabling condition from the parents' perspective.

The purpose of this research is to investigate in detail those experiences of a Mexican origin family who live with a child with a diagnosed disability between the ages of one and three years. I hope that such a study will inform about how the family's functioning is affected by challenges imposed by living with a child with a disabling condition and how the family functions with life events that include disability. This research will be under the direction of Dr. Zolinda Stoneman, Director, Institute on Human Development and Disability, 706 542-3457.

For this project I will be collecting data in the form of interview, participant observation, archive, fieldnotes, focus groups or any existing documents, photographic or videotape information either produced by me or provided by the participant. This will involve responding to several open-ended questions in interviews lasting approximately one to two hours concerning your family's experiences living with circumstances involving disability. You will receive one 10.00 gift card for the intial interview. With your permission, I will audio-tape the interview so than I can transcribe the tape and interpret the data.

No discomfort or stresses are expected for participants in the study. Likewise, I anticipate no risks to participants. All information collected during the study will be treated confidentially (unless required by law), and publications from my project will use pseudonyms. I will store, retain and dispose of all data related to this research. You are free to withdraw your participation at any time without penalty. Should you wish to read any reports from this study, please let me know.

If you have any questions or concerns, feel free to call me at either 404 862-0838. I hope you will enjoy this opportunity to share your experience with others.

Thank you very much for your assistance.

I understand that procedures described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form. I have read the above description and give my consent for the use of the information or records as indicated above.

Signature of Researcher/Date

Signature of Participant/Date

Signature of Participant/Date

The Institutional Review Board oversees any research-type activity conducted at the University of Georgia that involves human participants. Additional questions or problems regarding your rights as a participant should be addressed to:

The Chairperson, Institutional Review Board
University of Georgia
606 Boyd Graduate Studies Research Center
Athens, Georgia 30602-7411
Telephone: 706/542-3199
E-mail: IRB@uga.edu

APPENDIX C

CONSENT FORM (SPANISH VERSION)

Formulario de Consentimiento

Estimado Participante,

Esta invitado participar en una investigación titular “Living with a child with a disabling condition” baja de conducto de M. Irma Alvarado de el Departamento de Desarollo de el Nino y Ia Familia en Ia Universidad de Georgia.

El proposito de este estudio es para investigar en detalle las experiencias de familias de origen Mexicana que se encuentran viviendo con un nina/a de edad 0 —3 años con impedimiento/incapacidad. Espero que este estudio informa como funcióne una familia viviendo baja condiciones que incluyen impedimiento o incapacidad. Este estudio es baja Ia direccion de Ia Dra. Zolinda Stoneman, Directora, lnstituto de Desarollo y Disabilidad Humano, Universidad de Georgia, 706 542-3457.

Para este estudio se juntan datos en Ia forma de entrevista, observacciones, archivos, notas de campo, grupos enfocados, fotos, video, audio o documentos que existen para informar que se producen por mi o eI participante. Este processo involuca respuestas sobre las experiencias de su familia. Recibe una tarjeta de valor 10.00 dolares si usted participa en la entrevista individual. Con su permiso se graba Ia entrevista para producir y intérpretar Ia informacion.

No se espera estrés o riesgo para eI participante. Toda informacion se trata confidencial (a menos que exige ley). Publicaciones que resultan de este estudio usan seudonimos. Me encargo de mantener y guardar los datos relacionados con el investigación. Usted es libre retirar su participacion a cualquier tiempo sin pena. Esi desea leer resumens de este estudio, solamente pregunte.

Si tiene preguntas a inquietudes, llame con confiaza a 404 862-0838. Espero que esta opportunidad para compartir su experiencia con otros es agradable para usted.

Gracias por su ayuda.

Entiendo los procedimientos de este estudio previamente mencionado. Respuestas sobre mi preguntas son satisfactorias. Doy mi consentimiento para participar en este estudio y el uso de datos como indicado previamente. Tengo una copia de este formulario.

Firma de Participante/Fecha

Firma de participante/Fecha

Firma de investigadora

El Institutional Review Board supervisa investigaciónes dirigidos en Ia Universidad de Georgia que involucen participantes humanos. Preguntas sobre su derechos coma participante se dirigiren a:

The Chairperson, Institutional Review Board
University of Georgia
606 Boyd Graduate Studies Research Center
Athens, Georgia 30602-7411
Telephone: 706/542-3199
E-mail: IRB@uga.edu

APPENDIX D

DEMOGRAPHIC DATA FORM

Today's Date:

Place/Time:

Interviewer:

Participant #:

Pseudonym: **Gender:** **F** **M**

Age: **Birthdate:** **Birthplace:**

Residence Pattern:

Born in:
____________________until______ big, med, little, rural
____________________until______ big, med, little, rural
____________________until______ big, med, little, rural
____________________until______ big, med, little, rural
Special Comment: Migrant family, moved frequently____

Birth order: 1st__ 2nd __ 3rd__ 4th__ 5th__ 6th__ other__

Sisters:
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________

Brothers:
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________
Name _________ present age___ now lives in ________

Parents: Living in: _____________________________
Mother age ______died __ your age then___
Father age ______died __ your age then___
Marital Status:
Divorced: Y N Your age then ____
Lived with M/F between ages ____ & ____
Special Comments:
Birth Place Mother: Stepmother:
Birth Place Father: Stepfather:
Ethnic Background:

Mother:	Stepmother:
Father :	Stepfather:

Occupation:

Mother:	Stepmother:
Father:	Stepfather:

Respondent:

Education: Highest/Specialty
Occupation:
Marital Status & History **M D S R Co**
Married/Year _____ Divorced/Year_____
Remarried/Year _____ Cohabitating/Year_____

Children

Name _________ age___ gender: __ lives in ________
Name _________ age___ gender: __ lives in ________
Name _________ age___ gender: __ lives in ________
Name _________ age___ gender: __ lives in ________

Religion: ________________Self: _____Family_____
How often worship: Daily Wkly Mo x's/yr

Adapted from McCracken Preliminary Questions for Qualitative Research (1988)

APPENDIX E

INTERVIEW GUIDE

ID # or Pseudonym __________________________

Interview #___Time Start:__________/End:___________ Date:________________

Interview Setting/Persons present: ____

____

1. Tell me about your family. / **Dígame sobre su familia.**

2. Tell me a little more about (Child's name)? **/Dígame un poco mas sobre (nombre de nino/a). Detalles:**
    a. What is your child's diagnosis?/ **¿Cual es el diagnostico de su nino/a**
    b. What is your child's disabling condition like? Or describe your child's disability?/**¿Describe la inhabilidad/descapacidad de su niño?**
    c. Tell me what disability means to you. **¿ Dígame qué significa la inhabilidad/descapacidad para usted?**
    d. How does your child's disability compare to your definition?/**¿Cómo compara la inhabilidad/descapacidad de su nino a su definición?**

3. Tell me about the services you receive/people that help with (child's name) **Dígame sobre los servicios que su familia recibe o los proveadores de servicios que ayudan con su hijo/a.**

4. Think about some times when you experienced participating in your child's early intervention program and tell me about it./**Cómo fué su participación en el pograma de intervención temprana para su niño? Deme un ejemplo:**
    a. What did you do? / **¿Que hiso?**

APPENDIX F

PARTICIPANT DESCRIPTIONS

Participant	Nidia	Andrea	Karina	Odalis	Jamie	Janeth
Age/husband	43/61	21/23	28/28	35/22	26/35	21/30
Education	2nd grade	6th grade	6th grade	9th grade	9th grade	10th grade
Time Mother in US	5 yrs	4 yrs	4 yrs	3 yrs	10 yrs	6 years
Employment	Homemaker Child care	Restaurant 4 days/wk	Homemaker Former Poultry ˜ 1 yr	Homemaker Former Poultry 1 ½ yrs	Homemaker	Homemaker Former Poultry ~1yr
Child in EI*	Ruth	Gabi	Rubi	Soyla	Alex	Brigette
Birthplace*	US	US	US	US	US	US
Age*	1.10	2.2	2.6 11/10/02	10 mos	1.4	8 mos
Diagnosis*	Respiratory Failure¥ €	Spina Bifida	Down Syndrome	Oomphalocele€	Down Syndrome	Down Syndrome
Other Children (US born± Mexico born£)	0	5 y.o. ±	8 y.o.£	0	9 & 3 y.o. ± 6 y.o. £	0
Time in EI*	1y 3mo	2 yrs	2 y 4 mo	6 mos.	9 mos.	5mos.

¥ Bronchopulmonary Dysplasia (BPD), Gastroesophageal Reflux (GER), prematurity,
€ Significant Developmental Delay
* Educated in the U.S. middle and high school

APPENDIX G

PARTICIPANT’S PLACE OF ORIGIN MAP


UNITED STATES OF AMERICA
Mexicali
Tijuana
Ciudad Juárez
Nogales
Hermosillo
Río Grande
Conchos
Chihuahua
Nuevo Laredo
BAJA CALIFORNIA
Ciudad Obregón
Monterrey
Gulf of California
Torreón
Saltillo
Matamoros
Gulf of Mexico
Culiacán
Durango(2)
La Paz
Mazatlán
Tampico
Yucatán Peninsula
Aguascalientes
Tamuin
León
Bay of Campeche
Mérida
Guadalajara
MEXICO CITY
Irapuato
Puebla
MEXICO
Cuernavaca
Villahermosa
BELIZE
Tehuantepec
Acapulco
Zihuateneio
North Pacific Ocean
Gulf of Tehuantepec
HONDURAS
Escobia
GUATEMALA
EL SALVADOR
NICARAGUA

APPENDIX H

EARLY INTERVENTION SERVICES RECEIVED BY CHILDREN*

	Ruth	Gabi	Rubi	Soyla	Alex	Brigette
Occupational Therapy	X		X	X	X	
Physical Therapy		X				X
Speech Therapy	X		X			
Hearing					X	
Case coordination	X	X	X	X	X	X
Other	In-home Nursing			In-home Nursing		
Public Assistance	Medicaid WIC	Medicaid SSI	Medicaid WIC SSI	Medicaid WIC SSI	Medicaid WIC SSI	Medicaid

*Services provided at time of interview