UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

# PERCEPTION OF EARLY INTERVENTION FAMILY OUTCOME: INSIDE CHINESE-AMERICAN FAMILIES HAVING CHILDREN WITH DISABILITIES

A DISSERTATION

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment to the requirements for the

Degree of

DOCTOR OF PHILOSOPHY

BY

PEI-FANG RACHEL WU
Norman, Oklahoma
2009

# PERCEPTION OF EARLY INTERVENTION FAMILY OUTCOME: INSIDE CHINESE-AMERICAN FAMILIES HAVING CHILDREN WITH DISABILITIES

A DISSERTATION APPROVED FOR THE
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

BY

Dr. David Lovett Chair

Dr. Kathryn Haring

Joyce Brandes
Dr. Joyce Brandes

Jiening Ruan
Dr. Jiening Ruan

Dr. Charolette Myles-Nixon

# DEDICATION

I dedicated this dissertation to my parents Jenn-Hwa Wu and Chin-Chih Hong

for their extreme support and profound sacrifices.

# ACKNOWLEDGEMENT

I would like to thank the many people who have helped and inspired me during my doctoral study including but not limited to the following.

First and foremost, I thank my dear heavenly father for his endless love, for giving me strengths, for always protecting me, for helping in times of trouble, for reminding me to forget the past and focus only on what is ahead, for whispering into my ears and asking that I concentrate on reaching the goals He set for me. GOD, I thank you.

I extend my sincere appreciation to Dr. David Lovett for persevering with me as my advisor/chair of my dissertation committee. The inspiration for doing this research came from the passion and the love that he has for families of different cultures having children with disabilities. He was accessible and willing to help his students always. This assistance made the task of research a rewarding one for me.

I acknowledge also the support of my professors: Dr. Kathrin Haring for requiring me to think critically and motivating me to want to be a good special education teacher and researcher; Dr. Joyce Brandes, Dr. Jiening Ruan and Dr. Charolett Myles-Nixon, for serving on my dissertation committee; Dr. Brandes and Dr. Ruan for their encouragement, and Dr. Myles -Nixon who gave me my first special education research opportunity years ago. All three of them have generously given their time and expertise to better my work. I thank them for their contribution and their good-natured support.

I am grateful to many persons who shared their memories and experiences and they are those families and the early intervention services provider that who participated in my research study.

I extended my thanks to the faculty and staff in the department of educational psychology, program of special education for their support, consistent help and great friendship throughout my entire doctoral program.

My most loving thanks to my adopted American parents and best friends Ralph and Glades Tolls and the rest of the Tolls families who nurtured me during throughout my college term.

To my friends, Holly Rice, Tori Collier, Milton Collier, Chen-Ya Juan, Linda Wu, Wei-Dong Ran, Bei-Xi, Kai-Chen Tien, and the friends from FBC international department, I extend a special thanks.

My deepest gratitude goes to my family for their persistent love and support throughout my life. Completion of my dissertation and degree without them would not have been possible. I am indebted to my father, Jenn-Hwa Wu for his everlasting love and care. As a father, he worked hard and sacrificed so many personal opportunities just to make sure we had life's essentials and an opportunity to go to college. My mother, Chin-Chih Hong who was my first teacher professed an attitude and belief toward educating young children with disabilities which shaped my life and my view toward people with special needs. Words cannot express adequately the love my mother has given me, and I only wish someday I will have a daughter, who will love me as much as I love my mom. I am proud of my brother and sister, John Wu and Angel Wu and thank them for faithfully believing in me and fulfilling my family duties during my absence.

Last but not least I want to thanks my very best friend DK Yang for the love, support and encouragement extended to me. Because of you I become a better person every day, I love you.

# TABLE OF CONTENTS

ACKNOWLEDGEMENTS…………………………………………………………...IV
LIST OF FIGURES……………………………………………………….............IX
LIST OF TABLES…………………………………………………………………..X
ABSTRACT……………………………………………………………………….XI

CHAPTER 1 INTRODUCTION……………………………………………….1
- Introduction...........................................................................................................1
- Problem Statement……………………………………………………...1
- Significance of the Study……………………………………………. ……..2
- Asian-American Population in United States……………………………..3
- Research Questions……………………………………………………….7
- Limitations and Delimitations…………………………………………….8
- Chapter Summary and Overview………………………………………….9

CHAPTER 2 REVIEW OF THE LITERTURE…………………………………11
- Background of Early Intervention………………………………………11
  - Family-Center Care……………………………………………...14
- Structure of Culturally and Linguistically Diverse Families……………………19
  - Recently Arrived Immigrant Families…………………………...19
  - Immigrant American Families…………………………………...20
  - American-Born CLD families…………………………………....20
- Culture Competence………………………………………………………...21
- Collectivism, Individualism and Biculturalism………………………………21
  - Collectivism and Individualism……………………………………21
  - Biculturalism……………………………………………………..22
  - Stage of Ethnic Identity Development…………………………...23
  - Model Minority Myth……………………………………………24
  - Cross-Cultural Communication…………………………………26
- Culture Value………………………………………………………………27
  - Early Intervention Cultural Legislation…………………………29
  - Children and Childrearing………………………………………..31
  - Disability Beliefs and Early Intervention/Special Education……………32
  - Medical and Healing……………………………………………..33
  - Early Intervention and Special Education Approaches to Disabilities…..33
  - Family preparation for Participation in IFSP Development……………..34
  - Evaluation of Early Intervention Family Outcomes……………………..37
- Chapter Summary and Overview……………………………………………...41

CHAPTER 3 RESEARCH METHODS………………………………………42
- Research Design and Methodology……………………………………...42
- Introduction……………………………………………………………....42
- Comparison of Different Types of Research Methods…………………………..43
  - Experimental Research…………………………………………..44
  - Correlational Research…………………………………………...44

Single Subject Research……………………………………………………45
Qualitative Design Research……………………………………………..46
Design of the Study…………………………………………………………...47
Rationale for Methods ………………………………………………….....47
Developed Chinese-American Families Interrelationships Model………50
Methods of Data Collection…………………………………………………...51
Participants…………………………………………………………………51
Interviews of the Chinese-American Families with
Children with Disabilities……………………………………………..52
Families Needs Checklist……………………………………………….....53
Interview of the Chinese—American Families Services
Provider/Coordinators…………………………………………………53
Data Source, Research Procedures and Data Analysis…………………………..53
Data Sources……………………………………………………………….53
Informed Consent and confidentiality…………………………………...54
Research Procedures..........................................................................54
Social Validity and Trustworthiness of the Data………………………...55
Project Timeline……………………………………………………………55
Data Analysis………………………………………………………………57
Role of the Researcher……………………………………………………...58
Conclusion …………………………………………………………........60
Chapter Summary and Overview………………………………………...61

CHAPTER 4 DATA ANALYSIS AND RESULTS……………………………………62
Introduction…………………………………………………………………........62
Procedure……………………………………………………………………...63
Family Case Portfolios……………………………………………………………...64
Wang…………………………………………………………………………..64
Cheng………………………………………………………………………….65
Taso……………………………………………………………………………65
Ma……………………………………………………………………………..66
Response to Research Questions…………………………………………………...67
Q1: What are the Needs of Chinese-American Families………………...67
Q2: Have the Non-Child Related Needs of Chinese-American Families
Been Identified in IFSP Documents?................................................75
Q3: What are the Chinese-American Families Perceptions
of the Early Intervention Program and Services
as well as Family’s Role and responsibilities while receiving
the service?.......................................................................................76
Q4: Have the family outcome indicators (developed by the ECO Center
and the Office of Special Education Programs) effectively identified
Chinese-American families expected EI family outcomes?...............79
Chapter Summary and Overview………………………………………………..83

CHAPTER 5 GNERAL DISCUSSION……………………………………………………84
Parents' Emotions Upon Realizing a Child Has a Disability……………………84
Access to the Early Intervention Services and Information……………………..87
Child Rearing……………………………………………………………………….91
Family Structure/Adaptations to Mainstream Culture…………………………...95
Support from Family Members/Friends…………………………………………96
Father's and Mother's Role in the Family……………………………………….98
Parent's View of their child's Disability……………………………………….100
Culture Views Children with Disabilities………………………………………101
Alternative Medication/Treatment ……………………………………………..103
View on Culture Competence of the Early Intervention Services
And Providers…………………………………………………………………..103
Concerns for Their Child and Hope for the Future……………………………..107
Case Study……………………………………………………………………...109
Limitation of the Study…………………………………………………………113
Recommendation for Future Study……………………………………………..113
Conclusions……………………………………………………………………..114

REFERENCES…………………………………………………………………....117
Appendix A:
Research Recruitment, Consent Forms, and Interview Protocols (English version)…...137
Appendix B:
Consent Forms, and Interview Protocols (Chinese version)……………………………153
Appendix C:
IRB Approve Letters from OU and State Department of Health……………………….171

# LIST OF FIGURES

Figure 3.1
Interrelationships of Services and Outcomes
for Children and families adopted from ECO Center…………………………………………...132

Figure 3.2
Interrelationships of Services and Outcomes
for Chinese-Family and Children with disabilities
(Adopted and modified from ECO Center) …………………………………………………….134

# LIST OF TABLES

Table 1
Participant Family Demographic Chart………………………………………………...135

# ABSTRACT

This study seeks to determine whether Chinese-American Families having a child with disabilities experience different needs and expected early intervention family outcomes from families from the mainstream culture. The Researcher used different qualitative research techniques to examine Chinese-American Families who have children with disabilities. Participants shared their perceptions of many different issues around their young children with disabilities and the early intervention services that they had or have been receiving during the time of the interview. The results show parents from Chinese Cultures expect the same type of family outcomes as do mainstream parents; however, the data indicated that cultural differences and unfamiliarity with early intervention and special education systems have created a difference between the extent to which the Chinese cultures avail themselves of the available services which assist parents in dealing effectively with needs of the disabled children.

In the general discussion the researcher will discuss the culture related themes which have caused this underutilization of relevant services. The future research implications and limitations of this study are provided in the last chapter.

# CHAPTER 1

# INTRODUCTION

Early intensive intervention is one of the most important and effective tools necessary for families who have a child with a disability. Research indicates that the earlier children and their families are involved in early intervention programs, the better their outcomes will be. The Individuals with Disabilities Education Act, 2004 (IDEA, 2004) states that all children who are at risk or with disabilities are entitled to receive "family-centered" early intervention services through a multidisciplinary team. An Individual Family Service Plan (IFSP) is developed by the IFSP team to ensure that the child and the family receive quality early intervention services.  Unlike Individual Education Programs (IEPs) which focus primarily on the child with disabilities, the consumers of early intervention are both the children with disabilities and their families. The No Child Left Behind Act (NCLB) has brought much attention to issues of accountability within state and federally funded disability services and IDEA programs. In 2003, the United States Congress required all states that provide early intervention services to develop a set of outcome indicators that would ensure high quality early intervention services are provided to the families they serve. The federal funding that each state receives for their early intervention programs is based on the outcome indicators that have been established and accomplished through the services provided to the families and their children with disabilities.

## Problem Statement

Early intervention services providers can meet the needs of culturally and linguistically diverse families and children by implementing the Individual Disability

Education Act of 2004. There are many issues surrounding the development of the Individualized Family Service Plans (IFSP) for families and children from culturally and linguistically diverse (CLD) backgrounds. Unfortunately, most early intervention service providers lack training on how to work with families and children who are from CLD backgrounds. Service providers also do not have enough information about these families, or their culture, values and background to address the needs of the families being served. Research has indicated the inability of service providers to perform cross-cultural communication often makes the CLD families feel dissatisfied with the early intervention program. In the field of early intervention and special education, numerous studies have been conducted for the purpose of understanding different cultures, values, beliefs and languages. These studies help early intervention service providers better communicate with and serve CLD families and their children with disabilities. However, little or no research has focused on the perspectives of CLD families regarding the early intervention outcomes they and their children with disabilities have received.

## Significance of the Study

One of the most culturally and linguistically diverse countries in the world is the United States. The changing family structure in the United States provides unique challenges for early intervention services providers. According to a report from the Department of Homeland Security and the Office of Immigration Statistics (2000), there are nearly 70,000 immigrants arriving in the United States every day. About 2,200 of these daily arrivals are immigrants or refugees who have been invited to become permanent residents of the United States. Leak and Stodden (2002) suggested that more than half the K through 12th grade school population will consist of culturally and linguistically diverse (CLD) students by the year of 2040. Statistics from the Children's Defense Fund support the suggestion that between the years of 1985 and 2030 the total number of CLD students will have increased by 53 % (1989). One out of three children born in the United States are from CLD families (Hanson, 1998) and according to the United. States Department of Education (2001), 5.5% or approximately 145,000 are students with disabilities.

### *Asian-American Populations in United States*

Beginning in the 19th century, there was a large scale increase of Asian immigration to the United States. This has been often called the first wave of Asian immigration. Between 1939 and 1945, the United States Government allotted yearly immigration quotas for Chinese, Japanese, Koreans, Filipinos, and Asian Indians. During the year of 1965, U.S immigration office allowed a large number of Asians to immigrate to the United States each year. After the Vietnam War ended in 1975, many immigrants from Southeast and South Asia started to settle down in the United States. Unlike Chinese, Japanese, Koreans, and Filipinos, the immigrants from South Asia countries such as Cambodia and Burma often came from backgrounds devoid of educational experiences, which are issues inherent to refugees. Many also exhibited problems with second language learning.

In 1995, 268,000 new immigrants came to the United States from Asia and the Pacific Islands. In 2002, 40% of the newly admitted immigrants were from Asia (U.S Immigration, 2002). The Asian American population doubled between 1980 and 1990, and it will double again between 1990 and 2020. Asians, however, are not one homogeneous group. They represent more than 26 countries, 40 cultures, and 100 different languages (Dao, 1991). Furthermore, there is considerable social and economic variation between recent Asian immigrants and Asian Americans who have been in the United States for generations. The number of U. S. immigrants who originally came from Southeast Asian dramatically changed in the past 20 years (U. S. Bureau of the Census, 1993). Southeast Asia included people from India, Pakistan, Bangladesh, Sri Lanka, Thai, Burma, Laos, Cambodia, Hmong, Tibet, and Nepal (Dao, 1991). The number of Asian American school age children and youth increased from 212,900 in 1980 to almost 1.3 million in 1990. It is estimated that by the year of 2020 Asian Pacific American students ages five through seventeen will make up over eight percent of the school age population (Pang and Cheng, 1998). In 2000, 23% of Asian Americans and Pacific Islander families comprised of five or more members, and approximately 10 % of California newborns were Asian (Pang and Cheng, 1998; Choy, Yamashita, Foote, & Heer, 2000). The increase of Asian American students are centered in larger urban areas such as New York City, New Jersey, Chicago, Los Angeles, Washington, DC, Illinois, Virginia, Florida and Massachusetts (U. S Bureau of the Census, 1993).

All Asians do not have the same cultural practices (Bets, 1993). Asian Americans have different cultures which are based on their countries of origin, region, religion, social class, and education level. Although some basic beliefs and values are shared by all Asian groups, it is essential for general or special education teachers, service providers, and other professionals to recognize the heterogeneity of Asian students and their families so that they may avoid the myth of cultural homogeneity.

According to the Individuals with Disabilities Education Improvement Act of 2004 (P.L. 108-446) and Oklahoma early intervention law, there are federal and state mandates which require young children with identified special needs and their families to be served in Early Childhood Special Education programs. The most current IDEA child count data indicates that approximately 300,000 children are receiving early interventions/services under the Individual with Disabilities Educational Act (IDEA), Part C, Infant/toddler program (Child Count Data, 2006), and approximately 42% of these children are from Culturally and Linguistically Diverse (CLD) backgrounds (Child Count Data, 2006). In addition, of IDEA section 619 children most are preschool age with 700,000 currently being served. Approximately 37% of those children are from CLD backgrounds (Child Count Data, 2006). If these groups that are currently receiving IDEA part C and Part B section 619 services are compared to the number of those who received services in previous years, the numbers would indicate that there has been a considerable increase in the number of CLD families being served. This is particularly noteworthy when one recognizes that the majority of service providers are females from Euro-American backgrounds.

The number of immigrants in this population is reflected clearly in the early childhood outcome data in each state where students are receiving early intervention and special education services. Because of the changing demographics of the US population, family structures are becoming more and more diverse in terms of cultural values, beliefs, and languages. Early intervention service providers need to provide the same opportunities to CLD families as they offer to European-American families. The introduction of IDEA, acknowledges “over 20 years of research and experience demonstrated that the educations of children with disabilities can be made more effective by … strengthening the roles of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home according to the findings of the US Congress, section 601(c)(5)(B) (IDEA) 2004".

Many studies have found that CLD families display lower levels of participation than European American families in the special education process and suggest there is a lack of consideration of the traditional cultural values, beliefs, and languages of CLD families (Harry, 1992a, 1992b., Lynch & Stein, 1987). Furthermore, research also indicates that early intervention and special education services are underused by CLD families (Arcia & Gallagher, 1993; Sontage & Schacht, 1993; 1994). Factors preventing their participation in the IFSP process were identified as a lack of communication and misunderstanding from CLD families of the expectations of early intervention services.

Given these findings, there is a significant need for more studies to focus on the Chinese-American family's perspective of the quality of early intervention services that they receive. Based on the information that Chinese-American families provided, this study could lead to the development of Chinese-American family best practices in early intervention service provision and could provide suggestions for improving CLD guidelines. The purpose of developing recommended American-Chinese early intervention outcome guidelines is:

1. To prepare early intervention services providers to use better tools to assist Chinese-American families and their children with disabilities.

2. To help the State early intervention agencies assess the outcomes of early intervention programs under IDEA part C and part B in a more culturally responsive manner.

3. To ensure better outcomes of early intervention programs at the State level.

## Research Questions

The purpose of conducting research in this area is to investigate the perceptions and experiences of Chinese-American families who receive early intervention services. This investigation will seek to discern whether their needs, priorities, and cultural values have been considered in family-centered IFSP goals and objectives. Questions for further research in this area include:

(1) What are the needs of Chinese-American families? (Data will be acquired from family interviews and needs a checklist)

(2) Have the non-child related needs of Chinese-American families been identified in the IFSP document? (Data will be acquired from a review of children's IFSP document)

(3) What are the Chinese-American families' perceptions of what will enhance the quality of early intervention programs and services? (Data will be acquired from family interviews and by having the families read and discuss the Early Childhood Outcome (ECO) Center family outcome indicators).

(4) Have the family outcome indicators (developed by the ECO Center and the Office of Special Education Programs) associated with Chinese-American families effectively identified family outcomes (Data will be acquired from all data sources)?

## Definition of Terms

The following definitions were adopted in this study:

1. *Chinese-America*ns are Americans of Chinese decent. Chinese-Americans consist of one group which is a subgroup of Asian-Americans.

2. *Culturally Diverse* refers *to* persons who practice a culture other than the American mainstream culture.
3. *Linguistically Diverse* refers to persons who speak a native language other than English or English is not their native language.
4. *Cross-Culture Communication* is the ability or skill to communicate effectively with people from different cultural backgrounds and communication styles. Being cross-culturally also is to have the ability to demonstrate the characteristics of trust, awareness, respect, and honesty of differing cultures.
5. *Individual Family Service Plan*: a document required by the IDEA as of 2004. Children with disabilities are entitled to have an Individual Family Service Plan which will be implemented in their natural environment with assistance from early intervention service providers.
6. *Cross Culture Competence:* This study will adopt the definition of cross culture competence from Lynch & Hanson, 2004, who define "cross culture competence" as the ability to think, feel, and act in ways that acknowledge, respect, and build on ethnic, cultural or socio-cultural, and linguistic diversity"(p. 43). Each individual and group is unique and there is no way to compare which behavior is normal and which one is not.
7. *ECO* stands for Early Childhood Outcome Center.

## Limitations and Delimitations

This dissertation research is in no way an attempt to define the manner in which the state or national agencies measure the family outcome of early intervention services, nor is it intended to supplant or replace the existing methods, evaluation, or ECO center identified indicators. What this study does attempt to do is to study and understand the perceptions of how families from different cultural backgrounds could have different perspectives or perceptions regarding early intervention services. More specifically, this study attempts to understand what the family perceives early intervention family outcomes should be and what their struggles are in terms of receiving the services to which they are entitled. In addition, this study also attempts to demonstrate that one method of outcome evaluation is not sufficient to achieve early intervention success with families. Much more should be taken into account in order to increase the abilities of Chinese-American families to care for their children with disabilities, access the community supports and social services, and advocate for their children.

The participants in this study participated voluntarily. Research subjects were recruited from the parents whom the researcher met previously, as well as, from families identified through regional early intervention offices. The risk of interviewing people who knew the researcher previously is similar to what Glesne and Peshkin (1992) mentioned in their research. Studying known subjects could cause one to lose the viewpoint of an uninvolved outsider. But, at the same time, the researcher could have greater opportunity to learn more about the known subjects than the researcher thought was possible.

## Chapter Summary and Overview

Chapter one above includes the problem statement and significance of the study. The research questions for current study are discussed, as well as the definition of terms that will be discussed throughout the entire research. Chapter two will review the literature that is related to (a) early intervention family-centered care, (b) culturally and linguistically diverse families with children with disabilities in the United States, and (c) measurements and evaluations of early intervention family outcomes.

# CHAPTER 2

# REVIEW OF THE LITERTURE

The goal for this chapter is to review scholarly literature pertaining to the practice and delivery of early intervention related services for young children with disabilities in the U.S. The following research topics included in this literature review were published over the past 20 years and are as follows: the background of early intervention services, family-centered care, the structure of culturally and linguistically diverse families, cultural competence, and evaluation measurements for early intervention outcomes. The final section of the literature review includes a statement of the intent of the study.

## Background of Early Intervention

Head Start, which began in 1965, represents the very first example of federal emphasis on the importance of early intervention for children from low socioeconomic families. The intended outcome was to help improve the social, emotional, cognitive, and physical development of these children (Bailey & Wolery, 1992).

Three years later, the U.S. Bureau of Education for the Handicapped and the U.S. Department of Education began to form early intervention programs for children with disabilities (Bailey & Wolery, 1992). This nationwide program demonstrated to society the need for an alternative placement for children with disabilities**.**

In 1972, children with disabilities made up 10% of the enrollment in Head Start programs (Bailey & 1992). While the importance of early intervention for children with disabilities first was acknowledged in the Public Law (PL) 99-142 the Education for All Handicapped Children Act in 1975, this legislation was not aimed at serving infants and toddlers. Not until 1986, when Public Law 99-457 was passed, mandating a Free and Appropriate Public Education (FAPE) to children with disabilities from age 3 to 5 were infants and toddlers acknowledged. Nevertheless, this law plays an important role as an initiator of a nationwide early intervention program for infants and toddlers. An essential element of the framework provided by Public Law 99-457 was the reorganization and alignment of early intervention programs (infants and toddlers) and programs that serve children from age 3 to 21. Family-centered early intervention service was strongly suggested over other child-focused services (Bailey & Wolery, 1992).

In 1997, Congress reauthorized and amended IDEA. The reauthorization resulted in four parts: Part A, General Provisions; Part B: Assistance for Education of All Children with Disabilities, Part C, Infants and Toddlers with Disabilities; and Part D, National Activities to Improve Education of Children with Disabilities.

The purpose of early intervention, as stated in Part C, is to promote the child’s and family’s ability to meet developmental outcomes chosen by the family and outlined in their Individualized Family Services Plan (IFSP). Some parental rights under the law include, (1) the right to the development of an IFSP within 45 days between the date the child was referred and when he/she was found to be eligible for services, (2) the right to a referral, (3) an evaluation and assessment, (4) IFSP development and review, (5) service coordination, and (6) protection of family rights (IDEA, 2004).

Children with disabilities, from birth to 3 years old, are to receive services under Part C of IDEA. When a child is referred to the state early intervention program, early interventionists will conduct an assessment to determine whether or not the child is eligible to receive early intervention services (IDEA, 2004). Once the child is eligible for an early intervention program, services and support for the child and the family are provided. Many programs for infants and toddlers provide home-based intervention until the child turns 3 years of age, at which point he/she is transitioned to public school or other center-based services. The hallmark of Part C is the IFSP, which is designed for families to work in partnership with service providers in implementing early intervention services.

An IFSP is developed at a meeting consisting of the family, the service coordinator, at least one member of the evaluation team, and anyone else the family wishes to include. In order for the child to receive services, the parent must consent to the plan. Parents have the right to withdraw their consent at any time, and they are entitled to reject some services while continuing others. Parents may be charged for other services, but an inability to pay will not prevent the child from receiving help (IDEA, 2004). In terms of which type of early intervention program is better for a given child (center-based or home-based), professionals need to base their decision on each individual family's concerns and needs.

An assumption underlying the plan is that service providers understand the family from a systematic perspective. Relationships within a family are driven by interacting subsystems (Minuchin, 1988; Turnbull & Turnbull 1990), i.e., different members within the family make up several subsystems which influence each other. For example, the marital subsystem is composed of the interaction of two primary caregivers. Other subsystems include the parent/child, sibling, and extended family. Understanding the influence of these interacting subsystems will help service providers work more effectively with families. An acknowledgment of the family's wishes and a willingness to follow the family’s lead will help to establish the trust needed for a continued working relationship (Zhang & Bennett, 2003).

Current early intervention practices face numerous challenges due to diverse participants and various types of disabilities (Bailey & Wolery, 1992; Zhang, Fowler & Bennett, 2004). In addition to the complexity of early intervention programs themselves, the benefit of a home-based versus a center-based program is another major issue in the field.

### *Family-Centered Care*

Family-centered care is not a new model in early intervention for infants and toddlers. Family centered care was first used in the 1960s, but, it was not until the 1980s, after families had become fully integrated in early intervention programs, that family-centered care became an important component in the field of early intervention. Family centered care is directed by a set of principles that emphasize the importance of the family during service delivery (Shelton, Jeppson, & Johnson, 1987). A family-centered approach is considered the most effective way to improve families’ empowerment toward their children with disabilities and their family circumstances (Bruder, 2000). Part C of the Individual with Disability Education Act (IDEA) believes family-centered early intervention practices will enhance the family’s capability to meet the needs of their child with disabilities (34 CFR& 303.12(d)(13)). As family-centered early intervention became an important concept in early intervention programs across the nation in the 1990s, it changed from child focused to family-centered care (Bailey, McWilliam, Darkes, Hebbeler, Simeonesson, & Spiker, 1998; Simeonesson & Bailey, 2000). The following definition was adopted during that time and even today many early intervention programs proport that, “people can be best understood and helped in the context of their family of origin and current network of intimate relationship” (Laird, 1995, p. 151)

The majority of young children spend most of their time with their family or primary caregiver. Research shows that most children with disabilities are primarily nurtured in the home environment (Bailey, et al., 1998; Barnett et al., 2003; Hauser-Cram, Warfield., Shonkoff, & Krauss, 2001; Odom & Wolery, 2003). The intent of family-centered early intervention services is to utilize families’ strengths to diminish their weaknesses and to increase families’ ability to identify their needs and organize early intervention services for their children with disabilities. Furthermore, the development of invaluable partnerships between families and professionals is a significant element for most early intervention programs and is also embedded in federal legislation (Bailey et al., 1986 McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; Dunst & Deal, 1994; Epstein, 2001; Osher & Osher, 2002; Summers, Gavin, Hall, & Nelson, 2003; Dunst, 2002; Moore, 2000; Murray & Mandell, 2006). Families’ experiences and understanding of their children with disabilities is based on a strong partnership with service providers. Service professionals provide essential information about what parents need to do to enhance their children’s outcome (Park & Turnbull, 2003). Families’ knowledge regarding early intervention practices is crucial to their child’s lifelong development (Bruder, 2000) and is one of the most common used factors for involving the family in early intervention practices (Bailey, et al 1998; Barnett et al., 2003). The goal for many early intervention programs across country is to help families widen their childcare skills so they can better assist/educate their child with special needs at an early age (Bagdi & Vacca, 2005; Bailey et al., 1998; Bergen, & Coscia, 2001; National Research Council, 2000; Wasserman, 2007). Individualized services empower parents, teach them their rights, increase their opportunities for parent involvement, and will help them to reach their established goal (Bailey et al., 1998; Dunst, Johanson, Trivett, & Hamby, 1991; Gallagher & Desimone, 1995, McWilliam, Ferguson, Harbin, Porter, Munn, & Vandiviere, 1998; Parker & Zuckerman, 2000; Simeonsson, & Bailey, 2000). Other studies indicated that professionals and service providers need to become skilled at different intervention strategies (Beckman & Bristol, 1991; Shannon, 2004) so the families' values, beliefs, concerns, needs and priorities for their children with disabilities will be accommodated through the services they prefer.

Research in recent years has revealed that most early intervention professional training programs incorporate the family-centered care philosophy into their coursework (Grandlund & Bjorck-Akesson, 1999; Knight & Wadsworth, 1998; Mahoney & Filer, 1996; McBride & Brotherson, 1997; Murray & Mandell 2006). In addition, one of the key elements to a successful and high-quality early intervention service is having collaboration between families and the early intervention service providers (Wehman, 1998). McWilliam, Tocci, and Harbin (1998) studied ways to enhance family-provider collaboration by interviewing both early intervention service providers and parents of children with disabilities. Their findings led to the development of six principles to better help family and professional collaboration: understanding the family (family orientation), positive-ness, sensitivity, friendliness, responsiveness, and child and community skills. Another group of researchers also identified six key elements of successful family and professional collaboration which included: communication, commitment, equality, skills, trust, and respect (Blue-Banning, Summers, Frankland, Nelson, & Beegle, (2004).

Despite the promise of family-centered services, this delivery model is fraught with many challenges (Bruder, 2000; Guralnick, 1997; Shannon 2004). This may be the result of a gap between early intervention research and real-world practice. There is a clear association between providers' delivery of family-centered early intervention services and parents' perceptions of the service provider's professionalism (Dinnebeil & Rule, 1994; Dunst, 2000; Garshalis & McConnell, 1993; Gettinger, Goetz, Stoiber, & Caspe, 1999; Judge, 1997; Krauss, 1997; Mahoney & O'Sullivan, 1990; McBride et al., 1993; Minke & Scott, 1995; Stoneman 1993). For instance, if professionals lack the skills necessary to deliver effective services, parents feel their families' and children's needs have not been considered seriously by the service providers (Murray & Mandell, 2006).

Bruder (2000) summarized findings across several empirical investigations, including the following: (a) child-related outcomes are more frequently identified on the IFSP than family outcomes (b) professionals still face challenges in integrating parents into the early intervention services, (c) it is difficult to determine if early intervention services need to be family-centered or child-centered, and (d) current early intervention services not only enhance the relationship between the professionals and the family, but also has an impact on the relationship between a family and the child with a disability. Judge (1997) indicated that service providers play an important role in enhancing early intervention family outcomes by empowering the family's leadership role during the decision-making process, as well as, providing related service information from different perspectives.

One of the major accomplishments in the field of early intervention for children with special needs is the recognition of the importance of the family's impact on children’s early intervention services (Bailey & Wolery, 1992). Thus, an early intervention service and outcome model developed by Bailey and Bruder (2005) provides a clear vision of how the family’s priorities, ability to obtain resources, and concerns influence early intervention services and enhance positive outcomes (see figure 1). Researchers suggest families who have children with disabilities have challenges such as being isolated by the community and encountering problems in getting the services they need (Doctoroff, 1995; Magrab, 1992). Many studies have examined IFSPs to determine if the legislated recommended family-centered early intervention model is included in actual practice. Results have shown that instead of being family-centered, IFSPs are primarily child-centered (Boone, Moore, & Coulter, 1995; Jung & Baird, 2003; McWillian, Ferguson, Porter, Munn, & Vandiviere, 1998; Polmanteer & Turbiville, 2000; Robyn & Rena 2006). Despite an increased rate of including the family’s needs and concerns in IFSPs from 1995 to 2003 (Robyn & Rena, 2006), many factors prevent professionals from incorporating family-centered intervention into practice, including a lack of understanding and supportive work environment, including peers and administrators, and a lack of established policies and procedures specific to family-centered service delivery (Murray & Mandell, 2006).

From these findings, we may assume that many early intervention professionals still lack an understanding of the concept of family-centered early intervention service delivery. A similar conclusion was drawn by other researchers, indicating some early intervention programs do not embed family-centered approaches in their practices (Mahoney, O’Sullivan, & Dennebaum 1990), and it is the administrators’ responsibility to encourage and support family-centered early intervention practices to their fellow early intervention service providers (Robyn & Rena, 2006).

## Structure of Culturally and Linguistically Diverse Families

The number of individuals constituting a family, as defined by the U.S. Census Bureau, is two or more people connected by birth, marriage, or adoption, who dwell together (Iceland, 2000). Turnbull, Turnbull, Erwin, and Soodak (2005) further refine this definition by stating that a family may be defined as two or more people who recognize themselves as a family and perform typical family functions. These people may not be related by blood or marriage, and sometimes they live separately (p22).

According to Leaung (1998), there are three types of culturally and linguistically diverse families, including (a) recently arrived immigrant families, (b) immigrant American families and (c) American-born families, with varying levels of cultural differences. Each type of family has its own characteristics and needs. The following are some of the characteristics and needs for each type of family.

### *Recently Arrived Immigrant Families*

Immigrant families with children with special needs are, more often than not, unfamiliar with the mainstream English language and the early intervention special education services available (Igoa, 1995). As a result, they often have a difficult time finding the appropriate assessment process and early intervention/special education services. Parents from this type of family still have a strong attachment to their native cultures and may encounter difficulty practicing biculturalism. Biculturalism means maintaining their own cultural values and belief systems, while also learning to adopt the systems of the society in which they live (biculturalism will be further discussed in the later chapter). The survival skills attained in English or bilingual education may assist in developing values of biculturalism (Garcia, 2005). It is importance for the family to develop biculturalism to enable them to gain a better understanding of the early intervention system in the U.S. and help them advocate for needed services and supports need.

### *Immigrant American Families*

Immigrant American families consist of non-native parents with native or non-native-born children. The parents from this type of family are somewhat involved in the process of accessing services for their children with special needs and are more aware of services provided by mainstream early intervention special education programs. Family members often speak two different languages. Many parents do not speak the mainstream language fluently, often leading to communication problems with service providers (Leung, 1998).

### *American-Born CLD Families*

American-born CLD families include American-born parents and their American-born children (Leung, 1998). Parents from this type of family typically are involved more in school activities than those in the previous two groups. In addition, they understand the expectations of service providers, especially during the IFSP meeting. These families are influenced less by their traditional cultural orientations because they either have been acculturated towards, or assimilated into, the mainstream culture as demonstrated by their practice of mainstream cultural values **(**Lynch, & Hanson, 1998; Park, & Turnbull, 2001).

## Cultural Competence

If one were to ask 50 CLD families to define the word family, 50 different definitions may be given. The definition of family adopted in this paper was from Turnbull et al., 2005 which places an emphasis on the value of interdependence within the family unit. Professionals and families who desire to develop and provide culturally responsive early intervention and special education services need to understand each other's cultural values, beliefs, and language in order to anticipate possible conflicts such as beliefs on the effectiveness of early intervention programs, or the needs of community involvement.

The first step in this dialogue for professionals who work with CLD families in developing IFSPs is to recognize their own cultural values and how they may be different from those of CLD families and students (Sue, Arredondo, & McDavis, 1992; Zhang & Bennett, 2003). Successful and effective early intervention special education relies on service providers expanding their abilities to include awareness of cultural differences (Anderson & Fenichel, 1989). Early intervention service providers could alter their perceptions toward different cultures and beliefs. These attitudes could change from distrust to gladness, doubtfulness to surprise, and acceptance to appreciation (Hanson, Lynch, & Eleanor, 1990).

### *Collectivism, Individualism, and Biculturalism*

*Collectivism and Individualism*. Cultural values associated with collectivism and individualism play a gigantic role in both Eastern and Western families. Collectivism "is characterized by individuals subordinating their personal goals to the goals of a collective" (Leaung, 1998). The person who comes from a collectivist background usually belongs to fewer groups, has a higher attachment to the original group, and is defined by the group. For example, a collectivist individual may be very family-oriented, and decision-making may be based on the suggestions of the family. For most Asian American families, collectivism is an important cultural value; however, this cannot be generalized to all Asian American families.

The definition of individualism is “an orientation characterized by individuals of a group subordinating the goals of the group/collective to their personal goals” (Leaung, 1998). A person who values individualism can belong to many groups, for instance, family, religious, political, or social groups. Yet, no one group membership defines the person’s identity or determines his/her behavior.

*Biculturalism.* The rationale for discussing biculturalism here is to illustrate how the power of an individual’s cultural attachment to values of collectivism and individualism can influence IFSP development (Lamorey, 2002). Biculturalism is described as an awareness of personal and family strengths and limitations and the ability to set goals and make choices after considering goals of both the individual and the family and serves as an example to develop culturally responsive IFSPs (Turbiville, Turnbull, Garland, & Lee, 1996). Biculturalism allows families to practice values of both individualism and collectivism in order to preserve the integrity of the family and to facilitate access of services outside those available in the traditional manner of interdependence with the family. Interdependence, rather than independence, within the family involves older siblings, grandparents, and other relatives acting as the primary caregivers.  This is a familiar occurrence in Asian, African American, and Hispanic cultures (Hanson et al., 1990). For example, Asian American parents who have a child with special needs may seek help from both family members and professionals outside the family in an IFSP meeting. Furthermore, they will take the information back to other family members and then, as a group, make a decision of how to best meet the needs of the child and family. This process promotes cultural integrity as they develop a bicultural, rather than monocultural identity (Leaung, 1998).

### *Stages of Ethnic Identity Development*

Researchers have different views on how CLD families go through the stages of ethnic identity development. Young (1998) explained the development of ethnic identity as “one [who] goes from a stage in which ethnicity is not dealt with to one of internal resolution between the conflicting and opposing cultural perspectives” (p. 65). According to Young (1998), the four stages of ethnic identity development include avoidance, marginality, self-identity explorations, and self-acceptance.

1. Stage One, Avoidance - People in this stage are not aware of or do not want to deal with issues such as alienation, discrimination, and racism.
2. Stage Two, Marginality - This stage involves commitment toward one’s identity with little exploration of one’s ethnicity. People in this stage repeatedly exist between two cultures, and frequently the result is they either deny or do not deal with the fact they are confused about to which group they belong.
3. Stage Three, Self-Identity - The individuals in this stage attempt to discover who they are by discovering their roots. Such experimentation may include activities such as language learning, involvement in religious activities, or trips to their native countries. The people in this stage are trying to reach a

balance between two cultures by using their own thoughts to define who they are and where they belong.

4. Stage Four, Self-acceptance - Individuals become bicultural by recognizing their own ethnic identities. People who have reached this stage no longer experiment with their heritage and culture because there is recognition of the attachment to both. In other words, they have found a sense of balance and are able to use their heritage to function in the culture of power.

Biculturalism is the stage that best facilitates the development of culturally responsive IFSPs, but CLD families who are expanding their cultural values will still encounter barriers to full participation in IFSPs. For example, mismatches between the home and school language often result in miscommunication between CLD families and service providers (Lee, Ostrosky, Bennett, & Fowler, 2003).

### *Model Minority Myth*

Asian American children face various stereotypes which that limit their opportunities and access to a myriad of resources.  This causes emotional distress and creates conflicts with their peers, both those of different ethnicities and those in their own ethnic groups. The most popular image to influence Asian American children and families is that of the Model Minority Myth (Young, 1998). Research found that Chinese American and Korean American students have higher stress levels than African American, Hispanic, and the mainstream students. This is due to the fact that Asian children frequently experience peer discrimination such as being threatened, called by racially insulting names, and excluded from activities (Fisher et al. 2000). The mainstream society focuses on exceptional “Success Stories” and generalizes to all Asian

American without considering the large number of Asian American students and their families who suffer from poverty and illiteracy (Educational Services, 1997; Lee, 1997; Siu, 1996; & Yin, 2000. The Model Minority Myth extends educational and economic success to all Asian Americans with the danger because many people ignore the between and within group differences caused by assimilation, acculturation, social, political, economic, and education background (Educational Services, 1997; Lee, 1997; Siu, 1996; & Yin, 2000). Study shows that while only 5.6% of Japanese students have only an elementary education or less, 61% of the Hmong American falls into this category (Sui, 1996). Other research provides strong evidence about the differences between various ethnic groups of the Asian American population. Yin (2000) found that poverty rates for Japanese and Filipino American are 3.4 percent and 5.2 percent respectfully, 24 percent of Vietnamese, 42 percent of Cambodians and 62 percent of Hmong Americans live below the poverty line.

The Model Minority Myth also impacts the decision making on federal policies. When the U.S. government dedicates resources to higher education, efforts focus on African American, Native American, Native Hawaiians, Alaskan Natives, and Latinos. It does not provide the resources such as technical support and financial aid for Asian American students. Hall (1976) made a statement to the American education system, "the Mainstream educational system within the United States has its own unique culture characteristics." Thirty three years after 1976, the structure of the American education system has changed due to the large population of immigrants. The goal of the Individual with Disability Education Act (IDEA) in the United States for children from birth to 21 is to provide them with a Free and Appropriate Public Education (FAPE) in order to meet individual’s unique needs and be able to increase the children’s ability to function as independently as possible with adaptive behaviors (IDEA, 2004). When early intervention service receivers and school age children who came from different value backgrounds than the mainstream school system meet, the conflicts between parents, teachers, and services providers will occur more often. These circumstances will present not only in the special education classroom setting but in general education classroom settings as well.

### *Cross-Cultural Communication*

Cross-cultural differences in communication between families and professionals may be an issue in IFSP development, especially for newly arrived immigrants and new American immigrant families. Cross-cultural communication includes both verbal and nonverbal communication. Communicative competence is a key element to understanding cultural differences (Bennett, Zhang, & Tarnow, 2001). Studies indicate that, in order to be competent and communicative in two different cultures, professionals need to be familiar with both languages. Such competence allows professionals to know when, where, and what types of questions to ask and how appropriately to communicate with CLD families (Saville-Troike, 1989). In the Asian culture, for instance, giving and saving face are important matters in the process of communication. If professionals who ask questions seem as if they are challenging the parents’ knowledge on certain topics, parents may consider it a loss of face (Hanson, Lynch, & Wayman, 1990). Often when the CLD family lacks a command of the language of power, IFSP team members turn to interpreters for help. One problem with interpreters is often they are proficient only in the language that the families speak but are unfamiliar with the terms, knowledge, and skills of the professionals. Barrera (1994) suggests the “culture-language mediator,” sometimes referred to as a cultural guide or cultural liaison, should be proficient in the language that families speak but also have professional knowledge and skills.

Cultural language mediators, instead of interpreters, should be utilized to facilitate IFSP processes and meetings. One model, presented by Turnbull, Blue-Banning, Turbiville, & Park, 1999, consists of using families who have resided in the United States for a period of time as cultural mediators for newly arrived immigrant families, professionals, and community members. Additionally, parents who have knowledge of early intervention special education services and speak fluently in both the native and the dominant languages can be most valuable in training professionals and parents to engage in culturally responsive IFSP practices (Hains et al., 2005; Turnbull, Blue-Banning, Turbiville, & Park, 1999).

## Culture Values

The term *culture* includes the foundational values and beliefs that set the rules for how a group of people behave, interpret, and perceive, the family, school, and community (Lynch, & Hanson, 1998).  A common limitation of discussions of culture is the misguided focus on a person’s ethnicity and race (Chan, 1990). While it is true ethnicity and race are two strong influences in a person’s cultural identification, many other factors can affect the cultural values and beliefs of both individuals and groups. Turnbull, et. al, (2005), refers to those influences as the microcultures of language, gender, race, ethnicity, age, geography, exceptionality, and socioeconomic status. Kisanji (1995), includes in his definition of culture, the values, beliefs, and languages of a given community or society.

For purposes of this paper, culture is defined as the values, beliefs, and languages of CLD families having children with special needs.

In the field of early childhood special education, an awareness and understanding of the need to provide early intervention special education programs should be combined with responsiveness to the values, beliefs, and languages of CLD families (Bailey & Wolery, 1992; Lynch & Hanson, 1998; Quintero, 1999; Tabor, 1998). Such awareness is promising, as many articles note that professionals in the early intervention special education process tend to be predominantly European-American, middle class females with European-American values who speak only one language (Chan, 1990; Correa, 1992; Hanson, Lynch, & Wayman, 1990; Lee, Ostrosky, Bennett & Fowler, 2003; Lynch & Hanson, 1998). Special education professionals and service providers who are trained to deliver services for children from the mainstream culture are now beginning to understand they face a challenge in providing services to a growing CLD population (Zhang & Bennett, 2003). A study was conducted by interviewing two CLD families about their experience and perceptions of early intervention programs. One of the common findings across the four families was that they recognized that families have different needs in order to enhance their children’s learning and hoped services providers could approach the families without having an already existing early intervention model in mind (Wu, 2007). One model of early intervention special education services will not be successful for all CLD families.

Studies have shown CLD families are aware of the cultural insensitivity of many early intervention special education services. One study conducted (Bailey, Skinner, Rodriguez, Gut, & Correa, 1999) examined if different families’ cultural values and beliefs influenced the satisfaction of Hispanic parents of young children receiving early intervention special education services. The findings showed these families felt their cultural values, beliefs; language and needs received little consideration in the development of IFSPs. Further, Zionts, Zionts, Harrison & Bellinger (2003) examined African American families' perceptions of cultural sensitivity within special education services and found 64% of interviewees hoped special education services providers and professionals have a greater cultural understanding and acceptance when they are working with families and children from an African American culture.  Sadly, most early Head Start programs lack bicultural and bilingual early intervention services providers and special education professionals (Zhang & Bennett, 2003). These studies support claims that different cultural views and backgrounds of early intervention service providers and professionals can cause conflicts with CLD parents, especially CLD parents who are unfamiliar with special education legislation and services in the United States.

### *Early Intervention Cultural Legislation*

Early intervention service providers and professionals need to provide the same opportunities to CLD families as they offer European-American families. It is important that providers continually revisit the needs of the family with a child with special needs to improve the effectiveness of the early intervention program (Espe-Sherwindt, 1991), because levels of parents' participation in the early intervention program decrease if "non-child related" needs are not being identified in the IFSP (Dunst, Leet, & Trivette, 1988).  IDEA (2004) acknowledges "over 20 years of research and experience demonstrated that the education of children with disabilities can be made more effective by … strengthening the roles of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home” (p34).

Many studies have found that CLD families display lower levels of participation than European-American families in the special education process and suggest this is due to a lack of consideration of these families’ traditional cultural values, beliefs, and language (Harry, 1992a, 1992b; Lynch & Stein, 1987). Furthermore, research also indicates early intervention special education services are underused by CLD families (Arcia & Gallagher, 1993; Sontage & Schacht, 1993, 1994). Factors preventing their participation in the IFSP process were identified as a lack of communication and a misunderstanding of the expectations of the early intervention service providers. Asking a parent who does not speak the mainstream language to understand the framework of an early intervention program using the mainstream language is often too complicated. Frequently, confusion, misinterpretation, and rejection result from the language difficulty (Barrear, 2000).

IDEA (2004) Part C requires every child who is receiving early intervention services to have an IFSP. IFSPs are developed by a multidisciplinary and interagency team that includes parents, other family members, service coordinators, and professionals who provide early intervention services to infants and toddlers. The process of developing an IFSP consists of providing opportunities for both families and professionals to build a strong and respectful partnership in order to combine their creative knowledge to craft culturally responsive and family-centered IFSPs (McGonagal, Kaufmann, & Johnson, 1991). Turbiville, Turnbull, Garland, and Lee (1996) suggest that family and professional interaction should be included in the IFSP development process because, without the family's input the IFSP is a pointless and lifeless document. Another study also indicated early intervention programs are more effective when parents have a higher level of participation and when the early intervention services are focused on both a child with special needs "and" but not "or" his/her families (Shonkoff, Hauser-Cram, Krauss, & Upshur, 1988). The process of developing a culturally responsive and family-centered ISFP requires professionals to collect the family's information and arrange the resources to meet the needs of both the families and children.

### *Children and Childrearing*

Different ethnic groups have different views on children and childrearing. In the past fifty years, American views of the role of children in society have transformed from "children should be seen and not heard to a sentiment in which the voices of children influence a major segment of the marketplace" (Hanson, Lynch, & Wayman, 1990).This change in attitude differs from that held by many CLD families. For example, Asian parents believe that children are a gift to treasure and that love is not shown by playing with children, but by taking care of their needs. For instance, instead of letting children eat independently, they like to assist children in the eating routines until they are 3 or 4 years old (Hwa-Froelich & Westby, 2003). Latino families share the values of early gratification, close physical contact, and adherence to the needs of the child rather than the adults. Often times, Latino families value cooperation rather than competition and place more emphasis on closeness within the family and larger community than materialism (de Valdea & Gallegos, 1982). Further, some Pacific Islanders enforce the sharing of all resources with all family members at home and expect children to do the same at school. This can conflict easily with the mainstream school environment, which often favors competitive environments (Lynch & Stein, 1985). As a result, professionals encouraging CLD families to push their infants and toddlers toward more independence create cultural conflicts with many CLD families and may fragment the home-school relationship.

### *Disability Beliefs and Early Intervention/Special Education*

Families from different cultural backgrounds have their own explanations for the disabilities of children. For example, the role of fate is significant in many cultures in determining a person's outcome (Hanson, Lynch, & Wayman, 1990). Many Korean Americans view children with disabilities as God's will for the family and child. Others like Australian and Mexican-American parents view childhood disabilities as caused by magical, psychological and religious, biomedical etiology or socio-cultural factors (Lamorey, 2002). Many Asian-American families believe disability is a function of fate resulting from sins committed by parents and/or ancestors (Lamorey, 2002). For instance, parents of the child with special needs may feel guilt or great shame because they feel the cause of their child's disability resulted from something they did wrong during the pregnancy. Some cultures strongly influenced by Buddhism acknowledge the cause of disabilities as fate and believe that if the individual with a disability performs good acts, there will be a correlated reduction in the degree of suffering.

Other cultural groups assign numerous other explanations for the causes of disabilities. These causes run the scope from imbalance of the mind-body, ghosts, demons, to evil spirits possessing the individual or child (Lamorey, 2002). The views of the causes of disabilities by CLD parents affect how CLD families view early intervention special education and its approaches to remedying the disability.

### *Medicine and Healing*

The health care system provides assessments and deliverance of early intervention special education services to families with children with special needs (Hanson, Lynch, & Eleanor, 1990). Assessment results and recommendations for treatment often are interpreted to families by professionals who have been trained only to work with mainstream culture and, therefore, may disregard the needs of CLD parents, including their non-mainstream values and beliefs. However, many CLD families are learning to accept assistance from mainstream service providers. Southeast Asian Americans, for example, choose to take advantage of modern medicine as long as language and service accessibility barriers have been overcome (Lamorey, 2002). Some Asian-American families utilize Applied Behavior Analysis intervention which is considered a modern intervention for children with autism, but likewise, Asian-American families also are willing to subject their child to traditional acupuncture, which is considered to be a more holistic approach to healing infirmities in Chinese culture.

### *Early Intervention Special Education Approaches to Disability*

Early intervention special education in the United States is structured by American-Anglo cultural values. These values are concerned with identifying appropriate and effective educational and therapeutic treatments that allow children to lead “normal” independent lives, to the maximum extent possible. This differs from parents who maintain values outside those of the mainstream (Hanson, Lynch & Wayman, 1990; Ostrosky, Bennett, & Fowler, 2003). Many Asian-American and Pacific Islanders, for example, consider only children with physical disabilities as worthy of receiving special education services as opposed to those with mental retardation, autism, and other cognitive disabilities. Some families avoid seeking early intervention special education services because they think “it is not going to work” or that no matter how hard they try “nothing is going to make it different” (Hanson, Lynch, & Wayman 1990). Other families believe disabilities are shameful and assume full responsibility for their child with a disability. As a result, they handle their child with special needs in a very private manner (Chan, 1990; Correa, 1992; Nelson, Smith, & Dodd, 1992). Further, parents influenced by cultural values, who respect the family unit as the primary service provider, often refuse to seek outside support, instead choosing to seek help from members of the family or the cultural community network (Chan, 1990; Correa, 1992; Lee, Ostrosky, Bennett, & Fowler, 2003; Nelson, Smith, & Dodd, 1992).

### *Family Preparation for Participation in IFSP Development*

Family involvement is considered essential for improving intervention results for children with special needs (Research Connections in Special Education, 2001; Ridgley & Hallam, 2006). Furthermore, IDEA emphasizes that family involvement is a strong factor affecting learning, school performance, and level of services received by children.

For some of the reasons outlined above, CLD families often face greater challenges than those from mainstream society in attaining early intervention special education services due to differences in values, beliefs, languages, and needs. Often, the early intervention special education literature focuses on how important it is for professionals to prepare to work with CLD children and their families (Al-Hassan & Gardner, 2002), but fail to emphasize how important it is to prepare CLD families to work with professionals. In order to help children with special needs to receive effective early intervention special education services, professionals, parents and other family members need to discuss family beliefs, values, needs, and issues related to the family and the child, as part of the process of identifying appropriate goals and objectives.

Forming a solid relationship with the family, collaborating with other related early intervention special education professionals, helping parents to anticipate what might occur during the IFSP meeting, and identifying the CLD family's needs is challenging for many professionals (Zhang, Fowler, & Bennett, 2004). Yet, studies indicate that professionals playing major roles in developing IFSPs should have skills to facilitate the development of the IFSP goals and objectives (Callicott, 2003). Professionals with good interpersonal communication skills provide families opportunities to express their ideas for how best to meet the needs of the family and the child with special needs (Callicott, 2003).

One of the key elements when developing IFSPs for all children with special needs before age 3 is being "family-centered" (Harry, 1992a; Trivett & Dunst, 2000; Washington, Johnson, & McCracken, 1995; Wayman, Lynch, & Hanson, 1991). In addition, it is required by IDEA, as mentioned earlier. Family-centered practices not only provide services directly to the child with special needs but also focus on the needs and priorities of each family to ensure better outcomes (Bailey, Buysse, Edmonson, & Smith, 1992; Bricker, 2001; McBride, Brotherson, Joanning, Whiddon, & Demmitt, 1993; Ridgley, & Hallam, 2006; Wehman, 1998; Zhang & Bennett, 2001).

Several studies evaluating if family-centeredness and the needs of families were being identified in the IFSP found that most IFSP goals were linked directly to the child with disabilities with little emphasis on the needs of families (Bailey, Winton, Rouse, & Turnbull, 1990; Boone, Moore, & Coulter, 1995; Polmanteer & Turbiville, 2000). Further, many CLD families do not receive the services that they are entitled to due to differences in language, culture, values, and location of residence (Bailey, Skinner, Rodrigues, Gut, & Correa, 1999; Haring & Lovett, 1999; Zionts, Zionts, Harrison, & Bellinger, 2003). One study surveyed 123 early interventionists to determine if they provided culturally appropriate services to families and their children with special needs. Results showed early intervention service providers never thought that providing non-child related services to CLD families was part of their responsibility and did not consider this a factor as a high-quality early intervention service (Lee, Ostrosky, & Fowler, 2003).

With the passage of recent legislation, for instance IDEA and NCLB states now are being held more accountable for the dollars they spend and the impact those dollars have on the individuals who receive services. At the same time, researchers have shifted their focus from early intervention child outcomes to family outcomes and the family’s quality of life, because the family’s commitment in becoming involved in the early intervention process is one of the most important pieces of a successful early intervention program (NCEDL spotlights, 1999). Also, the move toward family-oriented early intervention programs has led the researchers in the direction of developing a set of indicators which will help to evaluate programs based on family outcomes of families who are participating in early intervention programs. Many studies began the research on the family outcomes based up on the families’ satisfaction with the early intervention and special education services (Dillenburger, Keenan, Gallagher, & McElhinney, 2004;

Hume, Bellini, & Pratt, 2005; Spann, Kohler, & Soenksen, 2003). The notion of “satisfaction equal to outcome” brought many other researchers to the opposite side of thinking (Bailey, et al., 2006; Bailey & Bruder, 2005), consequently many factors influence parents’ values, beliefs, perceptions, and satisfaction with the early intervention program. Those factors as mentioned by Bailey, Blasco, and Simeonsson (1992) include socioeconomic status of the family, the child’s age, and types of childhood disabilities. Latter studies showed that family satisfaction is always not equal to early intervention and special education program outcomes but certainly is an important element when doing the program outcomes evaluation (Roberts, Innocenti, & Goetze, 1999). Many published reports by Early Childhood Outcome (ECO) centers concluded that programs with high percentage of family satisfaction did not lead, necessarily to high program outcomes. This is because the research does not identify what the family actually gained from the services that were provided through early intervention (Bailey, et al., 2006; Bailey, & Bruder, 2005).

## Evaluation of Early Intervention Family Outcomes

In recent years, federal legislation has increased the attention to accountability in education, which has forced early intervention programs to start identifying and measuring outcomes. Children with disabilities are most often identified as the major consumer group for special education programs. The Office of Special Education Programs of the Department of Education has required states to measure family outcomes for early intervention programs (Early Childhood Outcome center [ECO], 2005). IDEA (2004) makes it clear it is the responsibility of early intervention programs to support and provide services to meet the needs of families who have children with disabilities.

According to the ECO Center, an outcome is defined as “a benefit experienced as a result of services and supports received.” Thus, an outcome is measured as neither the receipt of services nor satisfaction with services, but rather as the result of services provided to children and families. Some early intervention program providers might argue that they provide services heavily toward children with disabilities but not families; however, Bailey, McWilliam, Aytch and Simeonsson (1999) stated that family outcomes and child outcomes of an early intervention program are two inseparable domains. Thus, they encouraged early intervention professionals to incorporate both domains when identifying IFSPs goals and objectives. Early intervention programs have obligations to provide services to children with disabilities and their families, therefore children will be able to learn new skills, parents will increase their confidence level in their parenting abilities and improve their overall family’s quality of life ( Baily & Bruder, 2005).

Outcome measure is a way to help an early intervention program to verify whether the goals of the program have been reached and whether the program needs any modification. An early intervention program is well known for its complexity. The variation of family cultures may cause difficulties in the documentation of the quality of early intervention services (Bailey, 2001). None of the models best capture the participants’ needs, priorities, level of involvement, and children’s disabilities because of the diverse factors that influence the program (Bailey, 2001; Beckman, 1996; McWilliam & Gallagher 2000). This leads to the difficulty of measuring the outcome using one standard scale. Bailey (2001) suggests a three-level evaluation model that includes evaluating “(a) whether or not the early intervention programs are providing the services to the families they are entitled to, (b) whether opportunities are provided for parental involvement and family support services of high quality and consistent with recommended practices, and (c) what are the family outcomes of parental involvement and family support programs (p. 3)”. Bailey also encourages programs to utilize various ways of data collection and analysis in order to get the best possible understanding of how much a program has accomplished.

In 2003, the U.S. Department of Education, Office of Special Education Programs, established the Early Childhood Outcome (ECO) center to support states across the nation by providing recommended family and child outcome indicators, and outcome measurement tools. It is a mandatory procedure for states to report child and family outcomes of early intervention programs. The ECO center used several stakeholder groups to help identify what should be measured, possible methods of data collection, and family and child outcome indicators (Bailey, Bruder, & Hebbeler, 2006). Five outcome indicators have been identified:

1. Families understand their child’s strengths, abilities, and special needs.
2. Families know their rights and advocate effectively for their child.
3. Families help their child develop and learn.
4. Families have support systems.
5. Families access desired services, programs and activities in their community.

Bailey and Bruder (2005) suggested that states adopt these outcome indicators and modify them in a way that is appropriate in terms of culture, geographical, and characteristic differences of a given program. The survey method of data collection was the most popular method used in the data collection process across the nation. Although utilizing this data collection method can save time in obtaining the wished-for information, at times the data does not answer the “why” question or provide detailed information for how to improve in the future. For instance, when parents were asked if they received the support from the early intervention service providers they might answer “No” or “Some.”  These answers do not tell the researcher “why” it is they have not received the services or support. Also, language barriers can pose problems for survey evaluations. Further, even if the questions have been translated into the languages that participants prefer, they may not be able nonetheless to read or answer the questions appropriately, due to the unfamiliarity with early intervention systems in the United States (Bailey, Bruder, & Hebbeler, 2006). With the increasing number of culturally and linguistically diverse (CLD) families participating in early intervention programs, their perceptions have become important in terms of measuring early intervention outcomes. If the survey method of data collection cannot yield adequately a better understanding of family outcomes across all types of participants, including those families who hold different beliefs, values, and needs, then an alternative way of measuring CLD family outcomes is needed, such as a one on one interview or focus group interview.

States are required to develop their own family and child outcome indicators based on the individuality of different populations, cultures, and services of the state. The purpose of developing such outcome indicators is to assess whether or not the state’s early intervention and school special education programs reach 100% compliance with IDEA, both part B and C, as required by the Office of Special Education Programs. Due to their cost efficiency, surveys are used to measure family outcomes of early intervention programs. The drawback is the low return rate, less than 50 % (Bailey, Bruder, & Hebbeler, 2006), which may lead the agency to over generalize the results of family outcomes across different types of families. It is not surprising that recent survey evaluations of early intervention programs in some states yielded limited and confusing information about the outcomes obtained by those receiving services that were from CLD backgrounds (Early Intervention Family Outcomes Data, 2005).

CLD issues in special education were highlighted in IDEA (2004). Early intervention, because of its family-centered nature, poses several unique measurement challenges (Murray & Mandell, 2006). It is important to remember that although the nature of outcome measurement could be done in different ways**,** the progress of CLD children is linked intimately to the knowledge which the families possess. For this reason, it is essential to develop a set of CLD family outcomes indicators. As a result, early intervention agencies could use these indicators to assess the effectiveness of their program in more meaningful ways.

## Chapter Summary and Overview

The focus of this chapter has been a review of the literatures related to the background of early intervention, family-center care, and issues surrounded CLD families and early intervention services. The literature was divided into different sub-sections which included:  background of early intervention, structure of CLD families, Culture competence, Culture values, and evaluation of early intervention family outcomes. The final part of this chapter includes the grounds of this study. Chapter 3 will focus on the research design and methodology of this dissertation study.

# CHAPTER 3

# RESEARCH DESIGN AND METHODOLGY

## Introduction

As seen in the review of the literature, the family outcomes of early intervention programs have become one of the most important indicators in determining if children with special needs receive high-quality early intervention services. Due to the changing demographics of U.S. society, it is clear that we not only need to measure the outcomes of “all” families who have received services through early intervention programs for their children with special needs, but we need also to have a clear understanding of what we are measuring (Wu, 2006). One model of early intervention programs will not fit all the various types of families, similarly one set of family outcome indicators will not reveal whether we are providing quality services to all families of children with disabilities. It is essential to conduct further research on the needs, priorities, and concerns of families who are receiving early intervention services, especially those from culturally and linguistically diverse backgrounds. The proposed research is an attempt to (a) gather preliminary information about the needs, priorities, and concerns of culturally and linguistically diverse families from Chinese culture background, (b) evaluate whether their needs and concerns were addressed in their children’s IFSPs, (c) identify the perceptions of CLD families of the early intervention program and services they have received, and (d) assess the outcome indicators developed by the states, the ECO center, and the Office of Special Education Programs associated with families’ perceptions of family outcomes. This study will address the aspects of what is occurring while the family is receiving early intervention services, especially families who are not from mainstream society.

## Comparison of Different Types of Research Methods

Different types of research methodologies historically have been used in the special education field (Odom et al., 2005). Based on the complexity and variability of the participants, special education research has become one of the hardest to conduct (Berliner, 2002). The complexity and changeability of an individual with a disability helps to explain why several types of research methodologies are needed. For example, a methodology requiring a large number of participants in order to produce the power of analysis may be difficult to use in special education research due to the uniqueness of the environment, the special education policies, and the special circumstances. Many studies stress how research questions determine the most appropriate methodologies (Crowley, 1995; Jenesick, 1994; Mertens, 2005). However, some types of research questions are a better fit for one particular research methodology over another. For instance, the methodologies used to determine the effectiveness of an intervention program will differ from methodologies used to study a parent’s perception of an early intervention program simply because the researchers are seeking different types of information from research data.

Shavelson and Towne (1999) grouped different types of educational research questions into three major categories: (a) description (what is happening?); (b) cause (is there a systematic effect?); and (c) process or mechanism (why and how is it happening?) (p. 99). Odom et al. (2005) stated different methodologies will be needed in order to answer these various types of research questions; however, researchers need to make sure the research they have conducted is empirical and rigorous. The four methodologies used most frequently in special education research have been identified as (a) experimental research, (b) correlational research, (c) single-subject research, and (d) qualitative design research. Each of these will be discussed further below (Mertens, 2005).

*Experimental Research*. The use of experimental study has received increased attention as a result of The No Child Left Behind (NCLB) legislation. Use of "scientifically based research" to assess the success of interventions and teaching strategies has become one of the most discussed topics in the educational field. NCLB defined "scientifically based research" as using "rigorous, systematic, and objective procedures to obtain valid knowledge" (No Child Left Behind Act of 2001). Debate arose when researchers realized the complexity of conducting a random assignment study within the social arena (Mertens, 2005). The logic of experimental studies is to have many variables and to manipulate one or a few of the control variable (variables) systematically to evaluate the successfulness of the intervention. This could work well in fields such as biology and chemistry; however, in the field of special education, it is very difficult to do research with the use of this methodology because that we are dealing with human beings. Mertens (2005) urged researchers who employ experimental group designs not only carefully to control and manipulate systematically the variables, but also to interpret cautiously the results. Therefore, the intervention will be considered an "evidence-based" intervention while the results are verified continually within comparable conditions.

*Correlational Research.* Correlational studies contain different types of variables. Frequent comparisons of individuals with different characteristics, such as level of disability and races, make this type of research a commonly used research method in the field of special education. However, when researchers use correlational designs to study the cause-and-effect relationship between two different variables, it is important to note that the outcome of the research cannot be used as evidence of a cause-and-effect relationship because this method only illustrates either the positive or negative association between the two variables (Lomax, 2001; Mertiens, 2005). Correlational studies often have been employed to predict (the predictor variables) future performance. For example, Graduate Record Exam (GRE) scores were used widely to predict academic performance in many graduate programs in the United States. Correlation coefficients have both a negative and a positive, which means two variables can go in one direction or each may go in different directions but still maintain a relationship with each other. e.g., a positive correlation might occur between a deaf student's age and his or her reading abilities. On the other hand, the mobility and age of the students with a visual impairment could be an example of a negative correlation (loss of their mobility as they grow older).

*Single-Subject Research.* Single-subject research also is called a single case study. The research logic is similar to that of experimental research but using only one participant ($N$=1) (Kennedy, 2005; Mertiens, 2005). This type of research is very welcomed in special education, especially for those who are doing behavior research as well as people who are interested in seeing the effectiveness of a certain intervention on a particular individual (Kennedy, 2005). Issues surrounding the validity and reliability of this type of research have become more prominent since the method has been used with greater frequency in the field. In establishing the reliability and a functional relationship, it is suggested that one intervention must be carried out across 5 studies, 20 participants, and 3 different settings (Horner, Carr, Halle, Mcgee, Odom & Wolery, 2005).

*Qualitative Design Research.* A popular use of the qualitative research method has occurred in recent years in the field of special education (Brantlinger, Jimenez, Klingener, Pugach, & Richardson, 2005). Though debates continue over what is "evidence-based" research and what is not, more and more journal editors are accepting and encouraging researchers to submit manuscripts which have employed qualitative methods. The growing numbers of qualitative studies in journal articles and books have redefined the traditional way of conducting special education research (Crowley, 1995). Qualitative research not only helps to enhance our understanding of philosophical problems in special education but also assists researchers in analyzing their data in a more meaningful way in terms of special education policy and practice. Mertens (2005) states "qualitative methods have led to insights into the cultural values, institutional practices and interpersonal interactions that influence special education practices" (p232). For instance, the qualitative research process can help us look at different levels of social ecology through different subjects, such as indicate an individual's disability and where to place them. Unlike other types of research, in qualitative research the researcher is the instrument. For that reason, researchers must exam carefully the data, interpret others' experience as well as be aware of their own subjectivity towards the research topic or participants. Peshkin (1991) in the following passage depicts a process a researcher developed through his own awareness of subjectivity:

> "***First, I decided that subjectivity might be seen as virtuous. For its existence underlies a researcher's making of a distinctive contribution, one that results***

> ***from the unique configuration of the writer's personal qualitative data connected to the data he or she has collected. Second, I decided in subsequent studies I would actively seek out my subjectivity. I did not want to happen upon it accidentally as I wrote the data. I wanted to be aware of it in the process, mindful of its enabling and disabling potential while the data was still coming in, not after the fact"***( p287).

The research questions drive a researcher to review different types of research methods in special education research. For example, the research questions of this study may be answered with the use of survey or experimental research methods yet, problems may likely exist for the CLD families. Participants may not be able to read the survey due to the language barriers. Survey questions may not be appropriate because they are based on different culture value and beliefs, and CLD families may consequently not have a way express honestly about their feelings and perceptions. Single-case studies have never considered answering these types of research questions, because they are not related to the effectiveness of interventions. After carefully reviewing the characteristics of different types of research methods, qualitative research becomes the most appropriate method to use in this research in order to answer the research questions.

## Design of the Study

### *Rationale for Methods*

This research was used to obtain the preliminary data on the association/validation between ECO center family outcome indicators and the culturally and linguistically diverse consumers' perceptions of early intervention family outcomes. The early intervention program was developed fully in the United States; however, it was used widely by CLD families and has not been evaluated previously in a culturally responsive way (Liu, Kingler, & Olive, 2005).

The survey research approach is used frequently in determining the needs of families and the family outcomes of early intervention programs because of its cost efficiency (Bailey, Bruder, & Hebbeler, 2006). The cost of the distribution and collection of surveys was much lower than direct observation or interviews. The drawback to using survey research was that it did not explain the “why” and “how.” For instance, we may have known CLD families were not satisfied with early intervention services, but why and what was needed for their children with disabilities remained unclear (Bailey, Skinner, Rodrigues, Gut, & Correa, 1999; Zionts, Zionts, Harrison, & Bellinger, 2003). We knew also that CLD families largely did not participate in their child’s IFSP development process (Liu, Kingler, & Olive, 2005; Lynch, & Stein, 1987; Shriver, & Kramer 1993; Stein, 1983). However, many participants in the studies indicated that they had not had the opportunity to identify their needs, and their priorities had not been acknowledged by early intervention service providers. A multiple-case qualitative study was used in this research**.** There were several reasons why a qualitative research approach was selected that included (a) CLD families would have provided the researcher with rich and detailed information of their views on early intervention based on different cultural values, backgrounds, belief systems, and needs and (b) there were no consistent measures for family outcomes appropriate for families from different cultural backgrounds (Asian-American, African-American, Hispanic-American, and Native-American). Therefore, a review of documents, interviews with a combination of closed- and open-ended questions, and a checklist was used to investigate CLD families’ perceptions of early intervention programs. This helped to determine the family's need in order to enhance the intervention services for their children with disabilities. Conducting a qualitative research study to identify CLD families' perceptions regarding family outcomes of early interventions actually took more time. Yet, it provided a deeper, meaningful and more individualized expression of the extent to which family outcomes had been attained and "perhaps even provide[d] information about the program factors that contributed" (Bailey, Bruder, & Hebbeler, 2006. p12). This allowed participants to share their vision, values, and experiences of early intervention programs with the researcher. Yin (2003, p50) suggested a number of steps to consider in planning multiple-case studies, including the following:

1. Define the design
    a. Develop theory (indicators)
    b. Select cases
    c. Design data collection protocol
2. Prepare, collect and analyze
    a. conduct first case study (write individual case report)
    b. conduct second case study (write individual case report)
    c. conduct remaining case studies (write individual case reports)
3. Analyze and conclude
    a. draw cross-case conclusions
    b. modify theory (if there is any difference on the indicators)
    c. develop policy implications
    d. Write cross-case report.

This dissertation research incorporated these elements as a basis for the research design. Due to the different purposes of individual study, “design data collection protocol” was categorized into a set of particular activities that included:

1. Modification of the family needs checklist (made the checklist into a culturally and linguistically responsive instrument)
2. Practices to identify the child-related and non-child related goals and objectives in the IFSP document
3. Developing the IFSP goals analysis log
4. Develop family-structured interview questions, (the questions were approved by the advisory board.)

Emerging themes or topics was the procedure used commonly to organize data for case study research (Creswell, 1998; Glensne & Peshkin, 1992; Yin, 2003). Yin (2003) also recommended continuous reading in relevant areas during the data analysis stage and techniques for marking data texts. This provided the researcher an opportunity to view the data across a large number of participants. The following section describes the development of the theory; procedures for data collection of this section will describe the design and participants of this research**.**

### *Developed Chinese-American Families Interrelationships Model*

The current model of interrelationships of early intervention services and outcomes for children and families was developed by the ECO center (see Figure 3.1). Figure 1 illustrates how the family’s needs, concerns, use of available resources, goals, and priorities were the factors underlying quality early intervention services for children with disabilities and that influenced the outcomes of both family and child. However, some extra components were added to increase the appropriateness when implementing the model with CLD families and their children with disabilities. The family portion of the CLD issue affected the relationship of the family's needs and their concerns in obtaining the resources they required. Because of this, the outcomes of the CLD families may have been different than the mainstream families who were receiving early intervention services. With this being said, the predictors of early intervention family outcomes could have been different than what had been employed (see Figure 3.2).

### *Methods of Data Collection*

Participants. If time had not been an issue, the participants for this research would have included parents with children with disabilities from many different cultures, except those from mainstream society. But because that would have been time consuming research for a dissertation, the researcher focused only on four Chinese-American parents who had children with disabilities and received early intervention services from the state early intervention program. Their country of origin was irrelevant; so long as they practiced Chinese cultures and values at home they were selected. The participants were invited to participate in this research through their early intervention coordinator or related services providers or discovered by snowballing strategy. Parents who received the invitation and were willing to be part of this research were contacted by the researcher by phone or email. The disabilities of all the children were varied as well as were the parents' age, educational level, social economic status, location of their residence, and number of years of having resided in the United States. The above information was documented to support the data analyzing process. The purpose of having chosen four Chinese-American families was to attempt to demonstrate the logic of the replication in order to have predicted similar results (Yin, 2003). The researcher hypothesized that families from the same culture probably had similar needs in terms of early intervention services. Hence, it was believed that two to three cases from the different Chinese cultures due to the differences of origin should have been used to conduct and predict similar results and to contrast results for predictable reasons (across different people from same cultural background). These were the best ways to conduct this research.

The project advisory board consisted of the dissertation committee, directors of state early intervention programs and a services provider. Also consulted on data collection tools were Chinese-American parents whose children had been served by the state early intervention program. The purpose of the project advisory board was to obtain feedback from different points of view.

Interviews of the Chinese-American Parents with Children with Disabilities. One of the important components of research was the need to answer the question, “Can early intervention services help to improve the family outcomes? ” If someone were to study and wanted to understand the Chinese-American families with children with disabilities and tried to develop a measure and a process which accurately reflected what was important to Chinese-American families whom better to have asked than the families themselves? Therefore, the Chinese-American families and the advisory board were involved in the various development aspects of the interview questions as well as the crafting of how an early intervention program could have been coordinated with the Chinese-American families and their children with disabilities. Prior to this study, only a few studies had sought to understand the impact of early intervention services on

Chinese-American families and their children with disabilities (Bailey et al., 1999; Chen & McCollum, 2001; Garcia, Perez, & Ortiz, 2000). Most studies had focused on the impact of services to the child. This study attempted to reflect the Chinese-American families' needs based on their culture, belief systems, and their experiences with early intervention services.

Family Needs Checklist. The researcher reviewed the existing family functioning surveys on the basic needs of the family. In the process of reviewing the surveys, the researcher identified the items that had been mentioned repeatedly in different surveys. Once the questions were identified, the primary researcher revised the questions and added the Chinese-American components, so it measured appropriately the families' needs when used with Chinese-American populations.

Interviews of the Chinese-American Family Services Providers/Coordinators. The researcher also interviewed the Chinese-American families' services coordinators in order to obtain the perspectives of service providers. The primary focuses on the services provider interview were to help the researcher determine whether the service provider had developed the sense of culture competences and how they felt about serving families from a culture different than their own.

## Data Source, Research Procedures and Data Analysis

### *Data Source*

The researcher collected data from interviews, reviewed IFSP documents, family needs checklists and field notes. Supporting data were also gathered from sources such as audiotapes, videotapes, and other related documents.

### *Informed Consent and Confidentiality*

The researcher developed two forms for consent. Parents who participated in the study completed the informed consent form. Each participant was assigned ID number by researcher; therefore, the actual names of participants were not used. Only the researcher had access to the interview audiotapes, videotapes, interview transcripts, field notes, and related documents. All the research-related data was managed by ID number and locked in a file drawer located in the researcher's office located at University of Oklahoma.

### *Research Procedures*

At the onset, each family received an assigned number for confidentiality purposes. Services coordinators received the same number as the family that he/she had served for the data comparison. All of the interviews and reviewed documents were labeled by numbers instead of last names. Interviews and review documents were the main data collection techniques used in this research. The interviews were conducted through the participant's preferred language, i.e., Chinese instead of English. The interview occurred at a place the families deemed most comfortable. After identifying the participants, the researcher obtained permission from the participants and conducted the first visit. During the first visit, the researcher began by getting to know the family then conducted the parents' questionnaire, completing the family needs check list, and the first part of the parent's interview. On the second visit, the researcher conducted part two of the parent's interview, as well as had participants share the documents related to their early intervention program and their IFSP. Additional visits were conducted in order to close any gaps between the family participants and the researcher, and allowed the researcher more time to observe how parents or family members interacted with their children with disabilities. These procedures allowed the researcher to have a better appreciation of the participating families. A structured interview guide was used during both interviews parts I and II and each interview lasted more than an hour; as a result, deeper issues related to early interview services were discussed. Breaks were allowed at the participants' request. The researcher taped the interviews and kept an interview memo. In addition, the interview questions began with open-ended prompts like "share with me" and "tell me." The transcriptions of the interviews and the related documents were analyzed immediately after each interview. The process continued until no new theme developed in the data.

The researcher visited only once for the service coordinator's interview. Again, the researcher taped the interviews and as well as maintained the interview memo. The data analysis procedure was same as in parents' interviews.

### *Social Validity and Trustworthiness of the Data*

The interview questions were reviewed by two Chinese-American parents who had experience in receiving early intervention services. This was done so that the social validity for the interview questions was trustworthy. After the interview, the transcripts were reviewed by the participants to ensure the accuracy of their answers.

### *Project Timeline*

A research project timeline was developed to help the researcher to complete the data collection process within a reasonable time.

Quarter 1 (December 2008; January 2009):

a. Conducted prospectus meeting in January.
b. Formed project advisory board.

c. Developed the interview protocol, and obtained approval of the advisory board.
d. Obtained IRB approval.
e. Identified participants.
f. Developed an IFSP analysis log.
g. Revised the family needs checklist and obtained approval of the advisory board
h. Obtained interview videotape and audiotape equipment.
i. Met with committee chair for a progress report.

Quarter 2 (February & March 2009):

a. Conducted initial visit with the families (looked up IFSP document, Family needs checklist).
b. Conducted interviews
c. Began data analysis.
d. Began data transcription
e. Wrote the results.
f. Met with committee chair for a progress report.

Quarter 3 (April 2009):

a. Continued work from quarter 2
b. Drafted the results
c. Set up time for oral defense
d. Finished the interviews.

Quarter 4 (May, 2009)

a. Continued work form quarter 3
b. Met with committee chair for a  progress report

c. Data Analyzed and drafted the results and conclusion

Quarter 5 (June 2009)

a. Continued work from quarter 4

b. Oral defenses presented

*Data Analysis*

Interview Data. Each interview was transcribed word for word and typed into word files in preparation for the data coding process. Also the researcher summarized the interview and presented it to the participants in order to build the trustworthiness of the data by simply asked them “am I correctly retelling your story?” or “is this is what you meant by?” The data analysis process began after the trustworthiness of the data was built. The researchers read repeatedly the interview transcripts until themes of the phenomena and relationships among them emerged. Definition of different types of categories was defined further through the constant comparative method (Creswell, 1998). This method required the researcher to code the events by category or themes, compared with each other and finally compared with the definition of the category. Each case was written clearly with a set of categories or themes (variables). After the analysis of each case was completed, a cross-case analysis began. Categories and explanations developed for each case was then compared and contrasted with all cases.

The researcher also used stacking comparable case strategies which created matrices and other displays that analyzed each case in depth. Miles and Huberman (1994) stated that researchers who used the stacking comparable case strategies needed to “stack” the case level displays in a “meta-matrix” and additionally condense them, thus permitting a systematic comparison. Partitioning (within category sorting) and clustering (cross-category clustering) was also used while developing the meta-matrix. The matrix explained the interrelationships between categories and highlighted the emerging differences and similarities for all cases. In order to facilitate the data analysis process, interview transcripts were saved into different word files in preparation for use of the traditional flash card method that analyzed data. The reason that the traditional data analysis was chosen over Nvivo software was because the traditional data analysis method helped the researcher become more familiar with the data. The same data collection methods were used on the service coordinator's interviews.

IFSP Goals and Contents Analysis Log. IFSP goals analysis log data were typed in a double-spaced format to be used during the data analysis. An additional subdivision was used for further analysis.

Family needs checklist data. Once the checklist was completed, the researcher typed the identified family need into the word field and numbered it under the family's assigned number. The family identified needs list was kept together with the IFSP document for later data analysis purposes.

### *Role of the Researcher*

The purpose of this qualitative research was to gain a deeper understanding of Chinese-American families' perceptions about the early intervention programs and how the ECO center recommended outcome indicators related to the Chinese-American families' needs and priorities.

The nature of early intervention was "family-centered." Since the population served consists of a culturally and linguistically diverse population, one model measuring outcomes could not provide the necessary detailed information regarding questions such as “did the early intervention services provider meet the Chinese-American families’ priority needs?” As mentioned earlier, using the interview strategy to discover the outcomes of Chinese-American families may have been more time-consuming than other methodologies. However, it helped better understand how well we were serving the Chinese-American population and what could have been done to improve the services.

The role of the principal investigator included observing and interviewing participants, data analyst, and data organizing.

Two variables impacted this research project. First, as the principle investigator of this study who has been in the United States for more than 10 years, I had always believed in family-centered early intervention; however, I understood sometimes it was difficult for service providers to practice family-centered early intervention services for many reasons. I had experienced many cultural conflicts in my life. Since my research participants were from Chinese-American backgrounds, it was important for me to set aside my personal experiences (especially the negative ones) when interviewing Chinese American families. It was important for me as a researcher to control my personal emotions and feelings during the interviews. This was especially true since in certain cultures, Chinese parents did not want to feel that the researcher (the outsider) had empathy for their situation of having children with disabilities. Such a feeling may have prevented them from sharing their thoughts with the researcher. As an Asian principle investigator, it was important for me to remain neutral and give no advice. This posture would have prevented some parents from developing a complex and/or, prevented the researcher from obtaining sound and accurate data.

### *Conclusion*

Three philosophical assumptions may have guided this qualitative research project. This research targeted Chinese-American parents who had children with disabilities and who were receiving early intervention services. It was essential for me as a researcher to have minimized the *distance* or *objective separateness* due to the fact that disability issues were private in certain cultures. For the axiological assumption, my experience of working with Chinese-American families of children with disabilities and my knowledge of the field of early childhood special education may have played a significant role in terms of the value and beliefs employed in this research study. Yet, this could also generate bias in the research due to the fact that I also was from a “different” cultural background and did not represent other cultures different from mine. For the methodological assumption, a case study helped to determine whether or not there was a theory or particular set of expected outcomes in my study. But again, culture sometimes adapted because of the impact of society; as a result, my research questions very well may have been revised or changed due to my experiences in the field.

If the data supported the development of a set of family outcome indicators of early intervention services, it will have helped service providers generate more meaningful, attainable goals and objectives for the IFSP. In turn, this will have helped to provide high-quality services to both Chinese-American families and their children with disabilities. For state and federal level service providers, it will have measured family outcomes using a more effective and reliable system that will have improved the accountability of early intervention programs.

## Chapter Summary and Overview

Chapter 1 and 2 emphasized the current condition of CLD families who have children with disabilities, how service providers faced the challenges to serve CLD families, the significance of the study, and the review of literature that are relevant to this research. Chapter 3 featured the framework of the study and its design and methodology. Chapter 4 will present the results of this study.

# CHAPTER 4

# RESULTS AND DISCUSSION

## Introduction

This study investigated the Chinese-American families' perceptions about early intervention family outcomes, their experiences of obtaining access to early intervention services in the mainstream society, and types of the support they needed throughout the process of raising a child with disabilities from the birth and as the child matured. This chapter began with the family case and provider case portfolios. The research questions have been restated and the results from the participants presented.

The results section focused on four families who helped to answer four different research questions. A total of four Chinese-American families were selected for the cross-case comparison. The families were originally from different places in Asia which included, China, Taiwan, Hong-Kong and Malaysia, but the participants indicated that they were Chinese-American, spoke Chinese language and practiced Chinese Culture in the home. The children with disabilities ranged in age from two to seven years old and the types of disabilities varied. All of the participating families received early intervention services before their children reached the age of three. All of the participants interviewed were mothers. In this study, the data analysis was driven by four research questions:

1. What were the needs of Chinese-American families?
2. Had the non-child related needs of Chinese-American families been identified in the IFSP documents?

3. What were the Chinese-American families’ perceptions of early intervention programs and services as well as the individual family member’s roles and responsibilities while receiving the services?
4. Had family outcome indicators (developed by the ECO Center and the Office of Special Education Programs) effectively identified Chinese-American families’ expected EI family outcomes?

### *Procedures*

Eight interviews (two per family) were conducted for a total of 20 and more hours with the Chinese-American families who had received early intervention services from the state early intervention agencies. Every participating family had a child with a disability between ages of two to seven. Two families were receiving the EI services; the other two families had exited the EI program within three years. Interviews were conducted in the family home with participants having determined the date and time thereof. All interviews were done in Chinese and audio recorded with notes taken during the interview period for analysis purposes. The principal researcher transcribed the interviews from audio to Chinese, and to English, to increase the reliability of the data. Transcribing the data from Chinese interviews to English written words took more time than transcribing within English. One difficulty the researcher faced during the transcribing period was that one participant constantly used old fashion Chinese language words or terms to answer the questions; therefore, it was more difficult to translate the exact words or terminology into English language.

## Family Case Portfolios

Demographic information was requested from each family participant during the first meeting by using a parent questionnaire. A family needs checklist also was used to determine the family's basic and social needs.  During the first visit, the researcher went completed the parent questionnaire and the family needs checklist question by question with the family participants. The information gathered from these two research instruments was used to determine the parent's background, family annual income, and reason(s) for relocating to the United States, and needs of the family with a child with disability. Table 4.1 provided brief demographic information of each participated families.

*Wang Family (family number 1):* The Wang family immigrated to United States over ten years ago for the purpose of seeking better employment. The only child in this family was Andy, a 7 year old boy with a severe type of Autism. Andy had great independent living skills. For example, he could go to the restroom independently when necessary and he asked for food when he was hungry by pulling his mother's shirt. However, he did not have any functional speech. Andy's mother, Peng Wang, was a stay-at-home mom for the first 6 years of Andy's life.  Last year Peng decided to get a part-time job because she needed extra money to pay for Andy to attend a summer camp for children with disabilities. Peng's husband worked for a local Chinese store as a bookkeeper 6 days a week, 10 hours a day and earned $22,000 per year. Peng had a college degree from her country and her husband had worked in an accounting office before they moved to United States. Peng spoke a little bit of English and her husband spoke no English; but the main language they used to communicate with Andy was English even though both of them had difficulty speaking the language.  Andy attended first grade, his school hours were from 7:30am to 2:30pm. Because the Wang family earned $22,000 dollars a year, Andy qualified for Medicaid through the state and thus received speech language therapy and occupational therapy once every two weeks.

*Cheng Family (family number 2):* The Cheng family had been in the United States for 20 years. Both Lim and Ken attended college in the United States for their undergraduate and graduate degrees. After Lim graduated, she decided to look for a job while Ken finished medical school. The Cheng family had two children. Gabe, the younger child, was born deaf. While the parents were participating in this study, Gabe enrolled in the public pre-school program for his first semester. Lim had been the main caregiver since Gabe was born while Ken had a regular full-time job to support the family. Ken worked as a Medical professional and earned between $80,000 and $85,000 per year. They lived in a five bedroom house.  Both parents spoke fluent English; however Chinese was the main language spoken in the house for both parents and children. The Cheng family also carried on the “traditional” living arrangement as Lim’s parents, who were brought to United States six years ago, lived in the same house. Before reaching the age of 4, Gabe had two major surgeries to receive cochlear implants in both ears. He received speech therapy and had seen an audiologist every week for two hours.

*Taso Family (family number 3):*  The Taso family had been living in the United States for twelve years. A hope for better employment opportunities was the reason the Taso family came to United States. The Taso family had three children, and Cathy, the youngest in the family was 3 years old and had been classified as developmentally delayed due to her delay in mastering adequate language/communication skills. Cathy appeared to have exhibited many of the same behaviors that fit into the typical characteristics of Autism, i.e., hand flapping, withdrawing eye contact with others, and showing an interest in things that spin. Cathy's mother, Li, was a stay-at-home mother while her husband Kai worked in a local Chinese restaurant and earned $29,000 a year. Neither Li nor Kai spoke English. Each received high school diplomas in their native country. Cathy received speech language therapy and child development specialist services once every week provided by state early intervention program. During the research interview period, she reached her third birthday and was in the process of transitioning from early intervention services into early childhood special education. Like the other participants, Chinese was the main language the parents used in the home.

*Ma Family (family number 4):* The Ma family had been living in the United States for seven years. Both Chien and Ming came to the United States for their advanced degrees. After graduation, they accepted job offers from a local company in their chosen professions. Chien became a stay-at-home mother principally but worked part-time in an office located near her house, while Ming had become a partner in his architecture firm and earned $85,000 per year. Chein gave birth to their only child, Justin at the age of 39. Chein worried about Justin's language and gross motor development when he was 18 months old and decided to call the state early intervention agency for help. One month after Chein asked for help from the early intervention agency, Justin started to walk independently even before the early intervention services started, however his language development was still delayed. When Justin was 26 months old he liked lining things up, enjoyed the interaction with his mother, but still was not very verbal.

## Responses to Research Questions

Question 1: What were the needs of Chinese-American families?

*Results From Family Needs Checklist*

There were two parts of the family needs checklist that included the basic needs of the family and the social needs of the family. During the first part of the checklist, participants answer “yes or no” questions.  During the second part of the interview, participants responded on a scale of 0 (no help) to 4 (a lot of help) to determine how much assistance they obtained from social supports and whether they perceived a future need for that support.

Results obtained from part one family need checklist: When looking at the basic needs of the family, data indicated all four families had enough money for food/necessities, house/apartment payment, clothes, monthly bills, indoor plumbing/water, dependable transportation, home telephone access, toys for their children, and furniture for the house/apartment. The researcher noted that all four families felt they didn’t have enough time to spend with their spouses or close friends. Lime from Cheng family said:

> **“After Gabe was born, we don’t go to visit different place or go out for a date as often as we used to. It’s just really hard when you have a child with disability and he is at such young age, it’s not easy for me to find someone that can really take care of him, so we always go out as a family instead of only me and my husband. But I can remember in the past few years, I haven’t made any travel by air, and I have not visit my country for long time, the only time that I can remember was we travel to Dallas with my entire**

> **family. It’s almost impossible to have alone time only for me and my husband. I think its part of our culture that once you get married your focus is on your family. Everywhere you go, your children needs to be there. I cannot imagine leave my child at home with a babysitter and hang out with my friends alone. I think people might think I am a irresponsible mother, especially when my child is young and has a disability.”**

The Wang and Ma families had similar experiences of not having had sufficient time to spend with their close friends and spouses due to the issues of childcare. Not surprisingly, the data also showed fathers of the families less involved in childcare when compared to that of the mothers. On the other hand, there were unexpected responses for some questions. When the researcher asked Mrs. Wang “if she feels she and her husband both have a good job?” she replied:

> **“No”** and said **“ My husband used to work as an accountant in my country, ever since he got here, because of the language issue, he can only work as a bookkeeper for a Chinese company. I am not saying bookkeeper is a bad occupation, what I am saying is that it just doesn’t bring back home that much of money as we need as a family with a child like this. With the money that my husband bring home, we don’t have much of the flexibility in terms of buying things for entertaining purpose as well as materials or special things for my son. You know those things or therapy for child with Autism are all very expensive. Also since my husband’s company only cover his health insurance, I as a family member cannot join, therefore I am the only person in my family that doesn’t have health insurance and believe it or not I**

> **am the one need the health insurance the most, because I had thyroid cancer almost five years ago, and because of this I have to flight back to my country twice a year to do the check up and make sure everything is all right because my doctor still not yet told me that I am cancer free!"** (Peng, Wang).

When the researcher asked Peng if she would have liked to have had a job she said:

> **"I tried so many places before but there are so many things I need to take care before I can get a full time job. First, I need to find someone who is willing to watch my disable child after he get off school at 2:30pm, even with the after school program he can only stay at school until 3:30 or 4:00. Second, I think American school have a lot of day off, like professional days or parent-teacher conference days something like that, my kid will have to stay home, or sometime he got sick and I have to stay home and take care of him, so it's really hard for me to find a job because I don't think any company will be willing to accommodate the schedule with me and my child. Now I got a part time job in the fast food store, it's not a great job but at least I am making a bit extra money for my son so I can send him to summer camp for kids with special needs, but even with working part time, I cannot tell you how many times I almost got fired because I need to have days off when Andy gets sick and I have to stay home to take care of him. I remember one time my manager told me I need to stop using my kid as an excuse to ask for days off because he doesn't believe when I told him my child is sick [and] I have to stay home and watch him because I cannot find any childcare to take care of my sick child with disability. I think people don't understand how**

> **hard it is for a family like mine, well…I think because they don't and never have a child with disability in their family so they don't know how much extra care that I have to do, and how hard it is to find a child care that actually care about your disable child, or maybe you can say I cannot find one that I can totally trust! It really hurt me when I realized people from my work place think that I am lazy [and] that's why I didn't go to work. I think only God knows how much I am hoping everyday to get a full time job so I can better support my child's needs."** (Peng Wang).

Li, the mother from the Taso family, also was not pleased with her husband's job. When the researcher asked why she thought her husband did not have a great job, she said:

> **"Well, I am not sure how to define the meaning of great job. Well…he is a responsible husband he works 12 hours a day in the restaurant and hardly has any time to spend with our children or just be relaxed at home. He makes average money. It's enough for our family. We are not rich, but it's enough. I just feel his job is not considering a good job like what we Chinese people will think it is.**

The researcher then asked what type of job she would have considered as great in Chinese culture. She then responded:

> **"Jobs like teachers, professors, working in the computer company, more of the professional type of job will consider as a good job for my culture."** (Li, Taso).

When the researcher asked all four families about the needs and importance of learning English language, the families with better English communication skills and higher social economic status responded that a command of the English language was very important,

> **"I learn and used English even before I came to live in this country. English is the official languages that can be communicate in this country; I think it's important to learn how to speak it once you decided you are going to be the immigrant here. But I also love to keep my own language and culture as well, that why we speak Chinese at home and we try to provide as much culture inference as we can to our children"** (Lim, Cheng).

The other two families who did possess great English language skills agreed that learning English was important; however, Peng, Wang continued by saying:

> **"I know English is important and I know if I can speak better I might have a better chance to get a better job here, but all my time is dedicated to take care of my child, work with my child. I don't really have time to go out and learn the language. I am okay on the English written language, not perfect but okay, but I really have some problem on the spoken English language.**

Lack of time and opportunities also were the reasons which prevented Li Taso from learning English; however, she indicated:

> **"Language is important but I think learning their culture is essential too, especially their education system. Most of my friends are immigrants as well and they have no ideas about school system here in the U.S. Therefore, I don't really have anyone to go and ask my questions when I have concerns. I**

> **will love to learn the language but I just need help to have someone watch my child before I can take any class in the community. But I don't think that time will coming soon, since you know Kathy is still pretty young right now!"**

Results obtained from second part of Family need checklist: On part two of the family needs checklist, the families (excluding the Cheng family) responded in the range from 0 to 2 (didn't get much of the support from these group people or organization) when asked by the researcher. In addition, when asked what types social supports they needed the most before their children reached 3 years of age, all of them indicated professional help, (social worker, therapists and teachers), information on special needs child care center/program and networking with other families who have children with disabilities both inside and outside of Chinese culture. The Cheng family, because three generations were living together, felt they got a lot of support from both sets of parents in terms of child care and emotional support. Because of her husband's profession, she didn't have many of the concerns for her child in terms of medical options and needed therapies.

### *Results From One-On-One Parent Interview For Questions one*

The parent interview was another tool used by the researcher to locate data for the research questions. There were many interview questions asked in order to aid the researcher in better understanding the needs of Chinese-American families with a child with a disability. When asked what was needed most when they first learned they had find a child with Autism? Peng Wang replied:

> **"You know my early intervention services provider had never told me that Andy might have Autism. I understand they cannot label the child before**

**they turn eight or maybe they are afraid to make wrong diagnostic or something. But as mother, I was hoping that they told me that he might have Autism or there is a possibility that he could have Autism. I still memorize at that time they showed up in my apartment and do assessment and then I didn’t heard back from them for a long while and then they come again and did another assessment. Throughout all those time, no one had mention to me the word “Autism” until I finally get in contact with a child psychologist and paid lot of money to do a private assessment to find out that Andy is Autistic. He was …..Emm I will say about 30 months when I first heard the word Autism. After I learn that he might have Autism I was like…..What is that? I had never heard that word before and I don’t know what that is. So I went online and start to do a lot of research and go to library try to find books that will educate me how to help my child. Those times are really hard for me ……(sobbing sound)…….I am sorry….I hardly get this emotional but every time when I think back that time I still feel so helpless.( interview stop for 2 minutes). What I need the most at that time was for the early intervention services provider to provide me information and material on educate my child. However I felt they didn’t really help me on that part. Also, I need someone to tell me what type of government social support program that I can apply for my child and my family. For example, like Medicare, DHS, child care information, and explain to me my right as a parent in early intervention program or later when I have to send my child to the school.”**

The families expressed different types of needs when they responded to the researcher’s interview questions. Lim from Cheng family indicated:

> **“I was lost the first six months when Gabe was born. Crying was the only thing that she did during the first six months. Not only the pressure that I have a child with total hearing lost as well as I have no idea how to take care of him. I wish early intervention program had taught me how to take care of my child, and can provide me some emotional support back then.”**

Chien Ma explained her interaction had been positive with her services provider during his visits. She said:

> **“Every time when my services provider came and I am talking about the main services provider…what do you call them…services...Oh services coordinator. You can tell that he is really caring about my child, and worry about my child’s development a lot. A lot of time he will work with him over an hour and I asked him a lot of questions that I don’t know especially I am not familiar with the support system here. He will also ask me a lot of questions regarding my culture, and views about different things. I also had several good conversations with him, you know my child is young and a lot of time we are at home, I don’t really get the chance to go out and have deep conversation with other parents about how to educate my child. My services coordinator helped me a lot especially on how to help my child.”**

Question 2: Had the non-child related needs of the Chinese-American families been identified in the IFSP documents?

*Results From One-On-One Parent's Interview*

During the interview when the researcher asked the families to provide a copy of their Individual Family Service Plan (IFSP), three of the families responded that they did not have any idea what the document was. After the researcher explained to the participants what an IFSP was, Peng Chen insisted:

> **"I had never had a copy and I don't think we even have a meeting to talk about the goals and objective.**

Li Taso indicated: **"oh is that the paper thing that I signed on? If that's what you mean then, "Yes, now I remember but I had never known it has a name of it."**

After the researcher reminded Lim, Cheng and Chien Ma about the IFSP, they started to remember their experience in their child's IFPS meeting. Lim said:

> **"Except the first two times, we met at my house. The rest of the meeting was in the office of Gabe's audiologist. Gabe's audiologist was the one writing all the goals. Since she is the professional, I rarely have any suggestions. You know I trust the professionals. My EI services coordinator will write down the goals and objectives during the meeting. For me, I think they are just there to monitoring Gabe's progress, but not there to provide the needs that I need. I guess because I didn't know what to ask for or maybe I should say what I can ask for. For example, my services coordinator had never told me I can reimburse the mileage for the trip that I take him to the audiologist and speech. Neither do I know that I can ask the speech teacher to come to my**

> **house. You know the actual driving distance from my house to Gabe's audiologist office only take twenty minutes without any traffic. Back then, I used almost an hour and half or two hours to drove him, because he was fussy all the time and I have to stop several times on my way to the clinic. I don't know how many times I cried when I was on my way over there. It's like yesterday. I pray to God every week before I drove him to the city because that twenty minutes seems like a twenty hours trip to me and I was always frustrated over the situation."**

### *Results from IFSP Analysis Log*

Only two families provided a copy of their child's IFSP to the researcher. One of the families did not provide the document, because the mother did not have a copy with her at home and felt it was too much trouble to ask for a copy from the services provider. The other parent simply forgot that she needed to provide one. When the researcher later asked the parent for the IFSP, she told the researcher that she had misplaced it and could not find it. From the two IFSPs which were provided by the families, all the goals and objectives had been established toward children's language development therein. However, the Researcher did not discover anything specific for the family in terms of support systems or any other related information. Both IFSPs emphasized services directed toward the child with a disability such as the amount of services the child received each week, and specific type of therapy to be worked on during that time.

### Question 3: What were the Chinese-American families' perceptions of early intervention programs and services as well as the family's role and responsibilities while they serviced?

This research question sought to discover how Chinese-American families valued the EI services, whether they understood the purposes of the EI, and the types of services that they felt would have been most helpful and what their role as parent of a child with disabilities while receiving the services from EI would have been. Results showed all four families agreed that the EI program and the services were established to help parents of children with disabilities assess their children's abilities. All the families believed that a child with disabilities needed intervention as early as possible to enable the child to achieve better learning outcomes and to live as independently as possible.

> **"I think it is important for child with disability to start their treatment as early as possible, because those kids need time to develop a very common skill. Use my son as an example; we worked on going to restroom independently for more than a year. I started it early so by the time when he goes to public school, he was not wearing the diaper anymore and was able to go when he needed."** (Peng Wang)

Each of the family was appreciative of having received "Free services". Each mentioned that as the best feature of the EI program. Li from Taso family said:

> **"In my country, we didn't really have so call free services, and the services was always provided in the hospital instead at home. I really like what they are doing here; actually it helped a lot because it always took so much time to prepare before I can take Cathy out of the house. Since the therapist came to my house, I just get ready before she comes to my house, I really like that."**

When the researcher asked the parents how they had viewed the roles of parents who have a child with disabilities, the responses varied. Peng Wang said:

> **"I am not sure what my role should be to be honest with you. The only service that I asked was speech and she only come once a week. Sometime she doesn't show up and didn't even call to excuse her absent.  I don't have much of the communication with my services coordinator, because I cannot speak much and she had never said I can request for the translator. Honestly, I was really helpless. I know I need people to help me and show me how to work with my child, but they were not doing that with me as far as I concern. The speech teacher will come to my apartment and work with my child a little over 45 minutes and she sometimes will ask me to collect some materials when I don't really know what the material is for? I wish she could have taught me and show me how to use those materials with my child. I wish back then, I had courage to ask her, because it's my right to ask her questions.  Now I know…..seems like it's a little too late now as Andy is 7 now. Anyway, I didn't ask because her much of the questions, [because] part of the reason as I was worried that she cannot understand me and also if I ask too many questions, they will not want to come and teach Andy anymore."**

Chien Ma was excited when the researcher asked the question whether she knew what her role was as a parent during the services providing section. She said:

> **"I need help. That's why I called EI agency. Because my child was not able to speak and walk back then, therefore I was very worried. I had great communication with my services coordinator and he was really good. [He] explained to me the strategies that he used to work with my child. I adopted**

> **them pretty quick. But to be honest with you, there are still some differences when I saw him working with Justin. For example, they think eye contact or have ability to pointing to things is important, but in my culture, we don't think those things are important. But you know I was thinking it's a free services and if is benefit to my child I will be willing to try it even thought I don't really think those things are the big of deal in terms of his learning."**

Question 4: Had the family outcome indicators (developed by the ECO Center and the Office of Special Education Programs) effectively identified a Chinese-American family's expected EI outcomes?

In 2003, the Office of Special Education Program (OSEP) gathered a group of 22 key stakeholders to identify family outcomes indicators for IDEA part C services. It attempted to develop assessment methodologies to measure outcomes for programs that are serving children from birth through five. The indicators identified as EI family outcomes were:

1. Families understood their child's strengths, abilities, and special needs;
2. Families knew their rights and advocated effectively for their children;
3. Families helped their children develop and learn;
4. Families had a support system; and
5. Families had access to the desired services, programs and activities in their community. (Bailey, Bruder, & Hebbeler, 2006, P4).

The researcher adopted these five recommended family outcome indicators and presented them to the parent participants during the face to face interviews. The researcher then asked the parents participants to read through these five indicators

(Chinese translation version was provided). They were asked whether these outcomes were what they believed to be important for them as a Chinese-American parents who had a child with disabilities. All participating families insisted indicators did indeed recognize what they needed as the parents from a different culture. Yet, they believed the indicators were too broad in terms of measuring the outcomes. Lim indicated:

> **" I think this five indicators are important, and I think it's not only our culture, I believe all parents have child with disability they all need to know this, but I just feel I didn't learn all this or maybe I should I have not yet have those skills right now or after Gabe exited the early intervention services."**

During the interview Peng Wang expressed her feeling to researcher:

> **"I feel I did not learn anything from my early intervention services provider. Maybe Andy was only in the EI program six months or just like I told you earlier, they just didn't provide anything to me as a mother. I think these entire five things you told me were important but I sure didn't get that from EI services. I got some of them by asking people around, like what type of right I have, what services I can request them to do. I feel I learned more information as my son enter into public school because I started to go to IEP meeting and sometime when they make things hard on my child or my family I will try to fight for our right and my son's right for appropriate education. Because I realized if I don't say it when I feel things is not right and Andy is not really benefit from the school, no one is going to help me, and my child**

> **will never get what he is entitle to get. So I need to learn to stand up for my child.”**

Family outcomes were defined as “Benefits experienced by families a result of services received” (Bailey & Colleagues, 2006) and family outcome was the result of the services instead of delivery of the services (Bruder, 2005). During the research interview, the participants were asked if they developed the abilities identified by the outcome indicators during or after the early intervention services were provided. The response from the parents led the researcher to believe there were gaps or perhaps misunderstandings between EI services providers’ perceptions of identified indicators and how to actually accomplish them. Using indicator number two as an example, the identified indicator mandates that “families will know their rights and advocate effectively for their children.” All families confirmed they received the book of parent’s rights under IDEA. Yet all of them acknowledged that they had never read the parent’s right book and the services provider never asked if they had any questions regarding parent’s rights during the program. Two families (Wang & Taso) did not read the parent’s rights, because language barriers prevented their reading and understanding the words contained therein.

> **“I thought that’s a bit ironic for my services provider to tell me “this is the book about your right”, when she knows I don’t read or even speak English. I thought if she can give me a copy of the parent’s right book in Chinese or explain to me verbally during the meeting when I have a translator here that will actually be more beneficial for me and my child. I feel like she just gave me the parent’s right book because it’s required by their agency or maybe**

> **state, but she doesn’t really want me to know much about my rights so they can work less since I won’t know anything.**” (Taso).

Of the other two families, who happened to have had better English skills, only one read through the parent’s rights booklet. Both agreed that the document was too difficult to understand. They not only didn’t read through the entire book, even the part they read, they weren’t sure if they had understood. Lim Cheng stated:

> **“I feel the best way for me to understand my right is to get it from my service coordinator. I mean if they can explain everything clearly to me, like which kind of equipment or services I can get for my family and my children for free. My child is almost four now and I still don’t quite understand my right as a parent with a child have hearing problem. I remember they gave me the book without explanation and even with a college degree from U.S. I still have hard time understanding them. Anyway, take the FM the hearing aid for example. I paid $3000 dollars for that, but later they told me actually they could provide that. And for the batteries, they said they would provide, but up till now, I paid for all the batteries. So does the mileage reimbursement, all of my services coordinators. I said “all” because there are a total 6 of them. Every six months comes to different person. [They] had never told me I could reimburse my mileage as I drove my child to the services 2 times a week in the city. But at the end I did get my reimbursement for the last two months, and I got that information from my audiologist.”**

During the interview when talking about the family outcome indicators, all of the family participants expressed their frustration toward the services providers (which will be discuss in the next chapter) which could have affected the results of the measurement of early intervention family outcomes.

## Chapter Summary and Overview

In this chapter, the research questions were restated and the results related to the research questions were presented. The results section focused on participants’ responses that answered or related to the research questions. The next chapter will focus on a general discussion of other related issues surrounding Chinese-American families having a child with a disability which includes: the emotional path of the parents and their access to early intervention services; child rearing practices in the Chinese culture; family structure and support from the extended family/friends; the individual roles of the father and mother in the family and their views of their children with disabilities; cultural views of people with disabilities, alternative medication/treatment, transitions, cultural competence of the EI services, and concerns for their children and hopes for future. Chapter five also will state the conclusions and the implication of the results.

# CHAPTER 5

# GENERAL DISCUSSION

The focus of this study was to investigate Chinese-American families with children with disabilities by entering their home, openly talking about their perceptions and experiences with their early intervention services and other issues related to their backgrounds and cultures. The model that was established by the early childhood outcome (ECO) center has been illustrated in the previous chapter and the findings suggested the families' unique characteristics and backgrounds influenced their ways of working with their children with disabilities and how they viewed the effects on early intervention services. The major emphasis of this chapter is to discuss some of the themes investigated during the parent interviews. The responses completed picture that revealed the nature of Chinese-American families with children with disabilities in the United States and how the social service network supported them.

## *Parents' Emotions After Realized They Have a Child with a Disability*

The researcher tried to identify the differences of each family as well as their similarities as it related to each question asked. Clearly the parent's emotional paths during the first few months or few years of their child's birth were similar. However, the type and severity of their child's disability indeed affected the parents' attitude toward their child's early intervention services. Peng recalled the period during which she had been in the process of determining type of the disability Andy had:

> **"I cried all the time. I cried in the morning, I cried in the evening. I cried during the night when he was asleep. I was his primary caregiver. My husband was not lived with us at the time (he was still living in their home**

> **country making money to support the family, while Peng was home take care of their children in the U.S.). I often felt tired, both mentally and physically. Few months later, I find out from my doctor that I had cancer. I believe my cancer might be the result of my emotional path due to the fact that I was not able to take the truth of he was a "problem" child."** (Peng Wang).

Crying when the parents realized their child had a disability seemed to have been a common way most Chinese-American mothers revealed their anger in a stressful situation. It was difficult for the parents to deal with their child's disability immediately after giving birth, and it was even more difficult for them to have faced friends and relatives. Gabe's mother also addresses her crying two days after Gabe failed his hearing test in the hospital by saying:

> **"During that time I was totally lost. The only thing I knew was to feed him, when he was hungry and took care of him. In those evenings, well, I almost cried every day for about six months of time. I even blew out easily since I felt I couldn't handle, like you know. Every time someone comes, they were so negative. Negative when they saw me. Then few people will told me not to worry too much by saying "children with hearing lost might gradually recover itself", or told me that "some children was not able to speak until the age of three, how do you know your child couldn't speak?" I was not sure what their points were to be honest with you. I worried about him every time when someone comes to the hospital to see me. When people came, I cried. When people left, I cried even harder! I felt I am a pitiful creature and I brought the disaster to my family. My husband told me later that he had**

> **never had a thought about me bring the family a painful situation. I guess maybe because he is a doctor and they see things a bit different than regular people, and he knew my child's disability is not a big problem to solve. That's what my child's ear doctor told my husband and me. Few weeks later after I gave the birth to my child, I brought him to Dr. Lee's office, once he close his office door; he told me "it's okay to cry if you want to." So I cried out in his office for a long time. I told him that I really couldn't comprehend why God put me in such a position (couldn't stop sobbing), I really want to be a good mom. I love my children. I am so happy that I have a daughter and a son and I know Gabe is health the minute when I saw him except his ear. So you must help me. You must help me."**

For the family whose child's disability had yet been determined because the child had not shown obvious signs of disability, extremely different attitudes were displayed toward their children and how the parents reflected on their situations. Chein Ma said:

> **"I was worry about my child's development. That's why I called the early intervention services. I check on the characteristic of Autism and I don't think my child has it. I think he is just growing slow but not Autism. He cannot be I think. At least, this is what I am seeing right now. He started to walk alone and even he still cannot talk, but he can line up his toys and he smiles a lot. I think if he has a disability, my husband and I will still love him no matter what and we will try to give him the best therapies that we can find and help him to develop the better skills as he needs. But at the moment, to be honest with you, I don't even think he needs the early intervention**

> **services anymore. My services coordinator is a really nice person and it kind of make me feel bad to think that I want to ask him to stop the services because I don’t feel my child needs it anymore. He maybe has his concerns about Justin, but for me he seems normal beside he still cannot speak.”**

Parents’ emotional path in terms of grieving about their child’s disability could have impacted family’s view of the quality of their early intervention services. It was difficult for service provider to alter a parent’s feelings toward a disabled child. However, displaying sensitivity and being considerate were key elements in measuring a successful relationship between the provider and the family. As Peng Wang said in the interview:

> **“I wish when they contact me they could say to me “don’t worry, we are here to help you”, and you are not in this alone”. Or at least they can try to understand my background a little bit more, and work me through the process step by step, like getting the related services, apply for different social support, or even explain clearly to me on the things that I am entitle to know.”**

### *Access to the Early Intervention Services and Information*

In general, culturally and linguistically diverse (CLD) families faced the greatest challenge accessing early intervention services and information due to language barriers and a lack of familiarity with how the system worked in the United States. The families in this study received an average of one hour a week of EI service. Overall, they were grateful to receive any EI service, but they were not very satisfied by them. All families received support from a service coordinator who served in the capacity of case manager. The service providers sent by the early intervention regional office rarely had any background in special education, family systems theory, or home-based intervention. In this study, five services provider were interviewed. The professional training background of these five providers included: child development, psychology, speech language pathology, and occupational therapy. The researcher discovered those professional training programs mainly focused on their services delivery based on the medical clinical setting instead of home-based. And this could have been the possible reason why parents had not felt connected with their services providers. A typical comment from a mother regarding her services provider was:

> **“The person that was sent by the state early intervention program did not discuss anything about my kid’s disability. She keep asked my “what do you want for your kid?” I explained to her that I was not growing up here, so I didn’t know what they have to offer my family and my disable child. After that, she didn’t seem understand what I told her. She then again asked me what I want. How do I know what do I want when I do not know what do they have to offer?” (Peng Wang).**

Some of the occupational, physical, and speech therapists had training in the family-center and in home based intervention, and tried to work with the family by helping the parents understand some related services. However, one family had problems with the services provider because the family didn’t understand why the services provider was working with her instead of working with the child even though they knew service providers who worked in the home based settings were responsible for empowering parents’ skill to care for their children with disability. Thus families who were not familiar with the system might have had different expectations and those expectations led to the misunderstanding between services provider and the families.

> **“Early intervention! I don’t know if my child benefited much from it. My therapist came in and I assumed she was here to work with my child not me, but every time he just came in and talk to me for at least 45 minutes, and as I told you I don’t know much of English. In my mind, I was think like” come on, just stop talking to me and work with my kids first. I don’t care how much information that you tried to tell me. I don’t understand and maybe just tell me when you bring an interpreter. For me at this moment, have her teach my child is the most important thing. Show me how to work with her, so I can work with her when you are not here.” I was afraid to tell her how I feel simply. I was thinking, “Well it’s a free service, and what can I ask more?”**(Li, Taso)

Another mother reiterated “the problem is some people are not willing to help you” and she later explained to the researcher:

> **“My child’s doctor suggested me to contact the state early intervention program, but he didn’t give me any contact information. When I asked him “Do you know their phone number?” he just said “just find it yourself, I don’t know it either.” I finally got the program’s phone number through the operator by dialed my house phone.”** (Peng, Wang).

During the analysis of data above, the researcher recognized possible causes of the misunderstanding between the family participants and their services providers. In Wang’s case, she mentioned that the services coordinator asked her “what do you want or what do you need?”  Perhaps the services coordinator was practicing family-centered care and tried to have parents take the lead in their child’s early intervention services. Yet, these parents preferred the services coordinator to take the lead and explain to them what the EI programs had to offer the family and the child. It was a common mistake for the services coordinator to believe any family who had contacted the EI program had a basic understanding of EI and its services, or the services coordinator was not flexible enough to modify the model of services delivery which  led to an unsuccessful or low quality family early intervention outcome.

Most parents in the study also did not understand how to incorporate EI goals into their daily lives. Some of them did not even have any idea what their EI goals were. Although they appreciated EI services, when asked whether EI had been helpful for the child and the family and what else she would have liked to have seen happen during the EI service period, one mom said:

> **“Uh….I didn’t feel like…well, I am sure they mean to be helpful. Uh…but lifestyle and our need like I talk to other parents who maybe have a child with mental retardation, or a child who have the physical needs, the parent seems getting a lot out of them. But with my child, because she is active, and she will interact when she wants to interact with you, because she knows you and trust you , it’s harder, because when is not helpful, it’s almost like “ oh, well, it time for them to come, and I have to stop on what I am doing and be with them. For me, I need have someone, okay someone like you, who knows the system as well as understand where I am coming from to talk to me and tell me what my needs might be? You know at that time, I might need**

**marriage counseling and family support service. It would be great if they can put all those into the consideration when they talk about early intervention.**”(Li, Taso)

From the above example, the researcher made the assumption that EI providers should have spent a larger portion of time teaching families how to work with their children; the researcher assumed the provider would not have overlooked those services directed toward the “whole” family and looked only at those services directed at the individual child with the disability. The Services coordinators should have explained to the parents the possible services (non-child related) that they could have offered to the family when needed by the parents. The researcher assumed the services coordinator did provide the reading copy of parental rights to all Chinese-American parents as we investigated in the interview.  However, ensuring that the parents understood their rights was what the ECO center described as an integral part of family outcomes not the mere delivering of the document to the parent. At the onset of delivering the services to families from different cultural backgrounds, the feeling of apprehension by the families should have been expected.  However, if the provider began by explaining to the parents the type of the services available through the program and rights they had as the parents under the law trust could have been built with the families.

### *Child Rearing*

Feeding: Different cultures and families have their own beliefs and ways to rear children. The theories of individualism were more controlling in the mainstream culture while collectivism was reflected more in Chinese-American Child-rearing practices. The Cheng family was a traditional Chinese family who lived in the United States. The family members included not only the parents and their children, but the grandparents as well. During the interview, Lim admitted Gabe had not fed himself until the age of three. She added, **"Even to this day, because he is a slow eater, therefore I sometime will feed him myself instead of let him play with his food."** (Lim Cheng). It was difficult especially for parents who also lived under the same roof with their in-laws, because the two different generations had very different perspectives on the same child rearing issue.

> **"When my mother in-law is having dinner with us, she feeds Gabe more often that I will do. I understand we need to help him become more independent, and give him opportunity to feed himself, but my mother in-law feels that when he is feeding himself, he is not eating much of the food. Also it take too much of time for him to do it. So she started to feed him. I as a mother, of course will want him to eat things himself, but I also need to respect my mother in-law too. I know she does not doing that to hurt my child. She did that because was worry that he didn't eat enough. So in that case, I will let her do it."** (Lim, Cheng).

Data suggested that was not important to most Chinese-American parents that a child learned to feed himself before the age of three. The reason behind this fact: the child will not have consumed enough and the cleanup work after the meal time was completed was immense. The diet of the mainstream culture was dominated by the presence of finger foods while the diet of the Chinese American culture was not. Therefore, by age 3, the average American child can feed himself and can do so relatively free of making a mess so to speak. However, the diet of the average Chinese American family consisted of soups, rice, porridge and other nonsolid food dishes. It was more likely then that a child under the age of 3 who was attempting to feed himself would have failed to get proper amounts of food consumed and would have made a considerable mess in the process. This made more work for the parent who would spend more time with household cleaning than tending to the other needs of the child. Accordingly, it was easier for the parent to continue to feed a child who may have reached the age of 3. Moreover, Chien Ma pointed out her views of why parents from her cultural background provided fewer opportunities for their child to have fed themselves during the mealtime. She said:

> **"I have to say not only cleaning up take a lot of time. I think it also has something to do with the food we eat. American children eat a lot of finger food during their mealtime like chicken fingers, pizza, and fries. At home, I had never cooked that type of food for my child. We eat a lot of rice, soups, noodle, and vegetables. Most of the food that I serve for my child is not finger food; therefore it's hard for him to feed himself at such young age. I of course think have him feed himself is a good thing to do, but I will prefer not until he turns three or four, because then he will have better grasp skill and can hold spoon, chopstick, or fork in more steady way. Before he can do that, because of the concerns of his nutrition I choose to feed him instead of let him eat independently."**

The parent's response about child feeding led the researcher to see the possible conflicts that a services provider and family might have faced during the services delivery. Helping children with a disability to become as independent as possible was one of the goals of early intervention. Special education, family values and beliefs could have been different from our targeted goals. What a services provider should have done was to help family members to understand the value of this goal, as well as made recommendations for how parents could have helped their child reach the goal. This was imperative if the services provider had wanted to build the relationship with the family.

Sleeping Arrangements: During the interviews, two families from higher social economic status (SES) mentioned that they felt it was important to have a child sleep in their own bed even if had been in the same room. Chein Ma said:

> **"I think it's important for them to understand they need to sleep on their own bed and daddy and mommy sleep on theirs. I don't want my child still sleep with me and husband when he is in grade school. Some family they all sleep in the same room maybe because they don't have enough room in their house, but we have more than enough room why not let Justin has his own room. I also feel that by let him stay in his own room, it's like helping him to develop a sense of responsibility. When he become older, he needs to make his own bed, clean his own room and you know have his own space that he is response for whatever is in there, and I like to give him that."**

Li Taso indicated that because Cathy was the only other girl in the family and because of the limited of rooms in her house, she and her husband had decided to keep her in their room, but in different beds. Peng on the other hand had different reasons why she kept Andy in the same bed with her. She said:

> **"Andy had been sleep on the same bed with me and my husband sleep in the different room. We are fine with that, because Andy needs to go to the bathroom during the night, he needs help with that. Also he wants me to be**

**there than he wants his dad, so with him on my bed it's easier than have him on his own bed."**

*Family Structure/Adaptations to Mainstream Culture*

The subject families represented American-Immigrant families in the United States. None of the parents who participated in this research were born in the United States. Parents from two families received their college and advanced education here in the U.S., and that enhanced their ability to communicate their needs to EI services provider. In terms of adopting the mainstream culture in the United States, these two families had more friends from the mainstream culture, even though they did not grow up in the U.S.  Nonetheless, these families were not familiar with the EI system here, neither had been shy when they had questions about the system whether the question was related or not related to early intervention. Their American friends were the first people to whom they turned for additional help. Some of the service providers had become their longtime friends through the discussion of their children's disabilities. As far as adopting the mainstream culture, both Cheng and Ma feel they adjusted to life in the States very well. However, there were some roots about their culture they wanted to maintain.  For example, it was important for them to keep their language and belief in the value of education.  The other two families who did not receive their education in the U.S. had more difficulty adjusting to life here in this country due to the lack of communication skills, the satisfaction of quality of their life with a child with a disability, the small social circle, and little support from community they experienced. Also, when asked if they have any friends from different cultural backgrounds other than people who spoke the same language, they both replied “No” People who were from Chinese culture sometimes felt shy about asking for help or as Taso said:

> **“I don’t like to bother people with my own problems, or keep asking them to help me. It’s almost like I am begging them and I don’t like that feeling.”**

Taso’s response led the researcher to conclude that could have been a reason why instead of requesting an interpreter she asked her oldest son to explain things that she didn’t understand. Some research suggested the longer the family stayed in the mainstream culture the better they assimilated within the dominate culture. The data suggested time could not have been the only indicator in determining whether a person has assimilated into the mainstream culture; there could have been some other reason determinative of the level of a person’s acculturation such as a person’s education background, SES, occupation or even individual’s personality.

*Support From Family Members/Friends*

Parents who were from CLD backgrounds had to go through the same emotional stages as mainstream parents of children with a disability. Research indicated that some parents from minority groups dealt with their emotions privately. Three participants in this study shared their pain not only within their family but also reached out for their extended family members for support. One mother indicated:

> **“My mother who lives in my country was very helpful at that time. She accepted Andy totally. She felt sorry for Andy and me. My father on the other hand was really helpful too but he thought my son had destroyed the rest of my life and because of his disability and I have to take care of him for long time. My sister felt the same way too. But at the same time, they all**

**thought I gave the birth to Andy and I should be responsible to provide the care. My mother will said something like "child is innocent." Sometimes I think if I could just kill him, then I don't have to take any responsibility or taking care of him. When my mother heard me said that, she always told me that I shouldn't have that kind of thought. She told me, Andy is your child, no matter he is normal or not. You should be responsible for your child. My families are very supportive in many ways. I guess they taught me to face the truth."** (Peng, Wang).

One of the participants, when asked if family members had supported her emotionally and physically, commented:

**"My mother-in law was extremely not happy after she found out about my daughter's disability. She thinks I am a woman with bad luck that's why Cathy has Autism. Good things that we are not living with them and they are so far away from us. I dare to think what will happen if we actually live together. Since we don't have much of the relatives here in the states with my family, all the support I can get is to call my own mother back home to. She will ask me not to worry and sometimes listen to me if I have any complain. I also got some support from some Chinese families who also have children with disability. We will talk on the phone and exchange some ideas. I am not good in English so by talking to other moms it actually bring me some new information too."** (Li, Taso)

Families from different cultural backgrounds experienced different forms of family support for parents and children with special needs. Early interventionists needed to have understood and respected different family structures and different family needs. It was very important not to have generalized family characteristics and expected outcomes from early intervention services.

### *Father and Mother's Role in the Family*

The father and mother's role varied based on different cultural influences. Mainstream society values the importance of the father's role in the family and believed that the father needed to share the same amount of time as the mother with their children. From the interviews, the researcher learned that all the mothers in this study carried the larger burden as a caregiver and took on many duties within the household.

When asked what her role in the family was one mother indicated:

> **"Uh…..it's big, my role is big. You know, nurturer, care taker. I get the grocery. I take care of the money. Anything needs to be one I pretty much do it or coordinate it. Anything for my child's paper work, therapy, school work I do all that. Uhhh… you know wife, cook, try to pick up and clean. I guess just to get everybody together. You know, like say, that's go to church, you know. I guess, any type of society activities, I do get everybody out. For example, like once we finished dinner, I will said let's go out for a walk and my husband will say, "Oh I am tired, let's not go for a walk but watch a movie at home." I will said just go for a walk since we had just finished eating. So the role, I guess it is big, I don't even know how to categorize it because it's a lot of hats."** (Lim, Cheng)

Among all the participants in this study only one family actually shared a bit of responsibility between the two parents. When asked about their respective roles in the family, the mother said:

> **"I take care of my child half day when I got off work, but my husband helps a lot too. When he came home he will take over completely. They gave him bath, read him the story, and do fun things with him. We also take turn every night to help him go to sleep. One person will take care of Justin until he goes to sleep and the other one will have free time to do his/her own thing. My husband and I often make fun at each other by asking who get to be single tonight."** (Chien, Ma)

During the interview, Peng, Wang also appeared to be the one in charge of her family

> **"I do everything related to my child, my husband doesn't understand how it works, and I am okay with that. But when it comes to IEPs he will go to the meeting with me, even he doesn't say much but I guess when he is there it actually push me that I have go further for my son's education even if I have to fight for it. Besides that, I deal with the school and the services provider all by myself. At home, I taking care of him and teach him different skills. My husband doesn't know to interact with him. But once I told him how to do, he will try to use the way that I taught him to work with Andy and that I like it".** (Peng, Wang)

*Parent’s Views of Their Child’s Disability*

Types and severity of the disability as well as parents’ religious beliefs impacted very much on how parents view their child’s disability. Parents whose child’s disability impacted their family life only slightly view their child’s disability in a very positive way, even though it had been difficult in the very beginning. Gabe’s complete hearing loss served as a “tragic moment in my lifetime” as Lim recorded the day after she gave the birth to her baby boy. It had been six months of an emotional rollercoaster, since she and her husband finally learned that Gabe was eligible for cochlear implants on both of his ears. Their religious beliefs became even stronger throughout the process of Gabe’s cochlear implant procedure, recovery, and thereafter as he made tremendous progress in his speaking ability.

> **“I feel, no matter how difficult it is for Gabe, we can accept the face bravely. We don’t consider his hearing lost as a consequence for parents to suffer. You know since his implant everything is perfect already, we are trying to accept our child and help him to actively receive the therapy, and try our best, you know. We first had hearing aid and then implant. I try to help him learning new things. I won’t miss any opportunity to help him. I really thank God for all HE has done for my family and my child. I cannot even think what I will be without God’s support me throughout all those years.”** (Lim, Cheng).

Parents, who had a child who has less opportunity to grow into a typical developing child, have a less enthusiastic expectation of their child’s chances of improvement. This assumption did not infer that the parents had less love or did not care for their children, but parents felt so unsure about their future life. Andy’s mom Peng Cheng indicated:

> **“I feel my job of taking care of my son is and will never end. I tried my best to teach him things at home, but I don’t know if is because of my strategy or he simply just not smart or maybe both. He is not able to learn whatever I teach him at home. So what can I say? I am only hoping that he will have good teachers throughout his school years until he turn 21 and then I don’t really know what’s going to happen. I don’t even think that far.”**

### *Culture Views of Children with Disability*

One thing upon which all participants agreed was that modern Chinese-culture influenced Chinese people to have viewed an individual with disability as a pitiful human creature. The media also portrayed them as “always needed help” or often turned an ordinary learning accomplishment into a sensational headline story. Because of that, constant false information in people’s daily life created a wider gap between special and the general population in the mainstream society. I as a researcher believed that in order to understand people with a disability and the disability culture, services providers needed to learn the truth about people with disabilities.  A healthy dose of curiosity would have aided in the effective delivery of the services about which we have focused. Without that curiosity, there was a lack of understanding of the assumptions under which the Chinese American family was operating with respect to how they reared their children with disabilities and integrated them into mainstream society.  It should be noted that only one family in this research pool had positive thoughts of dealing with people from their culture as reliable partners in dealing with children with disabilities. The other three felt a sense of relief that assistance may be provided by members of the mainstream culture inasmuch as they had a very small social support circle here in the States and only had interacted with their immediate family through the phone.

> **"You know, I don't know if I told you this before, but when I first told my own mother about my child's hearing lost, her first reaction was like "you are still young, you can have another babe". It's almost like she was telling me I will have to give a birth to another child to replace Gabe. This was never in my mind. He is my child no matter he has or has no disability. But she is my mother and beside that I know she love my child and support us no matter what. What I cannot take the most were all my Chinese friends from church. When they came to hospital and found out that Gabe has hearing lost, a lot of them keep asked me, what I did when I was pregnant Gabe, or what did I eat. One of them even said to me "your ancestors must have done some sins to make you have a babe like this. Those types of comments have never stopped. When Gabe was about to go to his procedures of his implants one of my friend from church keep telling me don't do it because it will have infection and I am killing my child. You know sometimes Chinese people tend to talk with their mind; they don't realize they already hurt your feelings. Some friends that I thought I know them before my child's birth, their act made me think if I really know them all those years. You know Gabe will have to wear his implant for the rest of his life unless there is some type of new technology develops later in his adult years. I have a friend, who we see every week in church, keep asking me why is Gabe wearing his**

> **implant for such a long time and when am I going to remove it. You know, they thought implant is just temporary and we can simply fix the problem just like that.”** (Lim, Cheng).

### *Alternative Medication/Treatment*

All parents who participated in this research believed in using Chinese herb food therapy. The therapy was not used to treat their children’s disabilities but to improve their physical health. One family reported that they would never try alternative treatment or medicine because the father of the family was a doctor of western medicine and has stronger belief in its effectiveness over Chinese traditional medications or treatment. The other families indicated although their child visited western doctors for the physical sickness, they did sometime try to do the alternative treatments regardless of their disabilities. Peng Wang said:

> **“I took my child to do the acupuncture therapy in New York City for about two months, the treatment is so expensive. I have to say I didn’t see much of the differences, but you know there were a lot of children with disabilities receiving their treatment there.”**

### *Views on Culture Competence of the EI Services and Providers*

All families in the study indicated that their services providers were very polite and believed they were great people. Yet, the parents also believed their cultural difference, and different beliefs and values were not considered fully during the process of developing the IFSP or during the process of the early intervention services. Lim was a mother with a deaf child. She was proficient in English and a very well educated individual. When the researcher asked if she believed the cultural component had been incorporated into the process of IFSP or IEP development, she indicated:

> **"Sometime, I feel because I can speak the language is one of my disadvantage for my child. Culture not only included the language, but also the beliefs and the ways of thinking. People just don't get it, when they talk to me, they thought okay, you can speak English so you are suppose to understand and know everything we said. This is totally false. They don't know I am still thinking in my native language, at home, I am still practice my native culture and beliefs and even though I been here for a long time, I still consider myself as an Asian mom with a child with disability, but not a mom who can speak good English and know everything about early intervention or special education related services."** (Lim, Cheng).

All of the parents had concerns about how difficult it was to connect with the services coordinator, experienced inconsistency in the services, and preferred to have avoided frequent changes in the staff. Three parents stated that every time they needed to contact the services coordinator all they got was voice mail and many times they didn't get a return call from the coordinator. The researcher believed this was the result of the services coordinator having to do home visits with other clients while parents were trying to contact them in their office. Sometimes it was difficult for services coordinators to return calls with time constraints and large case loads. In terms of inconsistency in services, Chien Ma stated:

> **"You know I have no problem with my services coordinator, because from what he has been doing with my child. I know he really cares about Justin,**

> **but I have problem with my speech language services provider. She often not shows up at her appointment, and didn't even care to make phone call to let me know that she is not coming. After she missed her appointment she will call and ask me when did we said we are going to meet next week? I was thinking in my mind, "you didn't even come to your appointment this week, how am I suppose to know when are we going to meet next week?" I think she just didn't understand, missing an appointment without calling is very disrespectful in our culture. With her attitude, she not only didn't call but when she called she didn't explain to me why she missed her appointment, and just continuing on with her conversation. That makes me angry. You might think I am at home anyway, even if she didn't show up, but you know every time when she said she was going to come, I am always waiting for her, and put things that I need to do to some other time. After few times of waiting I am just like, this is too stupid to wait on her. The only reason I didn't say anything to her is because this is a free services, and I don't want to create any type of drama by confronting her on her missing appointment."**

Chien Ma's statement indicated that she had not developed the ability to advocate for herself and her child. At the same time it was true that in the Chinese cultures, people had not easily developed the skills necessary to defend their rights. Even if they had not felt comfortable with the situation they tried to see the positive instead of negative.

Two mothers were not comfortable with how often their service coordinator changed. One mother indicated that within three years in EI, she had a total of six services coordinators and the other one had three within a six month period. Neither parent, in this instance received the information to which they were entitled. These parents got the information frequently in piecemeal fashion. Valuable time was wasted repeating information to new service providers.

During services providers' interview, all participated services provider indicated the needs for cultural competence training in order for them to feel more comfortable to work with families from different culture background. One of the services providers Mark stated:

> **"We have culture training once a year, but I think it should change to be an ongoing training and because it's really hard to learn someone's culture within one or two hours. What I do when I work with family from different culture is asking questions, I constantly ask family questions, if I don't know the culture I ask them, and I often found that they are really enjoy share their culture with me, during that process I actually learning the families' culture and I also building the friendship with them during that time."**

The other service provider Mary said:

> **"I wish our training can bring in more different culture as you know the population that we are serving right now is more and more diverse. And I also hope that during the training we could have family from that specific culture to come and talk to us, instead of invited people who are not from that culture to talk about what Hispanic culture look like or what Chinese culture look like. I don't know about how others think but for me I think that's too general and it is just not functional enough for me when I go out to deliver the services."**

All services providers who participated in this study also expressed their concern to the researcher about the challenges that they had when they worked with the family who did not speak English.  Heather stated:

> **" It's really hard for me when the family is not speaking the language, I felt the interpreter sometime is not translate what I mean complete to the family and because of that it was extremely difficult for me to go into the family and try to build the relationship with them especially when I don't speak their language. I do feel if I could spend more time, we could have connected more but in the real word that's just not the case."**

*Concerns for Their Child and Hope for the Future*

All of the parents had many concerns for their children. For the children with a mild/moderate disability, two of the parents talked about their hopes for their children's success at attaining a college education. The mothers of the children with a profound disability talked about their hopes for their children's future. Over all, the concern seemed greater than what a typical parent might have for their developing child. Peng Wang indicated:

> **"I am worry about he will be bully by his peers. Andy is afraid of dark; I am worry with if someone turns off the light while he is in the restroom. I am also afraid that his teacher will lose their patient of teaching him. I am also wishing that he would be able to learn how to use verbal language to communicate instead of use pictures. I worry about sexual assault. I don't think my child will go out and commit a robbery, unless he hangs out with a wrong group of people, but I don't think my kid will."**

Li, Taso shared the concerns she faced when Cathy went to school and for the future living arrangement she said:

> **“ My concern?! uhhh, I was worry about will she be treated correctly, because she is different. Many times she is the only Asian child in the program. Uhh…so as a parent that is the first thing when you go in, you look at the diversity. When you see someone like you, it makes you feel better. And I know if you have an experience with the minority, you will treat my kid okay, you know…. Some people freak out when they see a kid looks different in their classroom. I know it sounds crazy,but you have to believe there are people still acting like that. So that was my first concern. Also I will like her to stay with me when she grows up, and I hope she will pass before me. It’s hard for a mother to say things like this, but I really hope she will die before me so I am sure that she has someone to take care of her”**

The future hopes for the Wang and Ma families were positive and more optimistic. They both indicated they will not behave like the traditional Chinese parents who often set expectations too high or chose a field of study in which the child has no interest. Both mothers understood the importance of providing their children with a positive learning environment which, encourages and supports individuality. Hope was shown more than concern during this part of interview on both participants. Lim Cheng had shared what Gabe told her in a conversation with the researcher, she said:

> **“One day, I was driving Gabe to school and he told me, “mom when I grow up I want to be a president of United States”. After I drop him off at the school I was crying all the way back to my house. I cannot believe how far we**

> **have come from completely hearing lost to now he is talking. I want him to dream big and follow his dream."**

*Case Study*

The case study of one family is now presented to illustrate better how an individual's family needs differ. The first family of interest was nontraditional. The Wang family lived in an apartment in an urban area. Andy, the only child, was identified for EI services by his mother when he was about 2 years old. He had no language skills, had difficulty communicating and engaging in daily activities, and consequently engaged in self-inflicted injury tantrums. Andy was eligible for EI, demonstrating delays over 50% in cognitive, language, and social/emotional development. His fine and gross motor skills also were poor. Peng, the mother, had immigrated to the United States from her country 10 years ago. Peng started her immigration application process in 1989, waited for twelve years, and paid a lot of money before she was allowed to enter the United States. Andy was born three years after Peng had relocated. During this time when Andy was diagnosed with Autism, Peng was also diagnosed with cancer. Her husband had not lived with the family for financial reasons. He remained in China and worked to support his family in the U.S. Peng cried a lot because she worried about who would take care of her son if she died. When I asked Peng if she had any friends here in U.S., she said:

> **"Friend…oh….My mother has a good friend lives in New York. She works as a housekeeper and often stays at other people's house and baby-sit their children. Because of that, I cannot call her, and I am always waiting for her calls. Also I have only one friend, who lives about 30 miles apart from here, and she also has a child with autism, other than her, I have some friends**

> **from Hong Kong or China, but we only met few times. I don't really consider them as close friends. Sometime they would call and asked how my child is doing, but not too often."**

Andy's disability was not expected. When Peng visited her parents abroad after Andy was born, her sister-in-law told Peng's mother that her grandson might have had a disability because he had not been making eye contact with people. After noticing the same behavior, Peng had concerns in her mind that Andy might have had a disability. Later, Ping found out that her sister-in-law also had an adult child with autism, however, when asked if the sister-in-law offered any support, she said:

> **"No. I called her after I returned from Hong Kong, and wondering if she can provide me more information about autism. Because you know, who knows what autism is. But she told me "it's been a long time after I found out about my son's disability, I do not want to talk about it." and I was so angry, because I really hope that someone could tell me what are the characteristic for children with autism, and what are their developmental milestone. I was hoping that she would have share that information with me even thought I was not living in Hong Kong, but I really wish that she would have done something for me. At least just share her experience with me, so I can get a better understanding of what autism is."**

After an EI service provider determined Andy's eligibility, the resource coordinator asked Peng what she wanted for Andy. Peng considered how little she knew about early intervention, and related services and she told the resource coordinator:

> **“Well, he is lack of the language, so what about a speech language pathologist? During that time, my biggest problem was lack of the information. From my understanding, I think early intervention should have provided this type of services. But they didn’t provide to me. Self-learning, looking for resources by reading through the books and search on the internet were my ways go gain more understanding about my child’s disability the recommended treatments and interventions.”**

The researcher asked Peng if the therapist provided the opportunity to involve her in the therapy session and whether she understood the IFSP goals during the process of receiving the early intervention services. She commented:

> **“The speech language pathologist taught me to buy several different materials, cut the pictures from the newspaper, take pictures of the store what I often go, but she never explained to me why she wanted me to do that. Now I know she was teaching me how to make my own communication tool for my child. I wish she could explain to me what her goals was for Andy, and what she type of skills that she is worked on with Andy so I can help him while he is not in the therapy section. We didn’t have much interaction, and she was not provided me any helpful information. Anyway, you can say I am totally upset about what we had received from the early intervention services.”**

Andy received early intervention services for a little over 3 months. IDEA indicated that when the child with a disability reaches three years of age, the parents have the right to ask for special education services from the local public school. When the researcher asked Ping if the early intervention service provider helped them successfully transition from home-based early intervention to the public school, Ping answered:

> **"At that time, because I didn't have very good experience with early intervention people, and I didn't think they can be helpful in anyway, so I only wish Andy can go to school as soon as possible. In my mind, I think school teachers have better quality, because they are certified to teach child with disability"**

After Andy started the transition from EI service to early childhood special education, she faced stronger challenges due to the lack of language skills to communicate with the school's administration. During the interview, she recalled her first IEP experience:

> **"My resource coordinator disappeared after she told me that she would contact the school about Andy. I felt like she did not help me in the transition because she thought that I wouldn't understand the information that she gives it to me. So she may as well not help me at all. Andy's very first IEP, his teacher wrote "PECS" and "Sign Language" on it. I was not able to understand what "PECS" and "Sign Language" was. They could have showed me the real product and explain to me how they use PECS as a communication tool, and demonstrate it for me so I will be able to understand it. But that didn't happen on the very first day of his IEP meeting. It was May-18-2004 as I can still remember the exact day. We met in Andy's classroom and…………I really think I was too naïve to think that they were really going to tell me**

> **everything relate to my child that I don't know about, or any resource that I could have use to my child."**

*Limitation of the Study*

One limitation of the study was the research data selection. The current study was built on the multiple data sources which yielded a large dataset. In order to focus on and answer the research questions, the researcher had to make the determination of which set of data is significant and valuable enough to report. The result of data reported might have answered the research questions; however it did not discuss the entire case since the researcher decided to show the responses only in these interactions that are the most interesting and related to the themes and the research questions. At the end of chapter 5, the researcher attempted to use a sample case study to display the completeness of one family's data.

*Recommendation for Future Study*

The study focused on understanding the perception of Chinese-American families with a child with a disability about early intervention services and what they expect to learn during the process of early intervention services of their families and children. All participants lived in the suburban cities of a south central state. Further study should be conducted in order to determine whether or not the geographic locale in which the Chinese-American families reside will affect the outcome of the study. Additionally, more studies should be conducted to include interviews of the fathers of the participated families, services coordinators who services Chinese-American families, and Chinese-American grandparents with the grandchildren with disabilities. It will be an interesting study to delve deeper into the participants' family and discover the family members' perception about early intervention services and views of their child or grandchild's disability. It also would be important to study how comfortable services provider are with providing the services to the families of different cultural backgrounds, what types of challenges they face, and what types of training they need to enhance the quality of services.

Other possible future studies include replicating the current study in states having larger populations of Chinese-American families and where services providers are from non dominate cultural backgrounds. Moreover, if the current study is conducted using all minority cultures the larger society would benefit. The researcher believes this will also help to build connection between culturally and linguistically diverse families and the EI services providers.

Two final elements that deserve attention are effective family-based parents training and transition process from EI to early childhood special education. Since most of the EI model is family based, how service providers can convey parent's rights under IDEA more effectively to the parents bears studying.

### *Conclusions*

Generally, young children spend most of their time in daily activities with their families. Family-centered early intervention services are to ensure that children with disabilities will grow up in the natural environment like their non-disabled peers as opposed to in an institutional setting. The EI program provides services to the parents who have children with disabilities. The goal of the program is to enhance the parent's ability to provide better care for their children with special needs. The researcher believes that the evaluation of the EI's family outcomes is one of the important elements for improving the quality of early intervention services for families from all different cultures. Research data supports the importance of individualized family-centered early intervention services due to the nature of all families. Families are different even if they come from the same cultural background.

The discrepancy between what Chinese-American families thought what they understood, and received from early intervention services and what the ECO center family outcome indicators tried to evaluate could have been the result of providers misunderstanding about the real meaning of family outcomes and the miscommunication between families and services providers. It is important for EI providers to understand that providing parental right documents to the families doesn't necessary mean the family will know how to advocate for themselves and their child with disability. The problems exposed from research data indicated that the issues surrounding Chinese-American families and the expected EI family outcomes likely was affected by the application from theories to practices, and the amount of the time the service provider had to work and connect with families.

It was an extreme challenge for the researcher to develop a set of practice guidelines that were based on the perceptions of Chinese-American families. As the researcher pointed out earlier, every family was different and had its unique characteristics, family history, and needs toward its children with disabilities. The uniqueness of the family created an even more important role for family-center early intervention practices. The best way to have ensured Chinese-American families reached their goals as set on IFSP, to have empowered Chinese-American parents' ability for caring their children with disability, was to have had the EI providers develop the connection with the family who could or could not speak English.

This could be achieved by having increased the observation time, asked questions when needed, delivered services with consistency, and understood that not one EI model fits every situation during the process of providing the services. The researcher believes by implementing the suggestions herein, based on the findings from this study, the distance between the services provider and Chinese-American families will be shortened and compliance on the EI program outcomes will be increased.

# REFERENCE

Addison, S. (2004). Early intervention matters, Part 3: Family-centered philosophy and the role of the family in early intervention. *Exceptional parent, 34*, 54.

Anderson, P. P. (1989). Issue in serving culturally diverse families of young children with disabilities. *Early Childhood development and care, 50*,167-188.

Arcia, E., Gallagher, J.J. (1993). Who are underserved by early interventionists? Can we tell? *Infant-Toddler Intervention, 3*, 93-100.

Bailey, D., (2001). Evaluating parent involvement and family support in early intervention and preschool programs. *The Journal of Early Intervention, 24*, 1-14.

Bailey, D., Blasco, P. M., & Simeonsson, R. J. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation, 97*(1), 1-10.

Bailey, D., & Bruder. (2005). *Family outcomes of early intervention and early childhood special education: Issues and considerations*. Menlo Park, CA: Early Childhood Outcomes Center. Available at http://www.fpg.unc.edu/~eco/pdfs/Family_Outcomes_issues_01-17-05.pdf

Bailey, D. B., Bruder, B, M., & Hebbeler, K., (2006). *Guidance for states in documenting family outcomes for early intervention and early childhood special education*. Menlo Park, CA: Early Childhood Outcome Center. Available at http://www.fpg.unc.edu/~eco/pdfs/guidance_for_states.pdf

Bailey, D., Buysse, V., Edmonson, R., & Smith, T., N. (1992). Creating family-centered services in early intervention: Perceptions of professionals in four states. *Exceptional Children, 58*, 298-309.

Bailey, D., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C., Kahn, L., Mallik, S., Markowitz, J., Spiker, D., Walker, D., & Barton, L. (2006).

Recommended

outcomes for families of young children with disabilities. Journal of Early

Intervention,

Bailey, D., Buysse, V., & Palsha, S. A. (1990 a). Self-ratings of professional

knowledge

and skills in carly intervention. *The Journal of Special Education, 23,*423-435.

Bailey, D. B., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, & R. J., Spiker, D. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children, 64,* 313-328

Bailey, D., Skinner, D., Rodriguez., P., Gut, D., & Correa, V. (1999). Awareness, use, and satisfaction with service for Latino parents of young children with disabilities. *Exceptional Children, 65,* 367-381.

Bailey, D., Skinner, D., Correa, V., Arcia, E., Reyes-Blenes, M., Rodriguez, P., et al. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104,* 437-451.

Bailey, D., Sorenson, R. J., Winton, P. J., Huntington, G. S., Comfort, M., Isbell, P., O’Donnell, K. J., & Helm, J. M. (1986). Family-focused intervention: A functional model for planning, implementing, and evaluating individualized family services in early intervention. *Journal of the Division for Early Childhood, 10,* 156-171.

Bailey, D., Winton, P. J., Rouse, L., Turnbull, A. P. (1990 b). Family goals in infant intervention : Analysis and issues. *Journal of Early Intervention, 14*, 15-26. NY: Macmillan publishing company.

Bailey D.B., & Wolery M. ( 1992). *Teaching infants and preschoolers with disabilities*.

Barnett, D., Clements, M., Kaplan-Estrin, M., & Fialka, J. (2003). Building new dreams: Supporting parents' adaptations to their child with special needs. *Infants & Young children, 16(3)*, 184-200.

Barrera, I. (1994). Thoughts on the assessment of young children whose sociocultural back ground is unfamiliar to the assessor. *Zero to Three*, 9-13.

Beckman, P. J. (1996). Strategies for working with families of young children with disabilities. Baltimore: Paul H. Brookes.

Bennett, T., Zhang, C., & Hojnar, L. (1998). Facilitating the full participation of culturally diverse families in the IFSP/IEP process. *Infant-Toddler Intervention, 8*, 227-249.

Berliner, D. C. (2002). Educational research: The hardest science of all. *Educational Research, 31*(8), 18-20.

Blue-Banning, M., Summers, J. A., Frankland, C., Nelson, L. G., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*(2), 167-184.

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195-207.

Brotherson, M. J. (2001). The role of families in accountability. *Journal of Early Intervention, 24*(1), 22-24.

Bruder, M. B. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topic in Early Childhood Special Education. 20*(2), 115-122.

Chan, S. (1990). Early intervention with culturally diverse families of infants and toddlers with disabilities. Infants and *Young Children, 3*(2), 78-87.

Chen, Y. J., & McCollum, J. A. (2001). Taiwanese mothers' perceptions of parent-infant interaction with children with Down syndrome. *Journal of Early Intervention, 24*, 252-265.

Creswell, A. J. (1998). Qualitative Inquiry and Research Design: Choosing Among Five Traditions. CA: Sage.

Crowley, P. E. (1995). Using qualitative methods in special education research. *Exceptionality, 5*(2), 55-69.

Correa, V. I. (1992). Cultural accessibility of services for culturally diverse clients with disabilities and their families. *Rural Special Education Quarterly, 11*(2), 6-12.

Department of Homeland Security: Office of Immigration Statistics (2000) available at http://www.dhs.gov/ximgtn/statistics/

Dillenburger, K., Keenan, M., Gallagher, S., & McElhinney, M. (2004). Parent Education and Home-based behavior analytic intervention: An examination of parents' perception of outcome. *Journal of Intellectual & Developmental Disability, 29* (2), 119-130.

Dunst, C. J. (2002). Family-Centered practices: Birth through high school. *Journal of Special Education, 20,* 95-104.

Dunst, F. J., & Deal, A. G. (1994). A family-Centered approach to developing individualized family support plans. In C. J. Dunst, C. M. Trivette, & A. G. Deal

(Eds.), Supporting and strengthening families (pp. 73-89). Cambridge, MA: Brookline Books.

Dunst C. J., Leet, H. E., & Trivette, C. M. (1988 a). Family resources, personal well-being, and early intervention. *The Journal of Special Education, 22*, 108-116.

Dunst C. J., Trivette, C. M., & Deal, A. G. (1988 b). *Enabling & empowering families: Principles & guidelines for practices.* Cambridge, MA: Brookline Books.

Epstein, J. L. (2001). *School, Family, and Community Partnerships: Preparing Educators and Improving Schools.* Boulder, CO: Westview Press.

Espe-Sherwindt, M. (1991). The IFSP and parents with special needs/mental retardation. *Topic in Early Childhood Special Education. 11*(3) 1-12.

Early Childhood Outcome Center (2005). Family and Child Outcomes for Early Intervention and Early childhood Special Education. Menlo Park, CA: Early Childhood Outcome Center. Available at www.the-eco-center.org.

Garcia, E. E. (2005). *Teaching and Learning in Two Languages: Bilingualism and schooling in the United States*. NY: Teachers College.

Glesne, C. & Peshkin, A. (1992). Becoming Qualitative Researchers. White Plain, N. Y.: Longman.

Granlund, M., & Bjorck-Akesson, E. (1999). Integrating training in family-centered practices in context: Implications for implementing change activities. *Infants/Young Children, 12*(3), 46-60.

Green, G., & Nefsky, P. (1999). Transition for culturally and linguistically diverse youth with disabilities: Closing the gaps. *Multiple Voices for Ethnically Diverse Exceptional Learners. 3*(1), 15-24.

Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation, 102*(4), 319-345.

Hanson, M. J. ( 1998). Ethnic, cultural, and language diversity in intervention settings. In E. W. lynch & M. J. Hanson ( Eds.). *Developing cross-cultural competence: A guide for working with young children and their families* (P3-22). Baltimore: Brookes.

Hanson, M. J., Lynch, E W., & Wayman, K. I. (1990). Honoring the cultural diversity of families when gathering data. *Topics in Early Childhood Education, 10*, 112-131.

Haring, K. A., & Lovett, D. L. (2001). Early intervention and early childhood services for families in rural areas. *Rural Special Education Quarterly, 20*(3), 3-11.

Harry, B., Allen, N., McLaughlin, M. (1995). Communicating versus compliance: African-American parents' involvement in special education. *Exceptional Children, 61*(4), 364-377.

Harry, B. (1992a). Making sense of disability: Low-income, Puerto Rican parents' theories of the problem. *Exceptional Children, 59*, 27-40.

Harry, B ( 1992b). Restructuring the participation of African-American parents in special education. *Exceptional Children, 59*, 123-131.

Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities. *Monographs of the Society for Research in Child Development, 66*(3)6-21.

Haw-Froelich, D. A., Westby, E. C. (2003). A Vietnmese Head Start Interpreter: a case study. *Communication Disorder Quarterly, 24*(2), 86-97.

Horner H. R., Carr, G. E., Halle, J., Odom S., & Wolery, M. (2005). The use of single-subject research to identify evidence-based practice in special education. *Exceptional Children, 71*(2), 165-179.

Hume, K., Bellini, S., & Pratt, C. (2005). The usage and perceived outcomes of early intervention and early childhood program for young children with autism spectrum disorders. *Topics in Early Childhood Special Educaiton, 25*(4), 195-207

IDEA child count data Retrieved September, 13, 2007 from www.ideachildcount.org

Igoa, G. ((1995). *The inner world of the immigrant child*. NJ: Lawrence Erlbaum Associates Inc.

Immigration to the United States: A 2001 Snapshot.

Retrieved September, 16, 2007 from http://www.usimmigrationsupport.org/

Janesick, V. J. (1994). The dance of qualitative research design: Metaphor, methodolatry, and meaning in N.K. Denzin * Y. S. Lincoln (Eds), *Handbook of qualitative research* ( pp. 209-219). Thousand Oaks, CA: Sage.

Judge, L. S., (1997). Parental perceptions of help-giving practices and control appraisals in early intervention program, *Topic in Early Childhood Special Education, 17*(4), 457-476.

Jung, L. A & Baird, S. (2003). Effects of service coordinator variables on individualized family service plans. *Journal of Early Intervention, 25*, 205-218.

Kennedy C. H. (2005). *Single-case designs for educational research*. Boston: MA, Pearson Education, Inc.

Leake, D. W., & Stodden, R. A. (2002). Strengthening IDEA to improve postschool outcomes for youth with disabilities of culturally and linguistically diverse (CLD) heritage. Honolulu, HI: CLD Transition Success Research Project.

Leung, P. B. (1998). Who are Chinese American, Japanese American, and Korean American children? In V, O. Pang., L. L. Cheng (Eds.). Struggling to be heard: The unmet needs of Asian Pacific American children. (pp.11-26). Albany, NY: State University of New York.

Laird, J. (1995). Family-Centered practice in the postmodern era. *Family in Society, 76,* 150-162.

Lamorey, S. (2002). The effects of culture on special education services. *Teaching Exceptional Children, 34*(5), 67-71.

Lian, M. J., & Fontánez-Phelan, S. M. (2001). Perceptions of Latino parents regarding cultural and linguistic issues and advocacy for children with disabilities. *The Association for Persons with Severe Handicaps, 26* (3), 189-194.

Liu, J., Kingler, K., & Olive, M. (2005). Culturally and linguistically diverse parents and their participation in special education. Paper presented in the CEC Annual Conference Baltimore Maryland.

Lee, H., Ostrosky, M. M., Bennett, T., Fowler, S. A. (2003). Perspectives of early intervention professionals about culturally-appropriate practices. *Journal of Early Intervention, 5*(4), 281-295.

Lomax, R. G. (2001). *An introduction to statistical concepts for education and behavioral sciences.* Nahwah: NJ, Lawrence Erlbaum Associates, Inc.

Lynch, E. W., & Stein, R. C. (1987). Parent participation by ethnicity: A comparison of Hispanic, Black, and Anglo families. *Exceptional Children, 54*, (2), 105-111.

Magrab, P. R. (1992). Rural issues in planning services for young children with special needs of families? *Topic in Early Childhood Special Education, 16*, 437-458.

Mahoney, G., O'Sullivan, P., & Dennebaum, J. (1990). A national study of mothers' perceptions of family-focused early intervention. *Journal of Special Education, 16,* 437-458.

McConnell, S. R. (2000). Assessment in early intervention and early childhood special education: Building on the past to project into our future. *Topic in Early Childhood Special Education, 20*(1), 43-48.

McBride, S. L., & Brotherson, M. J. (1997). Guiding practitioner toward valuing and implementing family-centered practices. In P. J. Winton, J. A. McCollum, & C. Catlett ( Eds.), Reforming personnel preparation in early intervention: Issures, Models, and practical strategies (pp. 243-276). Baltimore: Brookes.

McBride, S. L., Brotherson,M. J., Joanning, H., Whiddon, D., & Demmitt, A. (1993). Implementation of family-Centered services: Perceptions of families and professionals. *Journal of Early Intervention*, *17,* 414-430.

McNaughton, D. (1994). Measuring parent satisfaction with early childhood intervention programs: current practice, problems and future perspective. *Topic in Early Childhood Special Education, 14*(2), 26-48

McWilliam, R. A. Ferguson, A., Harbin, G. L., Porter, P., Munn, D., & Vandiviere, P. (1998). The family-centeredness of individualized family service plans. *Topic in Early Childhood Special Education, 18* (2), 69-83.

McWilliam, A, R., Tocci, L., & Harbin, L. G. (1998). Family-centered services: Service providers' discourse and behavior. *Topics in Early Childhood Special Education, 18*(4), 206-221.

Mertens, D. M. (2005). *Research and evaluation in education and psychology*. Thousand Oaks, CA: Sage Publications.

Moore, K. B. (2000). Establishing reciprocal relationships with families. *Scholastic Early Childhood Today, 14*(4), 8-9.

Murray M, M., & Mandell, C. J. (2006). On-the job practices of early childhood special education providers trained in family-centered practices. *Journal of Early Intervention, 28*(2), 125-138.

Odom,S, L., Brantlinger, L., Gersten, R., Horner, R., H., Thompson, B., & Harris, K. R. (2005). Research in special education scientific methods and evidence-based practices, *Exceptional Children*

Odom, S. L., & Wolery, M. (2003). A unified theory of practices in early intervention/early childhood special education: Evidence-based practices. *Journal of Special Education, 37(3)*, 164-173.

Osher, T. W., & Osher, D. M. (2002). The paradigm shift to true collaboration with families. *Journal of Child and Family Sutdies, 11*(1), 47-60.

Park, J., & Turnbull, A. (2001). Cross-cultural competency and special education: Perceptions and experiences of Korean parents of children with special needs. *Education and Training in Mental Retardation and Developmental Disabilities, 36* (2), 133-147.

Park, J., Turnbull, A., & Park, H. (2001). Quality of partnerships in service provision for Korean American parents of children with disabilities. *The Association for Persons with Severe Handicaps, 26* (3), 158-170.

Park, J., & Turnbull, A. P. (2003). Service integration in early intervention: Determining interpersonal and structural factors for its success. *Infant & Young Children. 16* (1), 48-58.

Peshkin, A. (1991). *The color of strangers, the color of friends: The play of ethnicity in school and community*. Chicago: The University of Chicago Press.

Polmanteer, K., & Turbiville, V. (2000). Family-responsive individualized family service plans for speech-langauge pathologists. *Language, Speech, and Hearing Service in the School, 31*, 4-14.

Quintero, E. (1990). The new faces of Head Start: learning from culturally diverse families. *Early Education and Development 10*(4), 475-497.

Ridgley R. & Hallam, R. (2006). Examining the IFSPs of rural, low-income families: Are they reflective of family concerns? *Journal of Research in Childhood Education, 21*(2), 149-167.

Roberts, R. M., Innocenti, M. S., & Goetze, L. D (1999). Emerging issues from state level evaluations of early intervention programs. *Journal of Early Intervention, 22 (2),* 152-163.

Shannon P. (2004). Barriers to family-centered service for infants and toddlers with developmental delays. *Social Work, 49*(2), 2004.

Shelton, T. L., & Stepanek, J. (1994). Family-centered care for children needing specialized health and developmental services, ERIC Document Reproduction Service No. ED 381926.

Shonkoff, J. P., Hauser-Cram, P., Krauss, M. W., & Upshur, C. C. (1988). Early Intervention efficacy research: What have we learned and where do we go from here? *Topic in Early Childhood Special Education, 8*(1), 81-93.

Shriver, M. D., & Kramer, J. J. (1993). Parent involvement in an early childhood special education program: A descriptive analysis of parent demographics and level of involvement. *Psychology in the Schools, 30*, 255-263.

Smith, W. T., Wu, P. F., & Johnson, S. (2004) Intercultural utilization of services through federally founded protection and advocacy systems. Paper presented in Join Nation Conference Huston TX.

Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents’ involvement in and perceptions of special education services: An Inerview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities, 18* (4), 228-237.

Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: sage.

Stein, R. C. (1983). Hispanic parents' perspectives and participation in their children's special education program: Comparisons by program and race. *Learning Disability Quarterly, 6,* 432-439.

Summers, J. A., Gavin, K., Hall, T., & Nelson, J. (2003). Family and school partnerships: Building bridges in general and special education. In F. E. Obiakor, C. A. Utley, & A. F. Rotatori (Eds), *Advances in Special Eduation: Psychology of Effective*

*Educationa for Learners with Exceptionalities* (pp. 417-445). Stanford, CT: JAI press.

Tabors, P.O. (1998). What early childhood educators need to know: Developing effective programs for linguistically and culturally diverse children and families? *Young Children, 53*(6), 20-26.

Torres-Burgo, N. & Reyes-Wasson, P. (1999). Perceptions and needs of Hispanic and non-Hispanic parents of children receiving learning disabilities services. *Bilingual Research Journal, 23*, 373-387.

Trivett, C. M., & Dunst, C. J. (2000). Recommended practices in family-based practices. In DEC Recommended Practices in Early Intervention/ Early Childhood Special Education. ( pp. 39-46). Longmont, CO: Sopris West.

Turbiville, V. P., Turnbull, A. P., Garland, C. W., & Lee, I. M. (1996). Development and implementation of IFSPs and IEPs: Opportunities for empowerment, In S. L. Odom & M. E. McLean (Eds), *Early intervention/early childhood special education: Recommended practices.* (pp, 77-100). Austin, TX: pro-Ed.

Turnbull, A., & Turnbull, R. (2001). Families, professionals, and exceptionality: Collaborating for empowerment (4th ed.). Upper Saddle River, NJ: Merrill/Prentice Hall.

Turnbull, A., Blue-Banning, M. Turbiville, V. & Park,J. (1999). From parent education to partnership education: A call for a transformed focus. *Topic in Early Childhood Special Education 19*(3), 164-171.

Unger, D., Jones, C. W., Park, E., & Tressell, P. A. (2001). Promoting parent involvement amoung low-income single caregivers and urban early intervention programs. *Topic in Early Childhood Special Education, 21*, 197-212.

U. S. Bureau of the Census. (2001) Statistical abstract of the United States, 2001. Washington, DC: U. S. Government Printing Office.

U.S. Department of Education. (1999). Family Outcome.  ERIC Document Reproduction Service No. ED 455934.

U. S Immigration facts. Retrieved July, 16, 2005 from www.ethicharrest.org/mission/immigratnfacts.htm

Wathum-Ocama, J. C., & Rose, S. (2002). Hmong immigrants' views on the education of their deaf and hard of hearing children. *American Annals of the Deaf, 147 (3)*, 44-53.

Wehman, T. (1998). Familiy-centered early intervention services: Factors contributing to increased parent involvement and participants. *Focus on Autism & Other Developmental Disabilities, 13*(2), 80-87.

Wesley, P. W., Buysse, V., & Tyndall, S. (1997). Family and professional perspectives on early intervention: An exploration using focus groups. *Topic in Early Childhood Special Education, 17*(4), 435-456.

Wu, R. P. (2006).

Young, L. R. (1998) Becoming American. In V, O. Pang., L. L. Cheng (Eds.), Struggling to be heard: The unmet needs of Asian Pacific American children. (pp.62-73). Albany, NY: State University of New York.

Zetlin, A. G., Padron, M., & Wilson, S. (1996). The experience of five Latino American families with the special education system. *Education and Training in Mental Retardation and Developmental Disabilities,* 22-28.

Zhang, C., & Bennett, T. (2001) Beliefs about and implementation of family-centered practice: A study with Early Head Start staff in six states. *Infant-Toddler Intervention, 11*, 201-222.

Zhang, C., & Bennett, T. (2003). Facilitating the meaningful participation of culturally and linguistically diverse families in the IFSP and IEP process. Focus on Austim and Other Developmental Disabilities. 18(1), 51-59.

Zhang, C., Fowler, S., & Bennett, T. (2004). Experiences and perceptions of EHS staff with the IFSP process: implications for practices and policy. *Early Childhood Education Journal. 32*(3), 179-186.

Zionts, T. L., Zionts, P., Harrison, S., & Bellinger, O. (2003). Urban African American families perceptions of cultural sensitivity within the special education system. *Focus on Autism and Other Developmental Disabilities. 18*(1), 41-50.

Yin, R. K. (2003). *Case study research design and methods*. CA: Sage Publications, Inc.

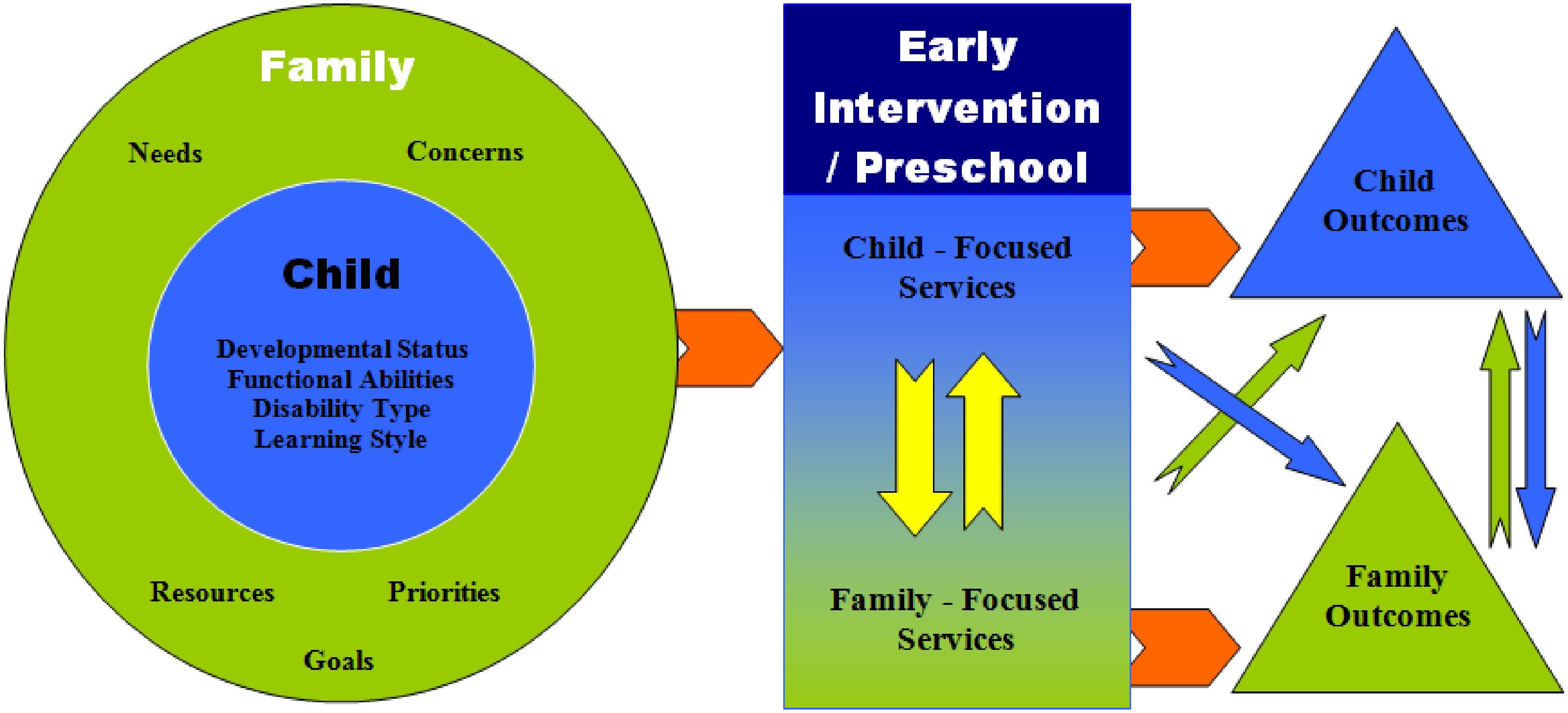
Young, L. R. (1998) Becoming American. In V, O. Pang., L. L. Cheng (Eds.), Struggling to be heard: The unmet needs of Asian Pacific American children. (pp.62-73). Albany, NY: State University of New York.

# FIGURES

Figures 3.1

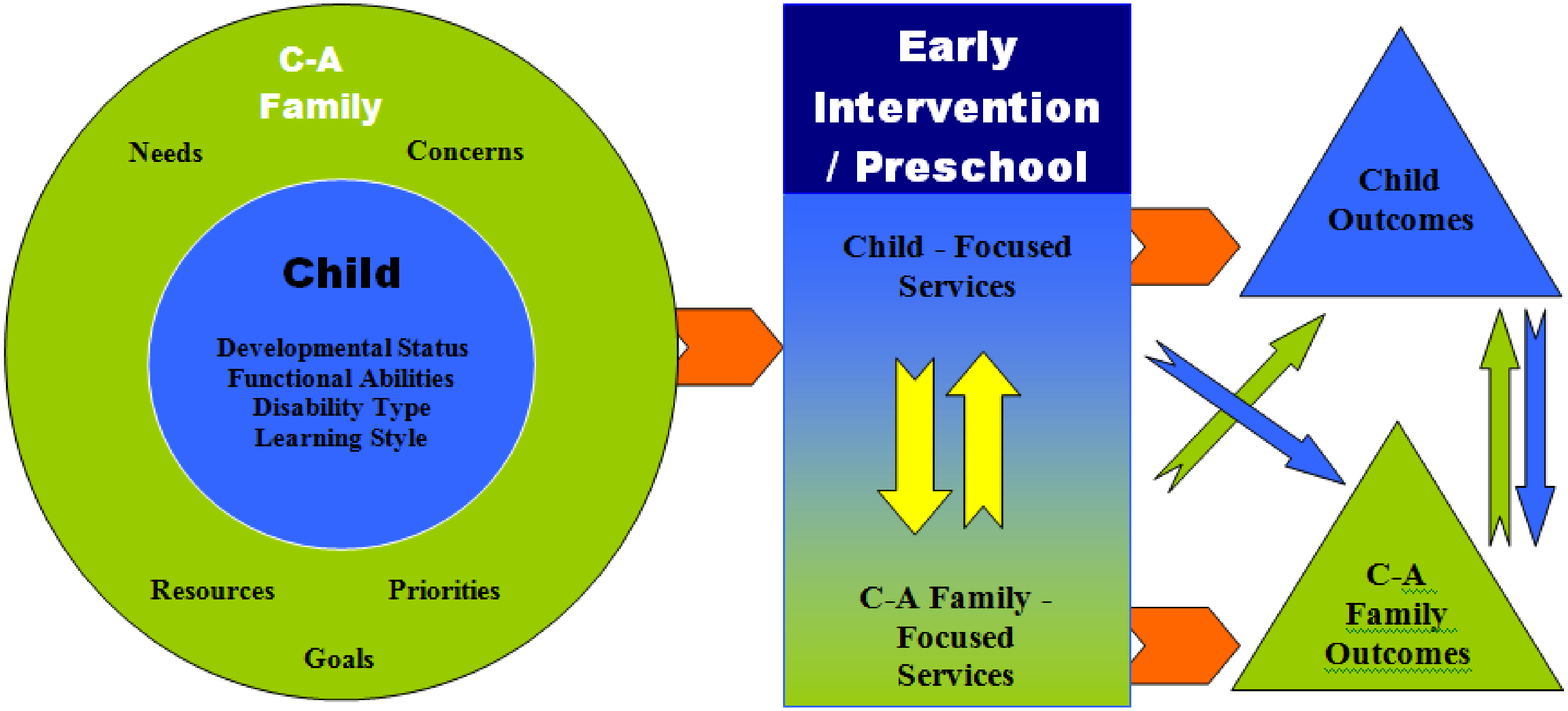
Figures 3.2

*Figures 3.1*



Interrelationships of Services and Outcomes for Children and families adopted form ECO Center

*Figure 3.2*



Interrelationships of Services and Outcomes for Children and families (adopted and modified from ECO Center)

# TABLES

## Table 4.1

*Table 4.1*

Family Demographic Chart

| Families | Name of the Mother | Name of the child | Type of the disability | Age of the child | Reason of moving to U.S. | Household Annual Income | Years of Living in the US. |
|---|---|---|---|---|---|---|---|
| Wang Family | Peng | Andy | Autism | 7 years old | Labor Immigration | 22.000 USD | 10 years |
| Cheng Family | Lim | Gabe | Hearing Lost | 3 & Half years old | Parents came to U.S for Education. | 80,000~85,000 USD | 20 years |
| Taso Family | Li | Cathy | Autism | 3 years old | Labor Immigration | 29,000 USD | 12 years |
| Ma Family | Chien | Justin | Developmental Delay | 2 years old | Parents came to U.S for Education | 85,000 USD | 7 years |

# APPENDIX A

## Research Recruitment, Consent Forms, and Interview Protocols (English version):

Informed Consent Form

Recruitment Flyer

IFSP Goals and Content Analysis Log

CLD Family’s needs checklist (English vs. Chinese)

Parent Questionnaire

Interview Protocols

Data collection procedure checklist

# University of Oklahoma
# Institutional Review Board
# Parental Informed Consent for Research Study

| | |
|---|---|
| **Project Title:** | Perceptions of Early Intervention/Early Childhood Special Education Outcomes: Inside Chinese-American families with children with disabilities. |
| **Principal Investigator:** | Pei-Fang Wu |
| **Department:** | Department of Educational Psychology, Program of Special Education. |

You are being asked to volunteer for this research study. This study will be conducted at your home. You were selected as a possible participant because you're a Chinese-American parent who has a child with special needs.

Please read this form and ask any questions that you may have before agreeing to take part in this study.

**Purpose of the Research Study**
The purpose of this research is to investigate the perceptions and experiences of Chinese-American families who receive early intervention services as a way to discern whether their needs, priorities and cultural values have been taken into consideration in family-centered Individual Family Service Plan (IFSP) goals and objectives

**Number of Participants**
About 10-12 Chinese-American Families who have a child with special needs will take part in this study.

**Procedures**
If you agree to be in this study, you will be asked to complete a parents' questionnaire, family needs check list, IFSP analysis, and participate in up to three face to face interviews.

**Length of Participation**
The three visits are expected to total about five hours of time. The three visits will be conducted over the course of three weeks.

**This study has the following risks:**

During the interview, you will be asked for personal or sensitive information. You can choose not to disclose any information that you feel is too personal. As a parent with a child with a disability, you can choose not to share your child's IFSP with the researcher if you feel uncomfortable.

**Benefits of being in the study are**
You will benefit from this research by learning how your views of early intervention program and your culture background can impact your children's early intervention outcomes and outcome measurement.

**Confidentiality**
The collected information and the transcriptions will be de-identified and assigned with a code and altering name for each participant. All research information will be stored in two locked file cabinets – one for the study code number, other study data and artifacts, and the other one for the direct identifiers. The locked file cabinets can only be accessed by the researcher whose name has been mentioned in this IRB application.

Your personal information (i.e. interview transcriptions, IFSP document, questionnaire, and family needs checklist) will be coded and given pseudonyms to replace your actual first and last name. All possible identifiers and coded documents will be kept separately in order to protect your confidentiality. All names, geographical locations, job titles, and any background information that could be related to you will not be listed or reported in the research study results.

In published reports, there will be no information included that will make it possible to identify you. Research records will be stored securely and only Pei-Fang Wu will have access to the records.

There are organizations that may inspect and/or copy research records for quality assurance and data analysis. These organizations include OU Institutional Review Board.

**Compensation**
You will be reimbursed for your time and participation in this study with $20 dollars cash or a gift certificate from the store of your choice. Your child will also receive a small age appropriate gift on each visit. There will be no compensation for early withdrawal.

**Voluntary Nature of the Study**
Your participation in this study is voluntary. If you decided to withdraw or decline to participate, you will not be penalized or lose benefits or services unrelated to the study. If you decide to participate, you may decline to answer any question and may choose to withdraw at any time.

**Request for record information**
If you approve, your confidential records will be used as data for this study. The record - used in this study is your child's Individual Family Service Plan (IFSP). The researcher- will ask **you** for a copy of your child's IFSP form. , The researcher will analyze this record and gain a better understanding of the types of IFSP goals and objectives that are being constructed by Oklahoma State services providers/coordinators for the children they are serving.

_____ I agree to provide my child’s Individual Family Service Plan (IFSP) to be used for the purposes described above.

_____ I do not agree to provide my child’s Individual Family Service Plan (IFSP) to be used as research data.

**Audio Recording of Study Activities**

To assist with accurate recording of your responses, interviews may be recorded on an audio recording device. You have the right to refuse to allow such recording without penalty. Please select one of the following options.

I consent to being audio recorded. ___ Yes ___ No.

**Contacts and Questions**

If you have concerns or complaints about the research, the researcher(s) conducting this study can be contacted at:

University of Oklahoma
Department of Educational psychology
Psychology
Program of Special Education
Pei-Fang Wu M.Ed/Doctoral Candidate
(405)812-1103
Peifang.wu-1@ou.edu

University of Oklahoma
Department of Educational
Program of Special Education
Professor Dr. David Lovett PhD.
(405)325-1507
dlovett@ou.edu

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

***You will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.***

**Statement of Consent**

I have read the above information. I have asked questions and have received satisfactory answers. I consent to participate in this study.

Signature Date

# Perceptions of Early Intervention/Early Childhood Special Education Outcomes: Inside Chinese-American families with children with disabilities

***Purpose of the study:***

The purpose of this research is to help professionals fully understand (1) what the perceptions of Chinese-American Families with children with disabilities on early intervention family outcomes. (2) If the family's needs regarding their children with disabilities have been served by the early intervention services. In order to do this well, the families' point of view must be fully understood by professionals and services providers. This study is trying to understand Chinese-American families well enough to guide how early intervention services are provided. We want to talk to you and learn what professional should know before they start to work with you and your family. Information will be gather which might be helpful to parents and to those who provide services to these families.

***Parent participation:***

Your participation will be completely voluntary, and all information given during the interview will be held in strict confidence. No family members will be identified in any way, ever.

Parents who chooses to participant in this study, the researcher will visit your house for three times, each time will take 60~90 minutes to finish all the study required tasks. Researchers will be asking questions concerning your feelings, perceptions, experiences with the early intervention process as it involves your family.

***Risks:***

This study holds no physical or psychological risk to you or your family. You may drop out at any time. No information shared with researcher will be available to those are providing services to your family.

***Benefits:***

The results of this study will be used to improve the way professionals are trained. This information will ensure that state and federal agency continue to recognize the facts of all families are different and culture differences can actually impact the ways parents think what the outcomes should be on the early intervention services.

“***The University of Oklahoma is an equal opportunity institution.***”

.

The participants will benefit from this research with most current early intervention (EI) services information such as type of services that state EI is providing, rights of parents with child with disability as well as strategies to collaborate with the services provider or services coordinator for the better EI child outcomes.

***Compensation:***
Parents who fully participated in this research, and allow researcher to completed three visits will receive a 20 dollars cash or gift card by the end of the study.

**I have read and understand the above and am interested in being contacted**

**Name**

**Phone Number & email address**

**Home address**

**If you have any questions please contact the persons listed below**

**Pei-Fang Wu M. Ed**
**Principal Investigator**
**(405)812-1103**
**Peifang.wu-1@ou.edu**

**Dr. David Lovett**
**Faculty sponsor**
**(405) 325-1507**
**dlovett@ou.edu**

*"The University of Oklahoma is an equal opportunity institution."*

# IFSP Goals and Services Analysis Log

**Number: ___________________________**

**Date: ______________________________**

**1. List the IFSP Goals:**

Family focus:

Child focus:

**2. Major list categories in the IFSP:**

**3. Type of the services (frequency/duration)**

**4. Anywhere in the document address on the difference of the culture and the language?**

**5. Additional information:**

# 家庭需求檢核表

# Family needs checklist

**ID # ____________________**
**Date:____________________**

## Part I: 基本需求 (請回答是或不是)

1. Have food for 2 meals a day for the family?
   有足夠的食物可以供應一天兩餐?
2. Have a house or apartment?
   有房子或者是公寓可以居住?
3. Have money to buy necessities?
   有錢可以購買日常生活所需的東西?
4. Have enough clothes for your family?
   有足夠的衣服可以穿和保暖?
5. Have heat for your house or apartment?
   房子或公寓有暖氣?
6. Have indoor plumbing/water?
   家裡面有自來水和廁所?
7. Have money to pay monthly bills?
   有錢可以支付每一個月的帳單?
8. Have good job for yourself and spouse?
   你有和老公/老婆都有一份覺得還不錯的工作?
9. Have Medical care for your family?
   家中每一位成員都有醫療保險?
10. Have public assistance, (SSI, Medicare ...)
    有公共的醫療輔助?
11. Have a dependable transportation?
    有可以依靠的交通運輸系統?
12. Have time to get enough sleep/rest?
    有足夠的時間可以休息睡覺?
13. Have furniture for your home or apartment?
    家中有足夠的家俱可以使用?
14. Have time to do your own thing?
    有足夠的時間可以做自己想做的是?
15. Have time for family to spend together?

全家人有足夠的時間可以在一起?

16. Have time to be with the child with disability?
    有足夠的時間可以跟您有特殊需求的小孩在一起?
17. Have time to be with the child without disability?
    有足夠的時間可以跟您正常發展的孩子在一起?
18. Have time to be with spouse or close friend alone?
    有時間可以單獨和您的先生 / 太太或者是較好的朋友相處?

19. Have telephone or access to a phone?
    家裡有家用電話嗎?
20. Have babysitting for your child or children when you need it?
    當你有要事的時候，有保母可以幫你照顧有特殊需求的孩子?
21. Money to buy special equipment supplies for children?
    有多餘的錢可以買特別的用具給您的小孩使用?
22. Have dental care for your family?
    全家人擁有牙齒的醫療保險?
23. Have someone to talk to?
    您心情好或不好的時候，有人可以聽您說說話?
24. Have time to socialize?
    有時間可以從事一些社交活動?
25. Have time to do the daily exercise?
    有時間可以做運動?
26. Have toys for your child/children?
    您的小孩有足夠的玩具可以玩?
27. Have money to buy things for yourself and spouse?
    有多餘的錢買自己想要的東西或另一半想要的東西?
28. Have money for family entertainment? Movie, eat in the restaurant?
    有多餘的錢給自己家裡面從事週末的娛樂活動? 比方說看電影，到餐廳吃飯?
29. Have money to travel/vacation?
    有多餘的錢從事旅行和假期活動?
30. Have money to save?
    有多餘的錢可以存錢或投資?
31. Have friends to help you develop the skill to function in the mainstream society?
    有朋友可以幫忙您更了解或者市更接近美國著主流社會?
32. Have opportunity to learn mainstream language?
    有學習美語的機會?
33. If yes, where? And how many time a week?

如果有的話,在哪裡,一個禮拜幾次?

34. If not, why? Would you like to learn?
    如果沒有的話,為什麼? 如果有機會,你會想要學習嗎?
35. Do you think if learning speaking English language is important? Why?
    你覺得學習英文對你來說重不重要？為什麼?

**Note page:**

## Part II: Social Support Needs (From scale 0 not at all to 4 extremely, if answer 0, ask if they feel they need that help.)

## 社會支持的需求 ( 評分從零到 4, 如果您回答 0 的話,請試著表示是否在那一個部分需要更多的幫忙)

1. Your parents?
   您的父母親?
2. Your spouse’s parents?
   您配偶的父母親？
3. Your relatives?
   您的親戚?
4. Your spouse’s relatives?
   您配偶的親戚?
5. Your friend?
   您的朋友?
6. Your spouse’s friend?
   您配偶的朋友?
7. Your own children?
   您的孩子?
8. Other parents you know?
   其他您認識的家長?
9. Church/Religious group?
   教會,或者是其他宗教信仰的支持團體?
10. Professional organization?
    其他相關的專業機構?
11. Co-workers?
    您的同事?

12. Your family or child’s physician?
    您小孩子的家庭醫生?
13. Professional helpers (social worker, therapists, teachers,) be specific on this questions.
    專業團體? 例如,社工,治療師,老師?

Note:

14. School/day care center?
    學校,幼稚園?
15. Do you have a hard time finding a day care center?( yes or no, explain)
    您在找尋照顧機構的過程當中,有沒有預到任何的困難?

Note:

16. Professional agencies (public health, social services, mental health.)
    專業政府機構?
17. Specialized early intervention services?
    特殊相關早期療育的機構?
18. others ( specify):
    其它?

19. Additional information:
    相關的資訊

# Parent Questionnaire (PQ)

## Participant Assigned ID #_______________

### CHILD

1. **Name: _____________________________________**
   **Age:__________________________**
2. **Birthday____________________________________ Sex: ________M___________F**
3. **Place of Birth:**
   **(City)_____________________State_______________Country____________**
4. **Address:__________________________________________________________________**
   **____**
5. **Home phone number (Include area code):_________________________________________**
6. **Number of hours per day child usually spend in day care or with a sitter who is not a member of the household:_______________________**

### MOTHER: maternal family, social status.

1. **Name:_____________________________________Age__________________________**
   **______**
2. **Relationship to child:_____ Natural parent ______ Foster Parent**
   **_____Adopted parent _____Step-Parent other:**
   **____________________________________**
3. **Currently living with child? Yes__________ NO____________**
4. **Approximately how many hours per day are spent with the child_______________.**
   **How many of these hours is the child asleep/awake? __________________________.**
5. **Marital status: _____Married _____Living with someone _____Separated**
   **_____Spouse deceased _____Single _________nature family separation.**
   **Comments:**
   **____________________________________________________________________.**
6. **Highest level of education completed: _____Grade school (1-8) _____**
   **______High School (9-12)_____ College (13-16) _____ Graduate School (17+)**
7. **Current occupation:**
   **____________________________________________________________.**
   **Number of hours/week: _________. Wages: ___________.**
   **Work phone number (include area code):____________________________________________.**
   **If unemployed, are you currently seeking employment: _______yes _______No**
8. **Are you attending school? _____________if so, what is your area of study?**
   **____________________________________________what degree are you working**

**toward?**
**___________________________________________________________________________**
**___.**

9. **Race/Ethnic Origin: ______________. Explain Background (reason to immigrated?_________________________________________________________________ _______**

**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_____________________________________________________________________________**
**_________________________________________________________.**

**Father: paternal family social status______________________.**

1. **Name:______________________________________Age___________________________ ______**
2. **Relationship to child:_____ Natural parent ______ Foster Parent _____Adopted parent _____Step-Parent other: _____________________________________**
3. **Currently living with child? Yes__________ NO____________**
4. **Approximately how many hours per day are spent with the child_______________. How many of these hours is the child asleep/awake? __________________________.**
5. **Marital status: _____Married _____Living with someone _____Separated _______Spouse deceased _____Single_____ Nature family separation. Comments: ________________________________________________________________________.**
6. **Highest level of education completed: _____Grade school (1-8) _____ ______High School (9-12)_____ College (13-16) _____ Graduate School (17+)**
7. **Current occupation: ______________________________________________________________.**
   **Number of hours/week: _________. Wages: ___________.**
   **Work phone number (include area code):____________________________________________.**
   **If unemployed, are you currently seeking employment: _______yes _______No**
8. **Are you attending school? _____________if so, what is your area of study? ______________________________________________what degree are you working toward?**

_________________________________________________________________________
___.

10. Race/Ethnic Origin__________________ Explain Background (reason to immigrate?
_____________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
________________________________________________________.

**Home**

1. List any other adult (over18) currently living in the home:

| Name | Age | Relationship to children | NO. Hrs/day spent caring for child |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

2. List all other children living in the home:

| Name | Age | Grade | Relationship |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

3. **Does any person in the home have a need for special services? If so, please give the name(s) and reasons for special needs.**

   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **________________________________________________________________________**
   **__________.**

4. **Primary language spoken in the home:________________________________________.**
5. **Other language regularly spoken in the home:_________________________________.**

## Parent Interview Part I

**Variable 1: Description of Family.**

- **Family composition:**

- Who are the members of the family system?
- Who are the key decision makers?
- Is decision making related to specific situations?
- Is decision making individual or group oriented?
- Are children allowed to make decisions in your family?
- Does your family spend time together? How many times per week and how long?
- Do family members all live in the same household?
- What is the relationship of friends to the family system?
- Do family members consult each other on their decisions?
- What is the hierarchy within the family? Is status related to gender or age?
- Do you think it is important for the family to be together?
- Does your family only like to do things in your immediate family?
  - Tell me about your family and who is in your family? Where are you from? Are you the first /second, or third generation to live in the U.S?
    - **Primary caregiver(s)**
      - Who is the main caregiver for your child with disability?
      - Who else participates in the care giving?
      - What is the amount of care given by primary caregiver versus others?
      - How much time does the -child spend away from the primary caregiver?
      - Is there conflict between caregivers regarding appropriate practices?
      - Are there any culture or environmental issues that influence the way you-care for your child? Please give examples.

**Variable 2: Child rearing practice in home culture.**

- **Family feeding practices**
    - What are the family feeding practices?
    - What are the mealtime rules?
    - What types of foods are eaten?
    - What are the beliefs regarding breastfeeding and weaning?
    - What are the beliefs regarding bottle feeding?
    - What is the family practice regarding the transitioning to solid food?
    - Is food purchased or homemade?
    - What are the family's views on independent feeding?
    - Which family member feed the child the most often?
    - Is there a discrepancy among family members regarding the beliefs and practices related to feeding an infant/toddler?
- **Family sleeping patterns**
- Is there an established bed time?
- Does the infant sleep in the same room/bed as the parents?
- What practices surround daytime napping?
- **Family's response to disobedience and aggression**
    - What form does the discipline take?
    - Who enforces - the disciplinary action?
- **Family's response to crying child**
    - How long before the caregiver picks up a crying infant?
    - How does the caregiver calm an upset infant?

**Variable 3: Adaptations to mainstream culture**

- From whom does the family seek help—family members or outside agencies/individuals?
- Does the family seek help directly or indirectly?

- What are the general feelings of the family when seeking assistance---ashamed, angry, demand as a right, view as unnecessary?

- With which community systems does the family interact (Educational/medical /social)?

- How are these interactions -conducted (face to face, telephone, letter)?

- Which family member interacts with other systems?

- Does that family member feel comfortable when interacting with other systems?

- If you don't speak much English, is an interpreter provided to you through out the meeting? Are all of your documents - translated into your language?
- Explain to me, what rights do you have as a parent of a child with a disability?
- What cultural values do you still practice other than mainstream, in terms of raising a child? Tell me more about it.
- How comfortably do you function in US mainstream society? Do you feel fully accepted in the society? Do you feel excluded? Why? Can you give me an example? What are some of the difficulties -you face when - trying to get - services for your children? What are some difficulties or challenges that your family faces?

**Variable 4: Description of child functioning + nature of disabilities.**

- Tell me more about your child?

- Can you describe the nature of your child's disability and what you have been told about it?
- Can you give me a sense of what your child's typical day is like?
- What are your desires and hopes for the child or the family in the future?

**Variable 5: Parent perception Vs. Diagnosis**

- How were you first informed about the condition or at-risk factors present in your child?
- How did that make you feel?
- Example of something they said…
- What were reactions from nurses, other mothers, friends, relatives and your spouse?
- Who said what?

What were your initial reactions to your child?

- What are the initial reactions toward your child from your spouse, siblings parents, extended family, friends, neighbors, church members, others.
- Have your self-perceptions (the way you see yourself) been affected by this process? Your family's perceptions?
- Has this experience changed how you feel about yourself? Your spouse, extended family member, etc?
- Has this changed how you view your relationships with significant others? How you view your own family?
- Has this process effected how you relate to your other children? How they feel about themselves? How information is related to their friends? Your friends?
- What coping strategies have you used? Probe "stage" specifics, for example, when you were most in shock, in - denial, most angry, saddest, felt most alone, felt overwhelmed, helpless, etc.
- What do you think when you try to imagine the future with your child? What do you fear the most? Hope for? What is your vision for your child?

**Family perception of child's disability**

- Are there cultural or religious factors that shape family perceptions?
    - To what /where/whom does the family assign responsibility for their child's disability?
    - How does the family view the role of fate in their lives?
    - How does the family view their role of intervening with their child? Do they feel they can make a difference or do they consider it hopeless?
- Family's perception of health and healing
- What is the family's approach to medical needs?
- Do they rely solely on Western medical service?
- Do they rely solely on holistic approaches?
- Do they utilize a combination of these approaches?

**Variable 6: Birth history medical story**

- Do all members of the family agree on approaches to medical needs?
- Describe to me what your pregnancy of this baby was like? Anything special that you would like to share with me?
- Can you think of any medical story or special birth history of your child?
- Who is the primary medical provider or conveyer of medical information? Elders? Friends? Folk healers? Family doctor? Medical specialists?

# Parent Interview Part II

**Variable 7: Initiation of EI services.**

1. How was initial contact made with Sooner Start?
2. What was initial communications with professionals like?
3. What kinds of information did the doctor give you? Was it helpful? Could they have been more helpful? How?
4. Did you try to get specific details concerning people from different professions and examples?
5. What do you feel your child needs the most?
6. What do you feel your family needs most?
7. How do the professionals make you feel?
8. Are the professionals meetings these needs?
9. Describe contacts or referrals from additional services?
10. Probe for different contacts in terms of professionals, support networks, national/ state/ local organizations, agencies, information sources.

**Support and information surrounding transitions between services**

How was the transition process work? (Hospital to home/home to center based Intervention center).

What kind of social support do you have? ( like your parents, friends, church, Group).

**Variable 8: Type and duration of services.**

- How involved have you been in the services offered for your child?
- Describe the type and duration of services that were/are being provided to you and your child. Please specify each person who has provided EI services and how they have helped you. Is there more they could be doing or providing?

**Variable 9: Parent understanding of the purpose/ objectives meet through EI.**

- What does IFSP mean to you?
- What do you think the purpose of early intervention is?

  The goals and objectives on the IFSP, what do they mean to you?
- What does your Child's IFSP look like? May I see it? How was that process handled? How many people were involved? How many goals do you have on your child's IFSP?
- Do you feel you have been listened to during the discussion of your child's service?

  What does the IFSP document means to your family and your child?

**Variable 10: IFSP analysis with comparison to ECO outcomes.**

- What do you think as a family with a child with a disabilities, what benefits will the family gain after they been through the early intervention program. What outcome will a child with a disability have after going through the early intervention program?
- List the family outcome indicators from ECO, and ask family see if they feel those indicators are important to them? And if they have gained knowledge in the area that were identified by ECO?

- What do you think early intervention services should be like, for example, what do you think state government can do to better assist Asian American families with a child with a disability?

**Variable 11: Family perception of their role and follow through responsibilities.**

- As Chinese-American parents with children with a disability, what do you want people to know the most?
- What are your responsibilities as a parent with a child with disabilities?
- What are the dreams you have for your child? What are your worries?

**Variable 12: Family attribution etiology of disability.**

- Tell me how your family views disabilities?
- Tell me about your culture's view on people with disabilities?
- In your culture, who do people believe is the cause of a mother having child with a disability? Do you believe it?
- Do you believe children with a disability are worth educating? Why or why not?
- In your experience or life time, have you heard anything within your culture, families who used an alternative medication or intervention to treat their child with disability? Share the store with me!

**Variable 13: Family perceptions of EI services.**

- How were your needs/concerns addressed by professionals?
- How much you have directed the services that were provided or providing?
- How do you feel about early intervention services that have been provided to you so far?
- Tell me who the consumers of early intervention programs are.
- Do you ask questions to the service providers or coordinator? Most often what kind of questions. Give me an example.
- Do you feel your children have been supported through the services?
- Do you feel your **family needs** have been met through this services?
- How were your needs/concerns addressed by professionals?
- What would have been more helpful? What could professionals have done better?

**Variable 14: Family perceptions of EI cultural competence.**

To what degree

- Is the home visitor proficient in the family's primary language?

- Is the family proficient in English?

- If an interpreter is used,

  - With which culture is the interpreter primarily affiliated?

- Is the interpreter familiar with the colloquialisms of the family members’ country or region of origin?

- Is the family member comfortable with the interpreter? Would the family member feel more comfortable with an interpreter of the same or opposite sex?

- Does the interpreter have any early intervention/special education related background?

- If written materials are used, are they in the your family’s primary language?

- Describe how your culture views children or adults with a disability?

- Do you feel your culture has been partially included in setting IFSP target goals for the families?

**Variable 15 Support Assistance from outside of family**

- What assistance has been most helpful to you?
- Have you been introduced to or sought out any support networks outside of the family (friends, church, etc) also included the positive?
- Do you feel you have been well supported through this process?
- What has troubled you most?

# Data Collection Procedure Checklist

## Participants' Assign ID#___________________

**First visit: Date______________. Length of time: _____________________.**

1. **_____ Family Needs checklist. Date of completion_______________.**
2. **_____ Parent Questionnaires. Date of completion_______________.**
3. **_____ Parent Interview I. Date of completion_______________.**
4. **_____ identified a service provider or service coordinator for interview.**
5. **_____ Schedule to interview parent identified services provider.**

**Second visit: Date______________. Length of time: _____________________.**

1. **_____ Social validity Check. Date of completion_______________.**
2. **_____ Parent interview part II. Date of completion_______________.**
3. **_____ IFSP Goals and Objectives analysis log.**
   **Date of completion_______________.**
4. **_____ Service provider or services coordinator interview completed**
   **Date of completion______________.**

**Follow up visit: Date______________. Length of time: _____________________.**

1. **______ Additional questions. Date of completion_______________.**
2. **______ Close the interview. Date of completion_______________.**
3. **______ Services Provider follows up. Date of completion_________.**

**Note:**

# APPENDIX B

## Consent Forms, and Interview Protocols (Chinese version):

Informed Consent Form

Parent Questionnaire

Interview Protocols

# University of Oklahoma
# Institutional Review Board
# 家長參與研究同意書

**研究名稱:** 早期療育/學齡前特殊教育成效:來自於中國文化背景之家庭的見解與看法.
**主要研究員:** 吳珮芳
**系所:** 教育心理學系,特殊教育組

您被邀請自願參與這一個學術研究,這一份學術研究主要會在您的家中收集資料. 您主要會被邀請的原因是因為您特殊的文化背景加上您孩子的特殊狀況.

在您同意參與這項研究之前,請您詳細閱讀以下的資料,如果您有任何的問題,請您提出來探討.

**研究目的:**
這一個研究最主要是要探討有中國文化背景的美國家庭,並且家中有經驗接受早期療育的服務對於整個早療的系統有什麼樣的看法,以及您希望的早期療育的過程可以如何幫助您的孩子和家人. 同時我們也希望透過您的個別化家庭服務計劃(IFSP)的目標是否有合乎您家庭和孩子的需求.

**參與研究的人數**
10-12 有中國文化背景的華裔美人家中有特殊需求的孩子, 將會參與這一個研究計劃.
**研究過程**
如果您同意參與這一個研究,您將會被要求與研究員配合包含有:

一份家長的背景資料, 家庭需求檢核表, 個別化教育方案計劃, 以及三次的訪談.

**研究參與的長度與次數**
您將會需要與研究員達成三次的訪談一共大約五個小時在您的家中. 三次的訪談我們會以大約三個禮拜的時間來完成.
**參與研究的可能的風險:**

在訪談的過程當中,您會被問及一些敏感和私人的問題. 您可以選擇不要提供任何的答案如果您覺得問題問的太過隱私. 您也可以選擇不和研究員分享您孩子的個別化家庭服務計劃,如果您覺的有任何的原因讓您覺得不舒服

**參與研究您會得到**

您將會學習到您的看法和想法可以幫助早期療育服務的機構提供更好的早療服務給您和您的小孩,一旦他們了解你的需求在哪裡,以及您源自於的文化背景. 您的文化背景更深深的影響著早期療育服務成效的評估和方法

**資料隱私的處理**

所有研究員跟您所收集的資料,在資料收集後的第一件事就是把您的真實姓名去掉,並把所有有相關您與您孩子的背景資料去除. 相對的您姓名會以數字以及其他的名字來代替. 所以有的研究資料會被存在兩個有鎖的櫃子在教育系研究員的辦公室中. 其中一個櫃子會儲存所有相關隱私的資料,另一個則會儲存資料無法任何跟您有關聯的研究資料. 所有的櫃子只有本研究的研究員可以有方法打開.

您的個人資料,(如; 面訪資料,早期療育服務文件,問卷,及家庭需求檢核表)會已密碼來代替真實姓名. 所有可能相關密碼及解碼文件會被保存在不同的地方來保護您的隱私. 所有可能跟你有關的名字,地理位置,工作職稱,及背景資料都不會些在研究報告中.

除非有您的允許,在公開的報告中,不會有資料可以追朔回到你,為了研究品質和資料的分析, 將會有某研究機構檢查,或拷貝本研究紀錄. 這一些機構包含奧克拉荷馬大學醫學倫理委員會.

**補助**

你將會被補助你花費的時間和參與這一個研究的熱情. 研究結束的時候,您會收到20 塊錢的現金或者是你選擇的禮物卡，您的孩子將會收到一份適合他們年紀的小玩具.如果您沒有完成三次的訪問，您將不會收到 20 塊錢的現金或者是禮物卡.

**自願參與**

您的參與這一個研究將是完全自願的.如果您決定要提早結束參與這一個研究，您不會有任何的罰則或者是其他的責任，更不會因此失去您已經擁有的早療服務.
如果您覺得有任何的問題讓您覺得不舒服，您都可以拒絕回答,或者是在任何時間選擇提早結束訪問.

**研究員將會要求相關的資料有**

如果您接受參與這一個研究，研究員將會跟您要一份您孩子的個別畫家庭服務計劃(IFSP)的副本. 主要的目的是讓研究員分析您孩子的個別化家庭服務計劃中有哪些服務,還有短程,和長程的目標為何.

_____ 我同意提供個別畫家庭服務計劃給研究員(IFSP)

_____ 我不同意提供個別畫家庭服務計劃給研究員(IFSP)

**訪談過程▪音**

為了要取得精確的資訊，訪談的過程當中我們將會要求把您的看法和想法, ▪音下來.

您有權利拒絕這樣的錄音,且不會有任何的損失或者是處罰，請選擇下列其中一項:

我同意在訪談的過程中被錄音. ___ 是 ___ 否.

**如果您有問題可以聯**

如果您有任何疑問或抱怨關於此研究，歡迎您聯絡這一個研究的研究員，或其指導教授.

University of Oklahoma
Department of Educational psychology
Program of Special Education
Pei-Fang Wu M.Ed/Doctoral Candidate
(405)812-1103
Peifang.wu-1@ou.edu

University of Oklahoma
Department of Educational Psychology
Program of Special Education
Professor Dr. David Lovett PhD.
(405)325-1507
dlovett@ou.edu

您如果有任何對於你的權利(比方說,當為一位受訪著的疑問或抱怨) 關於這個研究,但不希望跟這一個團隊的人討論或者是無法跟此研究團隊的人取得聯繫,你可以聯絡奧克拉荷馬大學的醫學倫理委員會.

University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

***研究員將會拷貝這一份資料給您，如果您沒有拿到備份請跟研究員反應***

**Statement of Consent**

我讀了以上的資料，我的疑問得到滿意的答案,我同意配合並參與這一項研究

Signature Date

# 家長的基本資料問卷 (PQ)

## Participant Assigned ID #________________

小孩:

7. 姓名: ___________________________________年齡:__________________________
8. 生日____________________________________ 性別: ________男___________女
9. 出生地: (城市)_____________________州_______________國家____________
10. 住址
    :_____________________________________________________________________
11. 家用電話 (請包含區域號碼):________________________________________
12. 您的小孩一天花幾個小時在幼稚園,又或者是在家人以外的人照顧_______

母親: 有血緣關係的母親,社會背景:

11. 姓名:_____________________________________年齡
    ________________________________
12. 和小孩的關係:_____ 親生母親 ______ 寄養家庭的母親
    _____領養的母親 _____繼母 other: ____________________________________
13. 目前有跟小孩子住在一起嗎? 有__________ 沒有____________
14. 一天花幾個小時跟小孩子在一起_______________.
    再這些時間當中小孩子有多少時間是清醒的? ______有多少時間是在睡覺?_____.
15. 婚姻▪況: _____結婚 _____跟伴侶居住 _____分居 _____配偶死亡 _____單身
    _________夫妻分居兩地.
    其它:
    ____________________________________________________________________.
16. 最高受教育程度: _____小學/中學 (1-8) _____
    ______高中 (9-12)_____ 大學 (13-16) _____ 研究所 (17+)
17. 目前工作的職稱:
    ____________________________________________________________.
    工作時數/▪星期: _________. 薪水/月: ___________.
    工作地點,電話號碼 (包含區域號
    碼):_____________________________________________.
    如果你目前沒有工作,請問您目前有正在找工作嗎: _______有 _______沒有
18. 您目前有在上學嗎? _____________如果有, 您就讀的科系是什麼
    ___________________? __________是什麼學位______________________?
    __________________________________________________________________________
    ___.
19. 您是什麼人,從哪裡來?: ______________. 可以跟我解釋一下您的背景嗎? (會移民的原因是什麼
    ?)_____________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

___________________________________________________.

父親: 有血▪關係的父親 ,社會背景:

20. 姓名:__________________________________年齡
    ______________________________
21. 和小孩的關係:_____ 親生父親 ______ 寄養家庭的父親______________________
    領養的父親 _____繼父 other: ___________________________________
22. 目前有跟小孩子住在一起嗎? 有__________ 沒有____________
23. 一天花幾個小時跟小孩子在一起______________.
    再這些時間當中小孩子有多少時間是清醒的? ______有多少時間是在睡覺?_____.
24. 婚姻▪況: _____結婚 _____跟伴侶居住 _____分居 _____配偶死亡 _____單身
    _________夫妻分居兩地.
    其它:
    _______________________________________________________________.
25. 最高受教育程度: _____小學/中學 (1-8) _____
    ______高中 (9-12)_____ 大學 (13-16) _____ 研究所 (17+)
26. 目前工作的職稱:
    ________________________________________________________.
    工作時數/▪星期: _________. 薪水/月: ___________.
    工作地點,電話號碼 (包含區域號
    碼):_________________________________________.
    如果你目前沒有工作,請問您目前有正在找工作嗎: _______有 _______沒有
27. 您目前有在上學嗎? _____________如果有, 您就讀的科系是什麼
    ___________________? __________是什麼學位_______________________?
    _________________________________________________________________
    ___.
28. 您是什麼人,從哪裡來?: ______________. 可以跟我解釋一下您的背景嗎? (會移民的原因是什麼
    ?)_______________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

___________________________________________________.

家庭▪況

**6.** 請列出其他超過 **18** ▪ 的成人居住在家裡面的**:**

| 姓名 | 年齡 | 跟小孩的關係 | 一天有幾個小時跟孩子相處 |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

**7.** 其它居住在家中的小孩**:**

| 姓名 | 年齡 | 年級 | 關係 |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |

**8.** 家中是否有其他的成員需要特殊教育的服務又或者有其他特殊須求**?** 如果有的話**,** 請提供姓名和需要特殊服務的原因**.**

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

**__________________________________________________________________________________________________________________________________________________________________________________________________________.**

**9.** 家中主要使用的語言**:____________________________________________.**

**10.** 是否還有其他不同的語言在家中使用的**:____________________________________.**

## 家長訪談問題:第一部分

**Variable 1: 家庭的基本資料**

- **家庭結構:**

- 您的家庭是由哪一些人所組成的?
- 在您的家庭裡頭,重大的決定都是由誰在主導?
- 有沒有在什麼情況下,會由確定的某一方做決定?
- 家庭中的決定是由一個人來做,還是一定會經過家中成員討論?
- 您允許家中小孩對任何的事情做決定嗎?
- 您家中的成員會花時間在一起嗎? 一個禮拜幾次,一次多少個小時?
- 家庭的成員都住在一起嗎?
- 您們的家庭對朋友的定義是什麼?
- 家庭成員做決定之前會相互問其他家庭成員的看法嗎?
- 家庭中是否有階級制度,一家之主之分? 是跟年紀或性別有關嗎?
- 您覺得全家人花時間在一起是否是重要的?
- 可以跟我分享您對家庭的定義是什麼嗎?您家庭中的成員有誰? 您從哪裡來? 您是中國人在美國的第幾代?

- **主要照顧者**
    - 誰是您家小孩主要的照顧者?
    - 除了主要的照顧者之外,有誰還會幫忙您?
    - 可以大概跟我說一下,主要照顧者大概一天花多少時間跟孩子在一起?其他照顧的人?

- 大概有多久的時間小孩是其他人幫忙照顧?
- 兩個不同的照顧者中會不會有什麼如何照顧孩子上的衝突?
- 您覺得在文化上,或者是環境上對照顧孩子大體上來說有沒有什麼影響?

**Variable 2: 家中的教養文化.**

- **家庭餵食的習慣**
  - 在家中,孩子最主要都是由誰來餵?
  - 吃飯時候,家中有沒有什麼餐桌上的規矩?
  - 大致上家裡都吃些什麼樣的食物?
  - 請問您對餵母乳的看法?您有親身經歷過嗎?
  - 您對餵孩子喝奶粉的看法是?
  - 您覺得時什時候孩子可以開始吃硬的食物?您是怎麼幫孩子改變的?
  - 孩子吃的硬實是買的還是家中自己做的?
  - 家中的成員對孩子自己餵食自己的看法是如何?
  - 哪一位家中的成員最常做餵食孩子的動作?
  - 家中成員有沒有針對孩子餵食這一個方面有很大不同的看法的?可以跟我聊一下嗎?
- **家庭睡眠的模式**
- 家中有固定幾點睡覺嗎?
- 小朋友是跟你們一起睡嗎?如果是的話同一張床嗎?還是只是同一個房間?

- 白天的時候小朋友會有睡覺的時間嗎?位什麼?
- **小朋友不聽話或者是亂發脾氣的時候**
    - 通常會用什麼樣的方式處理?
    - 都是由誰來辦黑臉?有固定一個人嗎?
- **小孩子哭的時候,家中的成員是如何應對**
    - 通常會讓小孩哭多久之後主要照顧的人會去把小孩抱起來?
    - 通常照顧的人會用什麼方式去安撫哭聲不斷的小孩?

**Variable 3: 對美國文的接受度和認同感**

- 通常家中有對孩子有相關問題的時候會跟誰請求幫忙? 家庭中的成員或者是家人以外的朋友?
- 請問您要會直接要求幫忙或者是間接?
- 當您請求他人幫忙的時候,您的感覺是怎麼樣的---不好意思, 生氣, 覺得這是你應有的權利, 覺得這是不需要的?
- 哪一個圈子中的人,您覺得跟你的家庭互動最多 (學校/醫療/社會工作)?
- 大部分是怎麼樣的一個互動方式 (面對面, 電話, 信件)?
- 大部分都是由家庭中哪一位成員來對外互動?
- 家庭中的成員對於互動的過程感到自在嗎?可以跟我分享一下嗎?
- 如果你不會說英文,在互動的過程當中,對方有沒有提供你翻譯? 你所有的相關文件有翻譯成中文嗎?
- 能告訴我,對一個特殊兒童的家長,在美國您有什麼樣的權利嗎?

- 能跟我分享您對教養孩子的方法,您覺得您適用美式的教育,還是中國式的教育?為什麼?
- 您覺得在這一個國家生活,你喜歡嗎?有沒有很要好的美國朋友?您覺得您的家庭有被這一個社會完全接受嗎? 您覺得您的家庭被這一個社會拒絕在外嗎? 為什麼? 可以給我一個例子嗎? 當你試著幫你的孩子爭取更多的早療或者是特教服務的時候,您有過什麼樣的困難? 以整個家庭來說,你們面對過什麼樣的困難?

**Variable 4: 對於小孩的能力和缺陷的描述.**

- 跟我說說您的小孩?
- 能跟我說說您小孩的特殊情況嗎?您是在什麼情況下發現您的孩子有問題?您是怎麼被告知的?
- 能跟我分享一下您孩子一天大致上的行程式怎麼樣的嗎?
- 可以跟我分享您對孩子未來的希望是什麼嗎?比如說您希望他未來會... ?

**Variable 5: 家長的觀念, 和診斷的結果**

- 可以回想一下,第一次有人告訴你孩子可能有問題時候事怎麼樣的一個
- 你當下的感受是什麼?
- 可以舉例一下他們當時對你說的話嗎…
- 護士的反應是什麼, 其他的媽媽?您的朋友?, 您的親戚和您的另一半?他們說了些什麼?
- 在知道孩子有特殊的需求之後, 您對您孩子最初的反應是什麼?
- 您的另一半對您的子最初的反應是什麼, , 其他的親戚, 朋友, 鄰居, 教會的朋友, 其他的人.
- 您對你自己的看法,你自己對自己的想法有被這整件事情影響了嗎? 那你覺得對於你的家庭?
- 這一個經驗有改變你對自己的感覺嗎? 您的伴侶?, 家中其他的成員和親戚? , etc?
- 這一個經驗有沒有改變你和你伴侶的關係? 你現在怎麼看你自己的家庭?

- 這一個過程有影響您跟您孩子的關係嗎? 他們怎麼感覺他們自己? 孩子的朋友對這樣的一個過程有什麼不同的感受? 哪你的朋友ㄋ?
- 你用什麼樣的方式來安撫自己的情緒? 最剛開始的時候,比方說當你在最驚嚇的時候,你不想相信這是事實的時候,你很生氣的時候,你很難過傷心得時候,你覺得很孤單寂寞的時候,你覺得很多事壓的你喘不過氣來的時候,你覺得很無助的時候.
- 可以試著想像你孩子的未來會是怎麼樣的嗎? 什麼是你最害怕的? 你覺得最有希望的? 你希望你的孩子未來是如何?

**家庭中對特殊兒童的看法**

- 文化和宗教有影響您或者是您其他家庭的成員對特殊兒童的看法嗎?
- 在什麼時候,什麼情況下,是誰會對您的特殊小孩一些應負的責任
- 在你的日程生活中,你相信 “命運”這樣的一個說法嗎,他對您有什麼樣的影響 ?
- 你覺得再跟您孩子互動的時候,您的角色是什麼? 你覺得你跟孩子的互動對孩子有很大的幫助又或者是您覺得很無助?
    - 家庭對治療和保建的觀念和看法
        - 當孩子有健康上面的需求的時候,你們是採取什麼樣的方法?
        - 你只有讓孩子接受西醫的治療嗎?
        - 你只讓孩子接受偏方或者是民俗療法嗎?
        - 你兩種都有嘗試過嗎?

**Variable 6: 出生的過程, 和醫療的歷史**

- 當孩子在健康上面有問題或需求得時候,您家的成員都贊同您在治療上面採用的方法嗎?
- 可以跟我描述一下您懷孕的過程嗎? 有沒有什麼特別的你可以跟我分享的東西?
- 您可以想得到有什麼醫療方面的小故事又或者是懷孕期間的小故事可以跟我分享的嗎?

- 大部分懷孕期間的一些與醫療有關的事項都是由哪裡得知? 老一輩的人? 朋友? 跟宗教信仰有關的人? 家庭醫師? 醫療專業人員?

## 家長訪談第二部分

**Variable 7: 最初接觸早期療育的時候.**

1. 剛開始得時候是怎麼跟 早療機構聯絡的? 怎麼知道的, 怎麼找到?
2. 可以跟我分享剛開始跟他們聯絡的時候是怎麼樣的情形嗎? 還記得第一次的對話是怎樣嗎?
3. 您孩子的醫生有提供過什麼資訊給你過嗎? 您覺得提供的資訊對您有幫助嗎? 你覺得再那個時候可以給你多一點幫助嗎? 怎麼樣的幫助?要如何幫助?
4. 您有從各種不同專業早療人士的口中得到詳細的解說和相關的資訊嗎?
5. 您覺得您的孩子最需要的事什麼?
6. 您覺得以一個家庭來說, 您家庭最需要的事什麼?
7. 這一些專業的早療人士讓你感覺…?
8. 對於您的需求, 這一些早療的專業人士有幫忙到你嗎?
9. 可以跟我描述一下在聯絡的過程或者是轉介的過程有發生過什麼事嗎?

11. 稍微停頓一下,問清楚對於每一個跟參與研究家庭有相關的機,家庭互助機構,地方的專業特殊教育機構,相關的資料

**a.轉銜時所得到的協助和相關的資訊**

- 可以告訴我轉銜的過程是怎麼樣的嗎? (醫院到家中/家裡治療到團體治療/從早療到幼兒早期特殊教育).
- 你有得到什麼樣的協助嗎? (比方說你的家人, 朋友, 教會的教友)

**Variable 8: 早療服務的項目和時間的長短.**

- 你對小孩子所接受的早療服務有沒有有沒有參與?可以說明一下您如何參與嗎?
- 可否說明一下,您所接受服務的項目有哪一些,在哪接受這一些服務,只有您的小孩子有嗎,哪您本身或家庭本身ㄋ? 可以跟我很詳細的說明一下,是誰提供

什麼樣的服務,時間的長度有多少嗎? 您覺得有哪一些項目的服務是可以再要求多一點時間的?

**Variable 9: 家長了解早期聊育的意義和目標是必須透過早療的服務來達成的**

- 個別化家庭服務計劃對您來說的意義是什麼?
- 您覺得早期療育的目的是什麼?
- 對您來說,在個別化家庭服務計劃上面所說的長期和短期目標的意義是什麼?
- 我可以看一下您小孩的個別畫家庭服務計劃嗎? 當初寫計劃的時候是怎麼樣的一個情形可以跟我描述一下嗎? 有多少人參與? 在計劃書中有多少的長期目標是被舉出來的?
- 您覺得您有參與或只是您的意見有被接納嗎,在討論整個計劃的過程當中? What does the IFSP document means to your family and your child?

**Variable 10: 個別化家庭服務計劃書的分析和早期療育成效的指標 (指標來自於早療成效研究中心) .**

1. 在您的想法中,一個像您這樣的家庭, 經過早療的過程當中或只後,家庭應該要有什麼樣的受惠,或者是好處. 在過程當中您覺得你的收獲最大的地方是什麼. 您覺得什麼樣的成效是一個有特殊需求的小孩子應該會有的,在接受過早期療育的服務之後?
2. 請看看這一些早期聊育的指標, 請問哪一些您覺得是很重要的? 對於這一些指標說說的區域,您覺得您因為早期聊育的服務,在這對這一些相關的領域有多一些的認識與了解嗎?或者說有更多的資訊嗎?
3. 您覺得早期療育的服務應該要怎麼樣做會比較好, 比方 ▪ 您覺得州政府要如何做才可以更加被的幫助亞洲美國家庭家中有特殊需求的小孩 ?

**Variable 11: 家庭對早療相關的責任概念**

- 以一個中文移民家庭有一個特殊需求的小家，你最想要別人了解，知道是什麼?
- 您覺得身為一個特殊兒童小孩的家長，您的責任是什麼?
- 你對您孩子的夢想是什麼? 您擔心的是什麼?

**Variable 12: 家庭對於造成特殊兒童的原因及看法.**

- 可以跟我分享您們家對於有特殊需求人的看法是什麼嗎?

- 在你所屬的文化當中，是怎麼樣看有傷殘的人?
- 在你的文化當中，一般人覺得是什麼原因照成特殊兒童，您相信這樣的一個看法或說法嗎?
- 您覺得這些孩子是值得教育的嗎? 為什麼是，有為什麼不是?
- 在您的人生當中，是否有聽過，看過除了用醫療的方法才治療特殊兒童之外，用其他的民俗療法，宗教來治療傷殘人士的? 可以跟我分享這一些故事嗎!

**Variable 13: 家庭對早療服務的看法及想法.**

- 您覺得您自己本身家庭的需求有被專業早療人員看到嗎?
- 有多少早療的服務是您自己主導的?
- 您覺得就目前，或者是之前孩子的早療服務狀況如何?
- 您覺得早期療育的消費者指的是誰.
- 您會對早期療育的專業人員提出問題嗎? 最常問的是哪一方面的問題，請舉例說明? .
- 您覺得在整個早療的過程當中，您的孩子有被各個相關的服務協助過嗎?
- 您覺得早療的系統和服務有提供或者是幫忙你家庭的需求嗎?
- 您的需求和擔心的地方您覺得專業早療人士有幫您解釋或者是達成嗎?
- 您覺得怎樣才會對您比較有幫助? 您覺得專業人士能怎麼做才能把整個早療做的更好?

**Variable 14: 早療系統或者是人員對於來自不同文化背景家庭是否能夠勝認? 家庭的看法**

在什麼程度之下

- 您接觸的早療人員對您的語言熟悉嗎?
- 您對英文這一個語言熟悉嗎?可以很正確的表達出您的要求嗎?
- 如果有使用翻譯的話,
- 翻譯的文化背景是什麼您知道嗎?

- 翻譯對您的家庭背景，文化，您的國家熟悉嗎?
- 家庭中的成員對翻譯熟悉嗎，覺得舒服嗎? 如果有翻譯的話男生或者是女生對您來說會比較好嗎，為什麼?
- 翻譯對早療系統和法令熟悉嗎?
- 所有跟孩子相關的文件是否有翻譯成中文給您閱讀?如果中文是您主要的語言的話
- 可否跟我在次說明您的文化對有殘障人士小孩或者是大人的看法?
- 您覺得您的個別化家庭服務計劃中的長程和短成目標是否有特別把您的文化的特性加入考量?

**Variable 15 家庭以外的協助和幫忙**

- 什麼樣的協助目前對您來說是最需要的，也是您接受最多的?
- 在這一些協助當中，不包還家庭的，您的經驗是如何，可否跟我分享?好的，不好的都可以
- 您覺得在這一個過程當中，從發現問題到目前為止您覺得您都有被很效率的協助嗎?家庭成員之外?
- 目前的狀況對您來說，什麼是讓您最困擾的?

# APPENDIX C

## IRB Approve Letters from State Department of Health and OU

May 5, 2009

Pei-Fang Wu
Research/Teaching Assistant
Educational Psychology
Program of Special Education
Oklahoma University
820 Van Vleet Oval, Room 302
Norman, OK  73019

Dear Ms. Wu:

Thank you for providing the requested information and making the requested corrections to *09-01 Perceptions of Early Intervention/Early Childhood Special Education Outcomes: Inside Chinese-American Families with Children with Disabilities*. The research proposal is hereby approved and you may begin subject enrollment. It is the Board's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent will be conducted in a manner consistent with the requirements of 45 CFR 46, as amended; and that the potential benefits to the subjects and to others warrant the risks subjects may choose to incur.

The study is approved for one year with a Periodic Progress Report due by May 4, 2010. Copies of the approved informed consent documents are attached for your use.

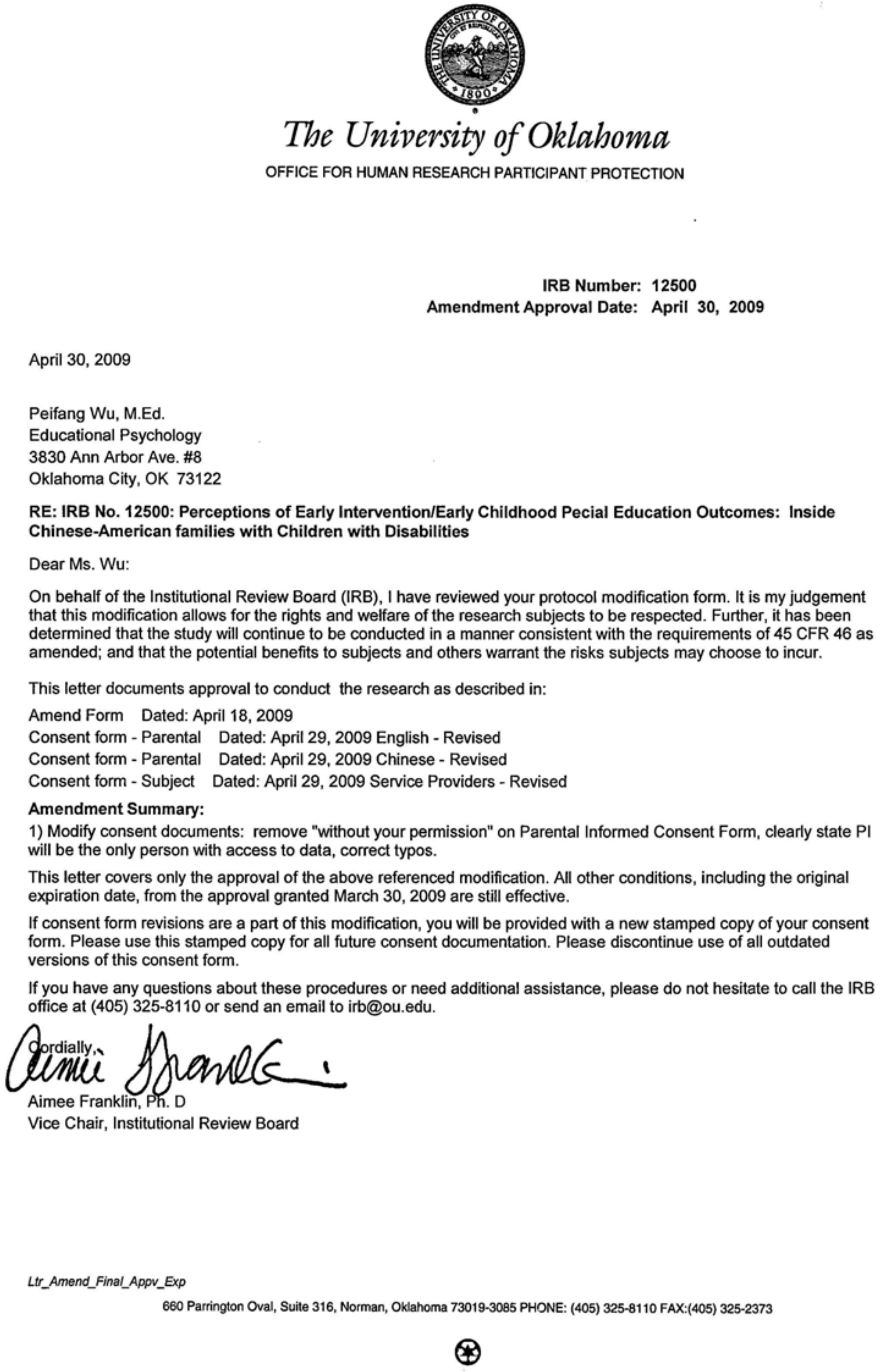
As principal investigator of this project, it is your responsibility to insure that this study is conducted as approved by the Board. Should you wish to deviate from the described protocol, you must notify this office, in writing, noting any changes or revisions in the protocol and/or informed consent document, and obtain prior approval. Changes may include but are not limited to adding data collection sites, adding or removing investigators, revising the research protocol, and changing the subject selection criteria.

If you have questions or need additional information, please contact Cheryl Noel at (405) 271-4200 or by E-mail at cheryln@health.ok.gov.

Sincerely,

Sue Mallone, RN, MPH
OSDH IRB Administrator

cc: David Lovett, PhD
Glenda Rogers



*The University of Oklahoma*
OFFICE FOR HUMAN RESEARCH PARTICIPANT PROTECTION

**IRB Number: 12500**
**Amendment Approval Date: April 30, 2009**

April 30, 2009

Peifang Wu, M.Ed.
Educational Psychology
3830 Ann Arbor Ave. #8
Oklahoma City, OK 73122

**RE: IRB No. 12500: Perceptions of Early Intervention/Early Childhood Pecial Education Outcomes: Inside Chinese-American families with Children with Disabilities**

Dear Ms. Wu:

On behalf of the Institutional Review Board (IRB), I have reviewed your protocol modification form. It is my judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, it has been determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

Amend Form Dated: April 18, 2009
Consent form - Parental Dated: April 29, 2009 English - Revised
Consent form - Parental Dated: April 29, 2009 Chinese - Revised
Consent form - Subject Dated: April 29, 2009 Service Providers - Revised

**Amendment Summary:**

1) Modify consent documents: remove "without your permission" on Parental Informed Consent Form, clearly state PI will be the only person with access to data, correct typos.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted March 30, 2009 are still effective.

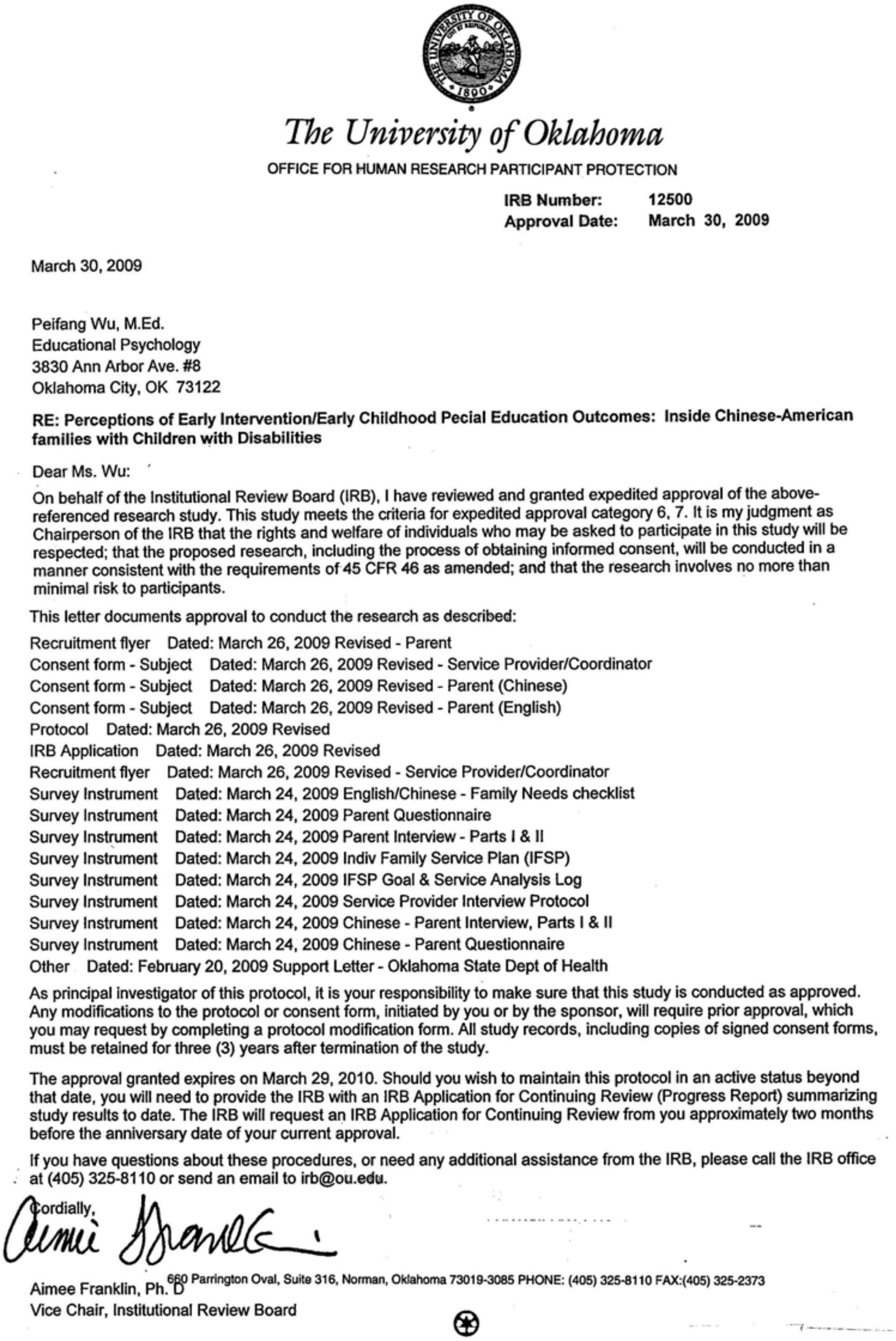
If consent form revisions are a part of this modification, you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please discontinue use of all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance, please do not hesitate to call the IRB office at (405) 325-8110 or send an email to irb@ou.edu.

Cordially,

Aimee Franklin, Ph. D
Vice Chair, Institutional Review Board

*Ltr_Amend_Final_Appv_Exp*



*The University of Oklahoma*
OFFICE FOR HUMAN RESEARCH PARTICIPANT PROTECTION

**IRB Number:** **12500**
**Approval Date:** **March 30, 2009**

March 30, 2009

Peifang Wu, M.Ed.
Educational Psychology
3830 Ann Arbor Ave. #8
Oklahoma City, OK 73122

**RE: Perceptions of Early Intervention/Early Childhood Pecial Education Outcomes: Inside Chinese-American families with Children with Disabilities**

Dear Ms. Wu:

On behalf of the Institutional Review Board (IRB), I have reviewed and granted expedited approval of the above-referenced research study. This study meets the criteria for expedited approval category 6, 7. It is my judgment as Chairperson of the IRB that the rights and welfare of individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with the requirements of 45 CFR 46 as amended; and that the research involves no more than minimal risk to participants.

This letter documents approval to conduct the research as described:

Recruitment flyer Dated: March 26, 2009 Revised - Parent
Consent form - Subject Dated: March 26, 2009 Revised - Service Provider/Coordinator
Consent form - Subject Dated: March 26, 2009 Revised - Parent (Chinese)
Consent form - Subject Dated: March 26, 2009 Revised - Parent (English)
Protocol Dated: March 26, 2009 Revised
IRB Application Dated: March 26, 2009 Revised
Recruitment flyer Dated: March 26, 2009 Revised - Service Provider/Coordinator
Survey Instrument Dated: March 24, 2009 English/Chinese - Family Needs checklist
Survey Instrument Dated: March 24, 2009 Parent Questionnaire
Survey Instrument Dated: March 24, 2009 Parent Interview - Parts I & II
Survey Instrument Dated: March 24, 2009 Indiv Family Service Plan (IFSP)
Survey Instrument Dated: March 24, 2009 IFSP Goal & Service Analysis Log
Survey Instrument Dated: March 24, 2009 Service Provider Interview Protocol
Survey Instrument Dated: March 24, 2009 Chinese - Parent Interview, Parts I & II
Survey Instrument Dated: March 24, 2009 Chinese - Parent Questionnaire
Other Dated: February 20, 2009 Support Letter - Oklahoma State Dept of Health

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form. All study records, including copies of signed consent forms, must be retained for three (3) years after termination of the study.

The approval granted expires on March 29, 2010. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request an IRB Application for Continuing Review from you approximately two months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB office at (405) 325-8110 or send an email to irb@ou.edu.

Cordially,

Aimee Franklin, Ph. D
Vice Chair, Institutional Review Board

660 Parrington Oval, Suite 316, Norman, Oklahoma 73019-3085 PHONE: (405) 325-8110 FAX:(405) 325-2373