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THE UNIVERSITY OF OKLAHOMA

GRADUATE COLLEGE

THE PERCEPTIONS OF TAIWANESE PARENTS TO THEIR YOUNG CHILDREN WITH DISABILITIES

A DISSERTATION

SUBMITTED TO THE GRADUATE FACULTY

in partial fulfillment of the requirements for the

degree of

DOCTOR OF PHILOSOPHY

By

Yea-Shwu A. Kang

Norman, Oklahoma

2000

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THE PERCEPTIONS OF TAIWANESE PARENTS TO THEIR YOUNG CHILDREN WITH DISABILITIES

A DISSERTATION
APPROVED FOR THE DEPARTMENT OF EDUCATION PSYCHOLOGY

By

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ACKNOWLEGEMENTS

I would like to express my sincere appreciation and gratefulness to the members of my Committee: Dr. David L. Lovett, Chairman; Dr. Kathryn Haring; Dr. James E. Gardner; Dr. Raymond Miller; and Dr. Michael Langenbach, for their suggestions of the problem, their endless guidance, support and motivation, and for their patience. Without their special interest, guidance, support, and humor, this study and the journey would not have been completed.

My gratitude is extended to the schools and the parents who participated in the study. Finally, I am especially grateful to my father, mother, sisters, and friends- for their love, patience, understanding, and support through out this endeavor.

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ABSTRACT

An understanding of parent perceptions regarding their children and the services they receive is important for the development and enhancement of special services for children with disabilities. Parental perceptions toward their children with disabilities must be considered when appraising the parents' opinions and support. Thus, the present study was conducted to address the following questions: (a) what perceptions do Taiwanese parents hold about their young children with disabilities; (b) what perceptions do Taiwanese parents hold about the adequacy of existing family-centered early childhood special education and related services; (c) what available sources of family support exist and to what extent have different sources of support been helpful to Taiwanese parents rearing young children; and (d) what perceptions do early childhood personnel in Taiwan hold about existing family-focused early childhood special education and related services. Two forms of questionnaires were developed and administrated to 8 early childhood educational agencies and 281 parents with young children with disabilities.

To program results, early childhood personnel in present study indicated that they had more children with developmental delays in their school settings, which was followed in descending order by children with multiple disabilities, children with physical impairments, children with visual impairments, and young children with hearing impairments. Regarding special services provided to young children and their families, information regarding special education or related services was the most common service provided by program personnel. In addition, all program personnel stated that all children in their programs had their own special, or individual, education goal or written program plans. They all invited parents to participate in their children's IEP/IFSP

meetings.

To family results, the study indicated that Taiwanese parents generally held positive perception toward their children disabilities and a high percentage of parents held positive perceptions toward integration. However, parents in this present study generally perceived that existing early childhood special education services were inadequate in Taiwan. In addition, regarding availability of sources of family support, Taiwanese parents generally perceived that sources of family support were rated to be either sometimes helpful or generally helpful in Taiwan, and "school teachers" was rated as very helpful. Finally, 5 open-ended questions were found to be consistent with the parents' responses on the other parts of the questionnaire. These parents expressed considerable ambivalent perceptions toward integration of their children with disabilities. Parents' concerns regarding integration included rejection of their children by children without disabilities and their families, teachers' reactions and commitment, program quality, and personnel quality. Parents perceived that most services were not available or were inadequate. The most inadequate services were recreational places, transportation for the children to school, and someone to help children and their families deal with emotional problems.

THE PERCEPTIONS OF CHINESE PARENTS TO THEIR YOUNG CHILDREN WITH DISABILITIES

CHAPTER ONE

Introduction

In Taiwan, although education has been viewed with deep respect for centuries, this respect has not always carried over to special education for individuals with disabilities. For over 25 centuries, the Chinese people have been guided by the teachings of Confucius in both their political and their personal development. The basic principle of Confucian philosophy is to develop the human personality to its fullest extent (Chen, Seitz, & Cheng, 1991). Confucius' teachings center on the development of proper relations between men by educating individuals on how to live moral, harmonious, and peaceful lives. In other words, the essence of Confucianism is to provide all people with an education that includes both basic knowledge and moral precepts so that they can develop their own capabilities to their utmost and become leaders of society.

China developed an educational system based on classical texts that were open to all, and advancement was based on the individual student's ability to pass standard examinations. Thus, without regard to a person's station in life or social status, an individual could advance himself through his own efforts to learn. An individual's only major limitation was his her own intellect, discipline, and desire.

The Chinese people hold education in deep reverence and have respected teachers for centuries. It can be said that for the Chinese, the teacher is the role model for their youth. The teacher is not only the transmitter of information and knowledge for youth, but also the standard for moral and ethical behavior. In this sense then, the scholar-teacher is viewed by the Chinese as being at the top of the social ladder, a position that

many Western teachers would desire today (Chen, Seitz, & Cheng, 1991).

Recently, an area of great emphasis in Taiwan has been the provision of educational and related services to young children with disabilities and their families.

The Importance of Early Intervention Programs

Early intervention, the provision of therapeutic and educational services to infants and young children at increased risk for developmental delays and their families, has received increased attention during the past decade (Bryant & Graham, 1995; Hanson & Lynch, 1995). The attention is multidisciplinary and often includes social workers even though the impetus has changed from the social services arena to the education system (Bryant & Graham, 1995). In the United States, following the legislative initiative of the mid-1970s requiring public schools to provide education to all school-aged children with disabilities, legal incentives were added in the 1980s to include services to children aged three to five. The most recent legislation added the birth to three-year-old age group.

The movement to provide early intervention services to infants and toddlers has not been without controversy, however, there is still discussion about the best ways of providing these services (Bryant & Graham, 1995). The underlying premise is that services should be family focused and community based. As communities have taken on the responsibilities of providing early intervention, a variety of both home-based and centered-based programs have emerged. This orientation is child-centered and parent-centered when the entire family system is provided intervention services. In other words, individualized service plans for each child are developed based on each child and family member's needs within a family ecology context. The concept of "family focus" is being implemented in a variety of ways as some families feel burdened by the

additional responsibilities of being teacher and therapist to their infants and others want professionals to teach them to do what is needed and then to leave them alone to do it (Bryant & Graham, 1995). Family-focused services coordinate and deliver comprehensive services to the child and the family, including (1) governmental (education, social services, mental health, and juvenile justice), community (child care, recreation, special interests), and (3) private (volunteer organization such Big Brother Sister, scouts, and special interest clubs) (Turnbull & Turnbull, 1997). They use a single point of contact, make funding arrangements cohesive, and thereby increase the likelihood that children and their families will achieve desired outcomes (Turnbull & Turnbull, 1997).

The importance of early intervention has been underscored by a major policy commitment in the United States- the passage of Public Law (P.L.) 99-457, the Education of the Handicapped Act (EHA) Amendments, 1986 (Hanson & Lynch, 1995). This law is now retitled the Individuals with Disabilities Education Act (IDEA), P.L. 102-119 of 1991. This early education of infants and toddlers with disabilities is addressed specifically in Title I of this landmark piece of legislation. It states that the early intervention program for infants and toddlers with disabilities is intended to:

(a) develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency program of early intervention services for infants and toddlers with disabilities and their families;

(b) facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources(including public and private insurance coverage);

(c) enhance the States' capacity to provide quality early intervention services and

expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families, and

(d) enhance the capacity of State and local agencies and service providers to identify, evaluate, and meet the needs of historically underrepresented populations, particularly minority, low-income, inner-city, and rural populations (34 CFR, Part 303, Early Intervention Programs for Infants and Toddlers with Disabilities).

The law further specified that children are to receive comprehensive, multidisciplinary evaluations and that an Individualized Family Service Plan (IFSP) is to be developed for each eligible child and family. The passage of this law was based on findings that make it clear that early services to young children with disabilities enhance their abilities to develop to their maximum potential, minimize later educational costs to society, and reduce the likelihood of institutionalization for children with disabilities (Hanson & Lynch, 1995).

There are a number of reasons for providing educational and therapeutic services to very young children with disabilities, including the following: increased likelihood of the child fulfilling his or her potential (Calhoun, Calhoun, & Rose, 1989; Hanson & Lynch, 1995; Strain, 1984); and reduced cost of care throughout life (Hanson & Lynch, 1995; Reaves & Burns, 1982); and improved educational, vocational, and social opportunities for the child's parents (Carney, 1983; Hanson & Lynch, 1995). Families who have had the opportunity to enroll their exceptional children in early intervention programs have expressed, in retrospective reports, great appreciation for the positive changes in their children and for a sense of life being easier (Widerstrom & Goodwin, 1987).

Early Intervention and Educational Programs for Children with Disabilities in Taiwan

In Taiwan, *handicapped* refers to individuals who have at least one or more of the

following handicap(s): mental retardation, visual impairments, hearing impairments, speech and language disorders, orthopedic handicaps, chronic illnesses, emotional disturbances, behavioral disorders, learning disabilities, multiple handicaps, and other evident handicaps (Ministry of Education of the Republic of China, 1994). Under the Special Education Law, all eligible school-aged children with disabilities from 7 to 15 have equal rights like those of their nondisabled peers to receive free education and are entitled to special education services in general classes, resource rooms, special classes, or special schools in the public school system. For school-age children with severe, profound, or multiple disabilities, a referral for home training provided by itinerant teachers or for special education services in public or private institutions or training centers in the social welfare system may be considered.

No current data on the prevalence of children with disabilities have been reported. However, the data in Table 1 illustrate the number of children with disabilities in Taiwan's Second National Prevalence Study conducted in 1992. This survey identified a total of 75,562 children with disabilities. The results from the survey also documented 2.121% of the 3,561,729 school-aged population as children with disabilities (National Taiwan Normal University, 1992). Until now, special education programs were provided in the form of resource rooms, special classes, special schools, and institutions or centers for those school-aged children who were labeled as mentally retarded, hearing impaired, physically disabled, visually impaired, learning disabled, or had multiple disabilities. Table 2 illustrates the placement conditions of children with special needs based on the Second National Prevalence Survey Study in Taiwan in the year 1992. Even though there are trends to integrate children with disabilities in the general schools, most continue to be placed in institutions, centers, or in special schools. All eligible

school-aged exceptional children, regardless of their placements, may be provided with related services, such as special devices (e.g. hearing aids, wheelchairs), transportation, and financial assistance once their needs are identified.

Table 1

Number of children with disabilities identified in the Second National Prevalence Study in Taiwan, R.O.C.

Categories	Number of Children	% of Target Population	% of General School-Aged Population
Mental Retardation	31,440	41.46	0.883
Learning Disability	15,512	20.53	0.436
Multiple Handicap	7,315	9.68	0.205
Behavior Disorder	7,089	9.38	0.199
Physical Handicap	3,456	4.57	0.097
Language Disorder	2,916	3.86	0.082
Hearing Impairment	2,876	3.81	0.081
Health Impairment	2,111	2.79	0.059
Visual Impairment	1,931	2.56	0.054
Autism	598	0.79	0.017
Facial Distortion	318	0.42	0.009
Total	75,562	100.00	2.121

Note. Adapted from *The Second National Prevalence Survey Study on School-Aged Children with Disabilities in Taiwan, R.O.C.* (1993). Taipei, Taiwan: Educational Research Council, Ministry of Education.

Table 2

Placement conditions of children with special needs based on the Second National Prevalence Survey Study in Taiwan in the year of 1992

	Total	General Class	Res. Class	Special Class	Special School	Institut.	Home-bound	UE	Other
Mental Retardation	31,440	23,084 (73.42)	141 (0.45)	5,771 (18.36)	937 (2.99)	937 (2.99)	251 (0.80)	740 (2.35)	54 (0.17)
Learning Disability	15,512	14,936 (96.29)	257 (1.66)	259 (1.67)	2 (0.01)	8 (0.05)	0 (0.00)	27 (0.17)	23 (0.15)
Multiple Handicap	7,315	4,231 (57.84)	34 (0.46)	1,157 (15.82)	441 (6.03)	602 (8.23)	254 (3.47)	578 (7.90)	18 (0.25)
Behavior Disorder	7,089	6,772 (95.53)	31 (0.44)	44 (0.62)	0 (0.00)	1 (0.01)	3 (0.04)	223 (3.15)	15 (0.21)
Physical Handicap	3,456	3,081 (89.15)	11 (0.32)	56 (1.62)	50 (1.45)	47 (1.36)	57 (1.65)	145 (4.20)	9 (0.26)
Language Disorder	2,916	2,756 (94.51)	27 (0.93)	62 (2.13)	1 (0.03)	14 (0.48)	6 (0.21)	42 (1.44)	8 (0.27)
Hearing Impairment	2,876	1,120 (38.94)	222 (7.72)	620 (21.56)	838 (29.14)	29 (1.00)	4 (0.14)	37 (1.29)	6 (0.21)
Health Impairment	2,111	1,977 (93.65)	3 (0.14)	26 (1.23)	0 (0.00)	2 (0.09)	4 (0.19)	93 (4.41)	6 (0.28)
Visual Impairment	1,931	1,700 (88.04)	9 (0.47)	15 (0.78)	175 (9.06)	4 (0.21)	2 (0.10)	24 (1.24)	2 (0.10)
Autism	598	202 (33.78)	4 (0.67)	214 (35.79)	33 (5.52)	97 (16.22)	14 (2.34)	33 (5.52)	1 (0.17)
Facial Distortion	318	311 (97.80)	0 (0.00)	2 (0.63)	0 (0.00)	0 (0.00)	0 (0.00)	4 (1.26)	1 (0.31)
Total	75,562	60,170 (79.63)	739 (0.98)	8,226 (10.89)	2,002 (2.65)	1,741 (2.30)	595 (0.79)	1,946 (2.58)	143 (0.19)

Note Numbers in parentheses are percentages; Res. Class Resource Class; Institut. Institution; UE Unenrollment Adapted from *The Second National Prevalence Survey Study on School-Aged Children with Disabilities in Taiwan, R.O.C.* (1993). Taipei, Taiwan: Educational Research Council, Ministry of Education.

Special education services have been expanded to children with disabilities at the senior high and preschool levels (Table 3). High school special education primarily is provided in special schools for students with mental, visual, or auditory disabilities who need vocational training. Any student with disabilities who completes the compulsory education program and passes the entrance exam given to their nondisabled peers can continue advanced studies with special assistance.

In Taiwan, early childhood special education was not mandated until the Special Education Law passed in 1984. However, even though Taiwan's early childhood special education program has existed for over 10 years, there is little research regarding early childhood special education services. Available research showed that due to lack of information and resources, most children with more significant disabilities remained at home and did not receive educational services (The Red Cross Society of China, R.O.C., 1990). Few young children with disabilities went to special preschools, hospitals, social welfare institutions, or organizations to receive education or therapy (Wang, 1996).

Table 3

Major landmarks in Taiwan's Special Education Law regarding early childhood special education services

1984	Law #4 states that early childhood special education should be provided by city, local, or private agencies. These include home, public/private general kindergartens, and public/private special preschools or classes.
1986	Law #2 states that special preschools or classes are only for those students who are gifted or have disabilities.
1987	Law #3, for a physically responsive environment, recommends a minimum of 2 meters square (about 21.5ft^2) of indoor playroom floor space per child, and a minimum of 4 meters square (43 ft^2) of outdoor play space per child.
1987	Law #4, for gifted students, with parent or guardian's agreement, the student would be able to start preschool under age 4.
1987	Law #5, there are no more than 10 students with disabilities in one classroom.
1987	Law #11, for certification as a special preschool educator, a person needs to be a certified preschool teacher and also have at least 20 credit hours of special education classes.
1987	Law #18, students with disabilities, between ages 3 to 6, can start school anytime earlier than children without disabilities.
1993	Law #13, every city should establish a special education assessment system to identify young children with developmental delays and provide them with services.

Note. Summarized from "*R.O.C. Education Yearbook*" by Department of Education, 1996, Taipei, Taiwan, pp.188-194.

In 1997, one important special education revised law stipulated that all levels of government draw up regulations for active implementation of special education for preschool children. With the passage of this law, the government expected that preschool special education would be extended in 1999 to the age of 5, in 2001 to the age of 4, and in 2003 to the age of 3, with the accent on universal, free education. Once this is successfully achieved, a compulsory approach will be introduced to ensure that children with disabilities fully attend school from the age of 3 to the age of 5, thus fully implementing early childhood special education.

In addition, to improve the quality of special education, the Taiwan government started implementing the zero-reject education ideal (R.O.C. Education Yearbook, 1996). The zero-reject policy prevents the exclusion of students with disabilities from entering schools. It actually forces those who should be in school, but are not, to enter school. More importantly, it guarantees the provision of educational content that enhances the students' development. Thus, the task of implementing the Special Education Law is to be completed as rapidly as possible: special education facilities are to be improved, and assessment, placement and school guidance work is to be strengthened to achieve equality of educational opportunity.

However, because all children under 7 are not entitled to free education, young children with special needs receive limited intervention services provided by the government (National Normal University, 1999). Fortunately, increasing attention and efforts have been given to early childhood special education programs for young children with disabilities. This is evident from the increase in the number of early childhood special education programs for children with disabilities from birth to 6 years old from 1982 to 1990 (Table 4) (Wang, 1993). In 1982, there were only 8 programs providing

special classes in regular schools, special schools, and private and public institutions, but in 1990 there were 58 programs offering early childhood special education. Among the early programs, approximately 17% of them provided early intervention services for children with disabilities whose ages ranged from birth to 3 (Wang, 1993). This was the most current data available, regarding these types of programs.

Table 4

Number of early childhood special education programs and number of children with disabilities aged birth to 6 in Taiwan, 1982-1990

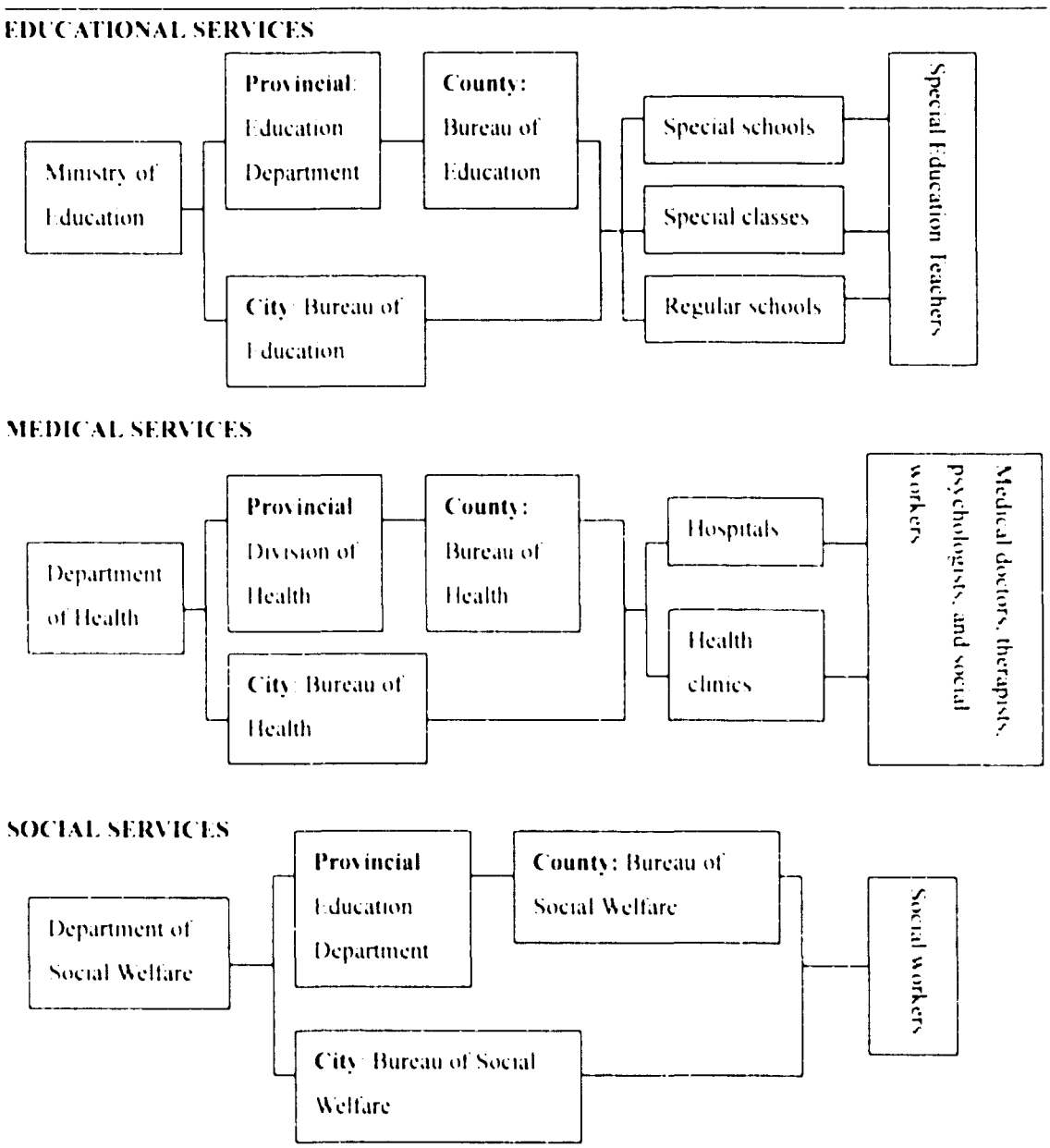
Year	Special schools	Special classes	Centers Institutions	Total
1982	3 (10)	2 (260)	3 (60)	8 (330)
1985	3 (10)	2 (369)	31 (62)	36 (441)
1987	3 (10)	2 (430)	44 (72)	49 (512)
1990	3 (11)	8 (515)	47 (83)	58 (609)

Note. Numbers in parentheses are the number of children served. Adapted from Wang, T. M. (1993). Families in Asian Cultures: Taiwan as a case example. In J. L. Paul, & R. J. Simeonsson (Ed.), *Children with Special Needs* (pp. 165-178). Orlando, FL: Harcourt Brace Jovanovich College Publishers.

At the present time, children who receive early childhood special education are mainly 3 to 6-year-olds. For most of the families with youngsters with disabilities in Taiwan, medical care rather than educational or therapeutic consultation may be the only service they receive from professionals during the child's first three years (Wang, 1993). Children with visible and more severe disabilities receive earlier identification and medical or rehabilitation services, which are provided only on request by their parents. Limited preschool special education programs, especially integrated ones, are provided to those whose disabilities are less severe. Most intervention programs are provided by private interest groups; only a very small number of them are government supported (Wang, 1993).

Furthermore, educational, medical, and social programs each providing separate services may compound the problems of the child and the family (Wang, 1993). For example, medical treatments or rehabilitation may be provided without coordination with educational services. Educational programs may likewise be offered without adequate attention to social or medical needs. Separate delivery systems operate under separate administrative structures in education, health, and social welfare (Figure 1), which makes an integrated approach very difficult to establish.

Figure 1 The Array of Services from the Health, Education, and Social Welfare Systems in Taiwan



Note. Adapted from Wang, T. M. (1993). Families in Asian Cultures: Taiwan as a case example. In J. L. Paul, & R. J. Simeonsson (Ed.), *Children with Special Needs* (pp. 165-178). Orlando, FL: Harcourt Brace Jovanovich College Publishers.

In the educational system, preschool education programs for children aged 4 to 6 are under the administration of the Department of Education. In Taiwan, there are a few special education preschools for 4 to 6-year-old children with disabilities in special schools, or special classes in college-affiliated centers and regular elementary schools. Most children with mild disabilities are unidentified and placed in regular kindergartens or nursery schools without special assistance. Children with disabilities who need medical care may receive medical or therapeutic services under the administration of the Health Department. These services of neurological or developmental diagnosis, medical treatment, follow-up service, or rehabilitation therapy, for example, are only provided when the cases are referred from medical professionals or are requested by parents of children with disabilities or who are at high-risk. Children with disabilities under 4 or those with more severe conditions receive social welfare services under the auspices of the Department of Social Welfare. These children may be placed in public or private institutions or served in training centers. Social workers in the social welfare system mostly provide services to children with disabilities from poor families or those who have been abused. The fragmentation of service delivery may be confusing to families of exceptional children and forces them to use much energy to work with professionals from different disciplines at different places and at different times.

Problems and Special Needs of the Family with Exceptional Youngsters

In Taiwan, limited resources and services delivered in a fragmented system compounded with traditional beliefs and child-rearing practices may cause parents a great deal of frustration and stress following the birth of their child with special needs. One study showed that Chinese families in Taiwan experienced more stress than American families of exceptional children (Wu, Wang, & Retish, 1987). It was also found that

parents of toddlers with Down syndrome age 12 to 31 months perceived less satisfaction with their parenting, and had more difficulty in reading their child's cues than parents of nondisabled children (Wang, 1990).

The mother typically bears most of the stress because of the traditional caregiving role she plays in the Chinese family (Chang, 1992; Wang, 1985). High expectations and great emphasis on the child's academic performance may result in stereotypically negative attitudes toward children with disabilities held by most of the Chinese public and also by the parents themselves (Chang, 1992; Wang, 1990).

To cope with the stress and difficult caretaking, parents, especially mothers, of children with disabilities usually find support inside the family first before turning to someone outside the family because of the inside-outside distinction. Family members, including those in the extended family or very close friends of the family, are frequently the ones that offer inside support and comfort to the family with a young exceptional child. They usually offer their support and help by sharing the frustration and daily caretaking work for the child with disabilities or other sibling(s). Parents who experience less support from family members or close friends have more difficulty in adjusting and handling the heavy caretaking demands (Wang, 1993).

Traditional beliefs of fate in Chinese culture may prevent the family from seeking outside help, either from a family having similar problems or professionals who try to offer their assistance. "Disability" or "handicap" in the child with obvious disabilities may be accepted by the parents as manifestations of their own wrongful deeds, either in this life or in the previous cycle of incarnation. The sense of responsibility and guilt may compel them to shelter children with disabilities as much as possible from any interferences from the outside world. It is considered to be a serious "loss of face" or

"failure of the family" when the offspring with disabilities is discovered by an outsider or stranger. In addition, traditionally, Chinese have thought that the actions of one's ancestors hold the key to one's fortunes and that one's own actions will affect the fortunes of one's descendants. If one gives birth to an abnormal child, whatever the real reason, it will be widely thought that the ancestors sinned. With this conception, many families have a tremendous sense of guilt (Chang, 1992). Therefore, parents may be hesitant to share their difficulties with "the outsider", for example, a family with similar problems. A clinical observation in a mother-child interaction study gave evidence that approximately half of the mothers of children with disabilities had no idea about the existence of parent support groups in the city they lived, and only about 28% of the mothers actively participated in the monthly meetings of the parent group (Wang, 1989). Similar findings have been found in the Nihira et al. (1988) cross-cultural study, which reported that Japanese parents much less openly discussed the child's disability and had less idea of the child's health and educational needs than American parents.

Defensive reaction may also occur when professionals are trying to offer help to the family with a child with disabilities, especially in mild cases (Wang, 1985). However, professional assistance has been reported to be helpful for parents who came from lower socioeconomic status families or whose child had more severe disabilities (Wang, 1985). For those who receive help from professionals, parents may tend to rely more on professionals for training of their exceptional child. Although there is no direct evidence provided in the Chinese literature, Japanese parents have been found to rely more on teachers and specialists than American parents (Nihira et al., 1988). As a result, parents may expend less effort to train the child than they might. Otherwise, the reliance on external control from professionals may be interpreted as reaction of differing

to authority figures.

It should be noted that due, in part, to the recent revolutionary changes in society and in the structure and characteristics of the Chinese family, a variety of family needs may be expected. Although traditional beliefs and family practices are still kept mostly within the family, there are families, particularly nuclear families in urban areas, that have adopted Western values and lifestyles. They experience stress and adjust to the crisis of having a child with disabilities differently than more traditional families. The family may lose support from the extended family because of physical separation. However, in the nuclear family, the father seems to share more and more caregiving work with the mother in the early years of their exceptional child's life (Wang, 1993). In addition, these parents are more likely to seek outside support and resources when they are needed.

Research Questions

The proposed research is designed to address the following questions:

1. What perceptions do Taiwanese parents hold about their young children with disabilities?
2. What perceptions do Taiwanese parents hold about the adequacy of existing family-centered early childhood special education and related services?
3. What available sources of family support exist and to what extent have different sources of support been helpful to Taiwanese parents rearing young children?
4. What perceptions do early childhood personnel in Taiwan hold about existing family-focused early childhood special education and related services?

Definition of Terms

The terms used in this study are defined in Appendix A.

Organization of the Study

The study has been organized into five chapters. The first chapter is an introduction to the research. Chapter 2 is a review of related literature. Chapter 3 describes the methods and procedures utilized in the study. Chapter 4 presents the results of the data analysis. Chapter 5 includes the discussion, limitations, recommendations, and conclusions.

CHAPTER TWO

Review of the Literature

In America, many changes continue to occur in special education services. One such change in early childhood intervention services is the movement toward family-centered care. Family-centered intervention recognizes the family and the child as the primary focus of an early intervention team. The team functions to meet the family's concerns and priorities (Effgen, 1994). Public Law (PL) 99-457, the Education of the Handicapped Act Amendments, now reauthorized and known as the Individuals with Disabilities Education Act Amendments of 1997 (IDEA), has helped shape early intervention services, especially family-centered practice. Part H of IDEA (now Part C), which supports services for infants and toddlers with disabilities from birth through age 2, emphasizes family-centered care by identification of family concerns, priorities, and resources, development of an individual family service plan (IFSP), and coordination of services. Under IDEA, families choose their level of involvement in the early intervention program through written consent before services are provided (Federal Register, 34 CFR300.13).

Some studies have addressed the changing trend toward family-centered care. These studies found that reasons change is occurring are associated with characteristics of service delivery in the 1980's and early 1990's where parents lacked involvement and the emphasis was on child-focused care (Beckman, Robinson, Rosenberg, & Filer, 1994; Guralnick, 1989; Simeonsson, Cooper, & Scheiner, 1982). Service providers developed child-focused goals with little or no parent input, and family outcomes were not assessed or measured. In a family-centered approach, the service provider respects and recognizes the role that the family plays in the life of their child, and the service

provider's main goal is to support families in their natural caregiving roles by promoting the family as a partner in the care of their child (Association For the Care of Children's Health, 1989). Practices comprising family-centered care, as defined by The Beach Center on Families and Disability (Murphy, Lee, Turnbull, & Turbiville, 1995), are:

--- including families in the decision-making, planing, assessment, and service delivery at the family, agency, and system levels,

--- developing services for the whole family, not just the child,

--- having families' priorities for goals and services guide practice,

--- and, having families' choices regarding their level of participation guide service provision.

Along with this shift toward family-centered care, service providers, administrators, and researchers have attempted to measure the effectiveness of early intervention services within their programs. Most commonly, the perceptions of service providers and families have been researched. In measuring service providers' perceptions, Bailey, Buysse, Edmondson, and Smith (1992) found that service providers rate parent involvement in early intervention services to be moderate. The authors used a 10-point rating scale to determine the perceptions of service providers toward family-centered services. A survey of 180 early intervention professionals found significant discrepancies between current and ideal family involvement in early intervention programs, specifically in parent involvement in decisions about child assessment, parent participation in assessment, team meetings, and decision making, and provision of family services. Service providers described the overall range within which their program involved families as between 3 and 7. The range of typical family involvement is 4-5 showing a moderate degree of family involvement. The ideal roles of families were

rated in the 7-8 range reflecting a desired high degree of family involvement. In addition, barriers to ideal programs for children with disabilities were identified as family and system barriers, such as family knowledge or skill, and lack of resources.

Mahoney and O'Sullivan (1990) concluded that services continue to be child-focused for most service providers, especially services for children 3 to 6 years old as compared to children birth to 3 years old. A survey of 989 service providers for birth to 6-year-old children with disabilities from six randomly selected states examined the degree to which early intervention activities focus on the family. The survey assessed perceptions of the value of working with parents, time devoted to family-focused activities, kind of services offered, achievement of objectives, and factors impeding services. The results of the study indicated that the familial concerns advocated by P.L. 99-457 had yet to be integrated well into the practice of service providers. Most goals selected by service providers were child-focused clinical goals, although family intervention goals were cited frequently. Published programs or curricula were rarely used as a basis for working with families. Service providers reported that they successfully achieved goals set for many of their families, yet they also encountered several problems, including insufficient time for family services (Mahoney & O'Sullivan, 1990).

Humphry and Geissinger (1993) found that the state or geographic region has a small but significant influence on a group of occupational therapists' attitudes related to family-centered care. A questionnaire, Issues in Early Intervention, was developed and utilized to measure participants' attitudes related to family-centered services and sources of influence on attitudes. Occupational therapists' attitudes on pretest, posttest, and a post-posttest were measured. A multiple regression analysis was selected for analysis of

the data. The study indicated that the greater the implementation of components of IDEA, the more positive attitudes toward family-centered care. In other words, state policy was likely to influence program administration's level of endorsement of a family-centered approach and the availability of funds for personnel training. One reason cited by the authors for this finding was that states vary in their level of implementation of IDEA. They also found, to a lesser extent, occupational therapists with more pediatric experience and advanced degrees expressed more consistent family-centered attitudes. These studies also found that inconsistent perspectives regarding family-centered care between program administrators and service providers are a barrier to implementing family-centered practices. Professionals with more pediatric experience, for example, expressed attitudes supporting family-centered services. Perhaps with more years of experience treating children, professionals are able to step back and see the importance of their role in supporting the family of the young child with special needs. Professionals who have recently entered pediatric practice may put increased emphasis on mastering child-focused intervention techniques and may not hold a holistic perspective of a professional's role with the family. Lack of resources, such as time, staff, and money, was also cited as reasons for limited family-centered services. Mahoney and O'Shullivan (1990) suggested that service providers need preparation, such as increased budgets, additional staff members and professionals and parental involvement, to become more family-centered, which will, in turn, help them spend more time with families developing and working toward family objectives.

Several studies have addressed families' perceptions regarding early intervention care (Able-Boone, Goodwin, Sandall, Gordon, & Martin, 1992; Bailey & Simeonsson, 1988; McWilliam et al., 1995; Sontag & Schacht, 1994; Summers et al., 1990). These

studies will be discussed in more detailed later in this review. A consistent theme in these studies was that families expressed a need to know about the availability of services and how to obtain those services. Other concerns were that parents want information about their child's disability and their child's needs, now and in the future, that they want the ability to talk with other parents with a child who has a disability, that the development of the IFSP needs to be ongoing, and that the coordination of services be improved. Summers et al. (1990) reported that families want sensitivity and respect, with the use of nonintrusive questions, in determining family strengths and needs when developing the IFSP.

Family perspectives differed according to where they lived, the type of programs in which they participated, and their ethnicity. Able-Boone et al. (1992) reported that parents from rural areas have more positive views of service coordination than parents from urban areas. They also found that parents who have children enrolled in home-based programs have more positive views of the accessibility of services and rate the service delivery system higher than parents of children in center-based programs. Non-Caucasian parents rate their satisfaction with current services higher than Caucasian parents. In the study by Sontag and Schacht (1994), Caucasian parents were more inclined to want to know how to get information, and American Indian parents generally wanted information on their rights and to know why a service could not be provided. American Indian parents reported that they did not have one person who coordinates their services and that they had difficulty understanding the professional language.

Family-Centered Services

Family-centered care in early intervention is considered the recommended practice for service providers today (Pearl, 1993). Family-centered care is a construct around

which a team works. The family and the child are the reasons for the team's existence, and the team functions to meet the family's concerns and priorities (Effgen, 1994). The primary federal legislation that helped to shape family-centered practice was Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, reauthorized as the Individuals with Disabilities Education Act Amendments of 1997 (IDEA, now Part C). PL 99-457 was designed to implement services for infants, toddlers, and preschoolers with disabilities and their families. Title I of the law, Handicapped Infants and Toddlers, which was also known as Part H, covered infants and toddlers with disabilities from birth through age 2 who were in need of early intervention services (Effgen, 1994). This legislation recognizes the family as most knowledgeable about aspects of the child, as the most constant factor in the child's life, and as the provider of physical and emotional supports (Smith & McKenna, 1993). When receiving services under Part C, the family chooses their level of involvement in the program, and services are documented through an Individualized Family Service Plan (IFSP) (Federal Register, 1993). Written consent of the parent(s) must be obtained prior to provision of services. A family assessment is available to families and it must be family-directed to determine the resources, priorities, and concerns of the family as they relate to their child with a disability (Federal Register, 1993). Focusing on families emphasizes parent-professional collaboration in providing family-centered care. Thus, service providers in early intervention today are challenged to adopt a family-centered approach (Bailey, Buysse, Edmondson, & Smith, 1992; Bailey & Simeonsson, 1988; Hanson & Lynch, 1995).

Factors that supported the movement towards family-centered care were related to problems associated with service delivery in the 1980's and early 1990's when parents had limited involvement and the emphasis was on child-focused care (Beckman et al.,

1994). Traditionally, families were involved in their child's program by being taught parent-mediated intervention programs by the service provider. Studies in the early 1980's focused on the use of a directive, instructional-oriented approach toward parents (Guralnick, 1989). Simeonsson, Cooper, & Scheiner (1982), for example, reviewed 27 studies to determine what constitutes early intervention practice for biologically impaired infants and young children. Studies were grouped into four classifications on the basis of experimental design as follows: retrospective, prospective-no control group, prospective-control contrast group, and prospective-random group assignment. A comparative analysis was made of the effectiveness of findings on the basis of statistical evidence and clinical support. Statistical procedures were used in 59 percent of the studies and statistical support for the effectiveness of early intervention was reported in 48 percent of the studies. Effectiveness on the basis of subjective, clinical conclusions was reported in 93 percent of the studies. Implications of the discrepancy between effectiveness based on statistical evidence and clinical conclusions were discussed. The authors found that the type of program provided was determined by the service provider's perceived needs of the child, with treatment geared toward the child instead of the child and parent. IQ scores, age equivalent scores on developmental tests, and behavioral frequency measures were used to determine treatment outcomes. The review showed that service providers were directed toward providing for the child instead of supporting the family members who care for the child with a disability. Service providers developed child-focused goals with little to no parent input, and family outcomes in relation to family goals were not assessed or measured. Within this process, the context of the family and the family's capacity to provide for a child with a disability was not addressed by service providers.

Family Systems Theory

The theoretical foundations of family-centered care are rooted in family systems theory and family empowerment. Family systems theory supports a family-centered approach (Pearl, 1993). Within family systems theory, a family is described as, "any group of people who are related legally or by blood, or who are perceived to be family by the members" (Guralnik, 1984, pp 201). This includes ties by marriage, blood, adoption, common-law marriage, support groups, communes, or religious communities (Thomas, 1992). Pearl (1993) describes the components of family systems theory as: (a) the family is dynamic and is constantly changing; (b) the family regulates itself to maintain homeostasis; (c) the family operates according to the principle of equifinality; (d) family behavior has a positive function for the family system; (e) every member of the family plays a part in the working whole; and (f) every action in the family system leads to reaction or feedback. From a family systems approach, the family is always in a state of change or on the brink of change. In order to balance change, a family tends toward a state of homeostasis through daily routines and routine social activities. When change occurs, such as the birth of a child with a disability, the family will experience some disequilibrium which leads to problem solving in areas of concern while still maintaining homeostasis within daily routines. Equifinality within a family is the inclination of the family to use the same interactional patterns to solve most problems which returns the family to equilibrium. Within family systems theory, service providers should respect the role each individual family member plays in maintaining homeostasis within their family system and how the family deals with new situations and problems that may arise when a child with a disability becomes part of the family structure. The service provider who recognizes the family's characteristics can help the family develop areas of

strength within the framework of their daily routine in caring for their child with a disability.

Some family characteristics which influence the family's participation in early intervention services are family structure, cultural traditions of a family, and a family's utilization of resources (Pearl, 1993). A traditional nuclear family of a married couple living with their children under age 18 is now just one of the various family structures present in American culture today (Pearl, 1993). Single adult parents raising their children alone or living with other adults who may or may not be related to the children can comprise a family. Married or unmarried teenage parents may raise their children sometimes with the assistance of their own extended families. One or both parents may raise their children in communal living arrangements. Often, married couples raise children from previous marriages, adopted children, or foster children. The early intervention service provider will encounter families having various structures. Within these various structures, families can help to be empowered by early interventionists to meet the needs of a child with a disability.

Within the family structure, cultural differences in values, approaches to child rearing, and language influence a family's involvement in early intervention services (Beckman et al., 1994). Often, many families participating in early intervention programs have different cultural or ethnic backgrounds from the majority of service providers in the community. Within their culture, a family will have their own verbal and nonverbal communication style which may differ from the communication style of the service provider. Role responsibilities and feelings about themselves and what others think about them affect how a family member responds to issues regarding their child with a disability. A family may place a special meaning on a child's illness or

delay based on their culture and traditions (Pearl, 1993). Communication styles, role responsibilities, and the effect of having a child with a disability within a family may differ from the experiences or perceptions of the service provider. Service providers are challenged to recognize their own cultural values in order to understand cultural values which differ from theirs. When cultural and ethnic differences are not recognized, service providers may assume goals of intervention for a family based on their own cultural background without fully acknowledging the family's strengths and needs within their unique background. Reaching a consensus between family members and between the family and the provider of early intervention services helps limit therapist directed goals. Collaboration and consensus on these goals and the means for accomplishing the goals are required within the early intervention team (Beckman, et al., 1994). The service provider who strives to work with families from a family-centered approach can help families affirm their own cultural identity and individual values in meeting their goals for their child with a disability (Beckman et al., 1994).

A family's ability to utilize resources impacts the functioning of their daily routine when they have a child with a disability. Families use concrete and emotional resources to maintain themselves in day-to-day functioning (Beckman et al., 1994). Food, shelter, clothing, and financial resources are concrete resources needed by families. Family members available to help with day-to-day functioning and support outside of the family are also concrete resources. Emotional resources include coping skills of the family members, the ability to resolve conflict, and the ability to achieve consensus among family members. A family adapting to the birth of a child with a disability who has limited concrete and emotional resources may have difficulty effectively coping with the

change in their family structure. Service providers may need to help families seek information on concrete and emotional resources available in their communities.

Family Empowerment

Empowerment means to authorize or enable (Webster's Dictionary, 1983). Within early intervention programs, family empowerment promotes self-determination, decision-making capabilities, and self-efficacy (Dunst, Trivette, Davis, Cornwell, 1988). Service providers can empower the relationship between infants and parents if they believe that parents are competent and have the capacity to take a positive, proactive stance when making decisions for their children with a disabilities (Kalmanson & Seligman, 1992). This stance is promoted when parents and caretakers are provided with information they are seeking to make decisions in meeting their own needs. They must feel that their decisions are attributable to their own actions. This creates a sense of control over life events (Dunst et al., 1988). Service providers in early intervention can enable parents through parent provider collaboration and provision of information to assist parents with decision-making.

Family-Centered Care

With an understanding of family systems theory and family empowerment, the service provider in early intervention is able to more fully address the needs and concerns of families from a family-centered approach. Within this approach, the service provider respects and recognizes the role that the family plays in the life of their child with a disability. The service provider's main goal is to support families in their natural caregiving roles by promoting the family as a partner in the care of the child (Association for the Care of Children's Health, 1989). Four practices comprising family-centered services have been defined by The Beach Center on Families and Disability (Murphy et

al., 1995). The first practice is inclusion of families in decision-making, planning, assessment, and service delivery at the family, agency, and systems levels. The second practice is the development of services for the whole family, not just for the child. Third, families' perceptions regarding goals and services guide practice. Finally, families' choices regarding their participation guide service provision. Within this definition of family-centered services, the family is an active member in service delivery and not a passive recipient. Pearl (1993) has outlined nine principles summarizing family-centered care:

1. Recognizing the family as a constant in the child's life, and intervention settings as temporary;
2. Facilitating parent/professional collaboration in the care of the child; in the development, implementation, and evaluation of programs for the child; and in the development of intervention policy;
3. Sharing information on the child's developmental status, behavior, and so forth in a nonbiased, supportive manner;
4. Implementing comprehensive policies and procedures that include emotional and financial services for families, as well as child-directed services;
5. Recognizing the individuality of families, including their strengths and different patterns of coping;
6. Understanding the developmental needs of delayed infant/toddlers and incorporating them into the service delivery system;
7. Encouraging parent-to-parent support systems;

8. Designing policies and procedures for comprehensive intervention systems in a manner that is flexible, accessible, and responsive to the unique needs of different families;
9. Recognizing and respecting cultural differences (p.88).

Impact of a Child with Disabilities on the Family

What impact does a child with disabilities have on the family? According to McDonald (1971) the observation that children with disabilities generally make handicapped families is almost a cliché today. Therefore, more and more parents are seeking help for their own personal and parental problems. Professional workers concerned with the habilitation of children with disabilities are increasingly recognizing that attention must not be given to the child alone, but also to the primary educators, namely the parents (Kotze, 1986).

Since the birth of a child is anticipated for several months, the parents, during this time, usually look forward eagerly to child's arrival and have bright dreams of its future. Kaslow and Cooper (1978) stated that a planned child is desired as the ultimate expression of a couple's love and dreams for the future. To many parents it seldom occurs that their child will be anything but perfect. Few parents are therefore prepared for having a child with disabilities, so it is easy to understand why many report being shocked and confused upon learning of their child's condition, that they experience feelings of disappointment, of embarrassment, of blame and guilt, of suspicion, of an inability and concern about the child and its future (Kaslow & Cooper, 1978; McDonald, 1971; Shea & Bauer, 1985). These feelings obviously influence the parents' relationships, especially their learning relationship with their child, for they are faced with difficult child-rearing conditions. In many instances these feelings originate due to

a lack of understanding their own attitudes, inadequate information about the child's problem and the absence of an educationally directed assistance program (Kotze, 1986).

General Behavior of Parents of Children with Disabilities

To enable the assistance-giver to render meaningful aid to parents of children with disabilities, it is necessary for the provider to be able to assess, recognize and anticipate behavior unique to the parents. It is also important to become more knowledgeable about the parents- about their hopes, joys, disappointments and frustrations (Kotze, 1986).

McCormack (1979) reported that while talking to parents of young children with mental retardation, she had been struck by their intensity, by a feeling of clinging desperately to hope in the face of odds. They seemed to laugh less. People who have lived for ten or twelve years with a child with disabilities can talk more easily about the child's idiosynerasies and laugh occasionally about the embarrassment and even distress they cause. The difficulties and the behavior problems have become more accepted as merely part of the child and there to stay (Shea & Bauer, 1985).

During the early years, parents are becoming aware of signposts that the child is different and it hurts less to ignore the differences or explain them away in normal terms, at least to outsiders. These realizations make some parents difficult and prickly companions at this time and relationships may suffer in the tense atmosphere (McCormack, 1979). The first few years are the hardest, not always because of any practical problem- indeed some children with disabilities will never be as manageable again as when they are small captives in pushchairs (Kotze, 1986). The greatest strains are the emotional ones of coming to terms with the problem and of learning to understand and live with the child. Not only will the way in which parents behave because of the

problems of the child differ, but also the nature of the various problematic educational situations will differ from family to family. It is important to note that the behavior and feeling of these parents are dependent on their total life situation such as the age of the parents, socio-economical status, religion, marital relations, personalities, the degree of the child's disabilities, etc. (Shea & Bauer, 1985).

What follows is the more or less general form of reactions of parents which may lead problems in the family and the development of the child with disabilities.

Shock and shattering of future perspectives. As indicated previously few parents are prepared for having a child with disabilities, therefore some of the first feelings they reveal are those of shock, disillusionment, bewilderment, dismay and disbelief (Shea & Bauer, 1985). Like most people in a crisis, parents may temporarily mispereeive reality, be unable to act, and experience confusion about their own and the child's future.

Embarrassment. According to McDonald (1971), embarrassment is one of the most common disturbances found with parents of children with disabilities. Some reveal feelings of discomfort, distress and disturbance while others feel like going to pieces at the thought of their relatives or friends knowing about them having a child with special needs (Shea & Bauer, 1985).

Denial of the problem. Many parents deny the existence of the child's disability. These parents usually feel threatened, insecure and confused. They are afraid of being stigmatized and therefore refrain from mentioning their problem to others, or they repress all notions that their child differs from other children (Shea & Bauer, 1985). In the struggle to convince themselves that there is nothing wrong with the child. Some parents do diagnostic shopping, trying to find a professional who is of the same opinion as they are that there is nothing wrong with the child.

Projection of blame and suspicion. A common reaction of parents with an exceptional child is to project blame for the situation on to something or somebody else (Kotze, 1986). For example, blame may be projected on to the doctor who brought the child into the world. Sometimes one parent becomes suspicious of the other parent, or seeks to place the fault on his/her relatives. These kinds of reactions usually result from a lack of information about the child's problem and the causes for the situation (Shea & Bauer, 1985).

Fear and anxiety. Deep concern, matching fear and anxiety about the child's welfare and future is a common parental reaction (Kotze, 1986; Shea & Bauer, 1985), so it is natural for them to ask such questions as: "Will my child ever be able to cope with life? What will happen to him when we are not there anymore?" If not properly directed, parents' concern may sometimes result in oversolicitousness and overprotection, which may rob the child of his opportunities for developing independence (McDonald, 1971).

Guilt and self-reproach. Parents often report that they feel they are to blame for what has happened to their child. Some feel that perhaps they should have done something differently or that the handicapping condition is in retribution for a misdeed (Chang, 1992). One of the major causes of such guilt feelings is the lack of accurate information about the nature of the child's handicapping conditions, its causes and its prospects (Kotze, 1986).

Impact of a Child with Disabilities on the Family

As has been postulated previously the presence of a child with disabilities may lead to severe educational and family burdens, and it may have an important impact on the family life, so much so that it influences the family life cycle in a negative sense (Kotze,

1986).

Families with a child with special needs differ only in degree from other families (Harris, 1983). However, the special needs of an exceptional child may serve to intensify the strains that exist in every family, disrupting a more or less harmonious functioning of the family as a whole (Kotze, 1986).

In this connection the following can be mentioned:

1. Additional financial pressure

Parents may exhaust themselves financially in the trek from one professional office to another seeking diagnostic and treatment help (Harris, 1983; Turnbull & Turnbull, 1997). The family may even, at a high financial loss, have to move houses, or change occupations in order to be nearer to medical and therapeutic facilities.

2. Restriction of social activities

Many parents report a drastic restriction of social activities of families of exceptional children. The more or less uncontrollable behavior of certain children with disabilities forces the parents to avoid visiting friends and relatives, or to leave the exceptional child at home. Feelings of shame, embarrassment, inferiority or guilt, the experience the being stared at, experience as being different, may further contribute to less free social contact (Kotze, 1986; Turnbull & Turnbull, 1997).

3. Role-change

In many instances the father, mother, and other children are burdened with tasks and responsibilities outside the normal functioning of the family. This can lead to fatigue, tension, jealousy, neglect, quarrels, antagonism and other disharmonic relations within the family (Kotze, 1986; Turnbull & Turnbull, 1997).

4. Continuous demands

Featherstone (1980) summarized the normal progression meant in which ordinary parenting follows a natural cycle that respects our mortality. It means that parents are usually young, healthy, and energetic, while young children require vast amounts of exhausting physical care. As both grow older, this demand tapers off, and eventually the children grow more independent. The prolonged dependency of many children with disabilities sharply alters the mother's role because she must provide basic physical care and supervision for the child for many years, perhaps her entire life (Harris, 1983; Kotze, 1986; Turnbull & Turnbull, 1997).

In Singer and Farkas' (1989) study, 27 mothers of infants and children with tracheostomies were given a modified version of the Impact-on-Family Scale as part of a study designed to describe maternal perceptions of the impact of infant disability on various components of family life. Maternal perceptions of intensity of stress in different life areas were also examined as a function of salient medical, social, and demographic factors associated with the child's disability. All mothers were requested to complete a modified version of the Impact-on-Family Scale. The original scale was designed to quantify the impact of childhood illness on family functioning in a 24-item, Likert-type questionnaire. The scale factors into four subscales which measure the impact of chronic illness and disability on various aspects of family life, namely: financial status, family social interaction, subjective distress, and a positive sense of mastery. A total score also yields a general measure of impact.

Mothers reported a high degree of stress related to caring for their young children with developmental disabilities, as indicated by their responses to the Impact-on-Family Scale. In keeping with other research (Harris, 1983; Kotze, 1986; Turnbull & Turnbull, 1997), respondents reported that the child's disability affected all aspects of family life.

Problems with family and social interaction and with finances were those cited by the majority of the mothers in this sample. The most salient negative impact involved financial status. Sixty-seven percent of respondents felt that their child's disability caused financial problems for the family, 60% felt that time was lost from work because of necessary care, and 59% stated that additional income was needed to cover medical expenses. Twenty-six percent of the mothers stated they had cut down on hours worked to care for the child, and 25% said they had stopped working to provide care. These financial problems and changes in employment are reflected in some of the items pertaining to family and social interaction. Fifty-five percent reported difficulty in finding someone reliable to care for the child. Forty-four percent said they were unable to travel out of the city because of the child's disability.

Other negative impacts involved emotional distress. Fifty-nine percent of these mothers felt they lived on an emotional roller coaster; they felt okay when they were able to manage and in crisis when they were not. Fifty-five percent agreed or strongly agreed that they worry about what will happen to the child in the future. Fatigue was reported by 41% to be a problem. Eleven percent said that the care involved made them live life from day-to-day and not plan for the future, while 22% felt that no one understood the burden of caring for a child with disabilities.

Expectations about family life and activities did not appear to be dampened completely by the disability. Ninety-three percent said they try to treat their child as if he/she were a normal person. Seventy-five percent said the disability did not affect their desire to go out and 63% reported that the care of a child with disabilities had not decreased the amount of time they spend with family and friends. However, family and social life were affected by the care of a child with disabilities. Fifty-five percent said

they sometimes have to change their plans at the last minute because of the child's state. Forty-eight percent said that the family gives up things because of the disability. Forty-one percent of these mothers agreed or strongly agreed that they had thought about not having more children because of their child's disability. Mothers also expressed concern about how the child with disabilities should be treated. Forty-eight percent said they sometimes wondered if the child should be treated specially or the same as a normal child.

Despite the problems these mothers experienced, the majority indicated that the experience had been positive. Eight-five percent said that their families were closer because of what they had shared. Ninety-six percent of these mothers also indicated that they shared their problems with their partners, while 89% of mothers reported that their relatives had been understanding and helpful with the child. Every mother in the sample agreed or strongly agreed that learning to manage the child's disability had made her feel better about herself, thus demonstrating a strong sense of mastery despite the problems of caring for a child with disabilities. Additionally, married caregivers felt more financial stress and more stress with family and social interactions. Being married was also associated with high levels of subjective distress. Surprisingly, high social class was correlated with higher levels of subjective distress. Although there were only 27 mothers in this study, this gives some indications of the impact having a child with a disability has on the family.

While both research and clinical evidence is available relative to the problems and stress these families face, some studies indicated that many families do not perceive any negative effects stemming from their child's disability. Dunlap and Hollinsworth's (1977) findings indicate that a large majority of parents do not feel the child with special

needs has any effects on their family. Korn, Chess, and Fernandez (1978) found that in approximately 75% of the families studied in the Rubella Birth Defect Project the exceptional child did not impair material quality or family patterns.

Blackard and Barsh's(1982) study examined what extent professionals were able to predict accurately parents' responses to a questionnaire on the impact of the child with special needs. The study was designed to answer three questions: (1) How do parents describe their exceptional child's impact on their family in terms of family relationships, community resources and acceptance, home teaching, and behavior management techniques? (2) How do professionals predict what parents will describe as the impact their exceptional child has on the family? (3) To what extent is there agreement disagreement between parents' responses and professionals' predictions?

Two groups of subjects, one parents of children with severe handicaps, and one special education professionals enrolled in training workshops conducted by the researcher under a training grant. All of the children were enrolled in a school program located in Seattle, Washington. The children resided throughout the greater Seattle area, which included urban, suburban and rural settings. Out of the total subject pool of 45 parents, 43 (40 mothers and 3 fathers) completed a family information questionnaire. The age range of exceptional children was 3 to 18 years, with 29 boys and 14 girls. Thirty-five of the children were Caucasian, four were Asian, three were Black, and one was Native American. The majority of the children had multiple disabilities, with hearing, vision, motor, and/or speech impairment, in addition to severe mental retardation. Most of the children were living at home with their natural parents; four children resided with foster parents. One 12-year-old boy had not previously been enrolled in school. Four children had previously been institutionalized.

A total of 101 professionals completed the questionnaire. They were instructed to answer the questions as they felt parents would answer them. Six different disciplines were represented: 49 teachers, 10 social workers, 8 speech and language therapists, 8 counselors/psychologists, and 18 administrators. The professionals worked with children with severe handicaps in Washington, Idaho, Wyoming and Montana. Most worked in large cities, although some rural areas were represented.

A family information questionnaire consisting of 32 questions was developed and used to gather information from parents and professionals. The results indicated that there were significant differences between parents' and professionals' responses. When compared to parents' actual responses, professionals tended to overestimate the negative impact of the exceptional children on family relationships. They overestimated the extent to which parents reported difficulty finding special schools and securing medical and dental care for their child with special needs. Professionals also overestimated the extent to which parents reported siblings of the exceptional child being teased in the school or neighborhood. Additionally, professionals also underestimated parents' ability to use appropriate teaching and behavior management techniques in the home.

What has been mentioned concerning the feelings and behavior of parents of exceptional children, influence their relationships, and may affect their abilities to help their child learn. Many situations are of such a nature that parents are at a total loss about their child's upbringing and therefore in need of the aid of professional educators.

Current Research in Early Intervention

With the emphasis of family-centered early intervention services, service providers, administrators, and researchers have begun to turn their attention to measuring the effectiveness of family-centered care within programs. In assessing whether service

providers and families engage in family-centered services within early intervention, researchers have investigated attitudes of families and of service providers.

Family Perceptions on Family-Centered Early Intervention

Early intervention services offer benefits to babies with severe handicaps, to their parents, and to society; yet because of the special demands of adjusting to the birth of a baby with a disability, parents may have difficulty in recognizing and accepting these benefits. Calhoun et al. (1989) studied parents' concerns about early intervention. The study focused on the concerns of a group of parents as they explored early intervention services for young children with severe handicaps. Their worries, questions, and expectations about early intervention programs were described. In addition, their reactions to the postenrollment experience were described.

Within the study, 15 parents of children with severe disabilities were interviewed by a special educator and a clinical psychologist both of whom were affiliated with a university and did not provide direct service in early intervention programs. Four couples and seven single individuals participated in 90-minute interviews. All parents referred to a new early intervention program for children in the age range birth to 3 years, with severe or profound disabilities. Twelve parents had children enrolled in the program, and three had decided not to enroll their child. Interviews were conducted after enrollment decisions about an individual child had been made. The parents were asked to answer six questions. The first question addressed was, "When did you first become aware of your child's special needs?" The second question was, "How was this information presented to you?" The third question was, " What information did you receive about early intervention services?" The fourth question was, "What aspects of early intervention services interested you? Worried you?" The fifth question was,

"What advice did you receive?" The sixth question was, "As you considered whether or not to enroll your child in a special program, what things did you think about?"

The interviews revealed these concerns: accepting a place in an early intervention program underscores the seriousness of a child's disability; the decision to enroll a child in an early intervention program may seem at odds with the family's decision to care for the child at home; enrolling a baby in a structured educational and therapeutic program seems age-inappropriate; and the child's health and safety or the equilibrium of the family might be endangered. Once an enrollment decision is made, however, families perceive clear benefits, including the ability to lead a more normal life. Implications for professional practice include flexibility in programmatic offerings and the importance of an up-to-date referral network.

Bailey and Simeonsson (1988) developed the Family Needs Survey to determine the needs of parents of children with disabilities. The survey was sent to 34 two-parent families participating in home-based infant intervention programs in North Carolina. The survey had a 35-item scale with the following categories: (a) needs for information about their child, how to teach or interact with their child, services available now and in the future; (b) needs for support from early intervention service providers, the opportunity to meet and interact with other families with a child with a disability, and support of family, friends, and religious organizations; (c) parents' needs for help in explaining to others their child's condition or disability; (d) assistance in accessing community services; and (e) financial needs ranging from basic needs such as food to transportation, job counseling, and financially caring for their child with a disability. A rating scale of 1 to 3 for questions in each category was used in the following order: 1 = I definitely do not need help, 2 = Not sure, 3 = I definitely need help.

The survey was sent to fathers and mothers. They were asked to complete the surveys separately. The most frequent needs reported by fathers and mothers were information about how to teach their child, services now available and services that would be available in the future, and reading material about parents who have a child with a similar disability. Mothers also wanted information about their child's disability, opportunities to meet other parents, more time for themselves, and financial help for basic expenses. The parents were also asked to list their five greatest needs as a family. Sixty percent of the needs determined by the open-ended question reiterate needs expressed in the survey. The other 40 percent of the needs identified by the open-ended question were not identified on the survey reflecting a total of 39 different needs. The most common concerns that had not been addressed on the survey were need for information about the future development and skill status of their child with a disability. Thus, the Family Needs Survey identified that most parents want more information on how to help their child learn, more information on services available, and they want to talk with other parents in similar situations. Interestingly, service providers cite lack of knowledge as a family barrier to family-centered care (Bailey et a., 1992; O'Sullivan & Mahoney, 1990), while parents cite the need for more information in caring for their child with a disability. The inconsistency suggests that service providers may not be providing information to families in a way that is helpful to them.

Mahoney et al. (1990) studied mothers' perceptions of family-focused early intervention. In this study Family Focused Intervention Scale results for a national sample of mothers of children currently enrolled in early intervention were described. Within this study, there were two purposes. The first was to examine three assumptions that appear to underlie the family-focused agenda of PL99-457: (1) few parents are

currently receiving sufficient services to help them adjust and cope with the burdens associated with raising and caring for their child with disabilities; (2) parents who are not receiving family intervention services have needs for, or would like to receive, additional family services; (3) children and families derive greater benefit from intervention when parents receive family-focused intervention services.

The second purpose of this study was to examine how variations in several dimensions of early intervention programs relate to the family-focused orientation of their services. In particular, the authors (Mahoney et al. 1990) attempted to determined the relationship of the age of the children being served, the location of intervention services, the severity of the children's disabilities, and use of IFSPs to the family-focused orientation of intervention services.

The Family Focus Intervention Scale was completed by a systematic sample of 503 mothers of birth to 6-year-old children with disabilities who were enrolled in intervention programs throughout the United States. Questionnaires were distributed by a group of professionals who belonged to the Division of Early Childhood (DEC) of the Council of Exceptional Children (CEC). A DEC membership list was obtained from CEC; it included members who indicated that their professional interests related to providing direct services to young children with disabilities. From this list of approximately 1,800 professionals' names, 1,000 names were randomly selected. Of the 1,000 professionals, 41 percent agreed to distribute the parent survey. Of the 820 parent surveys that were distributed, 503 were completed and returned.

The results indicated that the most common services were providing parents information about their child and helping parents and families become involved in the early intervention system. Resource assistance and person-family assistance were the

least common services provided. Family-focused services were reported more by mothers of children birth to 3 than 3- to 6-year-olds. In addition, the result did prove that programs with home-based components and programs with Individualized Family Service Plans tended to have a greater family-focused orientation. Generally, the need for family services was greater than that currently being received. However, the more family intervention services mothers received, the more they perceived their intervention programs as benefiting their families and their children.

Summers et al. (1990) studied family and practitioner preferences on the Individualized Family Service Plan (IFSP). The first question addressed was, "What are families' and practitioners' opinions about the expected outcomes for families of early intervention?" The second question was, "What are families' and practitioners' preferences for the methods to be used in gathering information on family strengths and needs for the IFSP?"

The authors (Summers et al., 1990) chose a qualitative design, implementing focus groups to identify the preferences of families and service providers. Nine focus groups were developed: two national leadership groups; three state groups; and four groups representing local early intervention programs in rural, urban, and suburban areas of Kansas. All groups were purposefully a mix of family members and practitioners in hopes of enhancing dialogue and in-depth data. A moderator facilitated discussion and an observer took notes and operated an audiotape recorder. The observer's notes were sorted by word and concept to form categories which were then grouped into areas. The three major areas that evolved are early intervention program principles, identification of family strengths and needs, and expected outcomes for families. The most frequently mentioned area in program principles was the need for sensitivity and respect for families.

With family strengths and needs, families emphasize the importance of informality and nonintrusive questions as well as the willingness of the service providers to take the time to develop rapport with families. In the area of expected outcomes, the families' need for information of all kinds such as normal child development, their child's special needs, and available resources, was identified. Enhancing family skills in meeting their child's basic needs and support in negotiating the service system were also recognized as expected outcomes. As seen in this study and the study by Bailey and Simeonsson (1988), families expressed the need for information about their child and available resources. They expressed a need for sensitivity and respect in a nonintrusive manner when working with early intervention service providers.

Harrison et al. (1996) studied families' perceptions of early intervention services for children with hearing loss. The purpose was to investigate the effects of Part H of PL 99-457 on the families of children with hearing loss. A national survey was distributed to families of preschool-age children who are deaf or hard of hearing to investigate parent's perceptions of family involvement in early intervention programs, as intended by the Individuals with Disabilities Education Act. Questions were organized into five categories: (1) the family's experiences with their early intervention program, (2) information provided by their early intervention program, (3) experiences in writing the Individualized Family Service Plan, (4) demographic information concerning the family, and (5) demographic information concerning the child.

Four hundred and thirty-five surveys were returned from all geographic regions of the United Sates, representing parents from a wide variety of backgrounds. Regarding parent reaction to early intervention programs, parents whose children had profound hearing loss responded in a similar pattern to those whose children had severe, moderate

or mild hearing losses. Responses to the question were also analyzed by the length of time the child had been enrolled in an early intervention program. Length of enrollment was not a factor in the degree to which the program interfered with daily routine. Slightly more than 90% of the parents agreed or strongly agreed that their child's early intervention program had encouraged them to be the major decision-makers regarding their child's education therapy program. When queried regarding the types of information provided by the child's early intervention program, 80% reported being told of the effects of hearing loss on speech and language. Additionally 70% of parents were made aware of all the communication options when entering the program. A slight discrepancy concerning parent expectations of meeting other parents of children with hearing loss and what their child's program actually offered was reported by the parents. Of the 83% who expressed interest in meeting other parents, approximately 76% received assistance from the program in doing so.

Regarding the IFSP process, of the families responding, 59.8% reported that they participated in developing a written IFSP that addressed their needs, concerns, and priorities. Within this study, the demographic data of all respondents were analyzed to determine whether the family's ethnic background or the mother's or father's level of education was a factor in the development of the IFSP. The results indicated that neither ethnic background nor parent's education appeared to be a factor. In general, results indicated that although almost one-half of the respondents were not involved in the development of an IFSP, those who responded reported overall satisfaction with their early intervention program.

Able-Boone et al. (1992) studied parents and service providers' viewpoints regarding family-centered provision of early intervention services and how services

should improve. Through a systematic sampling procedure, a total of 670 professionals and 1,068 parents in Colorado were mailed a survey which had been developed through interviews with families concerning implementation of PL99-457. The survey addressed five areas: (a) accessing services, (b) delivering infant/toddler services, (c) identifying family priorities and resources, (d) developing and implementing Individualized Family Service Plans (IFSP), and (e) coordinating services. For each item, participants rated the current or present situation and then they rated how they would ideally like services to be implemented on a 5-point scale ranging from "not at all" to "always". The authors found that parents reported more positive views of the current accessibility of services than service providers. Parents rate the ideal status of IFSP development significantly higher than service providers. Service providers rate current service coordination higher than parents, and parents rate ideal service coordination higher. An overall finding, when all items were combined, is that current status ratings are lower than ideal ratings. Significant differences are found in the parents' perceptions of services as a function of where they lived, as a function of ethnicity, and by the type of program in which they had enrolled their child. Parents from rural areas have more positive perceptions of service coordination than parents from urban areas. Non-Caucasian parents rate their satisfaction with current infant services higher than did Caucasian parents. Parents who had children enrolled in home-based programs have more positive views of the current accessibility of services and rate the service delivery system higher than parents of children in center-based programs. This study shows a discrepancy between ideal practices and current practices as perceived by parents and professionals with parents dissatisfied with the current IFSP process and service coordination. Parents' perceptions are also influenced by whether services were

received in the home or center-based, by ethnicity, and by whether parents lived in an urban or rural area.

McWilliam et al. (1995) used both a written survey and a semi-structured interview format with parents of infants, toddlers, and preschoolers receiving early intervention services in North Carolina to evaluate families' perceptions and satisfaction of early intervention services. In order to maintain confidentiality about what families were enrolled in early intervention, community programs were used to recruit families. The researchers obtained mailing lists from all the State agencies known to be providing early intervention services. Agency personnel provided the numbers of families served by each program on the lists. Every program was sent a packet containing instructions for the program, a letter to families, and the questionnaire. One survey was sent for every 15 families served by each program, with a minimum of two surveys per program. The program staff were instructed to select families randomly without regard to socioeconomic status (SES), race, satisfaction with the program, or child diagnosis. Through systematic selection, 1,540 families were mailed a 30-item questionnaire which had been developed by the Children and Families Committee of North Carolina Interagency Coordinating Council. Results showed the families perceived that service providers try to help with what the family told them they needed 65 percent of the time, while 16 percent of the families felt that service providers try to help only with the child's needs. Approximately 97 percent of the families reported that service providers give them opportunities for decision-making regarding services and goals, and that service providers support family decisions. Another finding was that 55 percent of families felt that services have improved since they first began receiving them.

Within this study, semistructured interviews with six families were completed. The questions covered child and family, services the child or family had received, how service providers treated the family, inclusion, comprehensiveness of services, payment for services, and anything else the families wanted to include. Families expressed much support from individual service providers and were generally pleased with the quality of early intervention services. However, families reported difficulty in obtaining services they felt are appropriate for their child.

Parents' perspectives of informational needs in relation to ethnic differences have been investigated by Sontag and Schacht (1994). The purpose of the study was to determine parent perceptions of their information needs, their sources for information, the nature of parent participation in early intervention, and the cultural differences in parent response due to ethnicity. The subject sample consisted of 536 parents who had an infant or toddler with developmental problems, who agreed to be interviewed, and who were also representative of the diversity of the population in a southwest state including White, Hispanic, America Indian, Black, and Asian parents. Interviews were conducted with parents in their homes. Of the many responses, parents most frequently indicated a need for information about the availability of services. Parents reported that the medical doctor was their main source of information. Parents had problems receiving information that sometimes was confusing or conflicting, receiving the wrong information, or not being told what resources were available. Next, parent participation in early intervention services was assessed. Taking their child to therapy services constituted 83 percent of parent participation. Only 37 percent of parents attended an agency meeting where they discussed services and their child's goals and signed papers to that effect. Parents helped make programming decisions 89 percent of the time. In

regards to identifying activities to help their involvement, the parents wanted all the information about services made available.

Ethnic group differences were that the American Indian and Hispanic groups needed to know how to get information regarding services as compared to the White group. The American Indian group requested information on their rights for their child and reported that they did not know why a service could not be provided. In the area of parent participation, a majority of parents reported that they helped make decisions about their child's program. However, fewer parents of minority children were engaged in this activity as compared to parents in the white group. American Indian parents reported more often that they did not have one person who coordinated their services and that they had difficulty understanding the professional language, which limits their participation in their child's program.

This study by Sontag and Schacht (1994) identified parents' need for information, specifically on the availability of services. Regarding parent participation, driving their child to therapy is much different than service providers and families collaborating as part of family-centered services. When parent participation is limited, family priorities and concerns may not be fully addressed. The needs cited by ethnic groups in this study indicate that parents were not receiving desired information from service providers, or that they were not receiving the desired information from service providers in a way that enabled them to make choices regarding services.

Wang (1996) studied early intervention services for young children with intellectual disabilities in Taiwan. A needs assessment was conducted to identify the needs perceived by families with youngsters with intellectual disabilities and the existing resources available in Taiwan. The study was also intended to explore the risk factors

which had prevented families from being served and the degree of satisfaction regarding the services families received.

A total of 879 parents of children under six who showed obvious intellectual disabilities and 58 service providers were surveyed. The results indicated that families with young children with disabilities expressed anxious needs about indirect services for their children and wanted more information. Financial assistance from the government and support services provided by parent groups were also needs reported by the families. Even though parents showed their satisfaction with services, mainly provided by private groups, the discrepancy between needs expressed by parents and the existing resources was obvious. The risk factors preventing families from receiving services included limited or no community resources available, inadequate knowledge of existing resources, difficulties in finding services of good quality, transportation problems, high cost of services, and high selection criteria set by agencies. Families who had younger children with disabilities or with more severe and complicated conditions, parents who had less education, families which had lower incomes or resided in the area where community resources were limited were all more at-risk to be under-served. The study thus suggested the government needs to initiate well-planned public awareness programs, child find and identification systems, comprehensive and coordinated services, and personnel preparation programs.

A review of studies on family attitudes toward family-centered services in early intervention was presented earlier (Able-Boone et al., 1992; Bailey & Simeonsson, 1988; Calhoun et al., 1989; Harrison et al., 1996; Mahoney & O'Sullivan, 1990; McWilliam et al., 1995; Sontag & Schacht, 1994; Summer et al., 1990; Wang, 1996). Most of the parents/caregivers expressed a need for information especially regarding the future of

their children, in meeting their children's needs, in coordination of services, in developing the IFSP, and in knowing what services are available. Parents also want service providers to develop a rapport with their families and to express sensitivity and respect when they work with families. Otherwise, parents are expressing, to some extent, satisfaction with family-centered practice within early intervention services (McWilliam et al., 1995).

Service Providers' Perceptions on Family-Focused Early Intervention

Humphry and Geissinger (1993) studied service providers' attitudes about family-centered services. Three hundred and nineteen participants of the study were occupational therapists across the United States who attended a three day workshop entitled "Family-Centered Care: An Early Intervention Workshop," sponsored by the American Occupational Therapy Association (AOTA). Content of workshop included information on family systems, working with families, and family-centered services. The authors believed that service providers' attitudes about families impacted their ability to provide family-centered care. The goal of the workshop was to change service providers' attitudes by having parents of children with special needs participate with service providers in small groups. In conjunction with AOTA, the Carolina Institute for Research on Infant Personnel Preparation (CIRIPP) evaluated the effectiveness of the workshops. When evaluating effectiveness, the authors considered possible sources of influence on attitudes, such as personal and professional experience, and the current work experience or role of the practitioner.

A questionnaire, Issues in Early Intervention, was developed and utilized to measure participants' attitudes related to family-centered services and sources of influence on attitudes. Occupational therapists' attitudes on pretest, posttest, and a post-posttest were

measured. A multiple regression analysis was selected for analysis of the data. Results were that the state or region of the workshop participants had the strongest influence on the occupational therapists' scores. One reason cited by the authors for this finding was that states vary in their level of implementation of IDEA. Also, program administrators and service provider teams varied in their understanding and endorsement of family-centered services. To a lesser extent, occupational therapists with more pediatric experience and with advanced degrees expressed more consistent family-centered attitudes. The authors suggested that occupational therapists with more years of experience may be able to step back and holistically look at their role with a family, whereas, occupational therapists new to providing services for children and their families may emphasize mastering child-focused intervention techniques. Occupational therapists with advanced degrees may have been introduced to ideas supporting a family-centered approach. The Issue in Early Intervention questionnaire used in this study showed that environment and experience affect attitudes of early intervention service providers. A further study of other factors influencing service providers' attitudes and behaviors, such as their personal value system and opinions of family functioning, is warranted (Humphry & Geissinger, 1993). In meeting the emphasis toward family-centered care, state early intervention programs will be challenged to address their level of implementation of Part C within IDEA, and the experience and educational background of early intervention service providers.

Another study used a survey to determine to what extent early intervention service providers have shifted from child-focused services to family-centered services (Mahoney & O'Sullivan, 1990). The survey was distributed to personnel who provide services for children from birth through age 6 years in six randomly selected states. One state was

randomly selected from each of six geographic regions of the United States: New Hampshire from New England; Virginia, the East Coast; Georgia, the South; Michigan, the Midwest; North Dakota, Plain states; and Colorado, the West. For each of the states, officials from state departments responsible for early intervention services were contacted and asked to participate. A total of 989 service providers for children with disabilities examined the degree to which early intervention activities focus on the family. The children receiving services were placed in subgroups of children age 0 to 3 and children age 3 to 6. The survey assessed perceptions of the value of working with parents, time devoted to family-focused activities, kind of services offered, achievement of objectives, and factors impeding services.

In the first part of this five-part survey, service providers were asked to select the three most important goals of services provided to children and their families by checking three goals from a list of 14 goals. Fifty-three percent of the goals were child goals such as the promotion of general development and remediation of the disability, 25 percent were service goals such as assessment, and 22 percent were family goals such as promotion of family activities with the child and provision of information. The three most frequently selected goals were the promotion of general development, assessment, and the remediation of the disability. The second part of the survey addressed the amount of time service providers devoted to family activities. Providers spent approximately 2 hours per case each week on family activities. In the 0 to 3 subgroup, 61 percent of service providers worked both in homes and center-based settings, and they spent 62 percent of their time with the parent and child jointly. Service providers of 3 to 6 years old children spent 12 percent of the time with the parent and child jointly, and 84 percent of the time service providers worked with the child in center-based settings.

Providers spent their time with families for instructional activities that parents could implement with their children. Next, educational and supportive family service activities were measured. In this category, the authors found that service providers of children age birth to 3 years engaged in more family intervention activities, which included teaching the family instructional methods and interaction skills as well as helping the family to identify resources. On the fourth part of the survey, service providers reported the number of families with whom they were meeting at least five family objectives. Service provider focus groups developed the content encompassing family objectives which were increasing parent acceptance of the child's disability, being a friend to the parents, helping the family adjust, helping the family understand their child's disability, and preparing parents for their child's future. Service providers reported that they successfully met five family objectives with about two-thirds of the families with whom they worked. The fifth part of the survey addressed factors that impede services. Service providers identified an inadequate budget, the need for additional staff members, and a need for training to work with parents and families.

Services continued to be child-focused for a majority of the participants in this study's sample. Most goals were child-focused as seen by service providers most frequently selecting improved general development and remediation of the disability as the goals. Service provider time was spent with the child instead of with the child and family, especially in the 3 to 6 years old subgroup. In both subgroups, the authors questioned whether the time spent with the family was dedicated to collaborating with the family in meeting family goals as the time spent with families was for instructional activities and not for other family support services. This study suggests that a theoretical change regarding a family-centered service delivery model has not occurred

for a majority of service providers.

Mahoney and O'Sullivan (1990) identified three problems affecting family-centered services. The first is that service providers do not spend enough time with the family working toward family objectives. The second problem is the lack of preparation of service providers to be family-centered with some service providers reporting that they rely on their intuition in providing services. The third problem is a lack of resources and validated programs and procedures for implementing family-centered services. Mahoney and O'Sullivan suggest that solutions are to adapt intervention models so service providers spend more time with the family, to address personnel preparation and continuing education toward family-centeredness, and to use a curricula emphasizing family-centered care. These solutions will require state level and administrative support to be successful in meeting family needs.

Bailey et al. (1992) found that "professionals are being told that early intervention must be family-center (p.298)." The authors used a rating scale to determine the perceptions of service providers toward family-centered services. In light of the expected role change of the service providers following implementation of PL 99-457, the study addressed three questions. First, what is the current status of a family-centered approach in early intervention programs? Second, do professionals perceive a discrepancy between current and ideal practices? Third, what do professionals perceive to be the barriers that make it difficult to achieve ideal levels of family involvement? Service providers in four states rated current program practices of family support. To measure the current status of the family-centered approach, rating scales of 1 to 10 were used with 1 reflecting services controlled by professionals and 10 reflecting services where parents were allowed choices and responsibility. The four dimensions of family-

centered approach measured were parent participation in decisions about the child assessment process, parent involvement in child assessment, parent participation in the team meeting and decision making, and provision of family services. One hundred and eighty service providers circled a range within which their program currently involved families in these four areas. Then service providers wrote the number that reflected how their program typically operated and the number that reflected how they believed families should ideally be involved. If service providers had a discrepancy between their rating of typical service provision and ideal service provision, they were asked to identify barriers that made it difficult to implement family-centered care.

One hundred and eighty service providers described the overall range within which their program involved families as between 3 and 7. The range of typical family involvement is 4-5 showing a moderate degree of family involvement. The ideal roles of families were rated in the 7-8 range reflecting a desired high degree of family involvement. Family and systems barriers were cited as limitations to family involvement. Specifically, family barriers such as family knowledge or skill are an obstacle due to parents lack of understanding of information concerning early intervention. Family attitudes are also an obstacle due to parental preferences, desires, and opinions. System barriers included institutional obstacles resulting from state or administrative policies, lack of resources (staff, time, and money), and established patterns of service delivery which are inflexible. Service providers expressly mention inconsistent perspectives between administrators and providers as a major limiting factor, with administrators maintaining a child-focused service provision perspective.

The identification of these family and system barriers shows that state programs have encountered obstacles in implementing family-centered care as provided for under

IDEA. Within this sample, a family's lack of knowledge and their attitudes are identified as barriers which indicates that a family-centered philosophy, embedded in family systems theory and family empowerment, has not been adopted by all service providers in early intervention service provision. Systems barrier findings of this study indicate that not all policies and practices are perceived as family-centered.

Common problems surface in these studies of service providers' perceptions on family-centered care (Bailey, Buysse, Edmondson, & Smith, 1992; Humphry & Geissinger, 1993; Mahoney & O'Sullivan, 1990). Lack of administrative support, perceived lack of interest and knowledge on the part of the parents, and limited inservice training in working with children and their families are problems reported by service providers. Service providers are more comfortable staying with child-focused service delivery rather than adopting a new philosophy when they are unsure of their training and support in this area. The perceived lack of parent interest and knowledge by service providers is evidence of a gap between their perceptions and the family-centered approach envisioned in IDEA.

When PL99-457 was passed in 1986, lawmakers wrote into policy family centered care through family participation. Reviews of service providers' perceptions and families' perceptions suggest that the theory of family-centered care has yet to be widely adopted by most service providers in early intervention. Approaches undertaken to determine if service providers follow a family-centered approach include measuring the impact of a workshop on family-centered attitudes, use of rating scales to measure the perceptions of service providers, and surveying service providers to see what extent their practices are family-centered. Service providers' perceptions are that most service delivery is not family-centered (Bailey, Buysse, Edmondson, & Smith, 1992; Mahoney &

O'Sullivan, 1990).

Parents' Perceptions of Early Childhood Integration

Early interventionists increasingly are focusing on the needs of families of children with disabilities. Recent publications suggest that services to families should be individualized and based on a systematic assessment of family needs (Bailey et al., 1986; Turnbull & Turnbull, 1986). Furthermore, family services should consider contextual variables that might affect family outcomes or create unique family needs. For example, family economic status, cultural background, and community or religious influences may each affect family needs. Likewise, different kinds of programs (e.g., home-based versus center-based) may differentially affect family outcomes (Moran, 1985).

One such contextual variable that is likely to contribute to unique family needs is integration (Bailey & Winton, 1987). Several publications have suggested a number of both positive and negative outcomes for families associated with integration (Cansler & Winton, 1983; Turnbull & Blacher-Dixon, 1980; Winton, 1986). For example, at least six potential benefits for families of children with special needs could occur: Parents may (1) develop a more positive attitude toward their child with disabilities if that child functions successfully in a normalized environment; (2) interpret their child's accomplishments and failures within a 'real world' perspective; (3) improve their knowledge of normal child development; (4) become more likely to encourage their child to engage in chronologically age appropriate activities; (5) improve their self-perceptions; and (6) feel less isolated due to increased opportunities to interact with other parents of children with and without special needs (Bailey & Winton, 1987; Reichart, Lynch, Anderson, Svobodny, DiCola, & Mercury, 1989).

Potential costs for families of children with special needs in integrated settings

include: (1) the daily reminder of discrepancies and delay in development; (2) stigmatization or rejection by families of children without special needs; (3) a lack of interests or problems in common with other families; (4) concerns about whether their child is receiving sufficient specialized treatment that might be available in a self-contained program; (5) the need to provide specialized therapeutic services (e.g., physical therapy, speech-language therapy) at their own expense; and (6) an expectancy that the child can and should function in a normalized environment, creating stress if the next environment is not willing or able to offer integration as an alternative or if, in fact, full integration may not be the most appropriate option at a later time (Bailey & Winton, 1987; Peck, Carlson, & Helmstetter, 1992; Reichart et al., 1989; Turnbull et al., 1982).

Families of children without disabilities also may experience different effects of integration. For example, possible benefits to families of children without special needs include: (1) an experiential basis for teaching their own children about differences in growth and development; (2) a greater understanding of persons with special needs; (3) a greater sensitivity to the needs of families of children with disabilities; and (4) inspiration and hope for families of children without disabilities striving to cope with problems associated with rearing their own children through observing families who cope with having a child with special needs (Bailey & Winton, 1987).

Likewise, negative outcomes for families of children without disabilities may occur as a result of integration. These may include: (1) concern their child may learn inappropriate behaviors from children with special needs; (2) concern that their child's teacher will have to spend so much time with the children with special needs that they will not be able to provide stimulating or emotionally warm experiences for children with disabilities; and (3) the development of inappropriate interaction patterns with parents of

children with disabilities (Bailey & Winton, 1987).

Research documenting family issues in integration has been sparse. Turnbull, Winton, Blacher, and Salkind (1983) interviewed 101 parents of children with and without disabilities in integrated kindergarten and found high levels of agreement regarding the outcomes of integration. The greatest benefits identified by parents were related to social outcomes, whereas the greatest drawbacks were perceived to be in instructional areas. Additionally, Turnbull and Winton (1983) interviewed mothers of 14 exceptional children (3-5 years old) placed in specialized preschools and 17 exceptional children (3-5 years old) placed in integrated preschools regarding factors that influenced their choice of preschools and their evaluation of their child's current preschool. The interview was conducted in two phases including a focused interview in the subjects' home and a telephone-administered questionnaire based on the themes that emerged during the focused interview. Similarities and differences were found in the perspectives of mothers toward integrated and specialized preschools. Overall, mothers who had placed their children in integrated settings were more likely to emphasize the opportunity for interacting with normal peers and exposure to the "real world," while mothers who had placed their children in segregated settings emphasized the importance of appropriately trained professionals.

Guralnick (1994) studied the possible benefits and drawbacks of early childhood integration by mothers of both special-needs and non-special-needs children representing a large community-based sample. Subjects meeting criteria for classification as cognitively delayed, communication disordered, physically disabled, or at risk were recruited through formal contact with local school districts and community agencies providing services to young children with disabilities in a large metropolitan community

in the northwestern United States. To be included in the sample, subjects were required to be between 48 and 71 months of age and met inclusion criteria for one of the three disability categories or the at-risk category. For this study, children who were legally blind, had major uncorrected hearing loss, lived with the primary caregiver for less than 6 months, or currently lived in a home without a female caregiver were excluded. No attempt was made to recruit children enrolled in programs serving those with severe or multiple disabilities. Non-English-speaking families were also excluded. A total of 250 families agreed to participate in the study, including at least 25 families from the physical disability group and the at-risk group.

Survey results revealed widespread support for the benefits of integration, particularly promoting the acceptance of children with disabilities in the community, preparing the child for the real world, encouraging learning to a greater extent, and providing opportunities for more interesting and creative activities. However, a substantial number of perceived drawbacks was also noted, especially in connection with the availability of special help, special services, and qualified personnel as well as concerns regarding rejection by peers. Findings related to drawbacks suggest parental views that might counteract perceived benefits and reduced confidence in integrated programs. In general, mother's perceptions of integration were similar across family demographics, child characteristics, and type of program placement. A major exception was children's behavior problems, in which integration was perceived to be associated with more drawbacks.

Although studies with parents of children with and without disabilities generally report positive feeling about integration, interviews and sociometric data suggest that some parents of preschoolers with special needs feel isolated and ill at ease around

parents of nondisabled children in mainstreamed settings, and that they rely primarily on other parents of exceptional children for support and assistance (Blacher & Turnbull, 1983; Cansler & Winton, 1983). Blacher and Turnbull (1983) interviewed 6 mothers of children with disabilities and 40 mothers of children without disabilities in an integrated preschool regarding the quality and quantity of their interactions with other parents. The parents of the exceptional preschoolers reported that they tended to interact equally often with other parents of preschoolers with and without disabilities. On the other hand, most parents of children without disabilities indicated that they were more likely to interact with other parents of children without special needs.

Families of children in integrated environments have varying expectations associated with these integrated placements. Although previous studies have described some of these expectations in a retrospective fashion, no study has assessed expectations prior to the initiation of integration or documented the extent to which such expectations changed during the course of an integrated experience. Bailey & Winton (1987) studied the expectations of families of both children with and without disabilities prior to the introduction of children with disabilities into a day care center that had previously served only nondisabled youngsters. The subjects included the parents of all children enrolled on September 1, 1984, in the day care center operated at the Frank Porter Graham Child Development Center of the University of North Carolina at Chapel Hill. Historically the day care center had never served children with documented biological impairments; however, beginning September 1, 1984, the center changed the direction and focus of its efforts by initiating an integrated program. At that time 9 children with diagnosed handicapping conditions were admitted to day care. Additionally, a total of 36 families of children without disabilities were asked to participate in this study.

All children ranged in age from 18 months to 5 years. The 9 children with disabilities demonstrated delays in one or more developmental areas. One child was classified as severely mentally retarded. Seven were mild or moderately delayed, and one (spina bifida) approximated normal cognitive development but experienced motor delays. The survey was administered twice to all participating families: once in the late summer of 1984, approximately 2 weeks prior to the enrollment of the 9 exceptional children, and again in the spring of 1985, following 9 months of integrated day care. In general, the data revealed that parents in the two groups were similar in their opinions of the benefits of integration. Parents in both groups gave their highest ratings to statement #1 ("Mainstreaming provides handicapped children with exposure to the real world") and #7 ("Mainstreaming promotes community acceptance of the handicapped"). These two statements were also more likely to be picked as the greatest benefit of integration on both pre- and posttest measures. In summary, for the most part, parents' expectations of benefits did not change much over time, especially for parents of nondisabled children.

Parents' rating of statements related to integration drawbacks suggested that parents in both groups were less likely to agree with statements related to drawbacks than with statements related to benefits. Initially, parents in both groups were more likely to expect disadvantages in two areas: one related to teachers and the other related to upset for families of exceptional children. In selecting the greatest drawback, both sets of parents were most concerned about the impact of integration as it relates to instructional effectiveness. On the second administration of the survey, parents of exceptional children were less likely to rate the statement about being upset as a drawback to integration. Other notable pre/post changes suggested that parents of nondisabled children became less concerned about the effects of integration in terms of their own

children. It is interesting to note that there was a pre/post reversal in rating of statement #10 ("nonhandicapped will not receive enough teacher attention) by both groups, but in opposite directions. The parents of children with special needs were more likely to agree that this was a drawback on the follow-up as compared to the initial ratings, while parents of normal children were more likely to agree that it was a drawback on the pretest as compared to the posttest.

Summary of Literature Review

Prior to the disclosure of their own child's disability, very few parents have detailed knowledge of the disability and many are likely to express a need for information (Cunningham & Davis, 1985). Few parents will have had prior contact with the variety of professionals on whom they suddenly find themselves dependent (Lynch & Staloch, 1988), and the equality of the information and advice provided is potentially of major significance.

Parental responses to a child's disability have been shown to include anger, shock, denial and guilt (Nicholas & Lewin, 1986). Lack of information at disclosure is now less prone to be accepted by parents (Down Syndrome Association, 1990) and parents are now likely to request factual information about the disability and access to relevant support services. It is clear important that parents receive useful and current information and are put in contact with appropriate services (Cunningham, 1987). The services recommended and provided will depend on what is available in the region and on the current professional viewpoint about the appropriateness of particular services.

Early intervention is now conceptualized as services for families with children with disabilities or at-risk for disabilities, rather than as services solely for the children. The emphasis is on addressing parents' or other primary caregivers' priorities. The first goal

of early intervention suggested by Bailey and Wolery (1992) is to support families in achieving their own goals. Other goals comprise of promoting the acquisition and generalization of child outcomes, promoting and preparing for normalized life experiences, and preventing future problems or disabilities (Hanson & Lynch, 1995; McWilliam, Lang, Vandiviere, Angell, Collins, & Underdown, 1995). An understanding of the transaction between child and family variables (Bailey & Simeonsson, 1984; Dunst, Trivette, Hamby, & Pollock, 1990) reinforces the notion that attention to families' priorities is likely to help meet both child- and family-level goals. It makes sense, then to focus evaluation to a considerable extent on consumers' (i.e., families') satisfaction with services.

If the family centered intent of P.L. 99-457 is to be realized, we must obtain parents' views of how early intervention services should be delivered. Researchers and practitioners have determined parent preferences for services in a variety of ways including consumer focus groups (Summers, et al., 1990), ethnographic interviews (Able-Boone, Sandall, Loughry, & Fredrick, 1990), family focus interviews (Winton & Bailey, 1988), and surveys (Bailey & Simeonsson, 1988; Mahoney, 1990). Despite these attempts to solicit parent preferences for services, parents may still be unduly influenced by the professional(s) working with their child. Early intervention professionals certainly have a stake in how services are implemented, and professionals often influence parents' views about services by the recommendations they make and the opinions they share. In summary, the measurement of parents' and professionals' perceptions should be studied as an essential component of early intervention program evaluation.

Summary of Previous Study

A previous study was conducted in the Summer of 1998 involving 134 early

childhood education agencies in Taiwan serving children with and/or without disabilities, between the ages of 3 to 5. For purposes of brevity, a summary of the previous study is provided. For a complete description of the previous study and detailed results see Appendix B.

Descriptive data on the early childhood programs were gathered through use of a questionnaire survey mailed to early childhood service providers who serve children with disabilities, between ages 3 to 5. The following characteristics of professionals and paraprofessionals in these early childhood programs were documented: title of job(s); years of experience; levels of education; receipt of specialized early childhood special education training; types of license, credential or certification; and inservice training opportunities. Further, program information such as the following was collected: total number of all students; number of exceptional students; staff-child ratio for center-based programs; type of service(s) provided by the program; and staff caseload for home-based programs.

Of the 314 program agencies identified, 134 program providers responded to the questionnaire making a total response rate for this survey of 42.7%. Overall, survey results indicated that early childhood special education program delivery models and staffing patterns varied across programs in Taiwan. Most young children with disabilities were served in center-based settings, and only a few of the programs provided home-based services. In addition, the types of exceptional children served and the ways used to communicate with parents were varied. Further, a wide range of services was offered and these services were delivered by a variety of professional and paraprofessional staff. The education, experience, and licensing (or certification, credentialing, and registration) also were found to vary considerably. Most program

providers valued a good personality as the most important qualification for hiring a person and only two-thirds of the respondents preferred that their staff possess teaching certificates. Further, a significant proportion of persons providing services in Taiwan to young children and their families had no specialized training in early childhood special education. Limited training opportunities and unmet needs for training were found as two major problems.

Most educators agreed that children with special needs had equal rights to receive education as other children. Moreover, with regard to the difficulties of inclusive education, most professionals felt that they did have a hard time making it work because of several difficulties. Limitations listed included, minimal understanding of special education students; not enough resources, equipment or training; and fear of rejection from parents of children without disabilities. In summary, currently in Taiwan early childhood special education programs vary widely as do the characteristics of the personnel providing services. In addition, resources for these services are limited and most personnel lack specialized training in early childhood special education.

CHAPTER THREE

Methods and Procedures

An understanding of parent perceptions regarding their children and the services they receive is important for the development and enhancement of special services for children with disabilities. Parental perceptions toward their children with disabilities must be considered when appraising the parents' opinions and support. Thus, the present study was conducted to address the following questions:

1. What perceptions do Taiwanese parents hold about their young children with disabilities?
2. What perceptions do Taiwanese parents hold about the adequacy of existing family-centered early childhood special education and related services?
3. What available sources of family support exist and to what extent have different sources of support been helpful to Taiwanese parents rearing young children?
4. What perceptions do early childhood personnel in Taiwan hold about existing family-focused early childhood special education and related services?

This chapter includes a discussion of the following components: (1) service sites, (2) population and sample, (3) instrumentation, (4) procedures, and (5) data analysis.

Service Sites

The primary source for identifying the population for this study was the booklet, Directory of Special Education, Rehabilitation, and Welfare Services in the Republic of China (Lin, Chao, & Shu, 1998), published by the National Taiwan Normal University. This booklet was comprised of three parts. The first part listed all special schools and special classes in Taiwan. The second part presented all social welfare organizations and institutions in Taiwan. The third part included teacher training institutions and other

resources in Taiwan. This booklet was used to identify target sites for this study.

Tainan was selected for the location of this study. It was selected because it is representative of Taiwan as a whole. Taiwan is composed of 17 municipalities and Tainan is Taiwan's oldest and the eighth most populous municipal area in Taiwan. Tainan is located in the southern part of Taiwan. A more detailed description of the Tainan area, regarding its special education system and the current status of special education can be found in Appendix C. The service sites selected consisted of all special preschools nurseries social welfare institutions and all special classes in regular schools in the Tainan area. Table 5 illustrates the demographics of all sites selected. Of the 8 agencies identified, 4 were city or provincial government-funded special schools or classes and 4 were private schools. Of these service sites, 4 were located in rural areas and 4 were in urban areas. Most families (60.1%) that participated in this study lived in urban areas, although some rural families (39.9%) were represented.

Table 5

Demographics of all sites selected

Site Characteristics	Site A	Site B	Site C	Site D	Site E	Site F	Site G	Site H
Numbers of Children Served	39	34	54	33	33	21	42	25
Public or Private	Public	Public	Public	Public	Private	Private	Private	Private
Location Urban or Rural	Urban	Urban	Urban	Rural	Rural	Rural	Urban	Rural
Total Children	281							

Population and Samples

A total of 8 program providers and 281 parents of all children with disabilities in Tainan area were invited to participate in the study. They were assured of confidentiality of their responses and total freedom to decline to participate in the study. A special identification code was assigned to every school or agency. The research proposal for the present study was reviewed and approved by the Human Subjects Committee of the University of Oklahoma.

Instrumentation

Available Assessment Instruments

Two assessment instruments were identified in the related literature for measuring family support and the perceptions of early childhood personnel about existing family-focused early childhood special education and related services:

1. Family Support Scale (Dunst, Jenkins, Trivette, 1984) is a 18-item self-report survey which assesses the availability of sources of support, as well as the degree to which different sources of support have been helpful to families rearing young children. Respondents indicate which of the 18 sources of support are available to them, and then rate those which are available on a five-point Likert-type scale ranging from 0 (not at all helpful) to 4 (extremely helpful).

2. Early Intervention Program Survey is a questionnaire developed by the current researcher and was used in a previous study which investigated the characteristics and perceptions of early childhood personnel in Taiwan. The survey design is a descriptive statistic method. Respondents were asked to complete 18 survey questions which included 10 yes-or-no questions, 4 short-essay questions, 4 multiple-choice questions, and 3 open-ended questions about opinions regarding early childhood special education

and inclusion.

The above two instruments were used as models for developing the instrument for the present study. Two forms of the newly-developed questionnaire incorporated items which reflected the contents of the instruments described above. Initial drafts of the two questionnaires were reviewed by an advisory group consisting of 5 professors at the University of Oklahoma, 2 Chinese professors at 2 Taiwan Universities, and 2 early childhood special educators. Of all 7 professors, 5 worked in the field of special education.

Translation of the Questionnaire

The researcher determined that a Chinese version of the questionnaire would be more comprehensible to Chinese parents than an English version. Many Chinese parents or program providers selected for this study could not read or speak English. Thus, it was necessary to translate the contents of the questionnaire into Chinese. The questionnaire was translated from English into Chinese by the researcher and, then presented to 2 Chinese professors in the field of special education who were fluent in both English and Chinese. They reviewed the English version and the Chinese version for language accuracy, simplicity, and validity of translation.

Content of the Questionnaires

Survey of Education & Service Needs for Children with Disabilities- Agency Form

A researcher-developed questionnaire was used in the present study to collect data on the perceptions of the personnel toward family-focused early intervention and related services (Appendix D). The questionnaire consisted of six questions, including questions about the number of children with special needs served in the center, the age of the children, the type and level of their disabilities, the special services provided to the

children and their families, individualized goals or written programs for the children, and parent participation in the children's individualized education programs.

Survey of Education & Service Needs for Children with Disabilities- Family Form

The family questionnaire consisted of five major sections (Appendix E). The first section included questions for collecting both parental demographic information (i.e. parent's age, level of education, income level, and living location), and demographic information about the child (i.e., gender, age, type and level of disability, birth order, number of siblings, the family structure, and hours of education and therapy received every week), as well as questions regarding the parent's participation in the child's individualized education program.

The second section of the questionnaire consisted of 25 statements for assessing the parents' perceptions toward their children with disabilities (i.e., Items 1-16), and toward special education and integration of their children in general education programs (i.e., Item 17-25). The 25 statements were clustered around 8 categories: child rearing, child's social interaction, expectations for the child, child's participation, child's potential, child's feelings, parents' feelings, and child's rights or opportunities. Responses were recorded on a five-point scale (i.e., 0 = strongly disagree; 1 = somewhat disagree; 2 = neutral; 3 = somewhat agree; and 4 = strongly agree).

The third section of the questionnaire consisted of a list of 18 special services which parents of children with disabilities evaluated in terms of adequacy of service provision. Again, a five-point scale was used to rate services (i.e., 0 = very inadequate; 1 = inadequate; 2 = neutral; 3 = adequate; and 4 = very adequate).

The fourth section assessed the availability of sources of support, as well as the degree to which different sources of support have been helpful to families rearing young

children. This section included a list of 14 items. Respondents indicated which of the 14 sources of support were available to them, and then rated those which were available on a five-point Likert scale (0 = not at all helpful; 1 = sometimes helpful; 2 = generally helpful; 3 = very helpful; and 4 = extremely helpful).

The last section included five open-ended questions asking for more details about parents' reflection or reaction about having a child with special needs (i.e., how parents became aware of their child's special needs, who first informed them of the disability, how parents reacted when they first became aware of their child's disabilities, and did the parents share this news with others).

Procedures

Before the questionnaire was distributed to the parents, school administrators were contacted through phone calls or visits to obtain their support and assistance in the administration of the questionnaire. School or agency personnel provided the researcher with the numbers of families served by their facilities. Every program was sent a packet containing an Agency-Form survey for the program provider, instructions for the survey, letters to families, and Family-Form questionnaires. The program staff were asked to distribute the questionnaire to all parents whose children received services by the agency. A cover letter (Appendix G) explaining the research study accompanied the questionnaire. The parents were asked to return the questionnaire either in a self-addressed stamped envelope provided with the survey or to return it directly to their child's teacher. Parents were assured that their responses would be anonymous and confidential. Four weeks after the surveys were distributed, a follow-up letter was sent to the program personnel, asking them to remind parents to complete and return the survey.

Analysis of Data

Participants were selected on a volunteer basis and therefore randomization was not possible. In general, with both questionnaires- Agency and Family Forms, a descriptive research design was utilized by the researcher. For the Agency Survey, descriptive statistics were computed from the demographic questionnaire. Measures of central tendency were calculated for continuous scores and for ranks. Categorical data, including dichotomies, were summarized by creating frequency distributions. The researcher expected this information to be relevant to the research question regarding the perceptions of early childhood personnel about family-focused early childhood special education and related services.

In addition, descriptive statistics were computed from the demographic questionnaire and the Likert-type questionnaires for the Family Survey. As mentioned, measures of central tendency were calculated for continuous scores and for ranks in Section I of the survey. Categorical data, including dichotomies, were summarized by creating frequency distributions.

The 25 survey items in Section II were grouped into 2 parts. The first part consisted of 16 items to assess the parents' perceptions toward their children with disabilities (Items 1-16). The second part consisted of 9 items to assess the parents' perceptions toward special education for their children (Items 17-25). Frequencies, percentages (%), mean scores (M), standard deviations (S.D.), and rank order of parental responses were computed for each item in Section II. The mean score for each item was then used to determine the direction of perceptions (i.e., positive or negative).

Section III consisted of a list of 18 services to assess the parents' perceptions of family-centered early intervention and related service adequacy. Frequencies,

percentages (%), mean scores (M), standard deviations (S.D.), and rank order of parental responses were computed for each service item.

Section IV consisted of a list of 14 self-report items which assessed the availability of sources of support, as well as the degree to which different sources of support were helpful to Taiwanese families rearing young children. Frequencies, percentages (%), mean scores (M), standard deviations (S.D.), and rank order of parental responses were computed for each item.

Pearson correlations and an analysis of variance (ANOVA) were performed to determine if significant relationships existed between the dependent variables (i.e., Taiwanese parents' perceptions investigated in present study) and the independent variables (i.e., parental age, educational level, income level, living location, child's age, child's gender, birth order, and type of child's disability). An alpha level of $p<0.05$ was established for all statistical procedures included in the study.

Finally, Section V consisted of 5 open-ended questions. Information from the questions was described using a content analysis method. After separating the data into categories, the information was incorporated into the four research questions where appropriate.

CHAPTER FOUR

Results of the Data Analysis

The purposes of this study were to determine (1) the perceptions held by Taiwanese parents about their young children with disabilities; (2) the perceptions held by Taiwanese parents about the adequacy of existing family-centered early childhood special education and related services; (3) the available sources of family support existing in Taiwan and the extent to which different sources of support have been helpful to Taiwanese parents rearing young children; and (4) the perceptions held by Taiwanese early childhood personnel about existing family-focused early childhood special education and related services. In this chapter, the demographics information related to the subjects of the study and the results of the data analyses are reported and discussed.

Return Rate of Survey

A total of 281 questionnaires were forwarded by school personnel at 8 early childhood agencies to parents of young children with disabilities. One hundred and nine questionnaires (38.8%) were returned. Each of the 109 questionnaires was coded into one of 8 groups based on the programs: Program A, Program B, Program C, Program D, Program E, Program F, Program G, and Program H. Among the 8 programs, only one (Program B) provided both center-based and home-based programs while the other were all center-based. The return rate for Program A was 43.6% (17 out of 39); for Program B was 44.1% (15 out of 34); for Program C was 40.9% (21 out of 54); for Program D was 31.7% (10 out of 33); for Program E was 22.4% (7 out of 33); for Program F was 48.8% (10 out of 21); for Program G was 40.9% (19 out of 42); and return rate for Program H was 39.3% (10 out of 25). A more detailed description of the 8 agencies, including survey return rate, can be found in Table 6.

Demographic Information

Survey of Education & Service Needs for Children with Disabilities- Agency Form

The demographic data for the 8 agencies are presented in Table 6. Table 6 includes information regarding the age of children served in the facilities, type(s) of disabilities children had, type(s) of services provided to children with their families, Individualized Education Program (IEP) and or Individual Family Service Plan (IFSP), and parent participation in writing IEPs and/or IFSPs.

Of the 8 programs, 100% stated that they provided information regarding special education to children with disabilities and their families. 7 (87.5%) agencies provided occupational and/or physical therapy, speech-language therapy, and social worker(s) to young children with disabilities and their families. 6 (75%) programs provided family counseling services to the families of children with special needs, and 5 (62.5%) provided medical support services to the families. In addition, 4 out of 8, or 50%, reported they provided psychology services to children and their families. 1 (12.5%) program provided nutrition support, while 1 (12.5%) provided audiological services.

All 8 programs, or 100%, reported that all children with special needs had their own special, or individual, education goals or written program plans. All 8 programs (100%) stated that they invited parents to participate in their child's IEP/IFSP meeting.

Table 6

Demographics of programs

Setting Characteristics	A	B	C	D	E	F	G	H
Type of Program	Center	Center Home	Center	Center	Center	Center	Center	Center
Numbers of Children Served	39	34	54	33	33	21	42	25
	17	15	21	10	7	10	19	10
Return Rate	(43.6)	(44.1)	(40.9)	(31.7)	(22.4)	(48.8)	(40.9)	(39.3)
Age of Children	3-6	0-3	3-5	0-6	4-7	3-6	5-6	3-7
Type(s) of Children Served								
Physical Imp	Y					Y		
Visual Imp					Y		Y	
Hearing Imp			Y					
Develop D	Y	Y	Y	Y	Y	Y	Y	Y
Multiple H	Y		Y	Y	Y	Y	Y	Y
Type(s) of Services Provided								
OT PT	Y	Y	Y	Y		Y	Y	Y
Spe Lang Ther	Y	Y	Y	Y		Y	Y	Y
Family Counsel	Y	Y	Y	Y	Y			Y
Sp Ed Info	Y	Y	Y	Y	Y	Y	Y	Y
Medical Supp	Y		Y		Y	Y	Y	
Psy Services			Y		Y	Y	Y	
Nutrition Supp					Y			
Social worker	Y		Y	Y	Y	Y	Y	Y
P-P Support Gr								
Audiological			Y					
Info Network								
IFPHSP	Y	Y	Y	Y	Y	Y	Y	Y
Parent(s) in IFPHSP	Y	Y	Y	Y	Y	Y	Y	Y

Note Numbers in parentheses are percentages

Physical Imp Physical Impairment, Visual Imp Visual Impairment, Hearing Imp Hearing Impairment, Develop D Development Delay, Multiple H Multiple Handicaps, OT PT Occupation Physical Therapy, Spe Lang Ther Speech-Language, Sp Ed Info Special Education Information, Medical supp Medical Support, Psy Services Psychological Services, Nutrition Supp Nutrition Support, P-P Support Gr Parent-to-Parent Support Group, Audiological Audiological Services, Info Network Information Network

Survey of Education & Service Needs for Children with Disabilities- Family Form

Table 7 illustrates the demographic data of parents who participated in the study, including parents' age, level of education, level of annual income, and living location. Of 109 parents, 75 or 68.8% were aged between 30 and 39, and 20 out of 109 (18.3%) were aged between 40 and 49. Among 109 respondents, 13 out of 109 (11.9%) were aged between 20 and 29, and only 1 (1.0%) parent was aged less than 20.

Regarding level of education, of 109 parents, 65 (59.6%) were high school graduates, 22 (20.1%) parents had college degrees, 18 (16.5%) were junior high school graduates, and 4 (3.7%) were elementary graduates.

As indicated, 29 (26.6%) families had annual incomes between NT$420,001 and 600,000 (about US$14,001- 20,000), 21 (19.3%) families had incomes between NT$180,001 and 300,000 (about US$6,000- 10,000), 18 (19.3%) families had incomes between NT$300,001 and 420,000 (about US$10,001- 14,000), 15 (13.8%) families had incomes between NT$600,001 and 840,000 (about US$20,001- 28,000), 14 out of 109 (12.8%) families had annual incomes less than NT$180,000 (about US$6,000), and 8 (7.3%) families made more money than NT$840,000 (about US$28,000) a year. Sixty-one out of 109 respondents (56%) lived in urban areas, while 48 (44%) respondents lived in rural areas.

Table 7

Demographics of families

Respondent Characteristics	Number	Percentage
Age		
Less than 20	1	1.00
20 to 29	13	11.9
30 to 39	75	68.8
40 to 49	20	18.3
More than 50	0	0
Educational Level		
Elementary graduate	4	3.7
Junior high graduate	18	16.5
Senior high graduate	65	59.6
Bachelor's degree	22	20.1
Master's degree	0	0
Annual Income (NT$)		
Less than 180,000 (US$6,000)	14	12.8
180,001 - 300,000 (US$6,000-10,000)	21	19.3
300,001-420,000 (US$6,001-14,000)	18	16.5
420,001-600,000 (US$14,001-20,000)	29	26.6
600,001-840,000 (US$20,001-28,000)	15	13.8
More than 840,000	8	7.3
No responses	4	3.7
Living Location		
Urban	61	56
Rural	48	44

Demographic information about the children is presented in Table 8, including the children's gender and age, type of disability, birth order, number of siblings, the family structure, and hours of education and therapy received every week, as well as questions regarding parents' participation in the children's individualized education program.

Of the 70 children who spent more than 21 hours a week in school, 10 were 7-years-old (14.3%), 27 were 6-years-old (38.6%), 13 were 5-years-old (18.6%), 20 were 4-years-old (28.6%), and none were under 4-years. All 7 children who spent 16 to 20 hours a week in school were 7-years-old (100%). Of the 5 children who spent 11 to 15 hours in school, 4 were 4-years-old (80%) and 1 was 3-years-old (20%). All 9 children who spent 5 to 10 hours in school were 3-years-old (100%). Among 18 children who spent less than 5 hours in school, 14 were 3-years-old (77.8%), 3 were 2-years-old (16.7%), and 1 was 1-year (5.6%).

Table 8

Demographics of children

Child Characteristics	Number	Percentage
Birth Order		
1st	53	48.7
2nd	40	36.7
3rd	13	11.9
4th	3	2.8
Gender		
Male	71	65
Female	38	35
Age		
7-year-old	17	15.6
6-year-old	27	24.8
5-year-old	13	11.9
4-year-old	24	22.1
3-year-old	24	22.1
2-year-old	3	2.8
1-year-old	1	0.9
Number of Siblings		
3 brother(s) and or sister(s)	4	3.7
2 brother(s) and or sister(s)	33	30.3
1 brother or sister	52	47.7
none	20	18.3
Living with		
Both parents	50	45.9
parents and grandparent(s)	34	31.2
One parent	5	4.6
Only grandparent(s)	13	11.9
Other relatives	7	6.4
Hours in School Center		
Under 5 hrs per week	18	16.5
5 to 10 hours	9	8.3
11 to 15 hours	5	4.6
16 to 20 hours	7	6.4
21 and above	70	64.2
Receive any therapy		
Yes	79	72.4
No	30	27.5

(table continues)

Child Characteristics	Number	Percentage
Where to receive therapy		
Hospital	47	59.5
Preschool kindergarten	40	50.6
Home	5	6.3
Center	12	16.2
Hours receive therapy		
Under 5 hrs per week	54	68.4
5 to 10 hours	13	16.5
11 to 15 hours	4	5.1
16 to 20 hours	0	0.0
21 and above	8	10.1
Who make(s) decision		
Child's father	5	4.6
Child's mother	32	29.4
Both father and mother	68	62.4
Other (grandparents)	4	3.7
IFP IFSP		
Yes	69	63.3
No	28	25.7
Don't know	12	11.0
Parent(s) participate in writing IFP		
Yes	80	72.8
No	19	27.8
Type(s) of Disability		
Physical Impairment	15	13.8
Visual Impairment	2	1.8
Hearing Impairment	8	7.3
Developmental Delay	31	28.4
Multiple Disabilities	53	48.6

Parents' Perceptions Toward Their Children With Disabilities

Sixteen items (Item No. 1-16) in Section II of the questionnaire were used to assess the parents' perceptions toward their young children with disabilities. Responses were recorded on a five-point scale (i.e., 0 = strongly disagree; 1 = somewhat disagree; 2 = neutral; 3 = somewhat agree; and 4 = strongly agree). Frequencies, percentages (%), mean scores (M), and standard deviations (S.D.) of parental responses were computed. Parents' responses with an M < 1.5 were identified as disagreements, while parents' responses with an M > 2.5 were identified as agreements. Among the 16 items (Table 9), parents perceived more disagreement than agreement on 7 statements, such as "My child must be treated less strictly than his her siblings"(Item 1), "My child must be treated more strictly than his her siblings"(Item 2), "My child does not interact with his her friends who do not have disabilities"(Item 3), "My child is kept at home most of the time"(Item 9), "My child is often a burden to our family"(Item 13), "My child is less loving than children who do not have disabilities"(Item 14"), and "My child often feels upset because of his her disabilities"(Item 15).

In addition, the study indicated that parents perceived more agreement than disagreement on 9 items, such as "My child participates in all family activities"(Item 4), "My child enjoys participating in public or community events"(Item 5), "I expect my child to meet the same academic standards as children who do not have disabilities"(Item 6), "I worry about my child's future"(Item 7), "My child has lower self-esteem than children who do not have disabilities"(Item 8), "My child gets along well with his/her friends who do not have disabilities"(Item 10), "My child should get more attention from his/her teachers than children who do not have disabilities"(Item 11), "My child should be expected to meet lower academic standards than his/her peers who do not have

disabilities"(Item 12), and "My child works hard to be independent"(Item 16).

Table 9

Parents' perceptions toward their young children with disabilities

Items	Parental Responses (%)				
	Disagree	Neutral	Agree	Mean	S.D.
1. My child must be treated less strictly than his/her siblings.	41.2	33.9	24.8	1.8	1.0
2. My child must be treated more strictly than his her siblings.	43.1	33.0	23.9	1.7	1.0
3. My child does not interact with his her friends who do not have disabilities.	62.4	21.1	16.6	1.2	1.3
4. My child participates in all family activities.	7.3	11.9	80.9	3.4	1.1
5. My child enjoys participating in public or community events.	11.9	20.2	67.9	2.8	1.1
6. I expect my child to meet the same academic standards as children who do not have disabilities	31.2	27.5	41.2	2.3	1.4
7. I worry about my child's future.	4.6	17.4	78.0	3.4	0.9
8. My child has lower self-esteem than children who do not have disabilities.	27.5	29.4	43.1	2.2	1.3
9. My child is kept at home most of the time.	42.2	22.9	34.9	1.8	1.2

(table continues)

Items	Parental Responses (%)				
	Disagree	Neutral	Agree	Mean	S.D.
10. My child gets along well with his/her friends who do not have disabilities.	14.7	24.8	60.5	2.9	1.1
11. My child should get more attention from his/her teachers than children who do not have disabilities.	10.1	14.7	75.2	3.0	1.1
12. My child should be expected to meet lower academic standards than his/her peers who do not have disabilities.	26.6	23.9	49.5	2.2	1.4
13. My child is often a burden to our family.	43.1	19.3	37.6	1.8	1.3
14. My child is less loving than children who do not have disabilities.	77.0	15.6	7.4	0.7	1.0
15. My child often feels upset because of his/her disabilities.	56.0	26.6	17.4	1.3	1.3
16. My child works hard to be independent.	16.6	34.9	48.6	2.6	1.1

Note. S.D. = Standard Deviation.

Parents' Perceptions Toward Integration

Nine items in Section II of the questionnaire (Item No. 17-25) were used to assess parents' perceptions toward integration of their children into general classes and/or schools. Responses were recorded on a five-point scale (i.e., 0 = strongly disagree; 1 = somewhat disagree; 2 = neutral; 3 = somewhat agree; and 4 = strongly agree). Parents' responses with an $M \leq 1.5$ were identified as disagreements, while parents' responses with an $M \geq 2.5$ were identified as agreements. As reflected in Table 10, a very high percentage of parents agreed with items 17 to 20. They included the statements of "My child should have the same educational opportunities as children who do not have disabilities"(Item 17), "Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem"(Item 18), " My child should be able to play with children who do not have disabilities"(Item 19), and "Going to school with children who do not have disabilities would provide more opportunities for my child to interact with nondisabled friends"(Item 20).

About half of the parents held neutral perceptions on items 21 to 25, including " My child should be educated in special classes where he/she is only with children who have the same disability"(Item 21), "Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem"(Item 22), " Going to school with children who have the same disabilities will make my child feel more secure (Item 23), " Going to school with children having the same disabilities will cause my child to have lower esteem "(Item 24), and " My child would be happier playing with other children who have the same disability "(Item 25).

Table 10

Parents' perceptions toward integration

Items	Parental Responses (%)				
	Disagree	Neutral	Agree	Mean	S.D.
17. My child should have the same educational opportunities as children who do not have disabilities.	0.9	13.8	85.4	3.6	0.8
18. Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem.	18.3	31.2	50.4	2.6	1.3
19. My child should be able to play with children who do not have disabilities	5.5	13.8	80.7	3.3	0.9
20. Going to school with children who do not have disabilities would provide more opportunities for my child to interact with nondisabled friends	8.3	17.4	74.3	3.1	1.1
21. My child should be educated in special classes where he she is only with children who have the same disability.	31.1	40.4	27.5	1.9	1.1
22. Going to school with children who have the same disabilities will make my child feel more secure	22.9	52.3	24.8	2.0	1.0
23. Going to school with children having the same disabilities will cause my child to have lower esteem.	32.1	58.7	9.2	1.6	0.9
24. My child would be happier playing with other children who have the same disability.	24.8	62.4	12.9	1.8	0.8
25. My child must be treated less strictly than his her peers who do not have disabilities.	33.0	48.6	18.4	1.7	1.0

Note. S.D. = Standard Deviation.

Parents' Perceptions of Service Adequacy

A list of 18 service items in Section III of the questionnaire was designed to evaluate parental perceptions of service adequacy. In this section, parents were asked to rate the adequacy of the listed services using a scale of 0 to 4 (i.e., 0 = very inadequate; 1 = inadequate; 2 = neutral; 3 = adequate; and 4 = very adequate). Frequencies, percentages (%), mean scores (M), standard deviations (S.D.), and the rank order of parental responses were computed (Table 11). As indicated in Table 11, 2 out of 18 service items were rated as inadequate ($M < 1.5$) (e.g., Items 9 and 10), while 16 service items were rated as neutral ($1.5 < M < 2.5$)(e.g., 1, 2, 3, 4, 5, 6, 7, 8, 11, 12, 13, 14, 15, 16, 17, and 18). The least adequate service identified by parents was Item 9, "A place for my child to go for recreation" ($M = 1.1$). When overlooking the neutral responses, most parents perceived 15 out of 18 service items as inadequate (e.g., Items 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, and 17).

Table 11

Parents' perceptions of service adequacy

Items	Parental Responses (%)							
	VI	I	N	A	VA	Mean	S.D.	Rank
1. There is someone to take care of my child so that we can go on a weekend or holiday trip without him/her.	22.0	35.8	13.8	13.8	14.7	1.6	1.3	12
2. There is someone to help us deal with out emotion problems.	31.2	17.4	29.4	12.8	9.2	1.5	1.3	16
3. There is someone to help my child deal with his/her emotional problems.	27.5	23.9	24.8	15.6	8.3	1.5	1.3	15
4. Medical services to deal with my child's unique health problems.	18.3	19.3	17.4	23.9	21.1	2.1	1.4	4
5. A place to get information about my child's disabilities.	16.5	25.7	21.1	12.8	23.9	2.0	1.4	6
6. A governmental agency to provide financial support or a loan to help my child.	17.4	12.8	29.4	17.4	22.9	2.15	1.4	2
7. A place to get needed therapy/therapies.	17.4	23.9	18.3	9.2	31.2	2.1	1.5	3
8. A place to get needed technological devices (e.g., wheelchair, hearing aide, etc.)	16.5	27.5	22.9	18.3	14.7	1.9	1.3	7
9. A place for my child to go for recreation.	42.2	22.0	17.4	12.8	5.5	1.1	1.6	18
10. Transportation for my child to school.	40.4	22.9	21.1	9.2	6.4	1.2	1.2	17

(table continues)

Items	Parental Responses (%)							
	VI	I	N	A	VA	Mean	S.D.	Rank
11. Convenient handicapped parking provided at places where we go often (e.g., shopping center, post office, park, hospital, bank, etc.).	26.6	19.3	26.6	11.9	15.6	1.7	1.4	10
12. Legal services to assist us when we have legal problems related to our child.	23.9	21.1	29.4	21.1	4.6	1.6	1.2	13
13. Training for my child on daily living skills.	23.9	26.6	12.8	12.8	23.9	1.9	1.5	8
14. Training for my child on physical development.	25.7	20.2	16.5	19.3	18.3	1.8	1.5	9
15. Training for my child on social development.	29.4	27.5	11.9	16.5	14.7	1.6	1.4	14
16. Training for my child on emotional development.	25.7	26.6	19.3	14.7	13.8	1.6	1.4	11
17. Training for my child on language and communication development.	12.8	25.7	25.7	17.4	18.3	2.0	1.3	5
18. Training for my child to improve his/her movement from place to place.	9.2	26.6	23.9	12.8	27.5	2.22	1.4	1

Note. VI = Very Inadequate; I = Inadequate; N = Neutral; A = Adequate; VA = Very Adequate; S.D. = Standard Deviation.

Perceptions of Sources of Family Support

The 14 items included in Section IV of the questionnaire were designed to assess the availability of sources of support, as well as the degree to which different sources of support have been helpful to Taiwanese families rearing young children. Parents were asked to indicate which of the 14 sources of support were available to them, and rated those which were available on a five-point Likert scale of 0 to 4 (i.e., 0 = not at all helpful; 1 = sometimes helpful; 2 = generally helpful; 3 = very helpful; and 4 = extremely helpful). Frequencies, percentages (%), mean scores (M), standard deviations (S.D.), and the rank order of parental responses were computed (Table 12). As indicated, 6 out 14 sources listed in Section IV of the questionnaire were rated to be no helpful or only somewhat helpful (e.g., Items 3, 4, 6, 7, 10, and 12) by most parents. Parents perceived 4 sources as neutral (e.g., 1, 2, 8, and 11). In addition, items 5 and 13 were rated as generally helpful, while Item 14 was rated as very helpful.

Among the 34 families living with grandparents (Table 8), 17 (50%) families indicated that grandparents were generally helpful, while 12 families (35.3%) said they were sometimes helpful and 5 families (14.7%) said very helpful.

To these Taiwanese parents, religion was rated as the 9th most helpful source of family support in rearing their children with special needs. Thirty-eight out of 109, or 34.9%, parents indicated that religion was not helpful, while half of the parents (56.9%) said that religion was either sometimes or generally helpful to them. Only a few parents (8.3%) declared that religion was very or extremely helpful.

Of the 109 respondents, 49 (45.0%) parents indicated that co-workers were not helpful, while 48 (43.1%) parents said that their co-works were either sometimes or generally helpful. Only 13 parents rated their co-workers as either very or extremely

helpful.

Table 12

Perceptions of sources of family support

Items	Parental Responses (%)					Mean	S.D.	Rank
	NH	SH	GH	VH	EH			
1. My parents	25.7	23.9	13.8	21.1	15.6	1.7	1.4	7
2. My spouse's parents	25.7	31.2	16.5	18.3	8.3	1.5	1.3	8
3. My relatives kin	33.9	35.8	16.5	10.1	3.7	1.1	1.1	10
4. My spouse's relatives kin	54.1	22.9	7.3	10.1	5.5	0.9	1.2	13
5. Husband/wife	7.3	17.4	12.8	13.8	48.6	2.8	1.4	2
6. My friends	37.6	31.2	18.3	10.1	2.8	1.1	1.1	11
7. My spouse's friends	59.6	22.0	11.0	4.6	2.8	0.7	1.0	14
8. My own children	24.8	15.6	30.3	14.7	14.7	1.9	1.4	6
9. Other parents/parent groups	17.4	18.3	22.9	26.6	14.7	2.0	1.3	4
10. Religion/church/temple	34.9	24.8	32.1	2.8	5.5	1.2	1.1	9
11. Social workers	18.3	28.4	13.8	25.7	13.8	1.9	1.4	5
12. Co-workers	45.0	28.4	14.7	7.3	4.6	1.0	1.1	12
13. Medical professionals, therapists	4.6	11.0	28.4	25.7	30.3	2.7	1.2	3
14. School/daycare center teachers	0.9	2.8	19.3	32.1	45.0	3.2	0.9	1

Note. NH - Not at all Helpful; SH Sometimes Helpful; GH Generally helpful; VH Very Helpful; EH Extremely Helpful; S.D. Standard Deviation.

Relationship of Parent-Related Factors to Parents' Perceptions

The Pearson correlation analyses and ANOVA were conducted to determine if selected parent-related factors (i.e., parental age, educational level, family income level, and living location) were related to the parents' perceptions investigated in the present study. Since there was only one parent aged less than 20, this group was combined with the group of people aged between 21 and 29. In addition, regarding the parental education level, groups of elementary graduates and junior-high graduates were combined into one group as well. The analyses of variance indicated that most parent-related factors were not significantly related to the parents' responses (Table 13). However, the educational level of parents was found to be significantly related to parents' perceptions of their children with disabilities. Parents with higher education tended to perceive more disagreement toward their young children with disabilities. In addition, Pearson correlation analyses revealed that besides educational level, income level was also significantly related to parents' perceptions regarding availability of sources of family support (Table 14). Parents with higher incomes perceived that more available sources of family support existed.

Table 13

Analyses of variance in parents' perceptions toward their children with disabilities, integration, service adequacy, and availability of sources of family support by parental age, educational level, income level, and living location

	df	F	Significant
Parents' Perceptions toward Children with Disabilities			
Parental Age	2/106	0.160	0.853
Educational Level	2/106	5.789	0.004*
Income Level	5/99	1.218	0.306
Living Location	1/107	0.367	0.546
Parents' Perceptions toward Integration			
Parental Age	2/106	3.034	0.052
Educational Level	2/106	1.414	0.248
Income Level	5/99	0.756	0.584
Living Location	1/107	0.004	0.948
Parents' Perceptions of Services Adequacy			
Parental Age	2/105	0.444	0.642
Educational Level	2/105	0.031	0.970
Income Level	5/98	0.707	0.620
Living Location	1/106	1.220	0.272
Availability of Sources of Family Support			
Parental Age	2/106	0.679	0.509
Educational Level	2/106	0.489	0.615
Income Level	5/99	1.609	0.165
Living Location	1/107	2.391	0.125

Note. * $p<0.05$

Table 14

Pearson correlation between parent-related factors and parents' perceptions of children with disabilities, integration, service adequacy, and availability of sources of family support

	Children with Disabilities	Integration	Service Adequacy	Family Support
Parental Age	-0.026	0.016	0.015	-0.110
Educational Level	-0.309**	-0.076	-0.024	0.058
Income	-0.143	-0.065	0.017	0.212*
Living Location	0.058	-0.006	-0.107	0.148

Note. *. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Relationship of Child-Related Factors to Parents' Perceptions

The Pearson correlation analyses and ANOVA were conducted to determine if child's age, gender, birth order, and type of disabilities were related to the parents' responses. In this section, children identified in this present study were regrouped by their age and disabilities. Children aged birth to 3 were in group 1; children aged between 4 and 5 were group 2; and children aged 6 and 7 were in group 3. Regarding level of disabilities, children were divided into 3 groups. Children with visual or hearing impairments, or mild physical handicaps, were assigned into the mild-disabilities group. Children with development delays or moderate physical handicaps, were grouped in the moderate-disabilities group. Children with multiple disabilities or severe physical handicaps, were grouped in the severe-disabilities group. Both the analyses of variance and Pearson correlation indicated that no child-related factors were significantly related to the parents' responses investigated in this study (Table 15 and 16).

Table 15

Analyses of variance in parents' perceptions toward their children with disabilities, integration, service adequacy, and availability of sources of family support by child's age, child's gender, birth order, and type of child's disability

	df	F	Significant
Parents' Perceptions toward Children with Disabilities			
Child's Age	2/106	0.177	0.838
Child's Gender	1/107	0.309	0.580
Birth Order	3/105	1.702	0.171
Type of Disability	2/106	0.607	0.547
Parents' Perceptions of Integration			
Child's Age	2/106	0.558	0.574
Child's Gender	1/107	1.289	0.259
Birth Order	3/105	1.018	0.388
Type of Disability	2/106	1.939	0.149
Parents' Perceptions of Service Adequacy			
Child's Age	2/105	0.239	0.788
Child's Gender	1/106	1.280	0.260
Birth Order	3/104	1.078	0.362
Type of Disability	2/105	3.039	0.052
Availability of Sources of Family Support			
Child's Age	2/106	0.404	0.669
Child's Gender	1/107	0.000	0.984
Birth Order	3/105	1.702	0.171
Type of Disability	2/106	0.928	0.399

Note. * $p<0.05$

Table 16

Pearson correlation between child-related factors and parents' perceptions of children with disabilities, integration, service adequacy, and availability of sources of family support

	Children with Disabilities	Integration	Service Adequacy	Family Support
Child's Age	-0.026	-0.016	0.015	0.009
Child's Gender	-0.054	0.109	-0.109	-0.002
Birth Order	0.105	-0.006	-0.102	-0.086
Type of Disability	-0.094	0.080	-0.015	-0.110

Note. *. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

More details about parents' reflections or reactions about having a child with special needs were obtained through the last section of the questionnaire, the open-ended questions. Of 109 respondents, 97 out of 109, or 89%, of the parents answered at least 1 question. Eighty-six out of 109, or 78.9%, parents indicated that a doctor was the first person to inform them regarding their child's special needs. Among 109 parents, 95 (87.2%) expressed that they were very shocked and painfully surprised when they first became aware of their child's exceptionality. Some parents (74 out of 109 or 67.9%) felt extreme unhappiness upon facing their child's special needs, while a few parents (15 out of 109 or 13.8%) perceived their changed circumstances as so severe that they lost their joy or reason for living. They also found it impossible to smile, laugh, or participate actively in life's common pleasures, because they felt enjoying themselves caused them to feel guilt.

When parents first found out about their child's special needs, most parents (70 out of 109 or 64.2%) denied their child's exceptionality, they sought opinions from different specialists in an effort to find a more acceptable diagnosis. A few parents (17 out of 109 or 15.6%) blamed themselves for their child's disability and they believed the exceptionality was their fault. They even felt ashamed and guilty (34 out of 109 or 31.2%). For parents, most of them knew little or nothing about their child's exceptionality, the diagnosis of their child made them feel frightened (94 out of 109 or 86.2%). They felt fearful and confused about the cause of their child's exceptionality, its normal course, its treatment, and its present and future effects. In addition, throughout the exceptional child's early developmental years and beyond, parents were frustrated by their inability to obtain needed services (87 out of 109 or 79.8%). After a period of coming to terms with their feelings about parenting an exceptional child, most

parents began to accept the reality of the child's special needs (95 out of 109 or 87.2%). As their crisis reactions lessened and parents became more accepting, they saw more reasons to feel good about themselves and their child.

In addition, 94 out of 109, 86.2% of respondents said that they shared their child's diagnosis with their relatives and close friends. Some parents (13 out of 109 or 11.9%) felt isolated after they told their friends regarding their child's condition, while a few parents (25 out of 109 or 22.9%) received extra caring and help from their relatives and friends. Despite the problems these parents experienced, the majority (79 out of 109 or 72.5%) indicated that the experience had been positive.

Table 17 includes a list of additional concerns parents expressed through the last open-ended question on the questionnaire. The parents of children with disabilities were concerned about their children's future. They worried about not knowing where to get help due to the lack of information on early childhood special education services and did not know how to choose suitable programs for their children. Parents expressed concern about the quality of early childhood special education personnel and the quality of the programs as well. Parents hoped to have a better place where all service personnel would cooperate well, including people from educational, medical, and social programs. For examples of descriptions regarding these questions see Appendix H.

Table 17

Additional concerns expressed by respondents regarding children's exceptionalities

Concerns	Parental Responses (%)
1. Quality of school personnel	76.9
2. Quality of early childhood special education programs	52.5
3. Lack of special education information and services	47.3
4. A place in which educational, medical, and social programs each providing a separate service may compound the problems of the child and the family.	33.6
5. Society rejection	26.0
6. Lack of parent-to-parent support group and parental organization	22.4
7. Parent-professional educator relationship	21.8
8. Rejection by normal children and their families	18.3
9. More early intervention programs	15.8
10. Inadequacy of the information network to provide the latest information on special education	11.4
11. Not enough special educators	10.9
12. Barrier-free environment	9.7
13. Opportunities for lifelong education	5.5

Summary of Results

The results of the present study were reported in this chapter in response to four research questions. The summary of the findings is as follows:

Question 1: What perceptions do Taiwanese parents hold about their young children with disabilities?

Taiwanese parents in this study generally perceived more agreement than disagreement on items regarding perceptions toward their children with disabilities. In other words, 9 out of 16-attitudinal items were found to be more agreed than disagreed (Table 9). Those 9 statements included, "My child participates in all family activities"(Item 4), "My child enjoys participating in public or community events"(Item 5), "I expect my child to meet the same academic standards as children who do not have disabilities"(Item 6), "I worry about my child's future"(Item 7), "My child has lower self-esteem than children who do not have disabilities"(Item 8), "My child gets along well with his/her friends who do not have disabilities"(Item 10), "My child should get more attention from his/her teachers than children who do not have disabilities"(Item 11), "My child should be expected to meet lower academic standards than his/her peers who do not have disabilities"(Item 12), and "My child works hard to be independent"(Item 16).

As reflected in Table 10, a high percentage of parents agreed with items 17 to 20, including "My child should have the same educational opportunities as children who do not have disabilities"(Item 17), "Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem"(Item 18), " My child should be able to play with children who do not have disabilities"(Item 19), and "Going to school with children who do not have disabilities would provided more opportunities for my child to interact with nondisabled friends"(Item 20). However,

about half of the parents indicated "neutral" on items 21 to 25, including "My child should be educated in special classes where he/she is only with children who have the same disability"(Item 21), "Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem"(Item 22), " Going to school with children who have the same disabilities will make my child feel more secure (Item 23), " Going to school with children having the same disabilities will cause my child to have lower esteem "(Item 24), and " My child would be happier playing with other children who have the same disability "(Item 25).

With regrouping or combining data, the Pearson correlation analyses and ANOVA were conducted to determine if selected parent-related factors (i.e., parental age, educational level, family income level, and living location) and child-related factors (i.e., child's age, child's gender, birth order, and type of disability) were related to the parents' perceptions about children with disabilities and integration. The results indicated that most parent- and child-related factors were not significantly related to parents' responses. However, educational level of parents was found to be significantly related to parents' perceptions of their children with disabilities. Parents with higher education tended to perceive more disagreement on items regarding perceptions toward their young children with disabilities.

Question 2: What perceptions do Taiwanese parents hold about the adequacy of existing family-centered early childhood special education and related services?

Taiwanese parents in this present study generally perceived neutral perceptions regarding existing early childhood special education services in Taiwan. Only 2 out of 18 items were rated as inadequate. The service item identified as the least adequate was Item 9, "A place for my child to go for recreation". When ignoring neutral responses,

most parents perceived 15 out of 18 service items as inadequate (e.g., Items 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, and 17). In addition, no parent-related or child-related factors were found to be significantly related to parents' perceptions regarding service adequacy.

Question 3: What available sources of family support exist and to what extent have different sources of support been helpful to Taiwanese parents rearing young children with disabilities?

Taiwanese parents in this present study generally perceived that sources of family support were rated to be no helpful or only somewhat helpful (e.g., Items 3, 4, 6, 7, 10, only 12). Four out of 14 were rated as neutral (e.g., 1, 2, 8, and 11), while Item 5 and 13 were rated as generally helpful. Item 14, school teachers, was rated as very helpful. In addition, the analyses of variance revealed that parents with higher incomes perceived more available sources of family support.

Question 4: What perceptions do early childhood personnel in Taiwan hold about existing family-focused early childhood special education and related services?

Among 8 early childhood personnel responding in the present study indicated that all 8 (100%) school settings provided services to children with developmental delays and their families, 7 (87.5%) provided services to young children with handicaps and their families, 2 (25%) provided services to children with physical impairments and their families, 2 (25%) provided services to children with visual impairments and their families and only 1 (12.5%) provided services to children with hearing impairments and their families.

Regarding special services provided to young children and their families, information regarding special education or related services was the most common service

provided by program personnel, which was followed by occupational and/or physical therapy, speech-language therapy, social worker(s), family counseling services, medical support services, psychology services, nutrition support, and audiological services. In addition, all program personnel stated that all children in their programs had their own special, or individual, education goals or written program plans. They all invited parents to participate in their children's IEP/IFSP meetings.

Finally results of 5 open-ended questions were found to be consistent with the parents' responses on the other parts of the questionnaire. These parents expressed considerable ambivalent perceptions toward integration of their children with disabilities. Parents' concerns regarding integration included rejection of their children by children without disabilities and their families, teachers' reactions and commitment, program quality, and personnel quality. Parents perceived that most services were not available or were inadequate. The most inadequate services were recreational places, transportation for the children to school, and someone to help the children and their families deal with emotional problems.

CHAPTER FIVE

Parental perceptions toward their young children with disabilities, integration, and services provided are key factors which affect the success of early childhood special education services. The present study investigated perceptions of these factors held by Taiwanese parents of young children with disabilities. A questionnaire was designed to assess Taiwanese parents' perceptions toward their young children with disabilities and their feelings about the integration of their children into regular environments. In addition, it explored their perceptions of the adequacy of existing services and sources of family support.

To more fully understand the results of this study, it is important to place the results in the context of present day Taiwan. Traditionally, all members of a Taiwanese farming family lived together in one household, caring for each other's needs. Three generations cohabiting was common, and five generations living together was seen as ideal (The Republic of China Yearbook, 1999). Each family member had certain responsibilities according to his or her age and gender. Young men worked in the field. Their wives cooked, managed the home, and took care of the family elders. Grandparents provided wisdom, guidance, and childcare. And children did light chores. When all members fulfilled their duties, everyone's needs were met, and the family was said to be in harmony.

The classical conception of family-based support has been challenged by the emergence of a modern, post-agricultural economy in Taiwan. By 1997, only 10 percent of the working population was employed in agriculture (The Republic of China Yearbook, 1999). Many young people have left the farming households in which they grew up and established nuclear families in urban areas. It is now common for both

parents to work full-time outside the home. Children are often cared for by the school system, and grandparents are only visited during major holidays.

As mentioned, the revolutionary changes in political and social systems and the strong influences of Western ideas and practices have brought changes in the structure and characteristics of the traditional Chinese family as well as families in other Asian countries. There are increasing numbers of nuclear families replacing the large family units made up of several generations. Therefore, some aspects of families have changed, including changes in child-rearing attitudes and practices. These changes include an orientation toward a reduction in authoritarianism and a greater involvement of the father in their children's early years (Wang, 1993). Now younger fathers are becoming more involved in childcare and education decision making.

Statistics show that women are having fewer children (The Republic of China Yearbook, 1999). Furthermore, among the 326,002 births registered in Taiwan in 1997, there were 109.04 boys for every 100-baby girls, while the global ratio of males to females at birth is about 105:100 (The Republic of China Yearbook, 1999). The ratio in Taiwan reflects the traditional preference among Asian parents for boys over girls (The Republic of China Yearbook, 1999). These factors may explain why there were more male children identified (65%) in the present study and most families had only 2 children (47.7%).

In regard to parents' education level, the Constitution of the Republic of China entitles all children to at least six years of basic education. The National Education Law promulgated in 1979, stipulates that all school-age children between 7 and 15 must attend six years of public elementary school and three years of junior high school (The Republic of China Yearbook, 1999).

In Taiwan, education above junior high school is not compulsory. Junior high school graduates who desire to continue their studies in either senior high school or vocational schools need to pass the Senior High-School Entrance Examinations. The accept rate for Senior High-School School increased from 61.6 percent in 1975 to 86.1 percent in 1981 (The Republic of China Yearbook, 1999). The percentage of high-school graduates in the general population increased from 18.9 in 1976 to 27.6 in 1985. Entrance into universities is competitive. In other words, only a few students are able to go to colleges or universities. By the year 1990, college graduates were 13.4 of percent of the general population (Education Statistics of Taiwan, 1997).

Taiwan's economic growth over the past 40 years has been powered by a well-educated and highly motivated work force. Over the years, the structural composition of labor has changed, but workers themselves have retained their traditional spirit of dedication and hard work. Today, Taiwan has a diversified and skilled work force of roughly 9.4 million people, with a comparatively low unemployment rate of less than 3 percent (The Republic of China Yearbook, 1999). The foreign exchange rate is NT$30:US$1. In 1997, the average income was about 420,000 (US$14,000) per year (The Republic of China Yearbook, 1999). It is important to keep these factors in mind to more fully understand the demographic information reflected in the present study.

Discussion

Program Results

According to the findings on program characteristics, the survey identified two groups. One group provided services to children with special needs aged birth to three (2 out of 8), and one group provided services to exceptional children aged three to seven (6 out of 8). As found in the literature regarding services in the United States

(Department of Education, 1998), the results indicated that children who received intervention are mainly aged 3 to 6-years. For most families with youngsters with disabilities in Taiwan, medical care rather than educational or therapeutic consultation may be the only service they received from professionals during their children's first three years of life. Children with vision or hearing impairments may require special personnel, equipment and environments for the provision of services. This may be one factor why most early childhood special education programs do not include these children. Indeed, only one program in this study served each of these two populations. In addition, these are both very low incidence disabilities; therefore there is not a need for a large number of programs to serve children with visual or hearing impairments. The early childhood programs which responded to the survey represented a diverse sample of services and programs.

In addition, all 8 agencies declared that they had individualized education programs for all children with special needs and invited the children's parent(s) to participate in the program development meetings. However, only 63.3% of the parents stated that their children had individualized education programs and 50 parents participated in writing their children's IEP or IFSP. This may result from miscommunication between program personnel and parents, and Taiwanese parents were not aware of their rights regarding participating in their children's education decisions making.

Family Results

The results indicated that most respondents to the family survey were between 30 to 39 (68.8%) years of age, high school graduates (59.6%), and lived in urban areas (56%). Although the largest number had annual incomes of 420,001 to 600,000 (26.6%), there was a broad range of incomes.

Taiwanese parents in the present study tend to hold (a) positive perceptions toward their young children regarding participation in family activities and social interaction with other children (Table 9, Item 3, 4, 5, 9, and 10), (b) positive expectations (Item 1, 2, 6, 11, and 14), and (c) positive feelings (Item 8 and 13) toward their children themselves. In other words, Taiwanese parents tend to encourage their children to participate in family or public activities and interact with other children without disabilities. They love their children with disabilities and do not perceive them to be a burden.

The Taiwanese parents in this study tend to protect their children with disabilities, although they do not tend to treat them less strictly (Table 9, Item 1). They tend to expect more attention from their children's teachers and expect lower academic standards than for children without disabilities (Table 9, Item 11 and 12). Taiwanese parents worry about their children's future and are afraid, according to their responses from open-ended questions, that nobody will take care of their children in the future the way they do at present. In response to parents' needs and feelings, early childhood special education services were not seen as adequate (Table 11, Item 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, and 17). More early intervention programs for special education services, medical support, therapy treatment, and training daily living skills, should be provided to young children with disabilities, so that parents' concerns about their children's future can be alleviated.

The survey results also indicated that parents with higher education tend to have more negative perceptions toward their children with disabilities than those parents with lower education. This might be a result of cultural influences: Chinese families are honored by their children's outstanding achievements. Parents of higher social economic status might feel ashamed and hopeless in keeping the honor they have

obtained for the family.

Taiwanese parents generally hold positive(Table 10, Item 17-20), but somewhat "conservative" attitudes toward integration (Table 10, Item 21-25). They tend to accept the concept of integration, but prefer special schools or special classes to be their children's educational environment. According to the open-ended questions, Taiwanese parents are aware of the benefits of integration, but are not convinced that they should actually accept it as a better service delivery system for their children. Like parents of youngsters with disabilities in the United States, Taiwanese parents have concerns regarding integration, such as nondisabled peers' attitudes, attitudes of parents of children without disabilities, program quality, and teacher's commitment to their children (Table 17). Taiwanese parents should be provided with further information and continuous collaborative services promoting the positive aspects of integration. They need explanations of procedures by which special services now provided in special programs will be delivered in the context of an integrated program. Parental advocacy activities need to be redirected from attempts to ensure special programming for their children toward improving the general quality of education for all children. Because concerns and fears were expressed in the present study, parents must be assured that integration will improve and increase educational opportunities available to their young children with disabilities. Governmental support for special services in early childhood education settings, preparation of both general and special educators, and national advocacy will be needed if the benefits of integrated programs are to be assured.

The data related to integration indicated that some uncertainty existed among the parents. The high frequency of "neutral" responses may be a reflection of ambivalence or it may reflect their uncertainty of what would be best for their child. For example, a

large number of parents indicated that they were uncertain as to whether their child would be happier playing with peers with or without disabilities (Table 10, Item 24). At the same time, a great number of parents were uncertain as to whether or not their child's self esteem would be enhanced by going to school with children without disabilities (Table 10, Item 18). Similarly, parents reflected an ideal that their children should be able to play with children without disabilities (Table 10, Item 19). They also reflected uncertainty that going to school with other children who have the same disability would make their child feel more secure (Table 10, Item 22).

Taiwanese parents in this study feel that the special services for young children with disabilities in Taiwan were generally inadequate (Table 11, Item 1, 2, 3, 5, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, and 17)). Only a few parents indicated in the open-ended questions that they felt satisfied with the current services for their children. Such findings should be presented to the service providers and policy makers in Taiwan. An increased awareness of parents' perceptions of service adequacy in Taiwan may lead to governmental agencies and private service providers taking more action to meet the service needs of young children with disabilities and their families. Services which have been found to be needed in the United States could be used as a basis for development. These would include, but not be limited to, medical, recreational, educational, therapy, counseling, parent support groups, and information network programs.

Survey results also indicated that the spouses (husband or wife) and school teachers were the two most helpful sources when Taiwanese families faced difficulties rearing their children with disabilities (Table 12). These were followed by medical professionals and therapists, the spouse's parents and their own parents. As mentioned,

to Chinese families, to cope with stress and difficult caretaking, parents, especially mothers, of the children with disabilities usually find inside support first before turning to someone outside the family because of the inside-outside distinction. Family members, including those in the extended family, such as grandparents who have more time to take care of young children in the family, are frequently the ones that offer inside support and comfort to the family with a young child with special needs (Table 12, Item 1 and 2). However, professional assistance has been reported to be helpful for the parents with young children with special needs as well. This may be interpreted as a reaction of deference to authority figures. To parents with young children with special needs, medical professionals or school teachers (Table 12, Item 13 and 14) seem the best persons to provide help, especially if the parents know little about their children's conditions. Furthermore, since school teachers were the ones distributing these questionnaires, this may influence the response of parents as seeing them as more helpful than others.

In addition, Taiwanese parents perceived religion and co-workers as less helpful sources of family supports (Table 12, Item 10 an 12). This may result from the facts that young parents today in Taiwan receive more education and become more involved with their families, friends, and jobs, but religion. Furthermore, as mentioned earlier, it is considered to be a serious "loss of face" or "failure of the family" when the offspring with disabilities is discovered by an outsider. Therefore parents may be hesitant to share their difficulties with an outsider, even their co-workers.

The results also revealed that parents with higher incomes perceived more available sources of family supports. It is possible that richer parents are more willing to look for the best available supports to meet their needs and to be able to pay for them. Or most families with lower incomes may be busy on their works and not able to have time to

look for services, or they may not able to pay for services.

Limitation

Several significant difficulties compromised the survey research efforts. First, the study was conducted only in Tainan. A more complete picture would be obtained by surveying all Taiwanese parents of young children with disabilities. Second, subjects were only parents of young children enrolled in preschools, nurseries, daycare centers, and social welfare settings, and did not include parents of young children in hospitals and parents of those children who were kept home. Third, some parents may have been concerned about the purpose of the survey and how the results were to be used. This may have influenced their responses, or they may not have responded at all. This may have also resulted in the limited return rate.

It is recommended that the present study be replicated among parents in various areas of Taiwan in order to determine if the data are representative of all Taiwanese parents. It is also recommended that the results of these replication studies be compared to results of similar surveys among parents from other cultural backgrounds, such as North American, Hispanic, European, and Asian-Pacific countries. This would help continue the validation of the questionnaire and expand its use into a global format for cross-cultural studies.

Implications and Recommendations

Taiwanese parents of children with disabilities need to become more aware of the magnitude that their affective signals carry to their children and how positive attitudes, coupled with their love, can be a significant factor in their children's successful education. Schools and other individuals need to make efforts to assist parents in becoming more cognizant of the power of their perceptions and how their perceptions can be expressed.

Further research should be directed toward delineating those specific parents' perception traits that are related to early childhood special education success and to identifying educational programs that can be used to ensure that parents manifest those traits.

In addition, the following specific actions should be taken based upon the present study:

1. Parent-education programs should be provided to help parents of young children with disabilities become more knowledgeable about their children's disabilities. Training programs should include such topics as how to raise their children more naturally, how to help their children to become more independent, the rationale for early childhood special education programs, and the benefit of early intervention services.
2. The government should conduct service-needs assessments to determine the specific services which are most important for young children with disabilities and their families.
3. Current services and facilities must be assessed and modified to meet the needs of young children with disabilities and their families.

Parents, educators, schools, and other services agencies, have much to contribute to each other's views of what is appropriate education and services for young children with disabilities. It will also be important to document the perceptions held by Taiwanese parents of children without disabilities toward young children with disabilities, early childhood special education programs, and related services. A potential negative backlash from parents of nondisabled children could have substantial effects on the implementation of early childhood special education services. In order to enhance the total success of early childhood special education programs, the needs and concerns of

parents of children without disabilities must also be recognized. If negative attitudes are found, programs should be provided to educate parents of children without disabilities through general mass media, (e.g., radio, newspapers, television, and magazines) in an effort to change their attitudes toward children with disabilities and services for them. Parents of children without disabilities need to be informed as to the benefits of heterogeneous groupings of children in regular service and school settings, how children without disabilities learn from being with peers who are different, and why integrated programs are most appropriate for all children. The support of parents of children without disabilities may be a critical factor affecting the success of early childhood special education programs.

This study is the only one to date reporting parents' perceptions toward young children with disabilities, integration, adequacy of services, and family support in Taiwan. There is a great need for more extensive research on this topic as well as assessing perceptions held by educators, administrators, nondisabled peers, parents of children without disabilities, and the general public in Taiwan toward young children with disabilities, service needs for them and their families, sources of family support and integration.

Conclusion

The study indicate that parents of young children with disabilities need assistance and special services to support their children's development. There are a number of challenges professionals and policymakers today in Taiwan need to confront in planning for early intervention as well as educational services. To ensure high quality services to young children with disabilities and their families, the first challenge is to provide comprehensive and multidisciplinary early intervention in a unified or integrated service

delivery system in which professionals from all related disciplines work and support each other. Only if an integrated service delivery model is adopted, can effective family support be delivered to decrease the possibility of families "shopping" for pieces of services.

Even though comprehensive and integrated early intervention services could be delivered to families with special needs youngsters, the quality of services is ultimately dependent on those who provide the services. Quality of services has been identified as one of the prime indicators relating to effectiveness of early intervention programs (Bryant & Graham, 1990). In this study, no direct evidence of such an indicator can be found, but the lesson learned from a previous study may remind readers of the importance of personnel competence (Tsai & Chuang, 1985). Therefore, the second challenge is to improve personnel preparation before the immense expansion of early childhood special education programs begins. To meet such a challenge, personnel training program designers may need to incorporate a number of areas, such as class management and teaching strategies, into the curriculum to prepare personnel not only to work with young children with special needs and their families, but also to work with other professionals.

In planning intervention and educational services for young children with disabilities and their families, special educators in Taiwan face a third challenge: to design programs that match Chinese/Taiwanese traditions and values. Professionals in Taiwan have adopted the theoretical and empirical models that have been developed by professionals from North America and Japan where most Taiwanese professionals have received training. However, when theoretical and empirical models are adopted from other areas, Taiwanese professionals need to be sensitive to differences in traditions and the political,

social, and economic situations unique to their particular culture.

Developed countries recently have emphasized providing broader family support to address a variety of needs for families of children with special needs (Wang, 1993). Therefore, the fourth challenge for professionals is to provide family support based on the particular needs of the family within the Taiwanese cultural and societal context. However, to provide family support or to involve parents, professionals in Taiwan may need to consider two critical issues suggested in Western literature. First, an intervention program should seek to create goals for family outcomes in their own right (Bristol, Reichle, & Thomas, 1987). Second, specific teaching functions that parents usually are asked to assume can, in many instances, prevent the development of appropriate parent-child relationships (Affleck, McGrade, McQueeney, & Allen, 1982). Hence the primary role of professionals is to provide important information, counseling, or training and, at the same time, to foster natural, supportive, and reciprocal relationships between parents and their exceptional children.

Finally, the goal for families of young children with disabilities in Taiwan is the same as in other countries; to develop effective coping strategies and draw on family support programs that consider the needs of individual families in particular cultural and societal contexts. This will ensure that a favorable quality of life for youngsters with disabilities and their families can be realized.

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Appendix A

Definition of Terms

The following terms are used in the study and are defined to provide clarification:

Perception - Physical sensation as interpreted in the light of experience: the integration of sensory impressions of events in the external world by a conscious organism especially as a function of nonconscious expectations derived from past experience and serving as a basis for or as verified by further meaningful motivated action (Webster's Third New International dictionary of the English Language Unabridged, 1971, p.1675). The definition used in the present study was, " the awareness of the parents toward their children, special services and their or their children's needs."

Children with Disabilities - Children who are physically disabled, mentally retarded, visually impaired, hearing impaired, or other health impaired.

Mild Mental Retardation - Cognitive development at least 2 standard deviations below the mean for the general population, with IQs ranging from 52 to 67 (Special Education Center of National Taiwan Normal University, 1999).

Moderate Mental Retardation - Cognitive development at least 3 standard deviations below the mean for the general population, with IQs ranging from 36 to 51 (Special Education Center of National Taiwan Normal University, 1999).

Severe Mental Retardation - Cognitive development at least 4 standard deviations below the mean for the general population, with IQs ranging below 36 (Special Education Center of National Taiwan Normal University, 1999).

Mild Physical Handicap – A physical disability that requires at least one year of therapy to gain some degree of functional improvement (Special Education Center of

National Taiwan Normal University, 1999).

Moderate Physical Handicap – A physical disability that requires at least two years of therapy to gain some degree of functional improvement (Special Education Center of National Taiwan Normal University, 1999).

Severe Physical Handicap – A physical disability that requires long-term or even a whole life of therapy and may not lead to functional improvement (Special Education Center of National Taiwan Normal University, 1999).

Partial Sight – Distance vision of 20/70 or less but better than 20/200 (Special Education Center of National Taiwan Normal University, 1999).

Blindness – Distance vision of 20/200 or less in corrected the better eye and field of vision no greater than 20 degrees (Special Education Center of National Taiwan Normal University, 1999).

Mild Hearing Impairment – A hearing loss ranging between 25 to 40 dB (Special Education Center of National Taiwan Normal University, 1999).

Moderate Hearing Impairment – A hearing loss ranging between 40 to 60 dB (Special Education Center of National Taiwan Normal University, 1999).

Severe Hearing Impairment – A hearing loss ranging between 60 to 90 dB (Special Education Center of National Taiwan Normal University, 1999).

Deaf – A hearing loss above 90 dB, even with the use of hearing aides (Special Education Center of National Taiwan Normal University, 1999).

Special Services – Any therapeutic, counseling, transportation, medical, financial, and other supportive services provided to children with disabilities (e.g. providing the Optacon or the Braille writer to children with visual impairments).

Appendix B

Description and Results of Previous Study

The purpose of the study was to investigate the characteristics and perceptions of early childhood personnel in Taiwan. This study presented the results of a survey examining existing early childhood special education practices in Taiwan, the Republic of China. Descriptive data on personnel representing several disciplines currently providing early childhood services were gathered through a questionnaire survey of 134 agencies in Taiwan. The following characteristics of professionals and paraprofessionals in these early childhood intervention programs were documented: title of job(s); years of experience; levels of education; receipt of specialized early intervention training; types of license/credential certification; and inservice training opportunities. Further, program information such as the following was collected: total number of all students; number of exceptional students; staff-child ratio for center-based programs; type of service(s) provided by the program or program setting(s); and staff caseload for home-based programs.

The research design used in this study was a descriptive statistic method. All participants were asked to complete 18 survey questions and 3 open-ended questions about their own feelings of inclusion.

Survey questionnaires were mailed to identified program providers. The list of program providers was developed by contacting the Department of Social Affairs and the Department of Education responsible for funding early childhood services for children with disabilities or at-risk conditions, local planning area coordinators, and major support organizations. Specifically, provider lists from the Department of Social Affairs, Department of Education, and Parents' Association for Persons with Intellectual

Disability, R.O.C. (PAPMH) were obtained. Further, additional agencies identified through the local planning area coordinators were surveyed.

The final total number of early childhood educational programs identified was 314. One hundred, or 31.8%, of the agencies were identified from the north of Taiwan (including 35 preschools, 49 nursery settings, and 16 other support organizations); 17, or 5.5%, of the sample came from central Taiwan (10 preschools and 7 other supporting organizations); 185, or 58.9%, of the sample were located in the south (1 nursery, 172 preschools and 12 other organizations); and 12, or 3.8%, of the sample from the east (9 preschools and 3 other organizations).

Of the 314 program agencies identified, 134 program providers responded to the questionnaire making a total response rate for this survey of 42.7%. When these programs were grouped according to the geography of Taiwan (north, central, south, and east groups), the response rates for the north group were 45 out of 100, or 45%, 13 out of 17, or 76.4%, from the central group, 70 out of 185, or 37.8%, from the southern group, and 6 out of 12, or 50%, from eastern Taiwan.

Survey items are described individually in the following discussion. The program characteristics are presented first followed by the professional characteristics.

Program Characteristics

Type of school. One hundred out of 134, or 74.6%, of the agencies provided early childhood services and all of them were center-based. Only 10 of these 100 agencies providing early childhood services stated that they also provide home-based services to whoever needed it. Moreover, 117, or 87.3%, of the programs had received inquires about educating children with special needs over the past few years. Seventy-four, or 55.2%, of all agencies were identified as public and 61, or 45.5%, of them, including both

public and private agencies, received government funding.

Staff-child ratios for center-based programs. The median ratio was 1:13.5 staff to children (mean ratio was 1:12) with a range of from 1:1 to 1:30. It is noteworthy that 8 programs reported a ratio as great as 1:30, only 7 programs had a ratio as 1:1, and 50 programs had a ratio less than 1:5.

Number of programs not accepting exceptional students. The results indicated that 34 out of 134, or 25.4%, of the agencies reported that they did not accept any children with special needs. However, 12 of these 34 agencies also stated that they would be willing to try, if they had enough resources.

Types of children with disabilities. Thirty-six out of 100, or 36%, of the agencies that provided early childhood programs stated that they had children with autism; 29% of the programs had children with mental handicaps; 20% of the programs had children with developmental delays; 17% of the programs had children with speech delays; 17% of the programs had children with AD HD; 16% of the programs had children with Down syndrome; 16% of the programs had children with hearing impairments; 16% of the programs had children with cerebral palsy; 15% of the programs had children with physical handicaps; 13% of the programs had children with multiple handicaps; 9% of the agencies had students with learning disabilities; 5% had children with visual impairments; 3% had students with moderate or severe disabilities; 3% had children with emotional disorders; 2% had children with mild disabilities; 2% had children with cleft lips or palates; and one program each served children with brain injuries, microcephaly, hydrocephaly, heart diseases, and health impairments. Eighty-four out of 100, or 84%, of early childhood programs reported that they served children with any types of disabilities or children with more than one type of disability.

Conditions not served. Some respondents indicated that there were children with specific types of disabilities they would not serve. Eleven programs excluded children with ADHD. Six centers did not provide services for children with moderate to severe disabilities and several declined to serve children with autism. Almost all (99%) stated that they could not provide services to certain children because the programs lacked qualified personnel or equipment.

Types of services provided. Figure 1 provides information on the number of programs providing various types of early childhood services. The survey found that 91 of the agencies did provide additional services for children with special needs. In addition, 9 of these 91 program providers stated that they did not provide services directly to children or families, but they would help children or families obtain necessary services or provide them with information, such as counseling or consultation about available services. Nine of the programs did not provide any special services beyond the regular classes. In summary, most of the agencies (98.9%) provided more than one kind of special service to children or families, and special instruction education was the service most likely to be provided (65.9%).

Individual Education Program (IEP). Seventy-four out of 100, or 74%, reported that every child with special needs had his/her own special, or individual, education goals or written program plan.

Parent contact and staff time devoted to special needs children. Ninety out of 100, or 90%, of the early childhood program providers reported that they did have more contact with parents of exceptional children than with parents of children without disabilities. The major reason for this was to communicate with parents and exchange information about teaching or learning strategies, to provide better and more effective

services. In addition, 97% of the early childhood program providers reported that they spent more time helping or working with children with special needs than with children without disabilities. This was because they thought those exceptional children might be slow-learners or have difficulties learning and therefore they needed more time to practice and learn.

Necessary changes of educators or school environment. Figure 2 provides information on changes perceived as necessary for educators or school environments to better serve children with disabilities. Of 134 respondents, 131, or 97.8%, of the providers believed that a teacher's knowledge/skills about teaching students with special needs and the teacher's training were the most important factor in need of improvement to better serve exceptional children. In addition, 119, or 88.8%, of the providers felt that the school environment should be made more accessible or supportive; 113, or 84.3% believed that more personnel were needed; 90, or 67.2% considered additional funding necessary; and 15, or 11.2% believed other changes were required.

Methods used to communicate with parents. The methods used to communicate with parents were varied and are depicted in Figure 3. The program providers stated that the more convenient, the better, because they did not want to cause the parents too much trouble. Thus, the survey reported that, of 134 respondents, the most common way to contact parents was by phone (97.8%), followed by notes to and from homes (85.1%), teacher-parent conferences (81.3%), field trips (47%), open house (23.1%), others (such as home visits, family days, or school parties) (22.4%), and school pick-up time (11.9%).

Professional Characteristics

Qualifications for teachers. One hundred and fifteen out of 134, or 85.8%, of

program providers stated that a good personality, loving, caring, and willingness to learn and help, were the most important characteristics of a teacher. In addition, 93 out of 134, or 69.4%, of program providers believed that a degree from a related discipline was beneficial, and 89 out of 134, or 66.4%, of program providers would like to hire teachers with related experience. Only 87 out of 134, or 64.9%, of program providers reported that having a teaching certificate would be important.

Providing funding or support for additional training opportunities for staff. A large percentage, 95.5% of the program providers stated that they provided opportunities for their staff to receive additional training. However, only 54 out of 134, or 42.5%, of the program providers responded that teacher training with exceptional children was available, convenient, or affordable. Some providers stated that available training times were not good for them, but most respondents explained that either they did not know where to get such information, or the training was available only to certain people. In addition, only 56.7% of the program providers reported that the training regarding children with disabilities they had received met their needs. Thus 43.3% of the providers believed that the previous training they received did not adequately meet their needs.

Respondent's job title, year(s) of experience, and educational or training background. Tables 1, 2, and 3 report percentages of all respondents' job titles, year(s) of experience, and their highest level of education or specialized training background. As indicated, 48.5% of the respondents were program directors or managers; 48.5% of the respondents had worked with young children for over 10 years. Only 5.2% of all respondents graduated from colleges of education and majored in special education.

Positive factors for educating children with special needs. The identified reasons for educating children with special needs can be divided into four groups. The largest group (55.2%) responded that they believed children with disabilities had a right to receive an equal education. The second most common answer (47.8%) was the benefit the children with special needs and their families received. Third was the challenge to educators (23.9%). Finally, the respondents felt that exceptional children had better personalities than those without disabilities (17.2%).

Advantages/disadvantages of inclusion. The most common response for the advantage of inclusion was to give general education students and exceptional students opportunities to learn from each other and make friends (70.1%). With regard to the disadvantages of inclusion, the most common answer was that educators had difficulties with class management (64.9%). Second, parents or educators felt it unfair or uncomfortable to include all students in one room since the teacher's attention could not be shared equally with everyone (59.7%). Third, the respondents cited the educator's limited knowledge or training regarding teaching students with special needs as a disadvantage (33.9%). Fourth, possible rejection from the parents of students without disabilities was identified as a concern (16.4%).

Table 1

Job Title of 134 Respondents

Program Director/Manager	65 persons (48.5%)
Educator	51 persons (38.1%)
Social Worker	13 persons (9.7%)
Aides	3 persons (2.2%)
Secretary	2 persons (1.5%)

Table 2

Year(s) of Experience of 134 Respondents

10 years or above	65 persons (48.5%)
5 - 9 years	47 persons (35.1%)
Under 5 years	22 persons (16.4%)

Table 3

The Highest Level of Education or Specialized Training Background of 134 Respondents

High School	5 persons (3.7%)
Bachelor	
General Early Childhood Education	59 persons (44%)
Other Majors, but have taken special education classes or received training	23 persons (17.1%)
Other Majors, but no training or specialized classes	28 persons (20.9%)
Special Education	7 persons (5.2%)
Master	
Other Majors	7 persons (5.2%)
Special Education	3 persons (2.2%)
Doctor	
Special Education	1 person (0.7%)
General Education	1 person (0.7%)

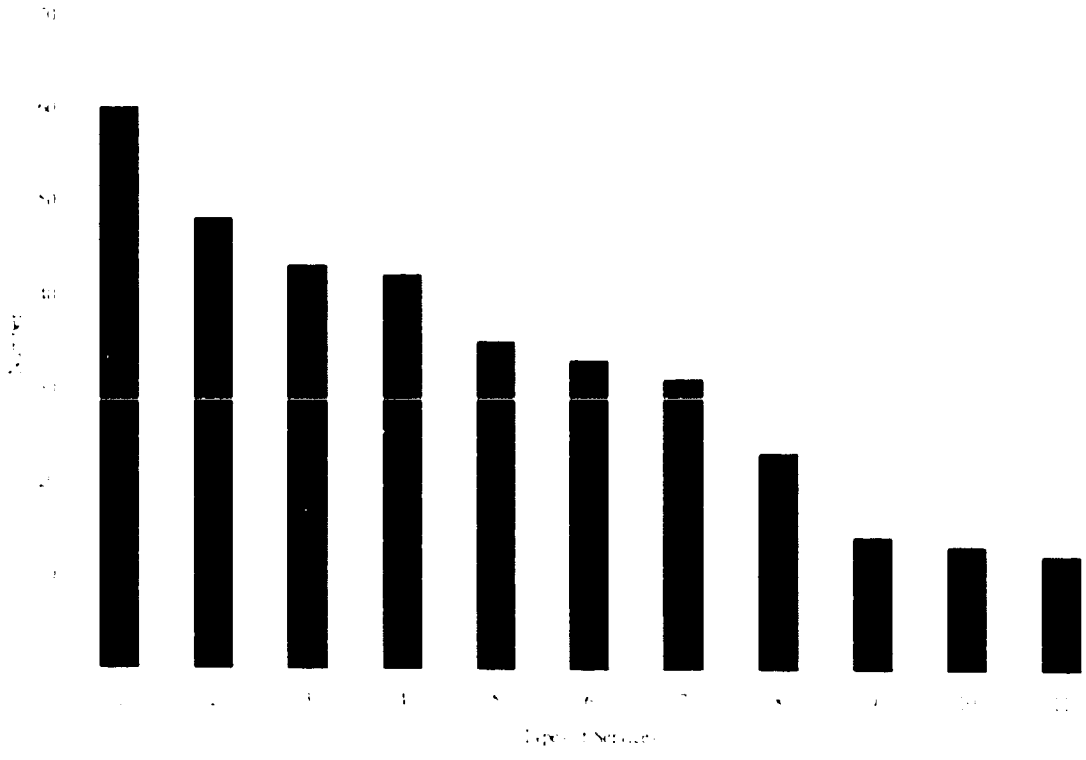
Figures Caption

Figure 1. The number of programs providing various types of services.

Figure 2. The number of necessary changes for educators or school environments to better serve children with disabilities.

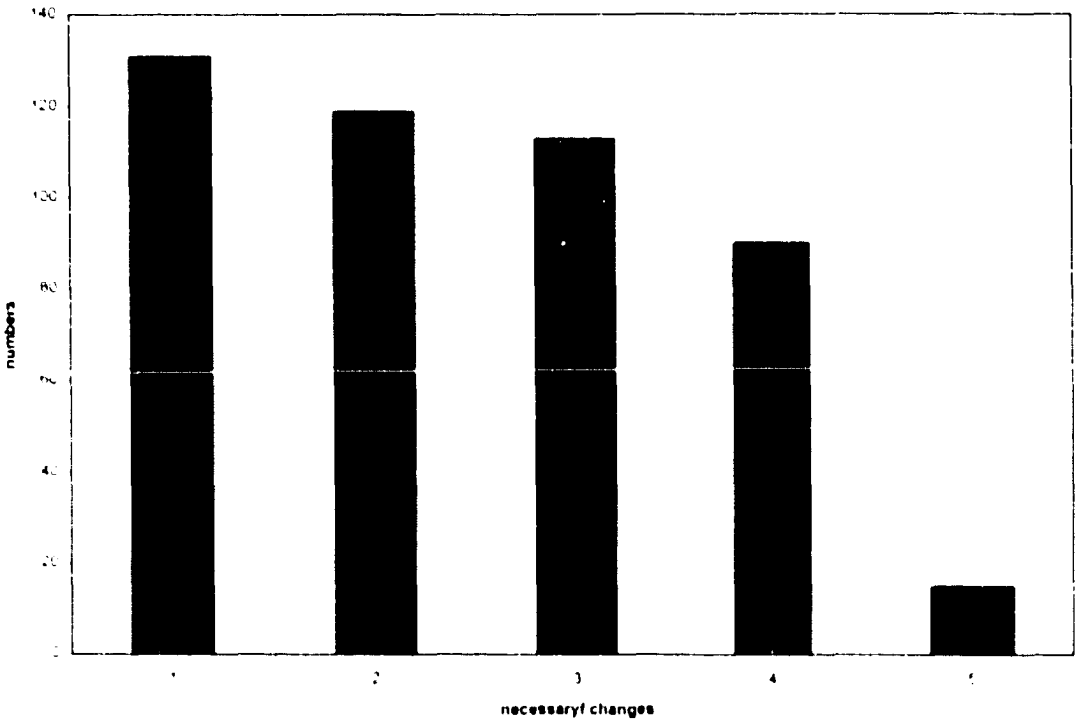
Figure 3. The number of methods used to communicate with parents.

Figure 1



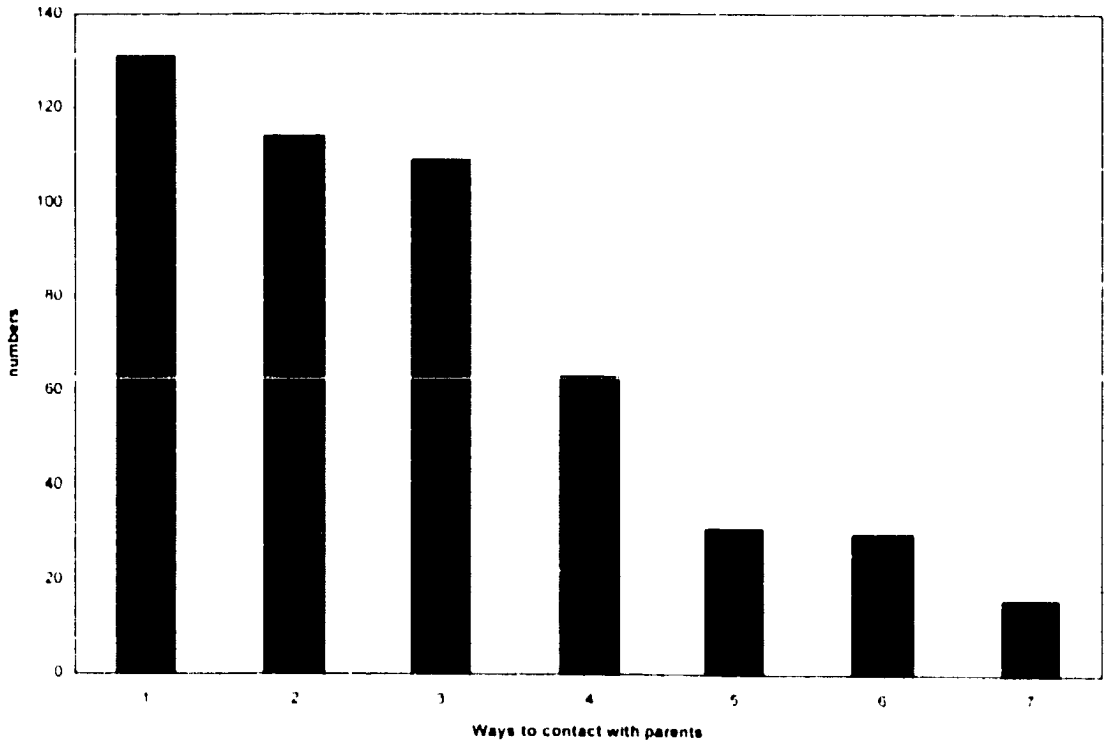
1. Special instruction education (60).
2. Special education information (48).
3. Speech-language pathology services (43).
4. Occupational physical therapy (42).
5. Social services (35).
6. Support group or parent-to-parent connections (33).
7. Family training and counseling (31).
8. Medical support (23).
9. Audiological services (14).
10. Nutrition support and counseling (13).
11. Psychological services (12).

Figure 2



1. Teacher's training (131).
2. School environment, such as wheelchair access or elevators (119).
3. Increasing the numbers of staff or decreasing staff-child ratio (113).
4. Funding (90).
5. Others, such as transportation services, social workers, and family counselors (15).

Figure 3



1. Phone contacts (131).
2. Notes to and from homes (114).
3. Teacher-parent conferences (109).
4. Field trips (63).
5. Open houses (31).
6. Others, such as home visits, family days, or school parties (30).
7. School pick-up time (16).

Appendix C

Description of Tainan

Tainan is located on the fertile Chia-Nan Plain along the southwest coast of Taiwan. With a total area of nearly 2,191.645 square km, Tainan makes up about 6.09 percent of the land area of Taiwan. Tainan is the eighth largest municipality of Taiwan's 17 municipalities (The Republic of China Yearbook, 1999). According to statistics released by the Ministry of Interior in 1997, the total population of Taiwan area was 21.74 million and Tainan was the eighth most populous area of Taiwan Island with the population of 1,800,000 (The Republic of China Yearbook, 1999). In addition, the percentage of urban population of Tainan was about 63.6 in 1997 (The Republic of China Yearbook, 1999). In Taiwan, highly populated urban areas have risen up around the official limits of major cities, forming large metropolitan areas. Metropolitan areas are defined as urban centers with populations of over 1 million people, and in 1997, they continued to grow and are now home to 67.8 percent of Taiwan's total population (The Republic of China Yearbook, 1999).

In general, Tainan is divided into 2 parts, Tainan City and Tainan County. Tainan is recognized as the oldest area in Taiwan and was the origin of the development of Taiwan. In 1661, Koxinga, a national hero, liberated Taiwan from Dutch colonialism and established his government in this area (Introduction of Tainan, 1999). Afterward, he endeavored to develop it very prosperously. Since then, the area of Tainan became very prosperous and is one of the major cities in south of Taiwan.

In 1684, the Ching Dynast conquered Taiwan and established the "Taiwan Fu" as the first official local government in Taiwan. In 1885, "Taiwan Fu" was renamed as "Tainan Fu" in accordance with the establishment of Taiwan Province (Introduction of Tainan,

1999). Until the late 19th Century, Tainan served as the political, cultural, and economic center of Taiwan (Introduction of Tainan, 1999).

Special Education in Tainan

Tainan has always been a center of learning and a magnet for people. Early in Tainan's history, there were already numerous schools established for the purpose of cultivating scholars. Tainan's educational development has not been limited to literary accomplishments. On the contrary, the educational system has been extended to encompass new knowledge and novel perspectives.

The first school for exceptional children was established in the city of Tainan in 1890 by Reverend William Gambel, a Presbyterian minister from England (Chen, Seitz, Cheng, 1991). The school was set up in a church for the purpose of training children who were blind. In 1900, when the Japanese occupied Taiwan, they moved the school to the Wen-Chang Temple. In 1915, the school was donated a piece of land and some funds, and a new campus was founded. The school expanded its services to the population who were deaf and was renamed the Tainan School for the Deaf and Blind (Chen, Seitz, Cheng, 1991). In 1946, after the Second World War, the school administration was changed, and the school was renamed the Taiwan Provincial Tainan School for the Deaf and Blind. In 1968, the name of the school was changed to the Taiwan Provincial Tainan School for the Deaf (Chen, Seitz, Cheng, 1991). The population who were blind was moved to Taichung Chi-Ming School, located in the central part of the island.

In 1976 the First National Prevalence Survey Study determined that there were more than twelve thousand children with mental retardation on the island (Department of Special Education of National Taiwan Normal University, 1976). The mayor of Tainan,

Chang, Li-Tang, founded the first school for children with mental retardation in 1976, and the school opened its doors for students with moderate mental retardation (Chen, Seitz, Cheng, 1991). In 1981, the school was officially named the Taiwan Provincial Tainan School for the Mentally Retarded.

In the immediate post-war period, in Taiwan, there were no statutory ordinances addressing the needs of students with disabilities. It was not until 1968, with the promulgation of the "Statute for the Implementation of Nine Year Public Education," that any regulations first appeared. This established opportunities for schooling for those with physical or mental handicapping conditions (Department of Education, 1996). The "Regulations for the Promotion of Special Education" promulgated in 1970 first set out detailed regulations covering the objectives, scope, methodology, establishment and management of schools, students and teacher training related to special education (Department of Education, 1996). The "Special Education Law" promulgated in 1984 was even more comprehensive. Special Education Law contained articles and basically provided the foundation for suitable education for not only students with physical or mental disabilities, but also gifted and talent students. Since then the Taiwan government has issued a series of regulations dealing with such matters as the implementation of special education curricula, teaching materials and teaching methods, detailed regulations for implementing the Special Education Law, and setting standards for special education facilities (Department of Education, 1996).

In the early post-war educational administration, no responsible agency was established specifically to deal with special education. However, with the growing need for special education, there is now a clearly defined authority for special education within the educational administration at various levels (Department of Education, 1996). The

Ministry of Education's Special Education Committee is responsible for drawing up special education policy and related coordination, promotion, evaluation and consultation. The Taiwan Provincial Government's Department of Education established a Special Education Unit within its First Section in July 1991 to handle special education administrative affairs throughout the province. In addition, all county and city governments have set up special children's assessment and school guidance committees, as well as asking related agencies or personnel to take concurrent responsibility for special education students.

Based on the most recent statistics, in Tainan area, there are 6 major hospitals in which children can receive medical assessment, necessary medical support, consultation, and treatment; 4 family counseling/educational centers where families can get help and information regarding special education, medical services, family counseling, family support, and other services related to family issues; and 4 major welfare associations for individuals with disabilities and their families.

In addition, there are 3 public preschools and 1 public day-care center for young children with mild or moderate disabilities aged birth to 6-years-old, and there are 4 private agencies or centers for children with more severe or profound disabilities aged 3 to 15-years-old.

The Special Education Center in the Department of Special Education of Tainan Teachers College serves as the center for research and development, teacher training/study, and educational consultation and guidance in the field of special education work for the Tainan area. The Center also assists with preschool, elementary and secondary school special education class teaching and student guidance. In addition to the guidance system of Teachers College Special Education Center, there are also

provincial special education resource centers and advisory groups. They are also special education advisory task forces of county and city government educational advisory groups, which directly visit schools to provide guidance. The scope of such guidance is focussed on recruitment and assessment, student placement, communication of ideas, educational workshops for parents and staff, and special lectures.

Appendix D

Survey of Education & Service Needs for Children with Disabilities
--- Agency Form---

1. In your school/agency center, how many children do you have?

2. How old are these children?

3. Please list the disabilities that children have.

4. What kind of special services do you provide to the children with disabilities and their families (please apply all)?
   - Occupational/ Physical Therapy
   - Speech-Language Pathology Service
   - Family Training & Counseling
   - Special Education Information
   - Nurses/Doctors/ Medical Support
   - Psychological Services
   - Nutrition Support & Counseling
   - Social Workers
   - Parent-to-Parent Connections/ Supporting Group
   - Audiological Services
   - Information Network
   - Others (please specify)

5. Does every child with disabilities have his/her own individual goal or written program plan (i.e., IFSP)? Yes No

6. Do you invite parents to participate in their child's IFSP meeting? Yes No

Appendix E

Survey of Education & Service Needs for Children with Disabilities--- Family Form

Section I:

Items in this section request general information about you and your child. Please circle the following items to most accurately describe you and your child or write your response in the space provided.

1. Your age:
   a. less than 20
   b. 20-29
   c. 30-39
   d. 40-50
   e. more than 50

2. Your highest level of education
   a. elementary school graduate
   b. junior high school graduate
   c. senior high school graduate
   d. bachelor's degree
   e. master's degree
   f. doctoral degree
   g. other, please explain

3. Your family's annual income (NT$)
   a. less than 180,000
   b. 180,001-300,000
   c. 300,001-420,000
   d. 420,001-600,000
   e. 600,001-840,000
   f. more than 840,000

4. Living location
   a. urban
   b. rural

5. Information of your child
   Birth order
   Gender
   Age
   Number of siblings

6. Other relatives (not including your children) living with you at home (Circle all that apply to you)
   a. your husband
   b. your wife
   c. your father
   d. your mother
   e. your father-in-law
   f. your mother-in-law
   g. other, please explain

7. How many hours does your child go to school/center per week?
   a. under 5 hours
   b. 5- 10 hours
   c. 11-15 hours
   d. 16-20 hours
   e. 21 and above

8. Does your child receive any therapy?
   Yes No (go to Question 11)

9. Where does your child receive the therapy?
   a. hospital
   b. school/center
   c. home
   d. other, please explain

10. If your answer is "YES" in question 8, how many hours does your child receive therapy per week?
   a. under 5 hours
   b. 5- 10 hours
   c. 11-15 hours
   d. 16-20 hours
   e. 21 and above

10. At your home, who is the person(s) making decision for your child?
   a. child's father
   b. child's mother
   c. both father and mother
   d. other than father or mother, please explain

11. Does your child have his/her own individualized education program?
   a. Yes
   b. No
   c. I don't know

12. Did you participate in the writing of your child's individualized education program? Yes No

13. According to your child's "Handicapped Certificate", what type and level of disabilities does your child has (circle all that apply to your child)
   a. mild mental retardation
   b. moderate mental retardation
   c. severe or profound mental retardation
   d. mild physical handicap
   e. moderate physical handicap
   f. severe physical handicap
   g. mild visual impairment
   h. moderate visual impairment
   i. blindness
   j. mild hearing impairment
   k. moderate hearing impairment
   l. deafness
   m. learning disabilities
   n. emotional disorder
   o. autism
   p. language/speech disorder
   q. facial distortion
   r. others, please explain

Section II:

Items in this section deal with your experience and your opinion regarding your child's needs and his/her educational program. The term "my child" in the following statements means your child with a disability.

Please circle your response in the right margin which you think will best fit your answer according to the following code: 0 - strongly disagree; 1 = somewhat disagree; 2 = neutral; 3 = somewhat agree; 4 = strongly agree.

1. My child must be treated less strictly than his/her siblings.....0 1 2 3 4
2. My child must be treated more strictly than his/her siblings.....0 1 2 3 4
3. My child does not interact with his/her friends who do not have disabilities.....0 1 2 3 4
4. My child participates in all family activities.....0 1 2 3 4
5. My child enjoys participating in public or community events.....0 1 2 3 4
6. I expect my child to meet the same academic standards as children who do not have disabilities.....0 1 2 3 4
7. I worry about my child's future.....0 1 2 3 4
8. My child has lower self-esteem than children who do not have disabilities.....0 1 2 3 4
9. My child is kept at home most of the time.....0 1 2 3 4
10. My child gets along well with his her friends who do not have disabilities.....0 1 2 3 4
11. My child should get more attention from his her teachers than children who do not have disabilities.....0 1 2 3 4
12. My child should be expected to meet lower academic standard than his/her peers who do not have disabilities.....0 1 2 3 4
13. My child is often a burden to our family.....0 1 2 3 4

If your answer is 1 or 2, please explain why

14. My child is less loving than children who do not have disabilities....0 1 2 3 4
15. My child often feels upset because of his/her disabilities.....0 1 2 3 4
16. My child works hard to be independent.....0 1 2 3 4
17. My child should have the same educational opportunities as children who do not have disabilities.....0 1 2 3 4
18. Going to school with children who do not have disabilities will be helpful for my child to build up my child's self-esteem.....0 1 2 3 4
19. My child should be able to play with children who do not have disabilities.....0 1 2 3 4
20. Going to school with children who do not have disabilities would provide more opportunities for my child to interact with nondisabled friends.....0 1 2 3 4

Note: 0= strongly disagree; 1 = somewhat disagree; 2 = neutral; 3 = somewhat agree; 4 = strongly agree.

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21. My child should be educated in special classes where he/she is only with children who have the same disability..... 0 1 2 3 4
22. Going to school with children who have the same disability will make my child feel more secure..... 0 1 2 3 4
23. Going to school with children having the same disabilities will cause my child to have lower esteem..... 0 1 2 3 4
24. My child would be happier playing with other children who have the same disability as he she does..... 0 1 2 3 4
25. My child must be treated less strictly than his her peers who do not have disabilities..... 0 1 2 3 4

Section III:

Please evaluate current services you and your child receive according to the following code: 0 = very inadequate; 1 = inadequate; 2 = neutral; 3 = adequate; and 4 = very adequate.

1. There is somebody to take care of my child so that we can go on a weekend or holiday trip without him her..... 0 1 2 3 4
2. There is somebody to help us deal with our emotional problems..... 0 1 2 3 4
3. There is somebody to help my child deal with his her emotional problems..... 0 1 2 3 4
4. Medical services to deal with my child's unique health problems..... 0 1 2 3 4
5. A place to get information about my child's disabilities..... 0 1 2 3 4
6. A governmental agency to provide financial support or a loan to help my child..... 0 1 2 3 4
7. A place to get needed therapy/therapies..... 0 1 2 3 4
8. A place to get needed technological devices (e.g., wheelchair, or hearing aide, etc.)..... 0 1 2 3 4
9. A place for my child to go for recreation..... 0 1 2 3 4
10. Transportation for my child to school..... 0 1 2 3 4
11. Convenient handicapped parking provided at places where we go often (e.g., shopping center, post office, park, hospital, bank, etc.)..... 0 1 2 3 4

0 = very inadequate; 1 = inadequate; 2 = neutral; 3 = adequate; and 4 = very adequate.

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12. Legal services to assist us when we have legal problems related to our child..... 0 1 2 3 4
13. Training for my child on daily living skills. 0 1 2 3 4
14. Training for my child on physical development. 0 1 2 3 4
15. Training for my child on social development. 0 1 2 3 4
16. Training for my child on emotional development. 0 1 2 3 4
17. Training for my child on language and communication development.....0 1 2 3 4
18. Training for my child to improve his/her movement from place to place..... 0 1 2 3 4

Section IV: Family Support Scale

Listed below are source that often time are helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to your family. Please circle the response that best describes how helpful the source have been to your family.

0 not at all helpful; 1 sometimes helpful; 2 generally helpful; 3 very helpful; and 4 extremely helpful.

1. My parents 0 1 2 3 4
2. My spouse's parents 0 1 2 3 4
3. My relatives/kin 0 1 2 3 4
4. My spouse's relatives/kin 0 1 2 3 4
5. Husband or wife 0 1 2 3 4
6. My friends 0 1 2 3 4
7. My spouse's friends 0 1 2 3 4
8. My own children 0 1 2 3 4
9. Other parents/parent groups 0 1 2 3 4
10. Religion/church/temple 0 1 2 3 4
11. Social workers 0 1 2 3 4
12. Co-workers 0 1 2 3 4
13. Medical professionals, therapists 0 1 2 3 4
14. Schools/day-care center, teachers 0 1 2 3 4
15. Others, please explain 0 1 2 3 4

Section V: Open-ended questions.

1. How old was your child when you and/or your family first became aware of your child's special needs?

2. How was this information presented to you and your family? Who presented this information (i.e. your child's school teacher or doctor)?

3. How did you feel about your child's diagnosis when you first became aware of your child's special needs? How about now?

4. Who have you shared this diagnosis with? What did you tell them and how did they react?

5. Please use the space below or the back of this page to tell me anything else you think is important.

Appendix F

Agency/School Consent Form

University of Oklahoma, Norman Campus

Permission to Conduct a Research Project

Agency/School Administrator

I understand that this study, "Survey of Education and Service Needs for Young Children with Disabilities" is sponsored by the University of Oklahoma, Norman Campus, Educational Psychology Department, Special Education program. It is also sponsored by Dr. David L. Lovett as part of Ph.D. dissertation with primary investigator being Ya-Shu A. Kang. This document serves as permission to conduct this research project.

The purpose of this research is to explore the education and service needs and perceptions for young exceptional children and their families. The research will identify characteristics of available and effective services in early intervention programs for youngsters age birth to 6 years old. Family members, including mother, father, or other caregiver, will be contacted and asked to participate in the study.

This study holds no foreseeable risk to participants in the study and participants may withdraw at any time. All records of the study will be kept confidential by using code numbers only on the questionnaires. The school or agency will not be named, the program location will not be identified, and the name of participants will not appear in any reports, publications or presentations concerning this study.

Overall benefits of this research will be useful for schools, agencies, or institutions when making educational programming and policy decision. It will also be helpful when identifying areas of future implications of early childhood special education programs for young children with or without disabilities.

Best Regards,

Ya-Shu A. Kang
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(Taiwan Address) 2 155LN, Hsiu-Wen St. Kaohsiung, Taiwan, R.O.C.

Appendix G

Cover Letter

Dear parent,

I am a doctoral candidate at the University of Oklahoma. I am writing to invite you to participate in a study. The purpose of the study is to investigate the perceptions about education and service needs for families and their exceptional children. The information will be used to implement effective practices in future early intervention services for children with special needs and their families.

The study will require approximately 30 to 45 minutes of your time to be completed at any your convenience. Your answers to the questions will be put into a computer with those of other parents and all of the answers will be analyzed together. There is no risk of injury as a result of participation in this study. Your participation is voluntary and you may withdraw at any time. No one will know any specific answers, or how any particular individual or family responded to any of the questions. The results of all of the questionnaires will be tabulated in such a manner so that no one family or person can be identified.

I hope this assurance will encourage you to be very frank in your responses to the questions. You are welcome to write additional comments if you wish. A postage paid return envelope is enclosed for you to use to return the completed questionnaire. The completion and return of the questionnaire constitutes consent of your participation. If you have any questions about this study, you can contact me at (07) 334-6319 (Kaohsiung, Taiwan) or (405) 360-2773 (Oklahoma, United States), or e-mail me ysk *a* ou.edu. If you have any questions regarding rights of the research participants, you can contact the University of Oklahoma, Office of Research Administration, 1000 Asp Avenue, Buchanan Hall, Room 314, Norman, Oklahoma 73019, U.S.A., phone number (405) 325-4757, and e-mail address (pjwolfe *a* ou.edu).

Thank you,

Yea-Shwu A. Kang
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Appendix H

Examples of Description

Question: Please use the space below or the back of this page to share with me anything else you think is important.

Parent 1(a parent of a 5-year-old girl who has multiple disabilities): I did not know what to do first, especially when some of friends knew about my child. They felt sorry for me, but sometimes I felt so embarrassment to tell people the truth about my child because I do care what people think about me and my child. We live with parents-in-law, sometimes they help me to watch my child and then I can go out or do something else. My husband and my own sisters help or provide assistance when they can. However, I feel this child is my job. I brought her to this world, and then I have to take care of her as long as I can. My husband and I would like to have another child, but we are afraid of trying. Recently, my husband and I start looking for a better school for my girl. It is hard to find a cheap place and also provide good services. We can not afford for a private school. I wonder that my child might be discriminated in a regular school because most teachers do not like the children with disabilities. Even though I can find a school for her now, I still worry about her future. What can her do when she grows up? Who is going to marry her or take care of her? I wish there is someone who can tell me what to do and answer my questions. I also hope more people pay attention on special education and not discriminate all children with disabilities.

Parent 2 (a parent whose child is 7-year-old and has visual impairment): I worry about my child because of his eyes. He will be in 1st-grade next semester. My husband and I decide to put him into the school for Blind. We thought this is a better choice for him, although he has to live in the dormitory with other students with visual impairments. The school told us that their teachers have more knowledge and experiences working with children with visual impairments and they also provide special services, such as audiological services and special education. It is quite a relief for my family because we really do not know much about where to get specific help or how to choose better services for my son. We do not know many people. We wish there is someone who could answer our questions earlier when we faced difficulties. These years have been really hard for my family, especially my son. One of my friends told me a story. It was about a boy who went to regular school got rejection from his peers. Some parents of his peers went to see the principle because they did not their children stay in the same

room with that child. So I prefer my child goes to a special school in which people educate him well and no rejection.

Parent 3 (a parent whose girl is Down-syndrome): My daughter went to school when she was 3. That was about 3 years ago. At the beginning, we did not know anything about special education and where to get early intervention services. So we sent her to a regular daycare. That was a class in which has 25 3- or 4-years children, 2 teachers, and no special teachers. My daughter did not receive any special services in school, but the school did give us some phone numbers to call in order to get information. Early intervention was not popular then and not cheap. Every time, I and my daughter had to take buses and spent at least one and half hours to get to the place and received therapy. When I was waiting for my daughter, I normally saw other parents whose children received therapy there as well. Sometimes we told, but only a few parents shared their feeling with others. Anyway, things got better now although I still do not know much about what I am going to do with my child. I think special education is important for my child. We need more teachers to teach students with disabilities. If possible, I would like to know more about special education and related services and parent organization regarding parents of children with Down syndrome. It would be helpful if other parents could share their experience with me. Sometimes I feel like I have no one to talk to. I think parent support group would help a lot of parents like me.

Parent 4 (a parent whose child has developmental delays): My baby boy was 28 months now and receive medical care, OT, PT, and early intervention services. Every week, I have to take my son to different places at different time for different treatments. I was so tired. I wish there is a place in which I can find any services I need, and then I do not have to travel around. In addition, I worry about my son, although he is still little. My husband and I are hoping my son can have a better education environment, but we have difficulties finding one. We have asked around. However, we can not decide anything without thinking of quality of the program and personnel.

Parent 5(a parent of a child with developmental delays): My girl receives early intervention services in a government-fund agency. It is cheaper and the quality of program and personnel is better, I guess. I think our special education services have been improved in these years. However, I think we still need more classes and special teachers, especially the good ones. As a working parent of a child with special needs, I would appreciate if our government or special education centers can provide information

regarding the latest information on special education and related services through information network. It would save me a lot of time for searching services.

Parent 6 (a parent of a child with hearing impairments): My child has mild hearing impairment. She is 4 now. She goes to a regular preschool with other normal children. Most people do not treat her differently. I think that is because her disability is mild. I have known some children were treated unequally because of their disabilities. My family will try our best to support my girl as long as we have to. We are quite happy with the situation now, although we still worry about her future.

Parent 7 (a parent of a child with physical disabilities): My most concerns are the quality of school program and teachers. In Taiwan, it seems some teachers who taught children with disabilities have no ideas about how to educate children with special needs. In addition, I think the number of special educators and our barrier-free environment are not enough. For example, when we go out together, my husband has to carry my son around, because my son's wheelchair is not working in some environments. It is also very inconvenient if we can not find a handicapped parking space. However, we still love to go out with our son. We do not care what people think of him. We only know he is our son and we love him.

Parent 8 (a parent of a child with autism): My child is only 3 year-old. I think the most important thing now is where I can find services served best for my child. The doctor gave me some brochures to study. It helps me to understand more about my child's disability. However, school teacher is important, too.

Parent 9 (a parent of a child with multiple disabilities): My husband first thought to put our girl to an institution since she has very severe disabilities, but my father-in-law did not agree. My father-in-law lived with us and sometimes he took care of my daughter when we can not. My daughter is 5 and goes to a special preschool. I worry about her future because I am not sure what she can do when she grows up. I guess I am ok if she does not do well in school, but I hope she receives skill training which she can use to make her own living someday when she grows up.

Parent 10 (a parent of a child with developmental delays): I wish someone has told me about how to raise a child with special needs. Before enrolling my child into the present program, I have asked around. I found that early intervention program delivery models

and staffing patterns varied across programs and a wide range of services was offered and these services were delivered by a variety of professional and paraprofessional staff. I like the program which my child attends now because teachers are friendly and work hard. In addition, they are more willing to share their knowledge and experience with me and teach me how to help my child at home. My child like her teacher and my relationship with her teacher is great, too. Furthermore, the school organizes a parent-support group. This parent organization has been really helpful for me because I got chances to meet with people and talk to some parents who have children with similar programs. Anyway, the experience has been really positive. I learn a lot.