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DEDICATION

With the deepest appreciation, I dedicate all I have achieved to my mom. You are the bravest person, best model, and the greatest mom in the world. I have never told you that I love you. But I always do in my heart.
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ABSTRACT

Research shows that foundational skills acquired in the early years of development like making choices, self-regulation, and engagement, are significant underpinnings for the future development of self-determination skills in adolescence and adulthood. This is particularly true for individuals with disabilities in the United States. Although family members play a key role in their child’s development of foundational skills for self-determination, no research has been conducted to examine whether these skills are valued with equal significance by families of young children with disabilities in countries outside the United States. The purpose of the phenomenological study described here is to increase understanding of two key issues: 1) what were the experiences in early childhood intervention of families of young disabled children within the People’s Republic of China (PRC)?, and 2) what were the families’ perceptions and practices in promoting foundational skills for self-determination in these children? Semi-structured interviews were used to collect data, and findings and discussion are presented in the following chapters.
CHAPTER 1. GENERAL INTRODUCTION

Introduction

Since the 1990’s, development of self-determination in individuals with disabilities has been studied by special education experts in the United States. Self-determined behavior refers to “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Numerous studies (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) have shown that self-determination plays a significant role in determining the quality of life of individuals with disabilities. Research shows that, upon graduating from high school, self-determined young people attain more positive outcomes, especially in employment, financial independence, independent living, and other benefits (Field & Hoffman, 2002; Wehmeyer & Palmer, 2003).

Because of the important role self-determination plays in defining the quality of life of people with disabilities, there has been increasing interest in the application of self-determination internationally (Bao & Zhang, 2005; Hu, 2010; Lee & Wehmeyer, 2004; Li, 2008; Ohtake & Wehmeyer, 2004; Wu, 2007; Zhang, 2005; Zhang & Benz, 2006; Zhang, Wehmeyer, & Chen, 2005). Studies have shown that most efforts to promote self-determination reflect values related primarily to Anglo-European cultures (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Leak & Boone, 2007; Zhang & Benz, 2006; Zhang, Landmark, Grenwelge, & Montoya, 2010; Zhang, Wehmeyer, & Chen, 2005). However, studies regarding the promotion of self-determination in international special education settings have indicated that, although the constructs are universal, certain aspects
of self-determination, like making decisions, are expressed differently in non-Anglo settings (Frankland et al., 2004; Zhang et al., 2010).

The development of self-determination is an ongoing process that continues across the life span (Brown & Cohen, 1996; Erwin & Brown, 2003; Palmer, 2010; Wehmeyer & Palmer, 2000). It has its roots in the early years and extends across the entire life span (Brown & Cohen, 1996; Doll, Wehmeyer, & Palmer, 1996; Erwin & Brown, 2003). There has been growing interest in this type of research during the past decade, especially as applied to young children with disabilities (Brotherson, Cook, Erwin, & Weigel, 2008; Brown & Cohen, 1996; Erwin & Brown, 2003; Palmer, 2010; Wehmeyer & Palmer, 2000).

**Foundations for Self-Determination**

Self-determination is often regarded as an outcome of adolescence and adulthood. However, it is highly unlikely that characteristics of self-determination appear suddenly at adolescence and adulthood (Brown & Cohen, 1996, p. 22). Children are not born with self-determination (Doll et al., 1996). The development of self-determination depends on a number of essential elements or a specific set of skills that emerge and are demonstrated in the early years (Brown & Cohen, 1996; Doll et al., 1996; Palmer, 2010; Wehmeyer & Palmer, 2000). These elements and skills may be regarded as the “precursor, or foundations” of self-determination in adolescence and adulthood (Palmer et al., 2012). Research has shown that newborn babies are able to express their preferences for people and objects in their environment. For example, they may express preference for particular caregivers (Doll et al., 1996). Being able to display and communicate preferences is regarded as one of the essential elements of making choices, one of the important components of self-determination. In this study, the phrase “making choices” will be used to describe opportunities for children
to make choices. Abery and Zajac (1996) opined that the development of self-determination should not be delayed until adolescence or adulthood. Between the ages of 3 to 5 years, specific, age-appropriate skills emerge that serve as the foundation for later development of self-determination for young children with disabilities (Summers, Brotherson, Palmer, Erwin, & Maude, 2009). The skills related to capability for making choices, self-regulation, and engagement are important foundational skills for self-determination (Summers et al., 2009). These skills are believed to provide the foundational base for development of self-determination throughout an individual’s entire life (Palmer, Summers, Brotherson, Erwin, Maude, Rentier, et al., 2012).

Development in the early years does not necessarily indicate preparedness for achieving self-determination, and increased age does not always give a child the needed chances to become capable of making decisions leading to self-determination (Erwin, Brotherson, Palmer, Cook, & Summers, 2009; Palmer, 2010). Children should consciously be provided ongoing opportunities to practice skills contributing to the development of self-determination over time. Families, by influencing the child’s choices, are of critical importance in fostering development of basic skills needed for self-determination in young children (Brotherson, Cook, Erwin, & Weigel, 2008). Brotherson and colleagues (2008) stated that “any discussion on self-determination in early childhood should place families at its center” (p. 23). The families’ cultural values and beliefs influence how they nurture and support the development of these foundational skills for their child to be self-determined (Turnbull & Turnbull, 1996). It is therefore essential to better understand the families’ experiences and practices regarding the development of foundations for self-determination in young children with disabilities.
Families of Young Children with Disabilities in the PRC

Research has indicated the importance of families in the development of their young children with disabilities (Bruder, 2000; Dunst, Trivette, Boyd, & Hamby, 1996; Wehman, 1998). In most countries, children with disabilities spend most of their time with their families. The family context and those experiences provided by the family play a critical role in a child’s development (Bruder, 2000). A family’s involvement in the range of services and supports, referred to in this study as early childhood intervention, has been shown to promote generalization and maintenance of skills learned by children with disabilities within their home and in other natural environments such as community settings (McCabe, 2007). Families that received such services and supports also demonstrated improved ability to cope with the difficulties of having a child with a disability (Wehman, 1998).

Research on families of young children with disabilities in the PRC has been quite limited. Few studies have detailed the challenges faced by families of young children with disabilities in the PRC (McCabe, 2007; McCabe, 2008; Wang, 2008; Wang, Michaels, & Day, 2011). Those families reported increased experiences with stress, anxiety, embarrassment, shame, and fear of discrimination or rejection (Huang, Kellett, & St. John, 2011; McCabe, 2007; McCabe, 2008; Wang, 2008). Although attitudes in the PRC toward people with disabilities have improved in recent years, many myths and misconceptions about disabilities still exist. Research has shown that Chinese people often feel that having a child with a disability is punishment for misdeeds or misbehaviors by the family or by actions of their ancestors (Holroyd, 2003; Huang, Kellett, & St John, 2011; McCabe, 2008; Wang, Michaels, & Day, 2011). The stigma related to giving birth to a child with a disability
often makes the family feel ashamed, embarrassed, stressed, or worried about being discriminated against or rejected by others (Holroyd, 2003; McCabe, 2008). To avoid the negative influence of such a stigma, many families were found to avoid leaving their homes and going into their communities, were reluctant to seek help or support, or were unwilling to admit to having a child with a disability (McCabe, 2007; McCabe, 2008; Wang, Michaels, & Day, 2011). Current practices in the PRC continue to marginalize families of young children with disabilities.

In addition to the negative emotional experiences previously reported by families in the PRC, others have identified challenges they may face in acquiring services and support with respect to their children’s education. In the PRC, early intervention services and support are sparsely available, and families report difficulty in accessing them (McCabe, 2008). According to Wang (2008), most children with disabilities do not receive any type of early intervention services. Among the few early intervention programs in operation across the PRC, the most common form of intervention is the “parents-as-teachers” approach (Wang, 2008, p. 97). Typically, this means that parents were trained to implement therapies or supporting activities at home. Therefore, families of children with disabilities are typically the primary or often the only source of support for young children living with disabilities (McCabe, 2007; Wang, 2008). Often, these families have expressed a need for more support, professional help, and information about how to raise a child with a disability (McCabe, 2008).

In the PRC, families of young children with disabilities are facing many challenges. Despite these challenges, recent research has shown that families who have offspring with disabilities “want the best for their children” (McCabe, 2007, p. 40). McCabe’s research
(2008) showed that families who had children with disabilities were committed to obtaining any available services for them, to paying as much as they could afford, and even to sacrificing their own careers when necessary. Therefore, within the specific PRC social context, families of young children with disabilities are not only the primary services and support providers for their children but are also their children’s main advocates. As McCabe (2007) stated, families of children with disabilities in the PRC “do not have a choice of whether to participate if they do not actively advocate for their children, and take measures to teach their children on their own; who else will step forward? Currently, there is no one else” (p. 48)”. Therefore, it is critical to better understand the experiences of families of young children with disabilities in the PRC.

**Purpose and Research Questions**

The purpose of this research was to increase understanding of the experiences of families with young children with disabilities in the PRC regarding development of foundations for self-determination in these children. Because of the key roles that families play in their children’s development of foundations for self-determination, I first studied the experiences of families with such children in the PRC with respect to early childhood intervention. I then explored how these same families perceived and promoted foundations for self-determination for their children. Two research questions were explored in this study: (1) How do families of young children with disabilities experience early childhood intervention in the People’s Republic of China? (2) How do families of young children with disabilities perceive and promote foundations for self-determination, including making choices, self-regulation, and engagement?
Method

A phenomenological research design was employed in this study (Merriam, 2002). Phenomenological research is interpretive and investigates a phenomenon from the perspective of the individual experiencing it (Flood, 2010). Phenomenology attempts to reduce experience to its essence; it was thus an appropriate approach for use in this study focused on the experiences, beliefs, and practices of Chinese families of children with disabilities as related to development of the child’s self-determination (Creswell, 2007).

Since disability is so often stigmatized, families are generally reluctant to expose their children to public scrutiny (Hu, 2010). Because of this negative stigma, it was difficult for me to locate this particular population of families. Steps employed to obtain access to this “hidden population” required me to first contact the administrators of the institutions providing early childhood intervention to young children with disabilities in an easy-to-access region. With the administrator’s help, seven children with disabilities under the age of eight in southwest China were recruited through a snowball sampling technique. Among the members of the seven families recruited and willing to participate in the interview process, five were mothers, one was a father and one was grandfather. All families reported that they had only one child, the child had a disability, and they varied in age from 3 to 8 years, with a mean age of 4.2 years. There were six boys and one girl. The types of disabilities reported by the parents included cerebral palsy, hearing impairments, autism, and language delays.

Significance

There is limited research with respect to the experiences of Chinese families receiving early childhood intervention services and supports. Since the family plays a powerful role in the development of a young child, it is critical to understand families’ concerns regarding
early childhood intervention (Stratford & Ng, 2000). There therefore exists a critical need to better understand what PRC families of young children with disabilities value and believe in terms of the development of foundations for self-determination. This information will assist practitioners and researchers, and will have important implications for policy-makers in the PRC.

As previously mentioned, scant research has been conducted on how the foundations for self-determination are perceived and promoted in the PRC, particularly in terms of the skills of making choices, self-regulation, and engagement, all regarded as fundamental to the later development of self-determination in adolescence and adulthood in the United States. Understanding how these foundations are perceived and promoted in a country other than the United States can help in better understanding of how self-determination is developed in different cultures. It also can have implications for practitioners here in the United States or other countries who may begin partnerships with PRC families who have immigrated or relocated to those particular countries.

**Dissertation Organization**

The alternative dissertation format is used for this dissertation. Two manuscripts that will be submitted for publication in leading journals are included. Chapter 2 is a manuscript entitled “Early Childhood Intervention in the People’s Republic of China from the Families’ Perspective”, which was prepared for submission to the *International Journal of Early Childhood Special Education*. Chapter 2 addresses the experience of PRC families of young children with disabilities regarding early childhood services and supports. This paper provides a brief review of special education in the PRC, legislation and policies in support of young children with disabilities, a brief description of the early childhood intervention
system currently in place, and the experiences reported by Chinese families of young children with disabilities in early childhood intervention.

Chapter 3 contains a second manuscript, entitled “Foundations for Self-Determination Perceived and Promoted by Families of Young Children with Disabilities in the People’s Republic of China”, prepared for submission to *Topics in Early Childhood Special Education*. Chapter 3 addresses how families of young children with disabilities in the PRC perceive and promote foundations for self-determination. It reviews the concept of self-determination and foundations for self-determination such as making choices, self-regulation, and engagement. It also describes the families’ perceptions about the foundations for self-determination and their practices in promoting the development of these foundational components.

Chapter 4 contains a general discussion related to both articles. It summarizes the major findings of the literature and research presented in Chapters 2 and 3. General conclusions to be drawn from both studies are proposed and recommendations are provided to help guide public policies, educational programs, and practitioners. Finally, limitations of this research are identified and future directions for this research are shared.
References


CHAPTER 2. EARLY CHILDHOOD INTERVENTION IN THE
PEOPLE’S REPUBLIC OF CHINA (PRC) FROM THE FAMILIES’

PERSPECTIVE

A paper to be submitted to the *International Journal of Early Childhood Special Education*

Abstract

Research highlights the importance of early childhood intervention for children with disabilities, and there is an increasing interest in the People’s Republic of China (PRC) with respect to research on early childhood intervention. However, little or no research exists exploring the experience in the PRC of receiving early childhood intervention services and supports by families of young children with disabilities. The purpose of this study was to understand the early childhood intervention experiences of families of such children. Issues related to early childhood intervention such as early childhood intervention history and laws or regulations related to early childhood intervention were overviewed. A phenomenological design was used in this study and data was collected through interviews with six families in southwest China. This study indicated that, although the PRC has made some progress in early childhood intervention for young children with disabilities, progress in this area is still at an early stage of development. Many issues must be addressed, including knowledge about human development and disabilities, early identification, professional development, increased government investment, and better implementation of existing laws.

Key words: early childhood intervention, families of young children with disabilities in the People’s Republic of China (PRC)
Introduction

In the People’s Republic of China (PRC), the most populous country in the world, a child with a disability is born every 40 seconds. Thus, 2,160 new children with a disability are born daily, and approximately 700,000-800,000 children with disabilities are born each year (Stratford & Ng, 2000). According to the *Sampling Survey on Disability in Children 0-6 Years Old in China in 2001* (as cited in Zhong Guo Gu Du Zheng Wang, 2005), it is estimated that that there were approximately 139,500 children with disabilities under the age of 6. Among children identified in this survey, 107,100 children had a single type of disability (e.g., hearing impairment) and 32,400 children had multiple disabilities (e.g., hearing and vision disabilities). This survey identified five major categories of disabilities: hearing, visual, intellectual, physical, and mental (Figure 1). This survey did not show the proportions between rural and urban areas of children with disabilities under the age of 6. However, the Chinese study entitled the *Second National Disabled Persons Sample Survey* (SNDPSS, 2006) can serve as a guide to these proportions. According to SNDPSS, 24.96% of people with disabilities were from urban areas and 75.04% were from rural areas (as cited in China Disabled Persons’ Federation, 2007a).

The *Sampling Survey on Disability in Children 0-6 Year Old in China in 2001* estimated that the number of disabilities among children between the ages of 0-6 years grew by approximately 15,300 per year (as cited in Zhong Guo Gu Du Zheng Wang, 2005). This figure is only an estimate, since actual numbers of PRC children under the age of 6 with disabilities may be much larger than the number reported in this survey. This is partly due to the differences in the identification of and terminology used for disabilities between the PRC and Western countries such as the United States (Ellsworth & Zhang, 2007). Disability
categories such as learning disabilities and autism that have a longer history and definition in the United States are not acknowledged in the PRC (Deng, Poon-McBrayer, & Farnsworth, 2001). In the PRC, according to the *Law of the People’s Republic of China on the Protection of Disabled Persons*, a person with a disability is defined as “one who suffers from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structures, and who has lost wholly or in part the ability to perform an activity in the way considered normal” (as cited in Disability Rights Education & Defense Fund, n. d.).

This law further defines categories such as “visual, hearing, speech or physical disabilities, mental disability, mental disorder, multiple disabilities and/or other disabilities.” There is a lack of diagnostic assessments and professionals experienced in the identification of disabilities in the PRC that makes survey numbers somewhat suspect (Deng, Poon-McBrayer, & Farnsworth, 2001). Most diagnostic instruments used in the PRC were translated from the West, and were applied without considering cultural understanding and biases (Deng et al., 2001). No matter what the exact number may be of young children with disabilities in the PRC, given its huge population base, providing services and support to such children is a major challenge for the PRC, especially for very young children (Chiang & Hadadian, 2010).

**Purpose of the Study**

Interest in research on early childhood intervention in the PRC is increasing (Hu, 2010; Liu & Raver, 2011; Pang & Richey, 2006). However, little or no research exists that has explored the experience of receiving early childhood intervention services and supports by families of young PRC children with disabilities in the PRC. Since the family plays a powerful role in the development of a young child, it is important to understand families’ concerns regarding early childhood intervention (Stratford & Ng, 2000). The purpose of this study was to explore the experience of families of young PRC children with disabilities regarding early childhood intervention by using a phenomenological study design.
History of Special Education in the PRC

Since ancient times, caring for people with disabilities has been regarded in the PRC as society’s responsibility (Chen, 1996). Special education did not formally exist until the establishment by European missionaries of the first school for the blind in Beijing in 1874, followed by the first school for the deaf in Shandong by U.S. missionaries in 1887 (Chen, 1996). In the interval from the late 19th century up to the foundation of the PRC in 1949, the PRC did not have an established public education system for children and youth (Ellsworth & Zhang, 2007). Education for people with disabilities during that period was quite limited as well. By the end of 1948, there were 42 special schools for individuals with disabilities. Most of these schools were run by religious and charitable organizations and served approximately 2,000 students primarily identified as having visual and hearing impairments (Chiang & Hadadian, 2010). Education did not exist for students with intellectual disabilities or other developmental disabilities (Chiang & Hadadian, 2010). The system supporting special education became part of the public education landscape and has subsequently been supported by the government since 1949.

When the PRC was founded, most private schools for individuals with disabilities were transformed into state-run schools (Ellsworth & Zhang, 2007). From 1949 to 1978, more schools were set up for people with disabilities; however, special education and services and supports for young children with disabilities developed quite slowly due to unstable politics and economic limitations (Ellsworth & Zhang, 2007). During the Cultural Revolution, between 1966 and 1976, radical reforms that impacted the delivery of special education services and supports were implemented. The special education system almost
stopped development during that time, with many schools being closed in an effort to eliminate counter-revolutionary elements in the country's institutions and leadership; this period was characterized by political zealotry, purges of intellectuals, and social and economic chaos. Special education started redeveloping in 1979 when the PRC initiated the Reform and Opening policy, reforming the national economic orientation by opening to the outside world. Because of international influence and economic development, the PRC has in recent times been paying more attention to bettering the living conditions of its people.

In terms of supporting a special education system, the PRC has issued a series of laws and regulations to safeguard the rights of people with disabilities. In 1986, the PRC issued the *Compulsory Education Law of the People’s Republic of China* (as cited in china.org.cn, n.d.). This law guaranteed all school-aged children the right to receive at least nine years of compulsory education (six years of primary education and three years of secondary education). Article 9 of this law states that “Local people’s governments shall establish special schools (or classes) for children and adolescents who are blind, deaf or retarded” (as cited in china.org.cn, n.d., para. 12). This law was the first official call for equal education for school-aged children with disabilities (Pang & Richey, 2006). In 1990, the *Law of the People’s Republic of China on the Protection of Disabled Persons (1990)* was promulgated (as cited in Disability Rights Education & Defense Fund, n.d.). The significance of this policy is that it is “the first law that exclusively stipulated children’s with disabilities rights for rehabilitation, education, vocation, social life, as well as their legal rights” (Pang, 2009, p. 64). In accordance with the *Law of the People’s Republic of China on the Protection of Disabled Persons* and other laws concerning education, in 1994 the *Regulations on the Education of Persons with Disabilities* was formulated to specifically safeguard the rights of
people with disabilities to education (as cited in China Disabled Persons’ Federation, 2008a). The Regulations state that education for people with disabilities is a component of the State education program.

Every five years since 1953 the Central Government of the PRC issues a new Five-Year Plan, a detailed outline for the country’s economic goals for the next five years. Accordingly, the government also issues a development plan for persons with disabilities every five years by the China Disabled Persons’ Federation. The Chinese government has continued its support for special education, and services and supports for young children with disabilities through its Outlined of the Work for Persons with Disabilities during the 8th Five-year Development Program Period (1991-1995) to the present Outline of the Work for Persons with Disabilities during the 12th Five-year Development Program Period (2011-2015) (http://www.cdpf.org.cn/zcfg/zcfg.htm).

Since the Reform and Opening policy began in 1979, the PRC has continued to make progress in education for people with disabilities, especially compulsory education for school-aged children with disabilities. By the end of the Eleventh Five-Year Plan (2006-2010), the enrollment rate of children with disabilities into compulsory education had further increased, with the average enrollment rate of children with visual impairment, hearing impairment, and intellectual disability rising to 80% (China Disabled Persons Federation, 2008b). However, it is unclear in the PRC just what the status of compulsory education is for many children with other types of disabilities. Availability of services and supports for very young children with disabilities is unclear as well.
Early Childhood Intervention for Young Children with Disabilities

Legislation related to early childhood intervention

In the PRC, researchers and policy makers use the term “early rehabilitation” to describe the systems supporting children with disabilities. Additionally, a series of services are also provided children with disabilities to reduce the impact of the disability on a child’s development. For example, children with hearing impairments may be offered speech and language services (Liu & Raver, 2011). For the purpose of this study, the term “early childhood intervention” (ECI) as defined by Bruder (2010) has been used to describe the services and supports for young children with disabilities and their families in the PRC. Bruder (2010) defined ECI as “the provision of educational or therapeutic services” provided to children and/or their families from birth through age 5 (p. 339).

Since 1979, a series of legislative and administrative actions have been issued to develop educational support for people with disabilities, particularly focused on the education of children with disabilities, beginning at age 6 (Deng, Poon-McBrayer, & Farnsworth, 2001). For example, the Regulations on the Education of Persons with Disabilities in 1994 states in Article 3 “Priority shall be given to compulsory education and vocational education, while efforts shall be made to carry out pre-school education and gradually develop education beyond the middle school level” (as cited in China Disabled Persons’ Federation, 2008a). In contrast to education for school-aged children with disabilities, early childhood intervention in the PRC for children younger than school age with disabilities in the PRC is less developed (Liu & Raver, 2011). The development of early childhood intervention for such younger children may be revealed and understood through some major laws and regulations issued by the PRC, as shown in Table 1.
Compulsory Education Law in 1986 (as cited in china.org.cn, n.d.) was the first official call for equal education opportunity for children with disabilities, it focused on education for school-aged children, with early childhood intervention not addressed until the passage of the Law of the People's Republic of China on the Protection of Disabled Persons in 1990 (as cited in Disability Rights Education & Defense Fund, n.d.). Its focus was still on compulsory and vocational education for school-aged children with disabilities, but it was the first law to mention educational supports for young children and to specify who was responsible for providing such services.

In 1994, the PRC further addressed early childhood intervention and mentioned that institutions were to provide early childhood intervention services. A series of Five-Year Plans was enacted by the PRC through the Outline of the Work for Persons with Disabilities during the 9th Five-Year Development Program Period (1999-2000) to the Outline of the Work for Persons with Disabilities during the 12th Five-Year Development Program Period (2011-2015). These plans further specified early childhood intervention services and supports for young children under the age of 6 with disabilities (China Disabled Persons’ Federation, 2001). Most recently, the PRC has started to put more emphasis on establishing a system to support pre-school age children with disabilities after achieving a great deal in compulsory education for school-age children with disabilities. The Outline of the Work for Persons with Disabilities during the 12th Five-Year Development Program (2011-2015) initiated the Children 0-6 Years Old with Disabilities Free Rescues Rehabilitation programs (translation from Chinese term of “Qian jiu xing kang fu”), attempting to establish a system to support children through early identification, screening, and reporting, as well as early rehabilitation and education (China Disabled Peoples’ Federation, 2011). The Outline also
establishes the *Sunshine Grant Program* specifically developed to fund services and supports for young children with disabilities who are from families with low-income status.

This particular outline is highly significant in the history of the early PRC childhood intervention system because this was the first time that the PRC specified services and support for children with disabilities from birth through age 6 years (China Disabled Peoples’ Federation, 2011). In accordance with this central government policy, local governments have initiated similar programs. For example, Shandong province, located on the eastern coast of the PRC, has issued a policy that pre-school children with disabilities shall receive free *Rescue Rehabilitation* training in assigned institutions and may continue to receive the training until the age of 9 years, if needed. It also provides RMB 500 (US$81) to 700 (US$113) monthly stipends for rehabilitation training for 4 years continuously up to the age of 7 years (as cited in shandong.org.cn, 2011).

Table 1
*Laws and Regulations Related to Early Childhood Intervention in the PRC*

<table>
<thead>
<tr>
<th>Time</th>
<th>Laws or Regulations</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Article 23 [Methods of Special Education] Preschool education institutions for disabled children, classes for disabled children attached to ordinary preschool education institutions, preschool classes of special education schools, welfare institutions for disabled children and families of disabled children shall be responsible for preschool education of disabled children.</td>
</tr>
<tr>
<td>Time</td>
<td>Laws or Regulations</td>
<td>Content</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------------------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1994</td>
<td>Regulations on the Education of Persons with Disabilities</td>
<td>Article 10</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-school education for children with disabilities shall be carried out by the following institutions:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1) Pre-school educational institutions for children with disabilities;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(2) Ordinary pre-school educational institutions;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(3) Welfare institutions for children with disabilities;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(4) Institutions of rehabilitation for children with disabilities;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(5) Pre-school classes of ordinary primary schools and pre-school classes of special education schools.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Families shall be responsible for the pre-school education of their children with disabilities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Article 11</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The education of children with disabilities shall be carried out in combination with child care and rehabilitation.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Article 12</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Health care institutions, as well as pre-school educational institutions for children with disabilities and families of children with disabilities, shall pay attention to early detection of childhood disabilities, as well as early rehabilitation and early education of children with disabilities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Pre-school educational institutions for children with disabilities and health care institutions shall provide consultation and guidance to children with disabilities with respect to early detection of their disabilities, early rehabilitation, and early education.</td>
</tr>
<tr>
<td>1996</td>
<td>The Outline of the Work for</td>
<td>Provide training for 60,000 deaf children with hearing and speech disabilities, and systematic training for 60,000 children with</td>
</tr>
</tbody>
</table>
Table 1 (continued)

<table>
<thead>
<tr>
<th>Time</th>
<th>Laws or Regulations</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>during the 9th Five-year Development Program Period (1996-2000)</td>
<td>mental disabilities.</td>
<td>Enrich and improve hearing and speech training system for children with disabilities; provide professional technical training for multi-level personnel and establish a stable teaching staff; develop, produce, and supply economical hearing aids, language training equipment and test equipment; strengthen the training for parents, and conduct extensive family training; conduct new-born baby hearing screening and gradually promote early intervention. If possible, build rehabilitation centers for children with mental disabilities in counties or cities. Establish pre-school classes in special education schools and child agencies for children with mental disabilities; ordinary pre-school institutions shall provide self-care skills and cognitive skills in partnership with families for children with mental disabilities based on the number of those children. Ordinary pre-schools and pre-school classes in ordinary primary schools shall actively recruit children with disabilities and, if needed, establish special classes, special schools, and pre-schools in child agencies to conduct early education and early rehabilitation.</td>
</tr>
<tr>
<td>2001</td>
<td>The Outline of the Work for Persons with Disabilities during the 10th Five-year</td>
<td>Strengthen and improve the rehabilitation network for deaf children with hearing disabilities; provide hearing and speech training for 80,000 children with hearing disabilities; establish schools to train parents and conduct community-based rehabilitation; establish a Beijing Institute of Hearing and Speech Rehabilitation and bring rehabilitation personnel training into the national education plan;</td>
</tr>
</tbody>
</table>
Table 1 (continued)

<table>
<thead>
<tr>
<th>Time</th>
<th>Laws or Regulations</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001-2005</td>
<td>Development Program Period</td>
<td>improve training methods research, and improve speech training quality, and enable 25% of trained children to enter ordinary preschools and ordinary primary schools; promote economical high-quality hearing aids and provide them free to language training programs for children with disabilities from poor families. Actively develop preschool-education; gradually form a pre-school education system.</td>
</tr>
<tr>
<td>2006</td>
<td>The Outline of the Work for Persons with Disabilities during the 11th Five-year Development Program Period (2006-2010)</td>
<td>Provide training for 80,000 deaf children and 100,000 children with mental disabilities. Improve the Children with Hearing Disabilities Rehabilitation Network; strengthen the China Deaf Children’s Rehabilitation Research Center, develop provincial rehabilitation centers for children with disabilities, and consolidate grassroots rehabilitation agencies for children with disabilities at the grassroots level; guide communities and families to carry out rehabilitation; support children with hearing disabilities from poor families to receive rehabilitation training; classify the work of hearing and speech rehabilitation training; gradually apply cochlear implant technology; and broaden hearing and speech rehabilitation services. Implement comprehensive rehabilitation services for intellectual disability by promoting cooperation of community, family, kindergarten, special schools, community service agencies and public institutions; motivate family members and friends of children with disabilities and provide self-care skills, cognitive skills, and speech training. Mobilize the enthusiasm of friends and family of children with mental disabilities, children with intellectual disabilities, self-care</td>
</tr>
</tbody>
</table>
### Table 1 (continued)

<table>
<thead>
<tr>
<th>Time</th>
<th>Laws or Regulations</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>The Outline of the Work for Persons with Disabilities during the 12th Five-year Development Program Period (2011-2015)</td>
<td>Implement free rescue rehabilitation programs for children aged 0-6 years. Establish a multi-sectoral system of screening of children aged 0-6 years; report, transition, early rehabilitation education, family training and personnel training system; encourage and support kindergartens, special education schools, rehabilitation and welfare institutions to implement pre-school rehabilitation education; implement a &quot;Sunshine Grant Program&quot; to support children with disabilities receiving rehabilitation; gradually further popularize pre-school rehabilitation; and emphasize rehabilitation education for children with disabilities from 0-3 years old.</td>
</tr>
</tbody>
</table>

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**Current Situation of Early Childhood Intervention in the PRC**

In the PRC there has been increasing attention on early childhood intervention for children with disabilities ages 0 to 6 years, yet it is still a recent phenomenon (Deng, Poon-McBrayer, & Farnsworth, 2001) and continues to lag behind the education services and supports provided for school-aged children with disabilities. Some form of ECI has been implemented in the PRC for approximately 30 years. The PRC did not really implement any specific programs in terms of early childhood intervention until the 1980s, when the *Gesell Developmental Schedule* and the *Denver Developmental Screening* test were translated and revised to identify infants and children who may be at-risk for delays or disabilities (Mu,
Yang, & Armfield, 1993). The Sampling Survey on Disability in Children 0-6 Years Old in China in 2001 indicated that 67% of children with disabilities from birth to 6 years received certain types of rehabilitation and only 43.92% of children with disabilities aged 3 to 6 years had received early childhood education. However, these percentages are still much lower than those for pre-school age children without disabilities who attended pre-school programs, and are also lower than the figures identified for school-aged children with disabilities who receive compulsory education (Liu & Raver, 2011).

Due to the social and cultural context in the PRC, the development of early childhood intervention is quite unique and is facing many great challenges. In the PRC, public free education or compulsory education starts from grade one or age 6 years and lasts for nine years for children with and without disabilities, unlike K (or P)-12, as in the U.S. Families, therefore, bear the main responsibility to pay for services and supports for their infants, toddlers, and preschoolers with disabilities (Eichner, Groark, & Palmov, 2011; Hu, 2010). Enrolling in pre-school is difficult even for Chinese children who are developing normally. Due to the high demand and limited availability, children may attend a kindergarten only after a long waiting period of one or two years. It is not unusual for families to apply for a kindergarten placement before or shortly after their children are born (as cited in People’s Daily Online, 2010).

Most Chinese kindergartens located in urban or rural areas have not included children with disabilities (Hu, 2010). There is also no program such as Head Start to serve young children with special needs or young children from families experiencing economic problems (Hu, 2010). When families with a child with disabilities are fortunate enough to obtain services from kindergartens, they are usually charged higher tuition fees for their child
compared to those families whose children without disabilities. For most families who have children with disabilities, especially in rural areas, obtaining ECI poses a great financial burden and may be virtually unaffordable. Therefore, many children with disabilities are often kept at home and do not receive any support or services (Chiang & Hadadian, 2010).

In recent years there have been an increasing number of public and private early childhood intervention programs developed for children under the age of 6 with disabilities (Deng, Poon-McBrayer, & Farnsworth, 2001). In 1983 the China Rehabilitation and Research Center for Deaf Children (CRRCDC) was founded. This center was the first, and is thus far the only, national center engaged in hearing and speech rehabilitation (http://www.chinadeaf.org/EN/index.jsp). The CRRCDC also serves as a technical resource center for practitioners and as an industry administration center. Similar institutions were subsequently established in several provinces, including Tianjin, Shandong, and Hubei (Deng, et al., 2001). A few private kindergartens, and childcare centers were established for children with intellectual disabilities in larger and more advanced cities (Deng et al., 2001). Mao (1993) established the first private experimental training school for pre-school aged children with intellectual disabilities and in the early 1990’s launched the first early intervention program in Beijing. By 1991, more than 700 language training centers had been established and around 10,000 children with hearing impairments had been educated (Mu, Yang, & Armfield, 1993). However, education and rehabilitation services for pre-school children with disabilities are mainly provided in big cities and almost no services exist in rural areas (Deng et al., 2001). The Sampling Survey on Disability in Children 0-6 Years Old in China in 2001 shows that, among the 43.92% of children with disabilities aged 3 to 6 years old who had received early education, 61.48% were from midsize cities, and only
26.41% were from rural areas (as cited in Zhong Guo Gu Du Zheng Wang, 2005). The population of children with disabilities in the PRC is not evenly distributed throughout the country as a whole, with most of the children living in rural areas (Stratford & Ng, 2000). At present, one of the requirements for pre-school education of children with disabilities is to actively develop and improve rehabilitation, education, and continued growth for the pre-school education of children with disabilities in medium-sized and economically developed areas (China Disabled Persons’ Federation, 2007b). How to meet the need for early childhood intervention with this particular population in rural areas is yet another great challenge facing the PRC.

In the PRC, in addition to urban-rural disparities, there are also disparities in the development of early childhood intervention for children 0 to 6 years old with different types of disabilities, with greater emphasis put on supporting children with hearing, vision, and physical disabilities. Childhood intervention for children with hearing and vision disabilities was initiated quite early and has been strongly supported through legislation. The Chinese laws and regulations shown in Table 1 also reveal this focus, as articulated in the Five-Year Plans. The numbers reported in Figure 1 indicate that there are many more children with intellectual disabilities (95,400) and physical disabilities (43,300) compared to the number of children with hearing disabilities (15,800) and visual disabilities (10,900) (as cited in Zhong Guo Gu Du Zheng Wang, 2005). Therefore, gaps continue to exist by disability category and supports provided. Most children with disabilities under the age of 6 years, who have already been identified as having certain type of disabilities have not yet been served (Mao, 1993). Early childhood intervention for children with intellectual disability is in its infancy and supports for children with autism are also scant (Mao, 1993).
The Sampling Survey on Disability in Children 0-6 Years Old in China in 2001 (as cited in Zhong Guo Gu Du Zheng Wang, 2005) showed that there were severe shortages of facilities and teaching staff for providing quality early childhood intervention for young children with disabilities in specialized settings, as well as a dearth of opportunities for children with disabilities to be included in pre-school settings supporting children with typical development.

With the development of an early childhood intervention infrastructure, there is also in the PRC an increasing interest in research on early childhood intervention (Chiang & Hadadian, 2010; Hu, 2010; Liu & Raver, 2011; Mao, 1993; Pang & Richey, 2006). Current research highlights the importance of early childhood intervention for children with disabilities and urges early identification of disabilities and early childhood intervention for all children with disabilities in the PRC (Chiang & Hadadian, 2010; Pang & Richey, 2006). Issues that continue to plague early childhood intervention in the PRC are lack of sufficient legislative support, shortage of qualified personnel with appropriate professional development, and inadequate facilities and programs (Chiang & Hadadian, 2010, Hu, 2010). There has been little or no research exploring the experiences of Chinese families receiving early childhood intervention services and supports. Families in the PRC play a key role in improving early childhood intervention (Eichner, Groark, & Palmov, 2011). Therefore, this paper will discuss the early childhood intervention experience of families of young children with disabilities in the PRC.

**Method**

The purpose of this study was to explore the experiences in the PRC of families of young children with disabilities regarding early childhood intervention. To achieve this goal,
because of the emerging understanding of this phenomenon, a qualitative interpretive approach was used. As Merriam states (2002), a qualitative design would be the most appropriate if the research purpose is to understand a phenomenon, uncover the meaning a situation has for those involved, or delineate how things happen. A qualitative approach enables researchers to obtain an in-depth understanding of a phenomenon, an individual, and a situation (Merriam, 2002). Within the qualitative approach, a phenomenological study was used here. Such a study can be used to describe the meaning for several individuals of their experience of living through a concept or a phenomenon (Creswell, 2007). The basic purpose of phenomenology is “to reduce individual experiences with a phenomenon to a description of the universal essence (a ‘grasp of the very nature of the thing’)” (Creswell, 2007, p. 58). A principal goal of phenomenology is to describe the point of view of participants of the phenomenon being studied (Moustakas, 1994). This approach was a good fit for the research questions posed because I aimed to explore the essence of the experience of PRC families children with disabilities aged 0 to 6 years in terms of early childhood intervention.

Participants

Six western-China families of children under the age of 6 with disabilities participated in the study. One family of an 8-year-old child with disability was excluded from the analysis because the study’s focus was on families of children from 0 to 6 years old. Among the six families, there were four mothers, one father, and one grandfather. Two participants were 24-29 years old, two were 30-34, one was 35-39, and one was over 65. Half of the participants (3) were farmers, two were unemployed, and one was retired. Half the participants were from rural areas and half were from urbanized areas. In terms of highest education level attained, one participant finished elementary education, one finished middle-
school education, one finished high-school education, and two finished university education. Each of the families had only one child and the age of the six children ranged from 3 to 6 years, with a mean age of 4.2 years. There were five boys and one girl. Parents reported types of disabilities as cerebral palsy, hearing impairments, and language disabilities. Parents reported that there were no problems with their children’s cognitive abilities. Table 2 provides a summary of characteristics of the studied families (pseudonyms are used for families’ names).

In this study, the participants were drawn through a convenience snowball sampling method. Convenience snowball sampling is useful for getting started when researchers have no other way to determine participants (Glesne, 2006). Some participants with certain characteristics are first enrolled, and then they help researchers enroll other needed participants (Bloomberg & Volpe, 2008). The purpose of this study was to explore the experience of families of young children with disabilities with respect to early childhood intervention in the PRC. Although attitudes in the PRC toward people with disabilities are improving in recent years, there still exists a cultural stigma against people with disabilities (Hu, 2010). Families usually hide disabilities or the individuals with disabilities from other people. It was difficult for me to locate the families that were key informants for this study. I recruited some participants with the assistance of institutions that provide early childhood intervention to young children with disabilities. The institutional administrators provided access to families. We subsequently contacted families who expressed interest in participating. Families were also encouraged to identify other families who they thought may be interested in participating in the study.
Table 2

*Summary of Participant Family Demographics*

<table>
<thead>
<tr>
<th>Family member/ Age range (yrs)</th>
<th>Occupation</th>
<th>Education</th>
<th>Community</th>
<th>Age (yrs)</th>
<th>Disability as described by families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feng Father 24-29</td>
<td>Farmer</td>
<td>Elementary</td>
<td>Rural</td>
<td>4/M</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Huan Mother 30-34</td>
<td>Farmer</td>
<td>Middle School</td>
<td>Rural</td>
<td>6/M</td>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Qian Mother 35-39</td>
<td>Farmer</td>
<td>Middle School</td>
<td>Rural</td>
<td>3/M</td>
<td>Hearing impairment</td>
</tr>
<tr>
<td>Yang Mother 24-29</td>
<td>Unemployed</td>
<td>University/ Bachelor’s Degree</td>
<td>Urban</td>
<td>3/F</td>
<td>Hearing impairment</td>
</tr>
<tr>
<td>Xi Mother 30-34</td>
<td>Unemployed</td>
<td>High School</td>
<td>Urban</td>
<td>4/M</td>
<td>Language delay</td>
</tr>
<tr>
<td>Gang Grandfather 65-over 65</td>
<td>Retired</td>
<td>University/ Bachelor’s Degree</td>
<td>Urban</td>
<td>5/M</td>
<td>Cerebral palsy</td>
</tr>
</tbody>
</table>

Notes: F=female; M=male

**Data Collection**

In this study, data were collected through in-depth, semi-structured interviews with participating families. Such interviews often ask about the experience of the phenomenon and in what type of setting it occurs (Creswell, 2007). In a phenomenological study, the interview is the major method used to collect data: “participants’ descriptions can be explored, illuminated, and probed using reflection, clarification, requests for examples, and
descriptions” (Flood, 2010, p. 11). The interview questions in this study were aimed at eliciting families’ experiences about the services and supports provided to their children with disabilities. For example, one of the research questions was: “Tell me about your child’s situation in terms of early childhood intervention”. Some follow-up probes include questions such as: “When did your child start early childhood intervention?”, “Where does he/she receive the early childhood intervention?”, and “What do you think about your child’s early childhood intervention?”

In this study, I went to the PRC twice to conduct the interviews. All the interviews were conducted in Mandarin at times convenient to families, at school or at home after obtaining the families’ consent forms. Interviews lasted for an hour or less, were voice-recorded, and later transcribed. All the interviews were conducted in a way that made participants feel most comfortable, respected, and protected. For example, one interview was conducted in the playground with one participant’s friends around. Notes were taken to record any changes from the previously-prepared interview protocol. Families were paid an equivalent of US$25. Family demographic information was collected through a survey at the end of the interview.

Data Analyses

The data analyses involved ongoing data collection, coding, and memo writing. The analyses were conducted through three iterative phases: open coding, focused coding, and selective coding (Saldana, 2009). Open coding, also called initial coding, divides qualitative data into separate parts and compares them for differences and similarities (Strauss & Corbin, 1998). Its purpose is “to remain open to all possible theoretical directions indicated by your readings of the data” (Charmaz, 2006, p. 46). In the open-coding phase in this study, I used
transcriptions and field notes. Some of the initial open codes, such as extended family, child’s age, and medical treatment expenses are included in Table 3. Short stories in the form of case studies were then written for each family to summarize the background of the family and their experience related to the services and supports provided to their children.

This study used open coding first, and then switched to focused coding. Focused coding aims to search for “the most frequent or significant Initial Codes” (Saldana, 2009, p. 155) to develop “the most salient categories” which “make the most analytic sense” (Charmaz, 2006, pp. 46, 57). Some of the emerging categories that developed in this focused coding are listed in Table 3.

In the last phase, selective coding, central or core categories were developed into themes. In selective coding, all categories are “systematically linked” and are developed into themes, which “appear to have the greatest explanatory relevance” to explain the research topic (Corbin & Strauss, 2008, p. 104). In this phase, five themes were developed around early childhood intervention, as illustrated in Table 3.

Table 3

*Data analysis phases and analysis result examples*

<table>
<thead>
<tr>
<th>Steps</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-coding</td>
<td>Open codes include:</td>
</tr>
<tr>
<td></td>
<td>Extended family; child’s age; medical treatment expenses;</td>
</tr>
<tr>
<td></td>
<td>diagnosis time; child’s problem; expectations the family has of the child;</td>
</tr>
<tr>
<td></td>
<td>support from the extended family; diagnosis process;</td>
</tr>
<tr>
<td></td>
<td>response to diagnosis; debt; teaching; policy.</td>
</tr>
<tr>
<td>Focused coding</td>
<td>Emerging categories include:</td>
</tr>
<tr>
<td></td>
<td>Family type; child’s problems; diagnosis process; response to diagnosis;</td>
</tr>
<tr>
<td></td>
<td>family understanding of disability; financial issues</td>
</tr>
</tbody>
</table>
Table 3 (continued)

<table>
<thead>
<tr>
<th>Steps</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selective coding</td>
<td>Five major themes include:</td>
</tr>
<tr>
<td></td>
<td>Disability diagnosis; child’s present early childhood intervention (ECI);</td>
</tr>
<tr>
<td></td>
<td>family’s expectations; family’s evaluations; and financial</td>
</tr>
<tr>
<td></td>
<td>effect of the child’s disability on families.</td>
</tr>
</tbody>
</table>

Throughout the whole coding process, I kept memos, regarded as an important component of data analysis (Charmaz, 2006). Memos are research notes taken to assist in interpreting the data (Esterberg, 2002). They can help researchers shape thoughts about the emerging analysis and document the research process (Esterberg, 2002). Esterberg (2002) states that a memo can be in any format with which the researcher feels comfortable, because they are written for the researcher. Memos in qualitative research can be either procedural or analytic (Esterberg, 2002). Procedural memos focus on recording the process of creating, including, or rejecting codes, categories, and themes (Esterberg, 2002). Analytic memos focus on the data and include hunches and ideas about what the data meaning (Esterberg, 2002). In this study, the researcher kept memos to explain the meaning of codes, categories, and themes, captured important quotes, and interpreted the data. Table 4 provides examples of procedural and analytical memos in this study.
### Examples of Memos

<table>
<thead>
<tr>
<th>Type of memo</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedural memo</td>
<td>(Date: 11-28-2011) The code “response to diagnosis” includes any kind of reaction to the diagnosis results, such as feelings and actions that interviewees mentioned in the interview after their children were diagnosed as disabled. It includes things like “I cried”, “I couldn’t believe it at all”, and “I couldn’t accept the fact.” It also included things such as “We went to the best hospital”, “I checked her myself at home again and again”, “We didn’t have money, so we took him home and kept him at home,” and “We were told to go to the Disabled People’s Federation to get training.”</td>
</tr>
<tr>
<td>Analytical memo</td>
<td>(Date: 12-14-2011) It seems that “being physically able” is a very important goal for the families. Families whose children cannot walk, eat, or use the bathroom independently hope their children will be able to do these things without help after early intervention. Families whose children cannot hear or speak hope their children are able to hear and speak the same as typically developing peers. They said that only after their children become “normal” could they be accepted by normal primary schools. They put nearly all their emphasis on “making” their children “normal”. The PRC has issued laws that children with disabilities should accept compulsory education the same as typically developing children. Are these laws not actually implemented in practice in the PRC? Where are these</td>
</tr>
</tbody>
</table>
Table 4 (continued)

<table>
<thead>
<tr>
<th>Type of memo</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>children going to get their compulsory education? Why don’t people in the PRC realize disability cannot be cured? Why don’t people in the PRC think of providing wheelchairs for children who cannot walk? Is it because there isn’t enough money or that there are no public programs that make it possible?</td>
</tr>
</tbody>
</table>

**Trustworthiness**

Various terms are used to describe the trustworthiness of research. “Credibility” is the degree to which the researcher’s descriptions accurately reflect the participants’ thoughts (Bloomberg & Volpe, 2008). “Dependability” is the ability to follow the process used to gather and analyze data (Bloomberg & Volpe, 2008). “Transferability” means that the reader is able to identify a similar experience in his or her own environment (Bloomberg & Volpe, 2008).

I used three processes to assess trustworthiness: peer debriefing, member checking, and reflexivity. Peer review involves having someone familiar with the study review the data and methods (Creswell & Miller, 2000). I conducted regular peer debriefing to discuss the analysis of the data with three research colleagues conducting research in a similar area. I performed member checking by returning to the study sites the following year for additional family interviews, as well as by contacting three families via the internet to give them final research results at the end of the study.

Participants agreed with the researcher on most of the analyses interpretations and there was no salient disagreement between the participants and the researcher. In addition, I
also kept a research log to record my thoughts about myself as a researcher and to reflect on how data was being interpreted (Merriam, 2002).

**Bracketing**

In a phenomenological study, “epoch” (or “bracketing”) (Creswell, 2007, p. 59) is a very important issue. It means that the researcher sets aside his or her own personal experience as much as possible to take “a fresh perspective” (Moustakas, 1994, p. 26) toward the phenomenon under examination (Creswell, 2007). Bracketing involves the process through which researchers attempt to suspend their prior knowledge and assumptions about a phenomenon being studied in order to understand the essence of the phenomena (Wertz, 2005). Reflexivity is often an important component (Moustakas, 1994). By bracketing, researchers are able to “temporarily suspend what we think we already know and actively listen to” participants and “their individual reality” (Hamill & Sinclair, 2010, p.17). Bracketing is conducted through the entire research process, “not just at the data collection and analysis phases” (Hamill & Sinclair, 2010, p.20). Bracketing requires a researcher to have qualities such as being reflective, curious, open, insightful, honest, precise, and willing to be wrong (Hamill & Sinclair, 2010). Bracketing can increase the trustworthiness of the phenomenological study (Groenewald, 2004).

In the present study, I first conducted bracketing by conducting a reflective self-introduction. I am Chinese, born and raised in the PRC, and come from a traditional family. Before I started to pursue a Ph.D. degree in the United States, I had worked for about six years at a Chinese university and had been a volunteer in a special education center for one year in western China. From my experience in the PRC, I knew that early childhood intervention was still at an early stage of development. There were not many early childhood
programs, especially free public intervention programs. I knew that most of the programs existed in big cities. Although I could contact some families with disabilities in the center where I was a volunteer, I did not have a chance to talk with them about their experience of early childhood intervention because the center administrators considered this to be improper without first getting the administration’s permission. I was eager to listen to families’ stories about early childhood intervention, so I tried to suspend my understanding of early childhood intervention in the PRC as mentioned above. I remained open and curious during the whole research process. In addition, I kept reflective journals during the whole process to document my thoughts, feelings, and perceptions. In my journals I kept examining my own positions on various issues raised and emergent themes (Hamill & Sinclair, 2010).

**Results**

The purpose of this study was to explore the experience of families of young children with disabilities regarding early childhood intervention in the PRC. Five major themes emerged from this study: disability diagnosis, the child’s present early childhood intervention, the family’s expectations, the family’s evaluations, and the financial influence of a disability on families (Figure 2). In Theme 1, the families discussed the process of how they arrived at a disability diagnosis and early childhood intervention, including the diagnosis time, diagnosis process, and their responses to the diagnosis of their children’s disabilities. In Theme 2, the families described their children’s present early childhood intervention (ECI), including beginning time, daily duration, providers, expenses, and contents. In Theme 3, families expressed their expectations for their children’s futures. In Theme 4, families evaluated the early childhood intervention that their children were receiving, as well as some
policies related to ECI in the People’s Republic of China. Finally, in Theme 5, the families discussed the financial problems the disabilities caused.

Figure 2. Five major themes

**Theme 1: Disability Diagnosis**

All families discussed their experience in their child’s disability diagnosis, including the diagnosis time, diagnosis process, and their responses to the diagnosis of their child’s disabilities (Figure 3).

Figure 3. Theme 1: Disability Diagnosis
Among the six children from six participant families, four children were diagnosed as having a disability after they were one year old, including one child who was diagnosed at the age of three. The remaining two children were diagnosed at the age of 2 and 4 months. All of the children were diagnosed at hospitals in the PRC.

The families described how their child received diagnosis. Five out of six families reported that they noticed abnormalities in their children before the diagnosis, but they thought it was because their children were so young. Feng, a father of a child with cerebral palsy, described:

We did find a little abnormality, not a little, it is abnormality. (He) did not like moving. Hands were stiff, and in the shape of claw. You know, we did not know. We thought (he) was young, 7 or 8 months old. But it turned out to be cerebral palsy after diagnosis when (he was) older than 1 year old.

Only one family in the study reported that their child was diagnosed with hearing impairments before they noticed it. The child received a new-born baby hearing screening at the age of 2 months in the hospital before the family discovered the hearing impairment with their child. The child’s mother Yang described: “(She) did not pass the new-born baby hearing screening. Within the first month (after the diagnosis), I did not believe at all…I always checked at home myself….but did find there were problems.”

Families responded to the diagnosis of their child’s disabilities quite differently. Two families thought it was a kind of disease and turned to different hospitals around the country for medical cures. Gang, a grandfather of a child with cerebral palsy, stated: “It is a kind of disease.” He described their eagerness for a medical treatment at that time: “As the proverb says, ‘Try any doctor blindly, when you’re gravely ill’. (We) tried (any) hospital as long as
people said they were good.” Gang further described: “Children’s Hospital did not work, then we went to Jinmen Hospital… (We) travelled anywhere, to Chengdu, to Shijiazhuang, and then to Yunchang.” Two out of the six families, due to insufficient finances, did nothing other than keep their child at home after the diagnosis. Huan, a mother of a child with cerebral palsy, explained that “The doctor said (the child) needed acupuncture and medicine. Six to seven thousand (RMB) (around $882 to $1029 USD) for only one month…His father and I did not have money, then we tried a small hospital, and then came back home and stayed at home.” The remaining two families in the study, whose children had hearing impairment, obtained services and supports for their children from the Disabled People’s Federation immediately after the diagnosis.

**Theme 2: Child’s Present Early Childhood Intervention**

All families were asked about their child’s present situation in early childhood intervention in terms of beginning time, providers, daily duration, form, expense, and contents. Table 5 provides a summary of the information about the children, including receiving services and supports (pseudonyms are used for children’s names).

**Table 5**

*Child’s Early Childhood Intervention Information*

<table>
<thead>
<tr>
<th>Child</th>
<th>Yue</th>
<th>Yu</th>
<th>Ting</th>
<th>Hai</th>
<th>Ban</th>
<th>Min</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability</td>
<td>cerebral palsy</td>
<td>cerebral palsy</td>
<td>hearing impairment</td>
<td>hearing impairment</td>
<td>cerebral palsy</td>
<td>language delay</td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td>1.5 y</td>
<td>1 y</td>
<td>2 m</td>
<td>1 y</td>
<td>4 m</td>
<td>3 y</td>
</tr>
<tr>
<td>Age at Initial Services</td>
<td>5 y</td>
<td>3 y</td>
<td>6 m</td>
<td>1 yr</td>
<td>4 y</td>
<td>4 y</td>
</tr>
</tbody>
</table>
Table 5 (continued)

<table>
<thead>
<tr>
<th>Child</th>
<th>Yue</th>
<th>Yu</th>
<th>Ting</th>
<th>Hai</th>
<th>Ban</th>
<th>Min</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider</td>
<td>DPF</td>
<td>DPF</td>
<td>DPF</td>
<td>DPF</td>
<td>Private</td>
<td>Private</td>
</tr>
<tr>
<td>Daily Intervention</td>
<td>2 h</td>
<td>2 h</td>
<td>1 h</td>
<td>1 h</td>
<td>Full-time</td>
<td>1 h</td>
</tr>
<tr>
<td>Expense</td>
<td>Free</td>
<td>Free</td>
<td>Free</td>
<td>Free</td>
<td>Charged</td>
<td>Charged</td>
</tr>
<tr>
<td>Contents</td>
<td>Physical therapy</td>
<td>Physical therapy</td>
<td>Listening, speaking</td>
<td>Listening, speaking</td>
<td>Physical therapy, language, academics</td>
<td></td>
</tr>
</tbody>
</table>

Notes: DPF=Disabled People’s Federation; h=hour; m=months; y=years;

The time for starting services and supports varied among the six children, with the youngest one at the age of 6 months and the oldest one at the age of 5 years. Half of them started receiving services and supports at 4 or 5 years of age. The average starting time was 2.92 years of age. The delays between disability diagnosis and receiving the services and supports varied according to the type of disability. Two children with hearing impairment started getting services and supports immediately after the diagnosis. However, three children with cerebral palsy and one child with language delay started receiving services and supports ranging from 1 to 3.7 years after diagnosis, with an average of 2.55 years. This means that most children began receiving services and supports about 2.5 years after the diagnosis.
Children received services and supports from two types of organizations. One was the Disabled People’s Federation (DPF), funded by the government and providing free services and supports to children with disabilities. The services and supports offered by the DPF lasted from one to two hours daily. Families were required to accompany their children during the services and supports at every occurrence. The major content of services and supports was rehabilitation training; academic learning was secondary. Yue, a child with cerebral palsy, was not able to walk. He received physical therapy for two hours every day with his father present at the DPF. Ting, a child with hearing impairments, mainly received listening and speaking training in the DPF for one hour every day in her mother’s company. The other type of organization providing services and supports was private schools. These schools charged by the hour for a full day of services to children with disabilities. With the exception of rehabilitation training, other educational activities like academic learning were conducted on a full-time basis. Families were not required to accompany their children during the services and supports. Ban, a child with cerebral palsy, received full-time physical therapy along with language and academic training every day at the private institute without his family being present.

**Theme 3: Family’s Expectations for the Future**

Families expressed the expectations they had for their children and the services and supports received. Their expectations of their children involved physical conditions, daily self-care skills, education, and future self-reliance as adults (Figure 4). Additionally, the families expressed their expectations regarding the outcomes of the services and supports that the child received.
All families hoped that their children could get rid of the problems caused by the disabilities. Feng expected his son, who had problems in walking due to cerebral palsy, to “be able to walk by himself in the future.” He stated: “(Whether he) can get married (or) work doesn’t matter, as long as (he) can take care of himself, not being carried on back or being held, that is.” Qian, whose son had a hearing impairment and had problems speaking, expected her child to “be able to hear.” She stated: “As long as he can speak normally, (I) am satisfied.”

Many families hoped that their children could gain basic living skills, such as dressing, cooking and eating, to take care of themselves in daily life. Feng hoped that his son would be “able to put on the coat and pants.” Gang, a grandfather of a child with cerebral palsy, expected his grandchild to be able to “use money if given by the adults.” He continued: “In the future, as long as he could be able to be independent. Of course, it doesn’t mean (he) goes out to contact with others and earn money, but as long as he is able to do grocery shopping and cook by himself.”

In terms of education, many families hoped that their children could be able to go to normal schools. Yang, a mother of a child with a hearing impairment, stated: “My wish is
quite simple. As long as she is able to integrate into the normal society, and then is able to communicate with normal children, and then go to a normal primary school, I am satisfied.”

However, children with disabilities usually could not go to normal schools due to the disabilities. Even so, families still hoped that their children could be able to go to normal schools. Feng stated:

As long as he is able to walk, I will take him to school, I guess. Because if he is unable to walk, if possible, suppose, the school really accepts (him), even he needs you to carry him to school; he will be willing to go to school. He does not have any problems in studying. The only thing is that he cannot walk. Because it is impossible for you to ask the teacher to take care of your child with disability, right? You have to face this reality. And it is impossible for you to accompany and wait for him in the school every day.

Some families hoped that their children could become able to make a living by themselves when they grew up. Gang stated:

For him, the most important thing is self-reliance, making his own living. It means that if in the future the parents earn some money for him, buy him a little insurance, or earn him some capital for a small business, (he) is able to manage a small business, is able to sell lottery tickets, and is able to support himself. Hmm… Self-reliance is the most important because no matter how rich or poor the parents are, it is impossible to support him for a life-time.”

Families also expressed their expectations of the outcomes of their children after receiving services and supports. As mentioned above, due to their disabilities, children were not really accepted by normal schools. All the families expected that the services and
supports provided to their children could enable them to develop the skills required to enter normal schools. Huan stated: “Now (he cannot) be accepted. Now, try best to practice here, (get) trained, after being trained well, depends on his ability, see if he is able to go to school.” Feng made his child “have to persist” in physical training and “let him cry…even he cried for five minutes” in order to enable his son to walk after the training.

**Theme 4: Family Evaluations**

Families evaluated the early childhood intervention that their children received and evaluated some policies related to services and supports for young children with disabilities (Figure 5). In terms of evaluation of ECI, families evaluated teacher’s performance, services and supports time, and their content. Two opposite types of evaluation emerged from these families. Negative evaluations were made by families whose children received services and supports from the Disabled People’s Federation, while positive evaluations came from families whose children received services and supports from a private institute. In terms of evaluation of policies, families evaluated policy information resources and implementation of policies.

![Figure 5. Theme 4: Family’s evaluations](image-url)
Early Childhood Intervention

Families were not satisfied with the services and supports in the DPF, mainly due to their evaluation of teachers’ performance there. They thought that the teachers were of low quality, snobbish, irresponsible, and lacking in teaching skills. The families believed that the teachers did not really work for the children with disabilities but rather for the social security benefits offered by public institutions. Some families even looked down upon the teachers there. Yang described the teacher:

Really bad, quality is quite low, really. Teachers in the Disabled People’s Federation are quite snobbish, then, and dawdle away time, you know. I think all these are not good. I feel they do not seem (to work) for the children, not to work for the children’s rehabilitation. I think the teachers work just to get social security within China’s social security system…in terms of their characteristics, of that kind of snobbishness, and that irresponsible performance, I look down upon them no matter they are teachers.

Yang described her disappointment:

I don’t think highly of the teachers in the Disabled People’s Federation at all…I feel, (they) gave me bad feelings. I think the teachers lack empathy for the disabled students; they don’t understand the feelings of parents of children with disabilities at all. We put our all hopes on this institution, you know. But after entering it, (I) feel very discouraged…I do not have any enthusiasm towards it any more.

Families thought that the DPF could not keep good teachers and the teachers there did not have passion for their work due to low salaries and too many children to serve every day.

Qian thought “a good teacher cannot be kept” in the DPF and “capable teachers all left.” She
expressed her understanding of these teachers. She stated: “The salary is around 1,000(RMB)(around 147 USD)… really not enough.” She advocated “increase the salary for teachers to keep the good teachers.”

There were additional reasons for these families to feel dissatisfied with the services and supports in the DPF. One reason was that the services and supports were thought to be far from adequate; they only lasted from one to two hours every day. Qian expressed her dissatisfaction: “Only one hour, it is far from enough, quite not enough.” And, sometimes, her child did not “listen to teacher and wasted the time.” Another reason for families’ dissatisfaction was related to the content of services and supports. The main content focused on rehabilitation training, and other aspects such as academic learning were ignored. Yang stated: “Up to now, we have been in the Disabled People’s Federation for so long; basically it seems that (they) only teach language to these children with hearing impairments, nothing else.” Her child “did not like the class at all.”

Families from the DPF thought that the family played the major role in services and supports to their children. Yang stated: “(It) totally depends on the parents and it does not work to depend on the teacher” due to the limited services and supports time in the DPF. Additionally, Yang thought: “There are a lot of children who need the teacher. The teacher’s time is far from enough.” Also, families reported that there was a lack of guidance and they eagerly hoped to get some help and guidance in working with their children. Yang stated: “I think my methods are quite few. I really, I really need some lessons from others.”

Conversely, all families whose children used the private institution positively evaluated the services and supports received there. These families thought the services and supports were effective and that their children had made great progress. They expressed their
satisfaction. Gang stated: “Here, I paid money, and there is some progress. (Even) spending some money, having progress, we feel satisfied.” Xi, the mother of a child with language delay, thought the services and supports were “really effective.” The teachers were described as “quite responsible.” Gang stated: “Teachers put all efforts on these children. We are together for these children.” Xi thought teachers “are really making their efforts” for their children. These families did not discuss the services and supports content there. However, from the description of progress that one child made, it was evident that the services and supports were more than rehabilitation and comprehensive, including some academic learning.

Families using the private institution did not evaluate the content negatively. Gang described his grandchild’s progress: “Teachers here taught how to count 1, 2, 3, 4, 5, 6, 7, 8, 9, 10 and he knows. This is the progress we saw. He could not know the different colors, made mistakes, but after coming here, yesterday I checked him, he had some progress.”

**Related Policies**

In addition to evaluating the services and supports provided to young children with disabilities, families also discussed their experience in terms of related policies, including policy information resources and implementation of policies related to services and supports for young children with disabilities.

Families were not very aware of the policies related to children with disabilities and policy information resources. Feng stated: “Someone told me. We didn’t know...We always didn’t know there was this subsidy, (or) that subsidy. We were never told about it.” He further stated:
Nobody told us this information, (such as) applying (for) disability certificate, nobody told us. Some warm-hearted person told us it would be better to have a disability certificate. Until the age of 4 years old, we got it done. (He laughs). My friends saw our family conditions was quite bad and asked us to get one, and then we went to apply. That’s it.

Qian heard about some related policies from “kind neighbors.” Some families had been given some information on these policies, but they did not know the exact details. Yang stated: “Anyways, heard (it) here, there… (as for) the actual content, I am not quite clear.” After the children from those families started to get the services and supports, the DPF and the teachers became the major policy information resources.

When families were asked to evaluate the present policy of services and supports for young children with disabilities, some families thought the policy had been changed for the better. The government provided free rehabilitation to young children with disabilities. Hua stated: “The present policy has become good now… conduct rehabilitation training for those with cerebral palsy, and also teach them how to read. These policies are quite good.” However, some families expressed their dissatisfaction with the present policy because the laws related to people with disabilities was not really effectively implemented and the people with disabilities did not really have the rights they are entitled to by the laws and policies. Gang stated:

Some of them (laws or policies) work, and some of them don’t work…But actually, according to our observation, people with disabilities do not get what they should have…Therefore, the really needy, the really disabled are not benefited (from the
policy). Sometimes, it is only surface work (huang zi)... Sometimes, I saw some (people with disabilities) participate, but did not actually get (benefits).

**Theme 5: Financial Influence of Disability on Families**

Families mainly discussed the influence of disabilities on their finances. The major financial problems related to disabilities include the expense of hospitals, services, and supports and factors like travelling allowances and loss of family wage earners, as shown in Figure 6.

![Figure 6. Theme 5: Financial influence of disability on families](image)

As mentioned in Theme 1, some families regarded the disability as a disease. After the diagnosis of disability, they tried different hospitals seeking medical treatments and often spent almost all the money they had. Some families even borrowed money and consequently were under heavy debt. Feng stated that he “was determined, borrowed some money and lived there (hospital)” for a treatment. He felt it was “quite hard” because of the “heavy loans” and “being unable to earn money now.” However, Feng still seemed determined to have a last try at the hospital even though he found that it was “quite hard” to afford the medical treatment and there was “not much improvement.” He stated: “I will wait until the New Year,
or earn some money, or borrow some money if (I) can, have a surgery…as the old saying
says, ‘giving medicine to a dying horse’.” Gang described his family’s experience in
hospitals: “I think there is not much progress, (but) only spending money. We cannot afford
it. If 100,000 or 80,000 (RMB) is spent, it works. But it does not work; it only consumes
money. (We) are unable to afford it at all.”

Parents whose child received services and supports from DPF were required to
accompany their children during the delivery of services. Family incomes were negatively
affected by the loss of important wage earners because parents were required to accompany
their child during these activities. Yang quit her job to accompany her daughter during
hearing and speaking training at the DPF. Feng stated: “(I) cannot go out of village to earn
money.” He further described:

(Our attention is not always entirely focused there (at the DPF), you know. We also
have a lot of other things we are responsible for, you know. There are five people in
the family who need to live…I am here for one to two hours in the morning every day
and go home in the afternoon. (I) find some work to do in the afternoon to earn a little
money.

Apart from the influence on families’ wage earners, there were some other issues
related to services and supports for these families. Some families applied for government
support like hearing aids and cochlear surgery for their children, but they had to wait a long
time. Before government aid arrived, they had to pay for the services and supports. Yang
“rented one pair of hearing aids from the DPF” before “the government donated my family
two pairs of hearing aids.” Qian’s family could not wait to get free cochlear surgery because
they did not want the child to miss the optimum time for such surgery. Qian described her experience of waiting for the government free cochlear surgery:

We waited and waited again. Last year, we could not wait any more and went to the hospital to have the cochlear surgery. Finally when we got the call from the government, Hai was already in the operation room. It was too late. More than 100,000 (RMB), it was really hard for our rural family.

Families also had to pay for the maintenance of instruments such as hearing aids because the government did not provide such aid. Yang stated:

For this kind of child who had cochlear surgery, you also want to save some money, for example in the future… if (it) is not done well, (you) need to change it for her. For example, if the cord is broken, the battery maintenance, all these expenses, I think we have to consider, I think. (It) is also quite hard.

Families choosing the private institution over the DPF for their children had to pay for the services. For some families, this was a big financial problem. Yang stated:

For the private rehabilitation school, for children with this kind of hearing impairment, the full-time school costs 1,800 (around 265USD), or 1,600 (RMB) (around 235USD) every month, but for a common rural family, this amount of money means one month’s food expense for the whole family. If (you) send (the child) to this kind of rehabilitation center, (you) spend over 1,000 (RMB) only on the child’s rehabilitation. And after that, at your own home, the whole family needs to handle the daily expenses. I think it is quite difficult. Seriously, a common family cannot afford this expense.
Discussion

The purpose of this study was to understand families’ experiences in obtaining the services and supports for their young children with disabilities in the PRC. There are five major themes related to their experiences: their children’s disability diagnoses and their responses to them; the services and supports that their children received; their expectations for their children; their evaluation of the services and supports; policies related to the services and supports for young children with disabilities; and the effect of such disabilities on families with young children with disabilities in the PRC. We discuss these themes from the following perspectives: early identification; family knowledge about human development, disabilities, rehabilitation and policies; the present services and supports situation for young children with disabilities; the inter-institute connection; and the laws and their implementation in the PRC.

All families in this study had their children diagnosed relatively late, around the age of 2 years, except for one family whose child was diagnosed with a hearing impairment at the age of 4 months during the new-born baby hearing screening. The earlier the disability is identified, the easier it is for young children with disabilities to receive early services and supports (Ramey & Ramey, 1998). However, there is a lack of early identification in the PRC due to the lack of proper assessment and professionals capable of making such assessment (Ramey & Ramey, 1998). Early identification of childhood disabilities in the PRC is a recent phenomenon and is at a rudimentary stage. In recent years some early identification programs such as new-born baby hearing screening have been set up in some PRC cities. However, there is an imbalance in the development of these programs — most of them are located in cities and most focus on hearing and visual impairments. There is a lack of early
identification in rural areas and for diverse types of disabilities and, because of this lack, most children are diagnosed rather late, delaying provision of services and supports. In this study, except for the children with hearing impairment, most children started to get services and supports only after long delays. Although some children received timely medical treatment, most children started to receive services and support relatively late, between the ages of 3 to 5 years.

I found that some PRC families did not have adequate knowledge about their child’s development, disabilities, rehabilitation, laws, and policies related to services and supports. Although some families found abnormalities in their child on their own, many lacked knowledge about the child’s development and disabilities and thought the problem was due to their children being too young or developing a little slowly. Some of them waited to get a diagnosis until the children were around 2 years old. In this study, most families were still influenced by the traditional attitude with respect to disabilities. Disability is traditionally called “canfei”, meaning “handicap and useless” or “canji”, which means “handicap and illness” (Pang & Richey, 2006). Due to the influence of such traditional understanding, some families in the study thought disability was a kind of disease and could be cured. They consequently turned to different hospitals around the country for medical cures, often spending almost all of their money in this way. Some families borrowed money and even accumulated great debt. Only after they did saw little improvement in their children and could not afford the medical treatment did they turn to early childhood intervention.

However, families still hoped that the services and supports provided to their children could enable them to overcome the problems related to their disabilities and become normal. Families did not have adequate understanding of the potential services and supports available
to their young children with disabilities (Mao, 1993). In addition, there was a lack of knowledge about laws and policies related to the services and supports to young children with disabilities. Most families reported that they knew little or nothing about the related laws and policies; they got the information about these laws and policies from neighbors, friends, or teachers. After the disability diagnosis, they did not know where they could get services and supports.

After diagnosis, families reacted differently, with some turning to hospitals, some keeping their children at home without any services and supports, and some getting services and supports immediately after diagnosis. One of the reasons for the different responses to diagnosis may be related to the diversity of available services and supports. For example, the PRC has set up programs to provide free rehabilitation training for young children with hearing, visual, and physical disabilities. Furthermore, there is an imbalance between urban and rural areas in the development of these programs. Most programs focusing on young children with hearing, visual, and physical disabilities are located in cities (Chiang & Hadalian, 2010). In this study, children with hearing and visual impairments received services and supports immediately after diagnosis. But, even in cities, the institutions that serve young children with disabilities are quite limited (Chiang & Hadalian, 2010). Due to the limited nature and locations of these programs, families are often not familiar with them. Some families had not even heard about them. Another reason for the differences in the families’ responses to diagnoses may be the lack of coordination between different institutions like hospitals and rehabilitation centers in the PRC. Most children were diagnosed by hospitals that may be unaware of services and supports providers and could therefore offer no suggestions to families other than regarding medical treatments.
Families using the public institutions were not satisfied with the services and supports provided to their children. They thought the daily one to two hours service was far from enough and the content was quite narrow, mainly focusing on rehabilitation. Families also mentioned some problems related to teachers in the public institutions, including lack of teaching skills, lack of passion, and irresponsibility. This is in line with Pang and Richey’s finding (2006) that there is a lack of quality professionals and service facilities. In the PRC, some professionals working with young children with disabilities graduated from secondary vocational schools, from normal secondary national schools, or from two-year colleges with or without special education knowledge (Pang & Richey, 2006). Only a small number of such teachers are graduates from four-year universities or graduate schools (Pang & Richey, 2006). The salary of professionals working with young children with disabilities in the PRC is low (Mao, 1993) and their work is not well-recognized by their society (Mao 1993), so it is not considered an attractive career to pursue. The lack of appropriately-trained professionals for young children with disabilities may influence the services and supports available to families. In addition, the PRC has a large population of young children with disabilities who need assistance, but only a limited number of service programs, and these are only at limited locations. Providing high-quality services and supports for young children with disabilities is a great challenge in the PRC (Mao 1993).

Apart from hoping that their children could overcome the problems caused by their disability, many families hoped their children could gain basic living skills such as dressing, eating and walking without help to take care of themselves in daily life. Families hoped their children would be able to make a living and live independently when they grew up. In particular, families hoped their children would be able to go to high school and college, and
have a happy, healthy, and smooth life without being despised by society. In recent years, the PRC has issued a series of laws and regulations to address education for young children with disabilities. However, these laws and regulations have not been fully implemented (Huang, 2007). For example, the Compulsory Law states that children with disabilities have equal rights to receive compulsory education through three major avenues of learning — in regular schools, in special education schools, and in special education classes located in a conventional school setting. However, many young children with disabilities are rejected by conventional schools due to lack of facilities and qualified teachers. Education is highly valued in the PRC and it is perceived to be a necessity to achieving a good life. Families in this study think that education quality in the schools for children with typical development is better than that in special-education schools. Families hope that their children are able to receive an education equal to that received by children without disabilities. However, they may fear their children will be rejected by a conventional school and would have to go instead into a specialized setting. Therefore, these families want their children to become “normal” to be able to go to the schools available for all children. Similarly, employment of people with disabilities has been addressed by laws that are not actually implemented.

Families play the major role in caring for their children with disabilities at this point in time. Families may worry about the future of their children after they cannot support them anymore. Furthermore, although there has been some attitudinal change, people with disabilities still have a low status in this society and may be despised. Therefore, families hope and expect their children to be like typically developing children, become independent, and make a living in the same manner as other people.
In this study, the financial issue was a major concern related to having a child with a disability in the PRC. Due to the lack of knowledge about disabilities, some families hoping for a cure spent almost all they had on medical treatments. Some families even went bankrupt with heavy debt. Although the government provides some support such as free hearing aids or free cochlear surgery for affected families, the application process for such support took so long that some families could not wait. In order not to miss the optimum age at which to have surgery, some families had to pay for it themselves before the application for PRC funding was approved. Families also needed to pay for the maintenance of instruments for their children. Due to limited services and supports programs at limited locations, some families from rural areas needed to travel long distances to get services and supports for their children, and they paid the travelling expense themselves. Another financial issue related to disabilities was the influence on the families’ incomes. Some parents had to be present each and every day while their children received services, requiring them to quit their jobs or limit their working time. Families therefore could to some extent lose a key and important wage earner. Although the government has started to provide supports to some of these families, the investment is not enough.

**Conclusion**

In recent years, the PRC has made some progress in improving services and supports for young children with disabilities. However, it is still in the rudimentary stage and there are many issues yet to be addressed including the following: 1) China’s lack of an early identification system to assist in identifying young children with disabilities; 2) scarcity in the number of professionals who are qualified to assess and/or support young children with disabilities and their families; 3) limited and lack of accurate knowledge about human
development, disability, rehabilitation, laws, and policies related to early childhood intervention; 4) inadequate investment in early childhood intervention by the central government; and 5) ineffective implementation of existing laws and policies related to early childhood intervention in PRC.

Early identification of diverse disabilities in the PRC is critically needed. Such identification should be mandated by laws, and related programs should be widely available in both cities and rural areas for diverse categories of disabilities. Inter-institutional coordination should be developed, especially between early identification institutions and services and supports institutions.

There is an urgent need in the PRC for more professionals to provide adequate services and supports needed by children with disabilities. In order to achieve this, there should be an increase in the comparatively low salaries that professionals in this field presently receive. Professional development through in-service training to teachers to improve their knowledge and skills for supporting young children with disabilities, as well as required laws, can further assist families and their children with disabilities in the PRC to live a better life.

Knowledge about development, typical and atypical, should be dispensed widely. Through increased knowledge about development, family members and their communities would be more aware concerning delays in development and better judge when to reach out for services and supports. Most importantly, existing laws and policies should be fully implemented within communities, and the PRC should be encouraged to reexamine current laws to determine future directions for ensuring that the rights of all people with disabilities
are obtained. A critical element of this policy review is the development of laws specifically addressing the required level of educational assistance for young children with disabilities.

The PRC needs more investment in services and support to young children with disabilities, and more programs should be set up to support and serve such children. More intensive daily services and supports are also needed. Due to the massive population in the PRC and limited government investment, private agencies should be encouraged.

Existing laws and regulations related to early childhood intervention should be effectively implemented in the PRC. In recent years, the PRC has issued a series of laws and policies to address education for children with disabilities. However, these laws and policies are not fully implemented for a variety of reasons such as a lack of qualified professionals. More efforts should be made to fully implement existing laws and policies.

The PRC is facing many challenges in ECI. However, it should be noted that the development of ECI is a process. ECI in the PRC is only at an infant stage now, and the PRC has been making some ECI progress in recent years. Greater progress could be made if some of the challenges discussed in this research could be properly addressed.
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CHAPTER 3. FOUNDATIONS FOR SELF-DETERMINATION
PERCEIVED AND PROMOTED BY FAMILIES OF YOUNG
CHILDREN WITH DISABILITIES IN THE PEOPLE’S REPUBLIC OF
CHINA

A paper to be submitted to *Topics in Early Childhood Special Education*

Abstract

Foundational skills such as making choices, self-regulation, and engagement in the early years are significant for the later development of self-determination in adolescence and adulthood for individuals with disabilities in the United States, but little research has been conducted to examine whether these skills are as important in other countries. The purpose of this study is to understand how the foundational skills of self-determination were perceived and promoted by families of young children with disabilities in the People’s Republic of China (PRC). A phenomenological design was used to collect and analyze interviews with seven families in the southwest region of the PRC. This study indicated that these foundational skills held in high regard in the United States were also valued in the PRC. However, Chinese families of children with disabilities promoted the development of these foundational skills differently from their counterparts in the United States. In the United States, families regard the development of these foundational skills of self-determination as an internal and personal need, emphasizing individualism, independence, freedom, self-expression, and uniqueness. However, in the collectivist culture of the PRC, families regarded development of these foundational skills of self-determination with an emphasis on dependence and obedience in accordance with external social norms and needs. Chinese families used the popular Chinese parenting practice of *guan* (training) to help their children
make choices and regulate themselves according to *li* — “propriety, moral rules of proper behavior and good manners” (Gao, 2010, p. 35) —, and engage in learning and studying, highly valued activities in Chinese culture.

Key words: Foundations for self-determination, making choices, self-regulation, engagement, Chinese culture, *Guan, Li*

**Introduction**

The development of self-determination in individuals with disabilities has become a research focus in the United States since the 1990’s. Thus far, studies from the field of special education (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997) have shown that self-determination plays an important role in enhancing the quality of life for individuals with disabilities. Self-determined young people were more likely to graduate from high school and able to attain more positive outcomes, particularly in the areas of employment, financial independence, independent living, and other benefits (Field & Hoffman, 2002; Wehmeyer & Palmer, 2003). Promoting self-determination is an important way to “achieve academic and social inclusion and to promote the involvement of students with disabilities in the general education curriculum” (Lee & Wehmeyer, 2004, p. 373).

Given the significance of self-determination in quality of life for people with disabilities, there has been increasing interest in the application of the construct of self-determination to international special education practices in the past decade (Bao & Zhang, 2005; Hu, 2010; Lee & Wehmeyer, 2004; Li, 2008; Ohtake & Wehmeyer, 2004; Wu, 2007; Zhang, 2005; Zhang & Benz, 2006; Zhang, Wehmeyer, & Chen, 2005). Studies illustrate that the values inherent in most efforts to promote self-determination, such as personal control over the environment, individualism, self-help, competition, future orientation, and goal
orientation, are associated with Anglo-European cultures (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Leak & Boone, 2007; Zhang & Benz, 2006; Zhang, Landmark, Grenwelge, & Montoya, 2010; Zhang, Wehmeyer, & Chen, 2005) (Frankland et al., 2004; Turnbull & Turnbull, 2001). These values may seem “unfamiliar or inappropriate” (Zhang, Wehmeyer, & Chen, 2005, p. 4) to people from non-Western cultures, and non-Western cultures may encourage values different from the essential values associated with self-determination (Zhang et al., 2005). These studies have also shown there is universality of certain aspects of self-determination, such as making decisions, although they are expressed in different ways from the Anglo’s perspective (Frankland et al., 2004; Zhang et al., 2010).

Much attention has been focused on self-determination in young children with disabilities because of the importance of self-determination as a key component in the quality of life of people with disabilities (Brown & Cohen, 1996; Brotherson, Cook, Erwin, & Weigel, 2008; Erwin & Brown, 2003; Palmer, 2010; Wehmeyer & Palmer, 2000). Self-determination develops continuously across the life span (Brown & Cohen, 1996; Erwin & Brown, 2003; Palmer, 2010; Wehmeyer & Palmer, 2000). It has roots and foundations in the early years and extends over the entire life span (Brown & Cohen, 1996; Doll, Wehmeyer, & Palmer, 1996; Erwin & Brown, 2003). Some of the skills and behavioral characteristics essential for self-determination emerge and are demonstrated in the early years of childhood (Brown & Cohen, 1996; Doll et al., 1996; Palmer, 2010; Wehmeyer & Palmer, 2000). These skills and attitudes may be considered to be the “precursors, or foundations” of self-determination (Palmer et al., 2012). Models have been developed to promote the acquisition and development of self-determination in young children with disabilities. For example, Wehmeyer et al (2000) developed the Self-determined Learning Model of Instruction (SLMI)
to promote the development of self-determination in children with disabilities during the preschool and early elementary years. However, no information is available about how foundations for self-determination appear outside the United States. Although it is difficult to determine whether foundations are viewed the same in other cultures, the foundations for self-determination seem likely to differ. Since research on self-determination suggests that contextual factors influence the meaning of self-determination, it would be interesting to study how the foundations for self-determination are perceived in other cultures such as the Chinese culture. Chinese culture, with a five-thousand-year history, is one of the oldest cultures in the world. Some big differences exist between Chinese culture and American culture. During thousands of years of development, Confucianism has become the dominant philosophy in Chinese culture. According to Confucianism, a person can only reach his/her fullest development in the company of other people (http://www.globaled.org/chinaproject/confucian/reading1.html), so it is important for a person to behave properly in his/her relations with other people. These relations form a social structure called hierarchy, where each person has a specific place and plays certain roles related to other people. Therefore, in contrast to the mainstream American culture that emphasizes independence and individualism, Chinese culture puts more emphasis on interdependence, obedience, and collectivism.

This paper explores how foundations for self-determination are perceived and promoted by families of young children with disabilities in the Chinese culture. The aim of this paper is to explore how families perceive the foundations for self-determination and how they can help young children with disabilities develop these foundational skills. The primary research question is “How do Chinese families perceive and develop foundations for self-
determination in young children with disabilities?” A phenomenological research design has been used to explore the answer to this question. The results of this study can help understand foundations for self-determination in a diverse country such as the PRC. It can also help practitioners in the United States to better work with families in building foundations for self-determination in young Chinese children with disabilities. The following sections of this paper describe the background of this study, including the definition of self-determination; the importance of building foundations for self-determination in young children with disabilities; and clarifying the three key factors of self-determination: making choices, self-regulation, and engagement. Following the literature review, the paper will present the research purpose, questions, and traditional research sections, including method, findings, and conclusions.

Definition of Self-Determination

Within the field of special education there are several conceptual frameworks for understanding and promoting self-determination (Abery & Stancliffe, 1996; Wehmeyer, Kelchner, & Richards, 1996). For the purpose of this study I based the discussion on the functional model of “self-determination” articulated by Wehmeyer (1996). Within that functional model, actions are viewed as self-determination based upon the function they serve for the individual (Wehmeyer et al., 2011). Self-determined behavior refers to “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Self-determined behaviors reflect four essential characteristics: “1) the person acted autonomously, (2) the behavior(s) were self-regulated, (3) the person initiated and responded to the event(s) in a psychologically empowered manner, and (4) the person acted in a self-realizing manner”
A number of specific skills or behavior characteristics have been identified as necessary for self-determination (Brown & Cohen, 1996; Wehmeyer, Kelchner, & Richards, 1996). These specific skills are called “essential elements or set of skills” (Palmer, 2010, p. 3), or “component elements” (Wehmeyer, Kelchner, & Richards, 1996, p. 632), and are important in achieving the essential characteristics of self-determination. These component elements include, but are not limited to, initiative, choice and decision-making, problem-solving, goal setting and attainment skills, internal locus of control orientation, independent thinking, positive self-efficacy and outcome expectancies, self-knowledge and understanding, self-regulation, and persistence (Brown & Cohen, 1996; Wehmeyer et al., 1996). These component elements provide the “building blocks” for self-determination (Palmer, 2010, p. 3).

Foundations for Self-determination in Young Children with Disabilities

Self-determination is not innate; as Doll and colleagues (1996) stated, “Newborns do not enter the world self-determined” (p. 65). Becoming self-determined in adolescence and adulthood depends on the development of a number of “essential elements or a specific set of skills” (Palmer, 2010, p. 3) or the above-mentioned “component elements” (Wehmeyer et al., 1996, p. 632). Self-determination emerges as children, youth, and adults develop and acquire these components (Doll, Sands, Wehmeyer, & Palmer, 1996).

Although self-determination is often regarded as an outcome of adolescence and adulthood, it is “highly unlikely that characteristics associated with self-determination suddenly emerge in adolescence or could be nurtured as effectively if efforts at facilitating self-determination were postponed until then” (Brown & Cohen, 1996, p. 22). It has its roots and foundations in early childhood (Doll et al., 1996; Palmer, 2010; Wehmeyer & Palmer,
2000). Some of the skills and behavioral characteristics essential for self-determination emerge and are demonstrated in the early years of childhood (Brown & Cohen, 1996; Doll et al., 1996; Palmer, 2010; Wehmeyer & Palmer, 2000). These skills and attitudes may be considered to be the “precursors, or foundations” of self-determination (Palmer et al., 2012). For example, newborns demonstrate the capacity for indicating preferences by discriminating between various objects and people in the environment, and display their preferences for caregivers (Doll et al., 1996). The capacity to display and communicate preference is one essential aspect of making choices, an important component element of self-determination. Abery and Zajac (1996) stated “it makes little sense to wait until a child has matured into an adult to enhance the development of self-determination” (p. 170).

However, Palmer (2010) stated that the capacities or abilities demonstrated in the early years “should not be markers of readiness to attain self-determination” and they are not “necessary or sufficient to promote self-determination for all” (p. 4). Ongoing opportunities to practice these skills should be provided to children, which should contribute over time to the development of self-determination. Erwin and colleagues (2009) stated “simply growing older does not provide all the needed opportunities to acquire the abilities to make choices and decisions that promote later self-determination” (Erwin, Brotherson, Palmer, Cook, & Summers, 2009, p. 28). The emergence of self-determination is a developmental process involving not only the acquisition of skills, but also the integration among these competencies (Abery & Zajac, 1996). Children “become self-determined through learning across multiple environments and through developing within multiple domains” (Doll et al., p. 65). Children can acquire and learn the component elements of self-determination if provided adequate opportunities in early childhood. Limiting opportunities for young
children to practice and learn skills necessary for self-determination at early ages can
“unduly constrain adolescent expression of self-determined behaviors” (Doll et al., 1996, p. 68). Self-determination is developed through a series of “developmental progressions” of the component elements (Doll et al., 1996, p. 68).

According to Abery and Zajac (1996), there are many advantages to developing self-determination during the early years, including the following: a) starting instruction at an early age allows sufficient time to develop competency; b) encouraging significant adults to provide opportunities to supervise and support in needed skills areas; c) providing children time to practice and refine skills; d) preventing over-dependence, low sense of self-efficacy, and external locus of control; and e) enabling learning opportunities to be easily infused into the developmental structure of early childhood to support the development of skills needed for self-determination. It may be easier for a child to become a self-determined adult through building “a solid foundation” for self-determination during the early years (Wehmeyer & Palmer, 2000, p. 466).

For children aged 3 to 5 years, there are specific, age-appropriate skills that serve as the foundation for later development of self-determination for young children with disabilities (Summers, Brotherson, Palmer, Erwin, & Maude, 2009). Three particular skills: making choices, self-regulation, and engagement, provide a base for the development of self-determination for an entire life (Erwin & Brown, 2003). The family plays a key role in nurturing and supporting the development of self-determination in the early years, especially for young children with disabilities (Brotherson, Cook, Erwin & Weigel, 2008). Brotherson et al. (2008) found that a family’s characteristics may influence how it supports and provides opportunities for young children with disabilities to develop the foundational skills of self-
determination. Thus, the family may be the first and most influential environment in which young children with disabilities can develop the foundations for self-determination (Brotherson, Cook, Erwin & Weigel, 2008). The three critical foundational skills will be discussed in detail in the following section.

**Making Choices, Self-regulation, and Engagement**

Making choices is defined as “a process of selecting between alternatives based on individual preferences” (Wehmeyer, 1998, p. 14). Choice-making behaviors “provide young children ownership of their daily activities and routines” (McCormick, Jolivette, & Ridgley, 2003, p. 4). This skill demonstrates the beginning of independence and autonomous decision-making (McCormick, Jolivette, & Ridgley, 2003). Self-determined behavior is volitional, which means that a child is “making conscious choices or (has) the actual power to make conscious choices, or will” (Wehmeyer, 2005, p. 117). Self-determination requires that individuals be good at making choices (Doll et al., 1996). According to Doll et al. (1996), the development of choice-making capacity is an ongoing developmental process involving several stages at different times across the life span. It starts with the emergence of capacity to indicate preferences at infancy and extends throughout the life span (Doll et al., 1996). Doll et al. (1996) stated that, once the capacity for identifying and communicating preferences was developed, the maturation of choice-making ability depends on the child’s opportunities to make choices and experience the consequences of those choices. Therefore, children aged 3 to 5 years should be intentionally provided with ongoing opportunities to acquire and develop the choice-making skills essential to self-determined behavior.

Providing opportunities to make choices can also provide “the initial experience and practice for children to begin in the life-span journey toward self-determination” (Palmer, 2010, p. 6).
Self-regulation has been defined as “a complex response system that enables individuals to examine their environments and their repertoire of responses for coping with those environments, to make plans (decisions) about how to act, to act, to evaluate the desirability of the outcomes of their action, and to revise their plans as necessary” (Whitman, 1990, p. 373). Self-regulation involves a number of complex self-management skills, including self-monitoring, self-instruction, self-evaluation, and self-reinforcement, as well as goal setting, attainment behaviors, problem solving, and self-observation (Agran, 1997). A self-determined person is self-regulated (Wehmeyer, 1998), and the development of this complex response system of self-regulation starts at infancy and extends across the life span. One example of this is illustrated by the process through which children develop “rudimentary self-regulation skills, including the ability to regulate their arousal and physiological states” during infancy (Shogren & Turnbull, 2006, p. 344). Infants may suck their thumbs after hearing a loud sound, indicating that they are regulating their responses to the environment (Florez, 2012). Children learn complex self-regulation skills gradually as they grow. Toddlers begin to inhibit responses and comply with wishes of adult caregivers (Florez, 2011). Later, typically at about the age of four, children begin to exhibit more complex forms of self-regulation, such as anticipating appropriate responses and modifying responses when circumstances are subtly different (Florez, 2012). As children develop, their regulatory skills become more sophisticated (Blair & Diamond, 2008; Kopp 1982). However, the development of self-regulation depends on the support within the environment, especially during the early years. It is critical that children have opportunities to learn and practice these skills (Florez, 2012).
Engagement refers to “the amount of time children spend interacting with their environment in a developmentally and contextually appropriate manner” (McWilliam & Casey, 2008, p. 3). McWilliam and Casey (2008) discussed the positive influence of engagement on children’s behaviors, including improved thinking, reasoning, and peer interaction. Engagement is one important factor of persistence, a component of self-determination (Brown & Cohen, 1996). By definition, self-determined behavior is intended to meet some preselected goals (Doll et al., 1996). In order to accomplish a particular goal or goals, engagement is required. Engagement has been identified as “a critical component” related to self-determination (Erwin & Brown, 2003, p. 80). Engagement has been shown to be promoted by the availability of developmentally-appropriate activities and materials across the life span (Almqvist, 2006). Therefore, “supporting children’s active and meaningful engagement in the world is perhaps one of the most important tasks related to the development of self-determination” (Erwin & Brown, 2003, p. 80).

**Purpose of the Study**

Many researchers and professionals have come to understand the value of foundations for self-determination in young children with disabilities. Models have been developed to promote these foundational elements in young children in the United States but little information is available about the foundations for self-determination in young children with disabilities in countries outside the United States. It is difficult to determine whether foundations are viewed in the same way in other cultures, such as within the Chinese culture. It is hypothesized that characteristics individuals identify or observe about foundations for self-determination may differ in other countries such as the PRC. The purpose of this study was to examine how the foundations of self-determination in young children with disabilities
are perceived and promoted in the PRC. The research question guiding this study was: How do Chinese families perceive and promote foundations for self-determination in their young children with disabilities?

**Method**

In this study, a phenomenological method was used to develop understanding as to how foundations for self-determination were perceived and promoted in young children with disabilities in the PRC (Merriam, 2002). A phenomenological study is an interpretive form of research seeking to study a phenomenon perceived or experienced by individuals (Flood, 2010). The major purpose of phenomenology is “to reduce individual experiences with respect to a phenomenon to a description of the universal essence (a ‘grasp of the very nature of the thing’)” (Creswell, 2007, p. 58). This approach was a good fit for the research question posed because I aimed to study how foundations of self-determination in young children with disabilities were perceived and how these foundations were promoted by families in the PRC.

**Participants**

In this study, seven participants were chosen through a convenience snowball sampling methodology, a useful approach for initiating a selection process when researchers have no other way to find the participants they want (Glesne, 2006). A few participants with certain characteristics are chosen, and then more participants are recruited with the help of these initial few participants (Bloomberg & Volpe, 2008). This study sought to understand how families perceived foundations of self-determination in young children with disabilities. It was hard for me to locate participant families in the PRC due to the existing negative cultural stigma towards people with disabilities (Hu, 2010). Families usually hide the disabilities or the individuals with disabilities from others. Procedures used to recruit a
sample included my first contacting the administrators of the institutions that provided early childhood intervention to young children with disabilities in the PRC. With the administrators’ help, a few participants were recruited by using a snowball sampling technique to recruit other potential research participants into this study.

In a phenomenology study, five to 25 individuals should be recruited to develop the possibilities of an experience (Creswell, 2007). In this study, seven participants were recruited in the PRC. The recruitment criteria included: 1) families with a child aged between 3 to 8 years, 2) the child had a developmental disability, 3) the family was willing to participate in an interview, and 4) the family was willing to provide feedback on ideas that emerged from the interviews.

Given the recruitment criteria, seven participant families in southwest China having children with disabilities participated in the study. Among the seven families, there were five mothers, one father, and one grandfather. Two participants were between 24 to 29 years old, three were between 30 to 34 years old, one was between 35 to 39 years old, and another was over 65 years old. Three participants were farmers, one was employed as a teacher, two participants were unemployed, and one was retired. Three of the participants resided in rural areas and the other four resided in urban communities. Highest levels of education completed included elementary (n=1), middle school (n=2), high school (n=1), and university (n=3). All the families reported having only one child, and the seven children varied in age from 3 to 8 years, with a mean age of 4.7 years. There were six boys and one girl. Types of disabilities reported by the parents included cerebral palsy, hearing impairments, and language delay. Table 1 presents a summary of the families participating in the study (pseudonyms are used).
Table 1

*Summary of Participant Family Demographics*

<table>
<thead>
<tr>
<th>Family</th>
<th>Li</th>
<th>Zhang</th>
<th>Huang</th>
<th>Tang</th>
<th>Wang</th>
<th>Yan</th>
<th>Ding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community</td>
<td>Urban</td>
<td>Urban</td>
<td>Urban</td>
<td>Urban</td>
<td>Rural</td>
<td>Rural</td>
<td>Rural</td>
</tr>
<tr>
<td>Family member</td>
<td>Mother</td>
<td>Mother</td>
<td>Grandfat her/ over 65</td>
<td>Mother</td>
<td>Father</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td>Age range(yrs)</td>
<td>/30-34</td>
<td>/35-39</td>
<td>/24-29</td>
<td>/24-29</td>
<td>/30-34</td>
<td>/35-39</td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>No job</td>
<td>Teacher</td>
<td>Retired</td>
<td>No job</td>
<td>Farmer</td>
<td>Farmer</td>
<td>Farmer</td>
</tr>
<tr>
<td>Education</td>
<td>High School</td>
<td>Bachelor</td>
<td>Bachelor</td>
<td>Bachelor</td>
<td>Elementary</td>
<td>Middle school</td>
<td>Middle school</td>
</tr>
<tr>
<td>Child’s Age (yrs)</td>
<td>4/M</td>
<td>8/M</td>
<td>5/M</td>
<td>3/F</td>
<td>4/M</td>
<td>6/M</td>
<td>3/M</td>
</tr>
<tr>
<td>/Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability described by Families</td>
<td>Language delay</td>
<td>Autism</td>
<td>CP</td>
<td>HI</td>
<td>HI</td>
<td>CP</td>
<td>CP</td>
</tr>
</tbody>
</table>

Notes: CP=cerebral palsy; HI=hearing impairments

**Data Collection**

In phenomenological studies, data collection most often consists of in-depth interviews, multiple interviews with each participant, and observations (Creswell, 2007). In-depth interviews with participants most often ask participants two broad and general questions: “What have you experienced in terms of the phenomenon?” and “What contexts or situations have typically influenced or affected your experiences of the phenomenon?” (Creswell, 2007, p. 61). The principle goal of a phenomenology study is to describe the point of view of participants of the phenomenon being studied (Moustakas, 1994). In this study,
semi-structured, in-depth interviews were conducted with families with young children aged 3 to 8 years with disabilities.

In this study, the interview protocols developed were based on a research study Building Foundations for Self-Determination in Young Children with Disabilities: Family-Professional Partnerships (Summers et al., 2009) funded by the Institute of Education Sciences of the U.S. Department of Education. This study is a consortia effort involving 3 universities in the U.S. aiming to design, develop, and pilot an intervention program to promote the development of self-determination in disabled children aged 3-5, through partnerships between families and early childhood practitioners. Based on the interview questions and procedures used with families in the U.S., I developed similar interview questions and procedures for parents in the PRC; however, some modifications had to be made to conform to practices employed in the special education system in the PRC. All documents, including consent forms, flyers, demographic information protocols, and interview protocols were prepared in the Chinese Mandarin language.

In this study, the open-structured interviews were comprised of some initial or grand tour questions focusing on four topics: 1) understanding the classroom environment/family, 2) making choices, 3) self-regulation and control, and 4) engagement. The six interviews were conducted in 2010 and once again in 2011 with different participants from the same settings. The interviews in Mandarin were conducted by me at the convenience of the families, with two conducted at home and five at school. The interviews lasted from 45 to 60 minutes and were audio-recorded. Field notes were maintained to document modifications and accommodations during the interviews. An interview summary sheet was recorded following each interview to summarize the main points of the interview and to identify any
emerging issues; this summary was used during the data analysis. The family demographic information was collected through a survey at the end of the interview. Each family received monetary reimbursement equal to $25USD in Chinese currency.

**Data Analysis**

The data analysis in this study involved ongoing data collection, coding, memo writing, bracketing, and completing summary sheets. The analysis was conducted through three iterative phases: 1) open coding, 2) focused coding, and 3) short integrative family case stories (Saldana, 2009). Open coding, often called initial coding, “breaks down qualitative data into discrete parts, closely examines them, and compares them for similarities and differences” (Strauss & Corbin, 1998). In the open coding phase in this study, the researcher used transcriptions, field notes, and summary sheets. Some of the initial open codes, such as extended family, likes, dislike, choice, choice ranges, cry, break things, coax, beat, and threaten are shown in Table 2.

Open coding in this study was followed by focused coding. The purpose of focused coding is to search for the most frequent or significant initial codes to develop “the most salient categories” that “make the most analytic sense” (Charmaz, 2006, pp. 46, 57). For these findings, “the most analytic sense” was to use the a priori categories of making choices, self-regulation, and engagement. Under each of these major categories, two subcategories emerged – the perceptions and practices of each. In focused coding, the significant salient issues for each sub-category were identified (Table 2).

In the last phase of writing family stories, short case stories were written for each family to summarize the background of the family and their experiences related to the development of foundations for self-determination in young children with disabilities. The
family stories provided an understanding of how each family perceived and practiced choice making, self-regulation, and engagement, and an understanding of some of the similarities and differences among families (Appendix G).

Table 2

*Data Analysis Phases and Analysis Result Examples*

<table>
<thead>
<tr>
<th>Steps</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open coding</td>
<td>Open codes included: Families understanding of foundational skills, child’s preference, choice opportunities, choice ranges, expression of emotion, regulation strategies, engagement strategies, engagement focus</td>
</tr>
<tr>
<td>Focused coding</td>
<td>Emerging categories included: Perceptions and practices in making choices, perceptions and practices in self-regulation, perceptions and practices of engagement</td>
</tr>
<tr>
<td>Family stories</td>
<td>Short case stories were written for each family to summarize the background and experiences of the family related to the development of foundations for self-determination in the young children with disabilities</td>
</tr>
</tbody>
</table>

During the whole process of data analysis, I kept memos, regarded as an important component of the data analysis (Charmaz, 2006). Memo writing is a process of making meaning (Esterberg, 2002). Memos are often regarded as “letters or notes” to researchers to help them understand the research data (Esterberg, 2002, p. 164). Keeping memos can help researchers shape thoughts about the emerging analysis as well as document the research process (Esterberg, 2002). Memos can be in any format that the researcher finds most
comfortable because they are written for the research himself/herself (Esterberg, 2002). Two major types of memos are often used in qualitative research: procedural and analytic (Esterberg, 2002). A procedural memo focuses on recording the process of creating, including, or rejecting codes, categories and themes (Esterberg, 2002), while an analytic memo focuses on the data and contains hunches and ideas about what the data mean (Esterberg, 2002). Table 3 provides examples of procedural and analytical memos from this study.

Table 3

*Examples of Procedural and Analytical Memos*

<table>
<thead>
<tr>
<th>Type of memo</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Procedural memo</td>
<td>(Date: 01-03-2012) The code of “practices in regulation” includes any kind of actions or strategies that families use to regulate or control their child, including verbal actions such as “talking”, “coaxing” and verbal “threatening”, and nonverbal actions such as “ignoring” or “beating.”</td>
</tr>
<tr>
<td>Analytical memo</td>
<td>(Date: 01-14-2012) When participant families were asked how their children regulate themselves, they spoke more about what actions they took to regulate their children. It seems that it is adult-regulation instead of self-regulation. Some families thought it was impossible for the children to regulate themselves and parents had to do something. Why did these families think so? Does it mean that these families did not want their children to be self-regulated? If not, why did the families emphasize that some of their child’s behaviors were not acceptable and had to be corrected so that they knew what was right and what was wrong? What does it mean to be a self-regulated person in the PRC?</td>
</tr>
</tbody>
</table>
Trustworthiness

In qualitative research, terms such as credibility, dependability, and transferability are often used to describe the trustworthiness of the research. Credibility refers to whether the participants’ perceptions match the researcher’s portrayal of them (Bloomberg & Volpe, 2008). Dependability refers to “whether one can track the process and procedure used to collect and interpret the data” (Bloomberg & Volpe, 2008, p. 78). Transferability concerns “how well the study has made it possible for readers to decide whether similar processes will be at work in their own settings and communities by understanding in depth how they occur at the research site” (Bloomberg & Volpe, 2008, p. 78).

Three major procedures were performed in this study to address trustworthiness: 1) peer debriefing, 2) member checking, and 3) reflectivity by maintaining a research journal. A peer review or debriefing refers to the review of the data and research process by someone who is familiar with the research being conducted (Creswell & Miller, 2000). I conducted regular peer debriefing about the analysis of the data with colleagues working on the same research team. Member checking was conducted with some of the participants in two major ways. First, when the researcher returned to the PRC in the following year to interview more families at the same location, face-to-face member checking was conducted with several families. The primary focus of the member checking was to discuss some parts of the analysis of their interviews. Second, three families were contacted online and were provided the results of the data analysis after the entire analysis was finished. Two of these three families felt surprised that they used the strategy of “beating” to regulate their children and thought it was not right during the member checking. However, there was no salient disagreement between the participants and the researcher. In addition, I maintained a research
journal during the whole research process to “reflect critically on the self as researcher” (Merriam, 2002, p. 26). The process of “reflexivity” (Merriam, 2002, p. 26) also enabled the researcher to understand how a particular interpretation of the data was achieved through bracketing.

**Bracketing**

In a phenomenological study, bracketing or suspending is an important way to demonstrate the validity of research (Ahern, 1999). Bracketing means that the researcher intentionally puts aside his or her values or assumptions in order to understand the essence of an experience (Ahern, 1999; Creswell, 2007; Wartz, 2005). Reflexive bracketing is commonly used in phenomenological studies (Ahern, 1999; Gearing, 2004); it means that the researcher reflects on his/her own values, assumptions, and motivations for research (Ahern, 1999).

Before reporting the research, I wanted to first reflect on my own experience so that the readers could understand the efforts I made to understand the essence of my participant family’s experience. In the next section, I describe my own experience with the development of self-determination, my assumptions about self-determination, my research experience in studying the construct of self-determination, and my motivation for performing this research.

I am a native Chinese. I was brought up and educated in the traditional Chinese culture. I am currently pursuing my Ph.D. at a U.S. university. Throughout my Ph.D. study, I have been taking part in a research project called *Foundations for Self-determination in Young Children with Disabilities*. This research experience has helped me understand not only the construct of self-determination but also the foundations for self-determination in Western culture.
I define myself as a quite self-determined adult. This is because I think I am the causal agent in my life. Although my parents still sometimes “suggest some decisions” (make some decisions) for me, I can make and pursue my own decisions for my life. For example, my parents were strongly against my decision to pursue my Ph.D. in the United States because I already had a good job in the PRC. However, I made the final decision for myself — quitting my job for higher education, which may lead to a better life for me. However, I would never have made such a decision during my childhood or before adulthood because I was thought to be too young to be able to make decisions independently. I was taught to be obedient and respectful to my elders and teachers while making choices. For example, if I was provided a chance to choose an apple, I was taught to choose the smallest one for myself and to leave the big or better one for my elders or others in order to convey politeness and respect. I was provided very limited chances to make choices; my parents made most of the decisions for me, such as what toy to play with, who to play with, and which school to attend. As for self-regulation, I was taught to suppress my own feelings so as not to show anger or cry in public. Most of the time my parents regulated me by reasoning or using punishments like hitting. As for engagement, it was primarily focused on my parents and immersion in my academic studies. When I was young I was required to sit for one or two hours learning how to write Chinese characters. My development was quite different from the practices parents in the U.S. use to promote the foundational skills. My curiosity about how my parents perceive these skills led me to this study. From the study, I became interested in knowing how families of young children with disabilities perceived and promoted the development of foundations for self-determination in the PRC.
Findings

The purpose of this research was to study how foundations for self-determination in young children with disabilities are perceived and promoted by families in the PRC. The question guiding this study was: How do Chinese families perceive and promote foundations of self-determination in young children with disabilities? Table 4 presents three major categories and subcategories and the salient issues identified through data analysis, and confirmed through member checking and peer debriefing. The discussion of results begins with two short case stories to help in understanding how two families integrated the three major categories: making choices, self-regulation, and engagement. The short case stories are followed by discussion of the major categories.

Table 4

A Summary of Major Categories and Salient Issues

<table>
<thead>
<tr>
<th>Major Categories</th>
<th>Subcategories</th>
<th>Salient issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making choices</td>
<td>Perceptions of Making Choices:</td>
<td>• Families related making choices to child’s preferences, interest or hobby. Families thought everyone knew how to make choices.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Families wanted their children to be able to make choices.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Families thought letting the child make every choice and satisfying all their choices amounted to “spoiling”.</td>
</tr>
<tr>
<td></td>
<td>Practices of Making Choices:</td>
<td>• Families had prerequisites to letting their children make choices: reasonable and good choices in their parents’ eyes; children were respectful to the parents’ decision; children were obedient to the parents; no choices regarding education.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• There was a continuum for families to provide chances to let</td>
</tr>
</tbody>
</table>
Table 4 (continued)

<table>
<thead>
<tr>
<th>Major Categories</th>
<th>Subcategories</th>
<th>Salient issues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>their children make choices: some families did not let or provide chances to make choices; some families provided some chances such as food and clothes, but no choices in education; some families let the children make all choices or do whatever they wanted because they did not know how to control the child and exert parental authority.</td>
</tr>
</tbody>
</table>

Self-regulation

**Perceptions of Self-Regulation:**
- Families valued regulating their child’s behavior.

**Practices of Self-Regulation:**
- Families helped their children to internalize acceptable behaviors by controlling or regulating their child’s behavior.
- Families used different levels of strategies to regulate their children: ignore (sometimes as the first or the last strategy); comfort or reason; punish or threaten.

Engagement

**Perceptions of Engagement:**
- Families thought engagement meant taking part in activities such as playing with others, getting rehabilitation training, learning, and studying.

**Practices of Engagement:**
- Families highly valued engagement in learning and studying.
- Families focused on helping their child engage in learning and studying by using strategies similar to regulate their child.
- Because of the bias against children with disabilities, families had to use different strategies, such as asking their relative’s
Table 4 (continued)

<table>
<thead>
<tr>
<th>Major Categories</th>
<th>Subcategories</th>
<th>Salient issues</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>children to play with</td>
<td>their child, or helping their children to engage with peers.</td>
</tr>
<tr>
<td></td>
<td>their child, or</td>
<td></td>
</tr>
<tr>
<td></td>
<td>helping their children</td>
<td></td>
</tr>
<tr>
<td></td>
<td>to engage with peers.</td>
<td></td>
</tr>
</tbody>
</table>

**Example Case Story of One Family**

Wang is the father of a 5-year-old child with cerebral palsy. His family lives in a rural area in southwest China. The family is an extended family that includes Wang, Wang’s wife, his son, and Wang’s parents. The whole family cooperates in taking care of the child. The father takes the major responsibility because the child cannot walk independently and needs to be carried. Wang carries his child on his back every day to the Disabled Person’s Federation to receive half-day training and stays with the child during class and training.

Wang thinks that everyone knows how to make choices. He said that even a fool knows how to make choices and express them by looking at others. His son knows his own preferences and interests quite well. Wang and other adults in the family let the child make choices such as food or clothes. However, he thinks that adults should not let the child make every choice or satisfy every choice made by the child. Otherwise, it amounts to spoiling. Due to the family’s limited financial situation, Wang’s family cannot satisfy some choices made by the child. Wang said that the family tried its best to satisfy their child’s choices as long as they are good, reasonable, or related to learning or studying, such as books. Wang said they did not let the child make any choices regarding studies and the child has to learn or study under adult guidance.

Wang often carries his son on his back in the neighborhood and lets him engage with other people. The child likes going outside, chatting, or playing with others. However, the
child has some problems in engagement while studying or getting rehabilitation training. Usually, Wang first reasons, talks, and coaxes the child to help him engage in studying such as doing math or learning. If these strategies do not work, sometimes he beats the child. He said it is not like “real” beating. He only "pretends" (uses light coercion) so that the child would do what he wants. Finally, if the child still does not cooperate after beating, he usually ignores the child’s crying and forces the child to study or get training. Wang understands the hardship his son is experiencing due to the disabilities. He said he has no choice because if the child does not get rehabilitation training and become “normal”, the primary school will not accept him. If the child does not study, he cannot make a living in the future. He said the parents would take care of the child as long as they were alive, but some day the child has to support himself.

Wang’s child often expresses his unhappiness, dissatisfaction, or depression through crying loudly or throwing things. Wang said that these behaviors are totally unacceptable and he and the family are trying to correct the child’s behavior. For this Wang uses strategies similar to what he found effective in engaging the child in studies, such as reasoning, talking, coaxing, beating, scaring, and ignoring. He said his child was quite obedient in general and listened to adults.

Another Example Case Story of One Family

Yan is the mother of a 6-year-old child with cerebral palsy. Yan’s belongs to an extended family in a rural area in western China, including Yan, Yan’s husband, her son and her parents- in-law. The whole family cooperates in taking care of the child. The child was diagnosed as having cerebral palsy at about 1 year of age. Due to the limited financial situation and no available free governmental early childhood intervention programs, Yan’s
family kept their child at home without receiving any services and supports until the child was around 4 years old. Since then, Yan’s family travels 3 hours daily with the child to receive 3-hour rehabilitation training.

Yan’s family does not let their child make choices in daily life, mainly because the child did not tinghua (obey his parents). Sometimes, when the child makes a certain choice that his parents or grandparents think is not good and is therefore denied by them, the child does not follow their directions. The child cries or becomes angry when his choice is not allowed and he is offered another choice. Now, the child is not asked to make choices at all; Yan’s family makes choices or decisions for the child. Yan thought engagement meant the child did what the adults thought was good, such as studying how to write and cooperating in the rehabilitation training. She thought her son had problems with engagement because he did not like studying or taking part in training. She often tried different strategies to help her child engage, such as reasoning, coaxing, and sometimes beating. However, she said her son is quite stubborn and disobedient. If he is unhappy he will shout, cry aloud, throw things, or otherwise be unreasonable. Most of the time, Yan just ignores the child because the child does not listen to them at all, even when she tries to regulate him.

**Finding 1: Making Choices**

*Perception of Making Choices*

Most of the families spoke about their children’s preferences while talking about making choices of their children. One family stated that letting the child “make choices” was “mainly developing her interest and hobby.” Wang, the father of the child with cerebral palsy, said that everyone who was conscious knew his/her preference and knew how to express the preferences:
As long as (being) conscious, he is able to make choices…Fool, (children) like our child who is severe (in disability), are conscious, you know. If he doesn’t want (something), he will bury his head. (If he) wants, he will raise his head, right? In terms of this (expressing preference), the expression ways are different.

Most families hoped that their children were able to make choices and encouraged them to make choices. Zhang, the mother of a child with autism, stated “of course, I hope that he is able to make choices.” Li, the mother of a child with language delay, stated she “definitely encourages” her son to make choices. Huang, the grandfather of a child with cerebral palsy, was against his son-in-law’s imposing his decision on his grandson. He stated “He (the father) doesn’t know the child development…At a certain stage, he (the child) likes certain things…you adult cannot force (him).” Families further explained the results of not letting their children make choices, and instead forcing their children to follow the adults’ decisions. Li stated “If you force him (the child), he will lose temper. It has bad influence on the child.”

All families stated that their children knew their preferences and were able to express their preference in different ways. Some families said that their children expressed choices or preferences by “telling” them directly. Some families said that their children told them their choices or preference by “pointing” or “looking at adults.” One child from one participant family advocated making choices for himself. Huang shared one story of his grandson who argued with his father for making his own choices:

He, yesterday, even argued with his father. He blamed his father for four things. He said “Dad, you, do not speak, listen to me. You do not let me play with water, (so) what do you let me play with? You asked me to eat beside the table, (but) I want to
eat not beside the table. You do not let me put on clothes myself.” He likes putting on clothes. “You do not let (me do it), what can you say.”

However, families mentioned that letting their child make every choice or satisfying his or her every choice was a form of “spoiling” the child. Families described some prerequisites of letting their children make choices. Yan, the mother of a child with cerebral palsy, stated“(It is) necessary to make some rules. You do not give him whatever he wants.” She further stated “(We) only give him what is good to him. (If it is) bad, (we) cannot give it to him.” She described another requisite: “if he (the child) listens to adults, (we) let him choose.”

**Practices Related to Making Choices**

When asked about how families let their children make choices in daily life, families shared different experiences from a continuum of providing children no chance to make choices to letting children make all choices, as shown in Figure 1.

Figure 1. A continuum of chances provided by families for children to make choices

One family who described their child as “not obedient at all” did not let their child choose. Yan said “He didn’t listen at all. How can you ask him to choose…If you let him (choose), he did not listen…He plays all the day. He is always naughty at home, doing this or that. If you shout at him, he doesn’t listen.” Conversely, another family let their child do whatever the child preferred to do, apparently due to lack of knowledge on how to “control”
the child. Ding, the mother of a child with hearing impairments, reported that her son “did not listen to her at all or was “rather violent” if she did not satisfy his choice. She stated “Mostly, I can only watch him, accompany him in play.”

The remaining families reported that they could let their children make choices in some aspects of their daily life, like choosing their food and clothes. Families also supported their children’s choices if they thought the choices were “reasonable” or “good.” Wang stated:

We try to satisfy him…for example, if we already cooked some dishes and he wanted something else, (it was) impossible…We tried to satisfy his choices as long as what he wants is good, we can satisfy him. For example, he likes writing, (we) buy pencils.

If he wants to read books, then (we) buy books for him.

Families reported that they provided limited opportunities to choose in terms of studying. Zhang stated “Mostly, (I) let him make choices and decisions. But (he) cannot choose (in terms of) studying.” Some families described that it was necessary to “force” their child to follow the parents’ decisions in terms of studying and learning instead of considering their children’s choices and preferences. Wang stated “He doesn’t like to practice writing words. You have to force him.” Huang indicated that they imposed their decisions on their child, such as “watch TV, read books, not listen to music, go outside to look at the environment, or look at cars to increase knowledge.”

Finding 2: Self-Regulation

Perceptions of Self-Regulation

Huang, the grandfather of a child with cerebral palsy, shared his ideas about self-regulation: “(It is) possible for normal children. (It is) impossible for this kind of children
(children with disabilities).” Most families described the situations in which their child could not regulate himself. Wang, the father of a child with cerebral palsy, described how his child behaved when he felt angry, unhappy, or dissatisfied, such as “making noise”, “crying” or “throwing things.” Ding, the mother of a child with hearing impairments, reported that her son “beat” his peers during play. She further said “Sometimes, he cannot control (himself); he will scratch you, pull you, and beat you. He is like this and is rather violent.” Families thought these behaviors not “acceptable” and it would be bad for the child to “integrate” into society in the future. They were “trying to correct” those behaviors through different approaches including scolding.

**Practices Related to Self-Regulation**

When asked about how their children regulated themselves, families said it was “quite rare” for the children to regulate themselves. Zhang said “Generally speaking, (the child) needs adults to comfort him.” The strategies used by these families to regulate their children generally progressed from least to most severe actions. Ignoring is sometimes used as the first or the last strategy, as shown in Figure 2.

Families reported that they sometimes used the strategy of “ignoring” first before they tried other strategies. Tang, the mother of a child with hearing impairments, stated “Most of the time I use the cold treatment, just ignore her.” Some families first used a strategy of “comforting”. Tang said that when her daughter felt unhappy or cried or lost her temper, the grandparents “will definitely…take (the child) away immediately and then comfort.” She further stated that the grandparents would try to satisfy what the child wanted, such as “buying ice cream” to help the child calm down. Zhang, the mother of a child with autism, shared her strategies such as “hugging” or “patting.” Zhang stated “Sometimes (I) hugged
(him) for a while and told him ‘Ok, our baby doesn’t like it today’, and so on. And then, touch him, pat his head, touch his back. In this way, (he) calms down.”

Some families reported use of strategies as “talking”, “reasoning”, or “coaxing” to help their children regulate behaviors. Wang, the father of a child with cerebral palsy, reported that his son often cried loudly while getting rehabilitation training. He often first “talked to” and “reasoned” with the child. He stated “I often told him in a low voice that it was shame for such a big boy to cry in front of the teacher and the classmates. Other people would laugh at him.” He further stated “Sometimes, I coaxed him and promised to buy what he wanted, such as a cake.”

Some families also reported that they used other strategies including “beating”, “scaring”, and “threatening” if needed when the child could not be calmed by the former strategies. Tang, the mother of a child with hearing impairments, stated “Because in the PRC, it is believed that ‘A good man comes out of beating’.” Wang, the father of a child with cerebral palsy, stated “Most of the time, I reasoned (with) him. If it doesn’t work, (I) beat him. It was not a real beating, just pretending to scare him.” Huang, the grandfather of child with cerebral palsy, said:

Beaten…even beaten, (he) doesn’t listen. He felt scared of his mom most. (His mom said) “(if you) do not listen to us, we do not want (you) and we’ll abandon you”. He felt scared…It was a great mental pressure, a kind of stimulus.

Some families reported that the strategy of “ignoring” was used when the other strategies mentioned above did not work. Wang also stated “If (beating) doesn’t work, (I) let him cry there.”
Finding 3: Engagement

Perceptions of Engagement

When families talked about engagement, they referred to “playing with others”, “doing exercises” (rehabilitation training), “taking part in an activity”, or “focusing on studying.” Wang, the father of a child with cerebral palsy, was asked what his child engaged in, and he stated “eat, ask him to do exercises himself in daily life, take part in activities such as cutting papers, asking him to use scissors, asking him to cut things, (ask) him to stand straight.” Zhang, the mother of a child with autism, said that she “often took him (her child) shopping” or “playing with children.” Often, families focused their discussion on engagement in terms of study and rehabilitation training, such as “sitting down to practice writing words,” “reading books,” or “doing exercises.”

Practices Related to Engagement

Families emphasized their children’s engagement in activities that the adults regarded as good for the child, such as rehabilitation training, especially studying. Families adopted different strategies similar to the strategies that they used to engage in something other than what the child wanted by using reasoning, coaxing, or using reinforcement. Wang stated “(If)
you ask (the child) to write, (he) will lose (his) temper. You have to coax (the child).”

Strategies such as forcing, beating or threatening were used when other strategies did not work well. Some families used their children’s interests to help them engage in what adults thought were good practices such as studying math.

Some families tried to help their child engage with the environment. However, due to the bias against children with disabilities, families had to use different strategies to help their children engage with peers. For example, Zhang, the mother of a child with autism, found it hard to find peers to play with her son. She encouraged her relatives’ children to play with him. Ding, the mother of a child with hearing impairments, accompanied her child while playing with others, because her son often fought with peers, making his peers reject him.

Discussion

Research reveals that in the United States the foundational skills of self-determination in early childhood, like making choices and self-regulation, are of significance if one is to become a self-determined individual in adolescence and adulthood (Brotherson, Cook, Erwin, & Weigel, 2008; Doll et al., 1996; Erwin & Brown, 2003; Palmer, 2010). The present study employed a qualitative research design to explore how these foundational skills of self-determination were perceived and promoted by families of young children with disabilities in the PRC. Results showed that families in the PRC valued these foundational skills. They wanted their child with disabilities to be able to make choices and self-regulate. They focused on the child’s engagement in learning and studying. However, families of young children with disabilities in the PRC promoted the development of these foundational skills differently from their counterparts in the United States. In the U.S. families may address the development of these skills from the internal perspective of the children. They may focus on
motivating the child’s internal needs to develop these skills, with an eye towards individualism, independence, freedom, self-expression, and uniqueness. Families of children with disabilities in the PRC may approach the development of these skills from the external perspective of the children. They may focus on the importance of considering internalizing the external needs of the child, with an eye towards dependence and obedience, so that it is more likely for the child to adopt groups values and comply with authorities (Bond, 1991). These differences in ways to promote the development of the foundational skills of self-determination are related to cultural differences between the United States and the PRC.

As stated by Wu (1996), how families rear their children and how children learn to become acceptable members of a society may be the most persistent part of a culture. Chinese parenting is situated in and influenced by Chinese culture. China has a five-thousand year history during which it has developed its own ideas about the concept of a child, the meaning of childhood, and the role of family in the child’s development (Wu, 1996). In recent decades, especially after the PRC’s Reform and Opening Policy in 1978, Western culture has been influencing Chinese culture, including Chinese parenting. However, the actions of Chinese people are still driven by traditional Chinese philosophies like Confucianism, Taoism, and Buddhism. Confucianism continues as the dominant philosophy and has a very strong influence on the psychology and behavior of Chinese people (Zhang & Geoff, 2008). The essence of Confucianism is the system of hierarchical authority involving five basic relationships: those between ruler and subject, father and son, husband and wife, elder and younger brother, and friend and friend (Gao, 2010). All these relationships, except that between friend and friend, involve the authority of one party over the other.

Power and the right to rule belong to superiors over subordinates, that is, to older
people over younger people, to men over women. Each person has to give obedience and respect to "superiors"; the subject to his ruler, the wife to her husband, the son to his parents, and the younger brother to the elder brother. The "superior," however, owes loving responsibility to the "inferior".

(http://www.globaled.org/chinaproject/confucian/reading1.html)

According to Confucianism, each party in these relationships has a specific place in the society, has a fixed role, and should accordingly act upon that role in a proper way prescribed by rules of correct behavior (li) (Gao, 2010). The concept of li refers to “propriety, moral rules of proper behavior, and good manners” (Gao, 2010, p. 35). It is the role rather than the self that determines an individual’s behavior (Gao, 1998). Personal choices are based in prescribed roles (Gao, 1998). For instance, not everyone is entitled to make all choices or decisions in the Chinese culture. Persons only “voice their opinion when they are recognized”, a status often derived from a position of power (Gao, 1998). In Chinese families, parents have authority over the child, so making choices or decisions is reserved for the parents. Children are supposed to “take in what their parents say” instead of voicing their own opinions (Gao, 1998, p. 172). This may explain why Chinese families in this study provided limited opportunities to let their children make choices. Some families even refused to let their child make any choices because they thought their child did not obey (“tinghua”) them. Through such practices, parents may help children internalize how choices should be made. Choices are not to be made by everyone and there are certain social norms governing making choices. Children are supposed to make respectful choices according to their roles. They depend on their parents who have greater authority to make the final decisions about those choices.
Li is also “a form of control over unrestrained expression of human desires” (Gao, 2010, p. 35). It calls for governing one’s actions to subdue personal emotion and seek harmony with the social hierarchy and reactions (Gao, 2010). To some extent, Li may be regarded as another form of self-regulation. It requires that an individual regulate their own behaviors so that they can “act in accordance with external expectations or social norms” rather than “act in accordance with internal wishes or personal integrity, because he would thus be able to protect his social self and function as an integrated part of the social network” (Gao, 2010, p. 42). However, an individual does not become an acceptable human being by birth, unless educated through deliberate efforts (Wu, 1996). Under the influence of these views, Chinese parents believe that it is their moral responsibility to train children to adhere to socially-desirable and culturally-approved behavior (Chao, 1993). It is the child’s responsibility to become human (“zuoren”) (Wu, 1996). According to Confucianism, the process of learning to become human for a child must begin in the family in early childhood to “lay the foundation for the child to become a future adult of proper manner” (Wu, 1996, p. 154). Therefore, Chinese parents pay great attention to training their children to develop proper manners, such as respecting and obeying elders, starting from childhood, acting on parents’ commands and accepting social obligations, with a relative lack of emphasis on independence, assertiveness and creativity (Wu, 1996).

In practice, Chinese parents use guan (training) to help their children become human (zuoren) (Chao, 1993). Guan describes the responsibility endorsed by parents in rearing their child (Wang & Chang, 2010). Wang and Chang (2010) stated “Central to this responsibility is that parents ‘govern’ and ‘train’ children by providing close monitoring, firm directives, and high demands to help children develop into well-functioning members of society” (p. 154).
Chinese families keep “governing, monitoring, interfering and controlling” their children so that they will behave according to “li” (Chao, 1993, p. 14). Western researchers often use the term “authoritarian” instead of “guan” to describe Chinese parenting. However, it is “ethnocentric and misleading” to use the term “authoritarian” to describe Chinese parenting, because guan has a distinctive meaning that is not included in the authoritarian concept (Chao, 1993, p. 3). The term “authoritarian” often evoked associations such as “parental hostility”, “aggression”, “mistrust”, “militaristic”, “regimented”, or “strict” that are interpreted as being very negative in the United States (Chao, 1993, p. 14), while Guan means “a stricter or more rigorous” teaching or educating full of care or love from the parents to make their child become an acceptable member of society, and is regarded as very positive in Chinese culture (Chao, 1993, p. 14). According to Confucianism, it is one important way for parents as the "superior" to show that they fulfill their loving responsibility to the "inferior" (http://www.globaled.org/chinaproject/confucian/reading1.html). The Chinese parenting practice of guan helps explain why families of young children with disabilities in the PRC spoke more about their strategies to regulate their children. In contrast to individualistic cultures in which behavior is mainly regulated by individual likes, dislikes, or cost-benefit analysis, in collectivist culture behavior is regulated largely by social norms. Chinese families may want their children to internalize that they should “regulate” themselves according to li. Parents may help their children to develop such self-regulation skills by demonstrating through direct regulation of the child in the early years. They train the child on what behavior is acceptable or proper in the society and what kind of social norms to consider while regulating one’s behavior so that when the children grow up they can regulate themselves properly. Parent-regulation in early years may be a necessary step to
self-regulation in children. A self-regulated child may mean one who “listens to” (tinghua) the family or people outside of the family (Gao, 1998, p. 172). In short, Chinese parents put more emphasis on how to become self-regulated from the external instead of the internal perspective of the child.

Families in this study also used *guan* to help their children engage, especially in learning and studying. Chinese culture is known for its emphasis on academics (Hau & Salili, 1996). In Chinese culture, education is regarded as the most effective avenue to social and economic advancement, as well as for the improvement of the person (Wu, 1996). Education is believed to be important because it is a ladder in the social hierarchy (Hau & Salili, 1996). In Chinese culture, children are often taught that “all jobs are low in status, except to study, which is the highest (job) (wan ban jie xia, wei you du shu gao)” (Hau & Salili, 1996, p. 128). Families put great emphasis on the child’s education. In a collectivist culture children’s education attainment is not only directly related to the child, but to the whole family as well. Such views could be one of the reasons why Chinese parents did not let their children make choices or decisions related to academics. It might also explain why the practices of Chinese families put more emphasis on engagement in studying, so much so that children may be forced to study.

In short, *guan* and *li* are two key concepts in this study to help us understand how families of young children with disabilities perceived and promoted the development of foundational skills of self-determination. To make sure their children will become acceptable members of society, families of children with disabilities perform their loving responsibility to *guan* their children.
Conclusion

The foundational skills of self-determination, such as making choices, self-regulation, and engagement, are regarded as important to the development of self-determination in adolescence and adulthood in the United States. This study shows that these foundational skills are also valued in the People’s Republic of China. However, compared to the individualistic culture in the United States that stresses independence, freedom, individual choices, self-expression, and uniqueness, Chinese collectivist culture puts more emphasis on obedience and dependence. Therefore, families of young children with disabilities in the PRC promoted the development of foundational skills of self-determination differently from their counterparts in the U.S. Chinese families used the popular Chinese parenting practice of guan to help their children make choices, regulate themselves, and engage in a proper way that fits into the Chinese culture. A self-determined individual in Chinese culture is still one who can conduct “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). However, a self-determined individual in the PRC may mean a person who can make choices and regulate himself or herself to behave in accordance with Chinese social norms prescribed by li and anticipated expectations of others, rather than in accordance to internal wishes or personal attitudes. It is quite critical for practitioners to understand that the practices of families from Chinese culture in terms of the development of foundational skills of children are different from those of families in the United States. With the results from this study, practitioners may build partnerships more efficiently and effectively with families from Chinese culture, especially when they are working on the development of the foundational skills of self-determination.
The research reported here was supported by the Institute of Education Sciences, U.S. Department of Education, through Grant R324A090267 to the University of Kansas. It was approved by Institutional Review Board (IRB) at Iowa State University. The opinions expressed are those of the author and do not represent views of the Institute of Education Sciences or the U.S. Department of Education.
References


CHAPTER 4. GENERAL CONCLUSION

General Discussion

The present research is designed to understand how families of young children with disabilities in the People’s Republic of China (PRC) perceive and promote the foundations for self-determination. The family plays a critical role in the development of foundations for self-determination in young children with disabilities (Brown & Cohen, 1996; Brotherson, Cook, Erwin, & Weigel, 2008; Erwin & Brown, 2003; Palmer, 2010; Wehmeyer & Palmer, 2000). In order to understand how Chinese families who have young children with disabilities perceive and promote the development of foundations for self-determination, I first conducted a phenomenological study in the PRC. Specifically, I studied how families in the PRC experienced services and support in the first 6 years of their children’s lives, referred to in this study as early childhood intervention. In this dissertation, two research articles were presented.

The first article reported the results of a study investigating the experiences with early childhood intervention by families of young children with disabilities. Five major themes were discussed: 1) disability diagnosis, 2) the child’s current early-childhood intervention (ECI) experiences; 3) the family’s expectations; 4) the family’s evaluations; and 5) the financial impact of the disability on families. This study has shown that families of young children with disabilities are facing many challenges, such as lack of accurate knowledge about human development, characteristics of disabilities, and how a disability can impact a child’s development, in obtaining comprehensive early intervention services and support. There are also problems that must be addressed regarding the early identification system,
employment of qualified professionals, governmental financial support, and implementation of legislation. These findings suggest that families of children with disabilities need more support, professional help, and information about how to raise their children (McCabe, 2007; Wang, 2008). However, this study extended the results of previous studies by showing that 1) there is a dire need for the early identification of diverse disabilities in the PRC, 2) governmental investment in early childhood intervention was quite limited, and 3) laws related to the rights of people with disabilities were not effectively implemented in the PRC. This paper calls for the establishment of an early identification system, an increase in services and supports for families of children with disabilities, enhanced governmental investment during this critical period of development, and enactment of policy and legislation to ensure that this comprehensive system of early intervention is developed, implemented, and evaluated.

The second article reports the results of a study investigating how families perceived and promoted foundations for self-determination in their young children with disabilities in the PRC. Findings were discussed in terms of three key components of self-determination: making choices, self-regulation, and engagement. Results indicated that Chinese families highly valued these key components. However, how these Chinese families valued and promoted the development of these skills differed from approaches reported by families in the United States. These data support the findings of previous studies, suggesting the universality of certain aspects of self-determination such as making choices, although how these components are expressed differs from the Anglo’s perspective (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Zhang, Landmark, Grenwelge, & Montoya, 2010). The results of this research indicate that families of young children with disabilities believe it is
important to develop the particular skills of making choices, self-regulation, and engagement. These family members expected their children with disabilities to be able to make respectful choices that were in accordance with the collectivist culture in the PRC, to be able to regulate themselves according to the social norms of Chinese culture, and to be able to engage themselves in educational activities that are highly valued in Chinese culture. Families of young children with disabilities reported the use of a common parenting practice “Guan”, which means “a stricter or more rigorous” teaching or educating practice full of care and love, and is regarded as very positive within Chinese culture (Chao, 1990, p. 14). Furthermore, this study contributes to a better understanding of the development of self-determination in young children with disabilities in a foreign culture rather than the mainstream or majority culture in the United States. These results provide key insights for practitioners in the United States who may work with families who have recently moved from the PRC, and/or who are immigrants or refugees from the PRC. With these understandings, practitioners may find they can work more effectively and in partnership on foundational skills of self-determination with families who are culturally Chinese.

**Limitations and Future Directions**

As in any study, the researcher needs to identify what, if any, limitations have occurred and assist the reader when interpreting the results. First, all the families in this study were recruited from large cities, small towns, and rural areas that were geographically located near a larger metropolis in southwest China. A majority of the families in this study reported they have limited financial resources. Therefore, the reader is cautioned to interpret these results given these factors, and the results here may not be representative of all families of young children with disabilities from across the PRC. However, the purpose of qualitative
research is not to make statistical generalizations; rather, its purpose is to promote in-depth understanding of a particular topic (Merriam, 2002). Future directions for this research would include a more expansive design that would address diversity of geographic locations, economic backgrounds, and possibly including observational data and a greater number of interviews. For example, a future study could include families of children with disabilities who reside in very remote rural areas. Next, a future study could include wealthier families; this could help in understanding whether wealthier families have the same experiences and/or have better access to services and supports compared to poorer families. Finally, the data in this research were collected through one interview per family. Given the qualitative research process, prolonged engagement with families across longer time periods would promote a better understanding of the complex issues regarding each family’s experience in early childhood intervention and the development of foundations for self-determination in their young children with disabilities. Prolonged engagement would give an opportunity to develop greater rapport with families and to gather more in-depth information regarding services and supports that families should receive.

Despite the limitations of this study, this research is exploratory and has much significance. It is an initial understanding of the development of the foundations for self-determination in a culture other than mainstream American culture and contributes to a better understanding of the development of foundational skills of self-determination in diverse cultures. It also has implications for practitioners in the United States who are working with families from the Chinese culture to help their children with disabilities develop foundational skills.
References


APPENDIX A. INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

Date: 6/8/2010
To: Dr. Mary Jane Brotherson
51A LeBaron

CC: Susan Maude
4380 Palmer, Suite 2360

From: Office for Responsible Research

Title: Foundations for Self-Determination: Building Skills in Young Children with Disabilities

IRB Num: 09-400

Approval Date: 6/8/2010
Continuing Review Date: 8/23/2010
Submission Type: Modification
Review Type: Full Committee

The project referenced above has received approval from the Institutional Review Board (IRB) at Iowa State University. Please refer to the IRB ID number shown above in all correspondence regarding this study.

Your study has been approved according to the dates shown above. To ensure compliance with federal regulations (45 CFR 46 & 21 CFR 56), please be sure to:

- Use only the approved study materials in your research, including the recruitment materials and informed consent documents that have the IRB approval stamp.

- Obtain IRB approval prior to implementing any changes to the study by submitting the "Continuing Review and/or Modification" form.

- Immediately inform the IRB of (1) all serious and/or unexpected adverse experiences involving risks to subjects or others; and (2) any other unanticipated problems involving risks to subjects or others.

- Stop all research activity if IRB approval lapses, unless continuation is necessary to prevent harm to research participants. Research activity can resume once IRB approval is reestablished.

- Complete a new continuing review form at least three to four weeks prior to the date for continuing review as noted above to provide sufficient time for the IRB to review and approve continuation of the study. We will send a courtesy reminder as this date approaches.

Research investigators are expected to comply with the principles of the Belmont Report, and state and federal regulations regarding the involvement of humans in research. These documents are located on the Office for Responsible Research website http://www.compliance.iastate.edu/irb/forms/ or available by calling (515) 294-4566.

Upon completion of the project, please submit a Project Closure Form to the Office for Responsible Research, 1138 Pearson Hall, to officially close the project.
ISU HUMAN SUBJECTS CONTINUING REVIEW AND/OR MODIFICATION FORM

TYPE OF SUBMISSION: □ Continuing Review  ☒ Modification  □ Continuing Review and Modification

Principal Investigator: Mary Jane Brotherson  Phone: 291-3677
Degree: Ph.D.  Correspondence Address: 51A LeBaron
Department: Human Development and Family Studies  E-mail Address: mjbrothe@iastate.edu
Project Title: Foundations for Self-Determination: Building Skills in Young Children with Disabilities
IRB ID: 09-400  Date of Last Continuing Review: Aug. 23rd, 2010

Alternate Contact: Susan Maude  Phone: 294-2370
Correspondence Address: 2360 Palmer  Email Address: smaude@iastate.edu

IF STUDENT PROJECT
Name of Major Professor: Susan Maude  Phone: 294-2370  E-mail Address: smaude@iastate.edu
Department: Human Development and Family Studies  Campus Address: 2360 Palmer

FUNDING INFORMATION:

☒ External Grant/Contract  □ Internal Support (no specific funding source) or Internal Grant (indicate name below)
Name of Funding Source: OSPA Record ID on Gold Sheet: 96404

☐ Part of Training, Center, Program Project Grant — Director: Overall IRB ID No: 09-400
☒ Student Project — No funding or funding provided by student

CONFLICT OF INTEREST

The proposed project or relationship with the sponsor requires the disclosure of significant financial interests that present an actual or potential conflict of interest for investigators involved with this project. By signing this form, all investigators certify that they have read and understand ISU’s Conflict of Interest policy as addressed by the ISU Faculty Handbook (http://www.provost.iastate.edu/faculty) and made all disclosures required by it.

Do you or any member of your research team have a conflict of interest? □ Yes  ☒ No
If yes, has the appropriate disclosure form been completed? □ Yes  □ No

ASSURANCE

I certify that the information provided in this application is complete and accurate and consistent with proposal(s) submitted to external funding agencies. I agree to provide proper surveillance of this project to ensure that the rights and welfare of the human subjects are protected. I will report any adverse reactions to the IRB for review. I agree that modifications to the originally approved project will not take place without prior review and approval by the Institutional Review Board, and that all activities will be performed in accordance with state and federal regulations and the Iowa State University Federal Wide Assurance.

Signature of Principal Investigator  Date  5/18/10

Student Projects: Faculty signature indicates that this application has been reviewed and is recommended for IRB review.

Signature of Supervising Faculty  Date  5/18/10

IRB Approval Signature  Date  6/8/10

For IRB Use Only

EXPEDITED per 45 CFR 46.110(b) ☒  Category __________  Letter __________
STUDY REMAINS EXEMPT per 45 CFR 46.101(b) __________________________
WAIVER of SIGNED CONSENT per 45 CFR 46.117(c) ☒ no ☐
WAIVER of ELEMENTS of Consent per 45 CFR 46.116 ☐ no ☒
VULNERABLE POPULATION per 45 CFR 46.934 ☒ FULL
DIRECTIONS: Section I: Key Personnel must be completed for all applications. Please complete Section II if this is an application for Continuing Review. If this is an application for continuing review and you will be modifying your project, please complete all sections of the form. If this application is only to request approval for a modification or change to your study, please complete Section I: Key Personnel and Section III: Proposed Modifications or Changes. Please answer each question. If the question does not pertain to this study, please type not applicable (N/A).

SECTION I: KEY PERSONNEL

List all current members of the project personnel, including any additions and excluding any deletions as described in Section III. This information is intended to inform the committee of the training and background of the investigators and key personnel.

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<tr>
<th>NAME &amp; DEGREE(S)</th>
<th>POSITION AT ISU &amp; ROLE ON PROJECT</th>
<th>TRAINING &amp; DATE OF TRAINING</th>
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<td>Mary Jane Brotherson</td>
<td>Principal Investigator</td>
<td>10-20-02 Has 25 years experience conducting research</td>
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<tr>
<td>Susan Maude</td>
<td>Co-Principal Investigator</td>
<td>02-26-07 Has 20 years experience conducting research</td>
</tr>
<tr>
<td>Nancy Peck</td>
<td>Research Assistant</td>
<td>8-31-08 Some exp. –PhD student</td>
</tr>
<tr>
<td>Yuzhu Zheng</td>
<td>Research Assistant</td>
<td>9-24-08 Limited exp. PhD student</td>
</tr>
<tr>
<td>Cindy Weigel</td>
<td>Research Assistant</td>
<td>11-16-04 Some exp. PhD student</td>
</tr>
<tr>
<td>Lindsey Brown</td>
<td>Project Coordinator</td>
<td>08-12-09</td>
</tr>
</tbody>
</table>

SECTION II: CONTINUING REVIEW

Part A: Enrollment Status

1. Yes ☐ No ☐ Is the research permanently closed to the enrollment of new participants?
2. Yes ☐ No ☐ Have all participants completed all research-related interventions?
3. Yes ☐ No ☐ Does research remain active only for long-term follow-up of participants?
4. Yes ☐ No ☐ Are the remaining research activities limited to data analysis? OR
5. Yes ☐ No ☐ Participant enrollment has not begun and no additional risks have been identified.

For definitions and guidance on how to determine enrollment, please see the document entitled Enrollment and Accrual of Study Participants on the IRB website.

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<td>Number of Screen Failures (participants who were screened and deemed ineligible) to date:</td>
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<td>Check below if this project involves:</td>
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<td>☐ Existing Data/Records</td>
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<td>☐ Pregnant Women/Fetuses</td>
<td>☐ Secondary Analysis</td>
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<td>☐ Cognitively Impaired</td>
<td>☐ Pathology/Diagnostic Specimens</td>
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<td>Asian or Pacific Islander:</td>
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<td>Black (Not of Hispanic Origin):</td>
<td>Hispanic:</td>
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1. □ Yes □ No  Have any participants withdrawn or have you asked any participants to withdraw from the study? List number for each and reason for withdrawal:

Part B: Protocol Summary – Please use the amount of space needed to adequately address the questions.

1. Please provide a concise summary of the purpose and main procedures of the study.

2. Please provide a summary of how the study is progressing (e.g., progress to date in terms of the overall study plan, success or problems encountered, reasons enrollment has not begun, etc.)

3. Is there any new information (positive or negative) from this study (e.g., interim analysis) or elsewhere (e.g., current literature) that might affect someone’s willingness to enroll or continue in the study? It is especially important for the investigator to notify the IRB of literature or information that’s relevant to the risks to participants in the study.

4. Please provide a summary of amendments or modifications since last IRB review.

Part C: Adverse Events and Unforeseen Problems

1. □ Yes □ No  Have there been any adverse events or unanticipated problems involving risks to participants or other people?

   If yes, please describe the event(s).

   If yes, was it reported to the IRB? Date reported

   If report was not submitted, please explain why.

2. □ Yes □ No  Have there been any participant complaints?

   If yes, please describe.

Attach any reports submitted to NIH or a Data and Safety Monitoring Board. □ Attached □ N/A
**Part D: Informed Consent**

1. [ ] Yes  [ ] No  If a signed Informed Consent Form was required, was Informed Consent obtained from all participants?

   If no, please explain.

2. [ ] Yes  [ ] No  Are all signed Informed Consent Forms on file with the PI?

   If no, please explain.

3.  
   - [ ] Attached
   - [ ] N/A

   Submit a copy of the currently approved Informed Consent Document or informational letter and an original unstamped copy so a current IRB approval stamp can be added. If changes have been made, please submit the original, a copy with the changes highlighted, and a copy to be stamped with IRB approval.

   - [ ] Attached
   - [ ] N/A

   Submit an unstamped copy of all survey instruments, interview questions, recruitment materials, instructions, and all other material participants will see or hear during their participation so that a current IRB approval stamp can be added. Any changes to materials should be described in Section III. Please also submit the original, a copy with the changes highlighted, and a copy to be stamped with IRB approval.
SECTION III: PROPOSED MODIFICATIONS OR CHANGES

If this application is to request approval for modification or changes to your project, please complete Section I: Key Personnel and Section III.

The submission of a modification form is required whenever any changes are made to an approved project. This includes, but is not limited to, a title change, changes in investigators, resubmission of a grant proposal involving changes to the original proposal, changes in the funding source, changes to data collection materials and informed consent documents, advertisements, confidentiality measures, inclusion/exclusion criteria, reports from a data safety and monitoring board, addition of a test instrument, etc. NOTE: All changes must be submitted and approved by the IRB prior to their implementation unless the change is necessary to protect the safety of participants.

1. ☐ Yes ☑ No Does your project now require approval from another institution? If yes, please attach letters of approval.

2. The following modification(s) are being made (check all that apply):

☐ Change in protocol/procedures.
☐ Change in type or total number of participants. New anticipated total: 812
☐ Change in informed consent document.
☐ Change in co-investigator(s). New co-PI name:

Signature of new Co-PI: ____________________________

☐ Change in funding source/sponsor. If federally funded, please attach copy of grant proposal.

☐ Other (e.g., change in project title, adding new materials, adding advertisement, etc.)

☐ Personnel/staff changes since the last IRB approval was granted? Please complete the following table as appropriate. NOTE: If the change involves a new Principal Investigator, a new Human Subjects Review form must be submitted.

<table>
<thead>
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<th>Add</th>
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<td>Aisha</td>
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</table>

3. Describe the modification(s) indicated above in sufficient detail for evaluation independent of any other documents. Be sure to describe all changes in detail and provide a rationale for the changes. When submitting revised documents please submit one clean copy of the new document and a copy with the changes highlighted.

This research project is focused on increasing our understanding about self-determination in young children. For this particular phase of the study, we want to explore self-determination with young children from diverse cultures. This information will help us better understand self-determination and the strategies one uses to develop it. There are little to no studies in the literature addressing self-determination within young children with disabilities conducted between the mainstream American culture and the mainland Chinese culture. So in order to get insights into how self-determination is perceived in the mainland China, we will be replicating the same interview questions and procedures with families and practitioners in the mainland China as we are using in Iowa.

In the original IRB proposal, approval, and first modification documents, we received IRB approval to interview practitioners (teacher) and families (parents) of young children with disabilities about self-determination in Iowa. The original informed consent forms and interview protocol that received approval from the ISU IRB 09-400 have been translated into Chinese and the same process described in our study in Iowa will be used with participants from China. Yuzhu Zheng, a doctoral student from the mainland China and a research assistant on this study, will conduct the interviews and collect the data from a sample of participants in China. All original and previously IRB approved forms are attached with this modification form as well as the translated versions.

The following paragraphs provide detailed descriptions of changes to any forms, sample participants, and data collection procedures for this new phase in China to be conducted in July/August 2010.
The following is a detailed description of changes made to any of the forms:

1. All original IRB stamped documents were translated into Chinese (all originals are attached with translated documents).
2. In the demographic data interview forms for families and practitioners (see Child/Family and Practitioner Information Form), the question “Which of the following best describes the size of the community in which you live? (circle one)” was changed into an open-ended question “please describe the size of the place where you live (such as population)? This change is needed due to the contextual variation in ways that cities are measured in China compared to the U.S.
3. In the practitioner demographic data protocol (see Practitioner Information Form), the question “What was your preparation for teaching? (Check all that apply)” was replaced by an open-ended question as follows: “What is your education level?” This is also due to the contextual variations in the education system and education degrees offered in China compared to the U.S.
4. In the practitioner demographic data protocol (Practitioner Information Form), question “how many student IEPs do you supervise each year?” was deleted because IEPs do not exist in mainland China.
5. In the practitioner demographic data protocol (Practitioner Information Form), questions “how many students’ IEP do you participate in each year? And what is the total number of children in your class?” were combined into one question “how many students do you have in your class?”. This change is needed because the education system in China for children with disabilities is in segregated special education schools and not in inclusive settings. Therefore, all the students in the class have special needs.
6. In the letters and flyers to families and practitioners, the contact person’s name (Lindsey Brown) was replaced with Yuzhu Zheng. She will be the main contact person for the participants from China.
7. Yuzhu Zheng’s name has been provided on all consent forms as the investigator since she will be conducting the interviews with families and practitioners from China.

The following is a detailed description of changes in the participants and procedures:

1. Parents and teachers will be contacted through personal connections or through flyers shared with parent support groups. Parents will also be asked permission to contact their child’s teacher for a possible interview. Recruitment flyers for parents and teachers are attached as well as recruitment letters for parents and teachers. We will interview approximately 6 parents and 6 teachers (practitioners). The consent forms are attached for both parents and teachers.
2. The translated interview protocols are attached for interviews for both parents and teachers (practitioners). The protocols have broad grand tour questions with possible follow-up probe questions. The interviews will have a conversational flow. Not all probe questions would be asked of each family or teacher – it will depend on their interests and experiences. The interview will last approximately 50-60 minutes and may include a follow-up interview for additional information.
3. The sample in China will include parents and teachers of children with disabilities ages 3 to 8. In Iowa we are only accessing children with disabilities ages 3 to 5. The modification in the selection of ages is due to the early childhood period in China extends from 3 to 8 as well as there are may be fewer children served in the 3 to 5 age group.
4. All forms to be used have been translated by Yuzhu Zheng into standard Chinese. These translated documents have been peer reviewed and a signed documentation of this review is included in this new modification request. Besides, the title of “Professor” was added to the other two investigators and “PhD student” was added to Yuzhu Zheng in the consent form. This is because most Chinese are more familiar with these terms, so they can understand the backgrounds of the investigators better.
Peer Review of Translation of

BUILDING FOUNDATIONS FOR SELF-DETERMINATION IN YOUNG CHILDREN WITH DISABILITIES:
FAMILY-PROFESSIONAL PARTNERSHIPS

1. Brief demographic information of the peer who reviewed the Chinese translation.
Yan Zeng, female, has been working as an English teacher in Chongqing University of Technology since 2003. I have been learning English for 18 years. I am always interested in English translation. I had undertaken the written translation work for some companies as well as for our university.

2. Brief description of the peer reviewing process.
Zheng Yuzhu sent me all the translation documents that she needed by email and I just chose some which I thought critical for her research. I read through the translation and checked them by referring to the original English. Then I sent all the revised documents to her by mail. As for some confusing points, I discussed with her online.

3. Comments on the Chinese translation from the peer.
The Chinese translation from the peer is very concise, accurate and to the point. Since the translator is a Chinese and has been learning English for many years, the translation is easy to be understood by Chinese people.

Peer’s Name (printed) Yan Zeng

Zeng Yan ____________________________ May 14, 2010 ____________________________
(Peer’s Signature) (Date)
APPENDIX B. RECRUITMENT LETTER

Date

Hello Family Member:

We are contacting you because either you expressed an interest in our project entitled, “Building Foundations for Self-Determination in Young Children with Disabilities: Family-Professional Partnerships” or because your name was given to us by another parent who thought you may be interested in this project. In order to participate in this study you must have a child 3-8 years old with a developmental disability, and be willing to participate in an interview and follow-up feedback. We could also be interested in contacting your child’s teacher to participate in an individual interview, but this is not necessary for your participation.

All information will be kept confidential. Participation in this study is voluntary and participants may withdraw at any time with no consequences. Each family member will be given a gift certificate as compensation for their time.

If you are interested in participating in a study to help us learn more about the families’ perspective, you may contact:

Yuzhu Zheng, PhD student in Iowa State University, U.S, at 023-68667883 or QQ: 1462280816 or 1462280816@qq.com.

Please feel free to share this information with other family members whom you believe may be interested in participating in this study. Thank you in advance for your participation and assistance in locating other families who might be interested in helping us.

Sincerely,

Mary Jane Brotherson, Ph.D.
Department of Human Development and Family Studies
51a Lebaron Building
Iowa State University, Ames, Iowa 50011
(515)-294-3677

Susan P. Maude, Ph.D.
Department of Human Development and Family Studies
2360 Palmer Building
Iowa State University
Ames, Iowa 50011
(515)294-2370

Yuzhu Zheng
Department of Human Development and Family Studies
51a Lebaron Building
Iowa State University,
Ames, Iowa 50011
(515)-203-1781 or 023-68667883(China) or QQ: 1462280816
Or 1462280816@qq.com
家长您好：

我们与您联系，是因为您表达了对我们题为“为促进障碍儿童的自决定能力发展而建立基础：家庭与专业人员之间的合作关系”的研究有兴趣，或因为另外一个家长认为您也对我们的研究感兴趣而提供了我们您的名字。为了这项研究，您必须有一个孩子3-8岁残疾儿童，并愿意参加采访以及后续的反馈。我们也有兴趣与您孩子的老师联系进行单独采访，但这不是您参加我们研究的必要的条件。

所有信息都会保密。您是自愿参加本研究的，参与者可随时退出，不会有任何后果。每个家长将获得现金或购物卡（25美元，但根据当时的汇率以人民币方式支付）以赔偿所付出的时间。

如果你对有兴趣参与这项研究，您可以联系：

1. 郑宇珠，美国爱荷华州立大学在读博士，电话是023-68667883，或QQ: 1462280816，或者发电子邮件：1462280816@qq.com。

请随时把关于我们研究的信息告诉给你认为也有兴趣的其他家长。预先感谢您的参与以及帮助我们找到其他的参与者！衷心感谢！

玛丽.简.布罗瑟森(博士) 人类发展与家庭研究系
人类发展与家庭研究系 51a 勒巴楼 柏尔默楼
爱荷华州立大学 爱荷华州立大学
埃姆斯，爱荷华 50011 埃姆斯，爱荷华 50011
1-(515)-294-3677 1-(515)-294-2370

郑宇珠（在读博士）
人类发展与家庭研究系
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1-(515)203-1781
电话 023-68667883(中国)
QQ: 1462280816
电子邮件：1462280816@qq.com
APPENDIX C. INFORMED CONSENT DOCUMENT

INFORMED CONSENT DOCUMENT

Parent/Family Interview

Title of Study: Building Foundations for Self-Determination in Young Children with Disabilities: Family-Professional Partnerships

Investigators: Mary Jane Brotherson, PhD, Professor.
Susan Maude, PhD, Assistant Professor
Yuzhu Zheng, PD student

This is a research study. Please take your time in deciding if you would like to participate. Please feel free to ask questions at any time.

INTRODUCTION
The purpose of this study is to learn more about how young children with special needs learn to: make choices, control their behavior and emotions, become involved with people and objects around them, and how parents and professionals work together. You are being invited to participate in this study because you are a parent of a preschool aged child with a special need.

DESCRIPTION OF PROCEDURES
If you agree to participate in this study, we will interview you about your experiences at home with your child and your experiences working with your child’s teachers or other professionals who work with your child in the preschool setting. We expect our interview with you to last about 60-90 minutes. We will conduct the interview at any time and place that you find convenient. The interviews will be audio taped with a tape recorder and the audio tapes will be erased at the end of the study. You may be contacted for a follow-up interview to clarify information.

RISKS
We don’t believe this study will involve any risks. If you are uncomfortable responding to a question, you may choose not to answer. If you would like to stop participating at any time, you have the right to do that.

BENEFITS
If you decide to participate in this study there may be no direct benefit to you. It is hoped that the information gained in this study will benefit society by helping us to learn how to better serve families with young children with disabilities and the professionals with whom they collaborate.
COSTS AND COMPENSATION
You will not have any costs from participating in this study. You will be compensated for participating in this study. To compensate you for your time, you will receive a $25 gift certificate for your participation. We will ask for your social security number to comply with federal and state tax and accounting regulations.

PARTICIPANT RIGHTS
Your participation in this study is completely voluntary and you may refuse to participate or leave the study at any time. If you decide to not participate in the study or leave the study early, it will not result in any penalty or loss of benefits to which you are otherwise entitled.

CONFIDENTIALITY
Records identifying participants will be kept confidential to the extent permitted by applicable laws and regulations and will not be made publicly available. However, the Institutional Review Board (a committee that reviews and approves human subject research studies) may inspect and/or copy your records for quality assurance and data analysis. These records may contain private information.

To ensure confidentiality to the extent permitted by the law, the following measures will be taken. Everything we learn from you will be strictly confidential, and only members of our research team will have access to the individual information for your program. When we report the results of this study, you will never be named or identified in any other way. Names of participants will not be identified on the audio-tapes or transcripts, and both will be kept in a secure location. Tapes will be erased when the analysis is complete.

Information collected for this study is part of a collaborative study with the University of Kansas and Montclair State University; therefore data collected will be shared with researchers from those universities. Like Iowa State University, the University of Kansas and Montclair State University, are required to maintain the confidentiality of research data and to ensure that research is done in an ethical and legal way, and that participants are treated fairly. By signing this consent form, you give us permission to use and share this information, within the limits described above.

QUESTIONS OR PROBLEMS
You are encouraged to ask questions at any time during this study.

- For further information about the study contact Mary Jane Brotherson, PhD, Professor, Department of Human Development and Family Studies, 515-294-3677 or Yuzhu Zheng, PhD student, Department of Human Development and Family Studies, 86-023-68667883 or 1462280816@qq.com.
- If you have any questions about the rights of research subjects or research-related injury, please contact the IRB Administrator, (515) 294-4566, IRB@iastate.edu, or Director, Office for Responsible Research, (515) 294-3115, 1138 Pearson Hall, Ames, IA 50011.
SUBJECT SIGNATURE

Your signature indicates that you voluntarily agree to participate in this study, that the study has been explained to you, that you have been given the time to read the document and that your questions have been satisfactorily answered. You will receive a copy of the signed and dated written informed consent prior to your participation in the study.

Subject’s Name (printed) ____________________________________________

(Subject’s Signature) ____________________________ (Date) ________________

INVESTIGATOR STATEMENT

I certify that the participant has been given adequate time to read and learn about the study and all of their questions have been answered. It is my opinion that the participant understands the purpose, risks, benefits and the procedures that will be followed in this study and has voluntarily agreed to participate.

(Signature of Person Obtaining Informed Consent) ____________________________ (Date) ________________
知情同意书

家长和家庭采访

研究题目：为促进有障碍儿童的自决定能力发展而建立基础：家庭与工作人员之间的合作关系

调查人员： 玛丽·简·布罗瑟森(博士,教授)(Mary Jane Brotherson)
             苏珊·莫德(博士，教授)(Susan Maude)
             宇殊·郑 (在读博士)(Yuzhu, Zheng)

这是一项研究，请你花点时间决定你是否要参加这项研究。请随时向我们提出任何问题。

研究介绍
这项研究的目的是要了解有特殊需要的儿童如何学会：做出选择，控制自己的行为和情绪，参与到活动中，以及家长和专业人士如何为儿童发展一起工作。你被邀请参加这项研究，因为你是一个有特殊需要的学前儿童的家长。

研究程序
如果你同意参与这项研究，我们将访问你和孩子在家生活的经历及你与你孩子就读的学校的老师和其他专业人士的合作经历。我们期望与你面谈约60-90分钟。我们将在你觉得方便的任何时间与地点进行面谈。访谈将用录音机录音，录音将在研究结束时被删除。我们可能联系你进行后续采访以阐明一些信息。

风险
我们认为这项研究将不涉及到任何风险。如果您不愿意回答某个问题，你可以选择不回答。你有权在任何时候停止被采访，如果你想那样做的话。

益处
这一研究有可能对你没有直接的好处。我们希望从这项研究中获得的信息将有利于帮助我们了解如何更好地促进残疾儿童的发展，更好的服务于家庭，促进社会和专业人士与家庭的合作。

费用和补偿
你不会为参与这项研究支付任何费用。你的参与将得到补偿。为了感谢你接受采访而付出的时间，你将得到25美元（根据当时的汇率折算成人民币）现金或礼券。

参与者的权利
你是否参与这项研究是完全自愿的，你可以拒绝参加或在任何时候终止这个研究。如果你决定不参加或提前结束，也不会导致任何罚款或利益的损失，因为你有权这样做。

保密
有关参与者的任何记录将根据在有关法律，法规允许的范围内加以保密，不会被公开。但是研究机构审查委员会（它是一个审查和批准对人进行研究的委员会）可查阅和或复制你的信息以保证研究和数据分析的真实性。这些记录可能包含私人信息。

为确保在法律允许的范围内进行保密，将采取以下措施。我们从你处获得的所有信息将严格保密，只有我们研究小组成员将有机会获得你的个人信息。当我们在报告这项研究的结果时，我们永远不会提到你的名字，也不会让你以其他任何方式辨认出来。录音带或谈话全文不会有参与者的姓名，并且这两样东西都将被保存在一个安全的地方。当分析完成后，录音将被删除。

这项研究收集到的信息是与堪萨斯大学和蒙特克莱尔州立大学合作研究项目中的一部分，因此收集的数据将与这些大学的研究人员共享。像爱荷华州立大学，堪萨斯大学和蒙特克莱尔州立大学都须对研究数据保密，并确保研究工作是在道德和合法的方式下进行，并且公平对待参与者。签署此同意书就意味着你同意我们在上述限制下使用和共享这些信息。

问题
在本研究中，我们鼓励您在任何时间提出任何问题

- 如果您想了解更多有关这项研究的信息，请联系玛丽.简.布罗瑟森，博士，教授，人类发展与家庭研究系，1-515-294-3677，或者与郑宇珠联系，在读博士，人类发展与家庭研究系，023-68667883，或者通过电子邮件1462280816@qq.com。

- 如果您对研究课题或研究有关的伤害和权利有任何疑问，请联系金妮.奥斯汀.陈奕迅，IRB 行政官员 1-(515) 294-4566，austingr@iastate.edu，或黛安.阿门，IRB 办公室主任 1-(515) 294-3115，dament@iastate.edu。
参与者签名

您的签名表示您自愿同意参与这项研究，我们已经向你解释这项研究，并且您已经获得了时间去阅读这份同意书，而您有关这项研究的问题已得到满意的回答。在您参与研究之前，您将得到一份签署后并注明日期的书面知情同意书。

参与者姓名（打印）

（参与者签名） （日期）

调查者声明

我证明参与者已获得足够的时间来阅读和了解这项研究并且所有问题都得到了回答。我认为，参与者已理解了研究目的，风险，利益和参与这项研究将要遵循的程序，并且参与者是自愿同意参加。

（获得知情同意书者签名） （日期）
APPENDIX D. FAMILY DEMOGRAPHIC DATA PROTOCOL

BUILDING FOUNDATIONS FOR SELF-DETERMINATION IN YOUNG CHILDREN WITH DISABILITIES: FAMILY-PROFESSIONAL PARTNERSHIPS

Family Demographic Data Protocol

This demographic information can be collected from the family after the qualitative interview has been completed. Some of these questions may have already been discussed in the interview.

Introduction (Interviewer script) I want to thank you again for participating in this study. For the purposes of our records, would you mind answering the following questions? This will be helpful to us in better understanding and organizing the information across participants. We will be discussing 4 areas: you as the study participant, your family, your child and home-school relationship.

Study Participant’s Name: ________________________________

A. Understanding the Study Participant

1. Gender (circle one)       Female       Male

2. What is your age group? (circle one)
   18 or younger
   18 - 24
   24 - 29
   30 - 34
   35 - 39
   40 - 44
   45 - 49
   50 - 54
   55 - 59
   60 - 64
   65 or older?

3. Please describe the size of the place where you live (such as population)?

4. What is your ethnic background?

5. What is the last educational degree you received?

6. Do you work outside home? If so, what do you do?
Understanding the family

1. How many children do you have and what are their ages?
2. Who are the adults (and their roles) who live in your household?
3. What languages are spoken in your home?

Understanding the Child with Disabilities

1. What is the age and disabilities of your child with special needs?
2. Where and with whom does your child spend most of her/his time?
3. How is your child doing at the preschool?
4. Why did you choose this preschool?

Thank you for your time in sharing this information.
为促进有障碍儿童的自决定能力发展而建立基础：家庭与专业人员之间的合作关系

家庭的基本信息资料

这个信息资料在采访了家庭以后获得，有些可能已经在采访中涉及到。

导言（采访者脚本）我要再次感谢您参与本研究。为了方便我们的记录，你介意回答以下问题吗？这将有助于我们更好地理解和组织参与者的信息。我们讨论4个方面的一些问题，作为这个研究的参与者，有关您的情况；您家庭的情况，您小孩的情况和学校与家庭之间的关系。

参与研究者的姓名：

A. 了解研究的参与者

1. 性别（选择一个）
   - 女
   - 男

2. 你属于哪个年龄段？（选择一个）
   - 18或18以下
   - 18-24
   - 24-29
   - 30-34
   - 35-39
   - 40-44
   - 45-49
   - 50-54
   - 55-59
   - 60-64
   - 65或65以上

3. 请你能描述一下你现在的生活所在地（如人口）

4. 你属于什么民族？
5. 你所得到的最后学历程度是什么？

6. 你有工作吗？你的工作是什么？

B. 了解参与家庭

1. 您有几个孩子，他们的年龄？

2. 您家里主要有哪些大人，他们主要做什么事情？

3. 在家里，你们使用什么语言？

C. 了解您有障碍的孩子

1. 您小孩的年龄多大，他、她有什么方面的障碍？

2. 您的这个孩子主要和哪些人呆在一起？

3. 您的这个小孩的学习情况如何？

4. 您为什么选择这所学校？
APPENDIX E. INTERVIEW PROTOCOL

BUILDING FOUNDATIONS FOR SELF-DETERMINATION IN YOUNG CHILDREN WITH DISABILITIES: FAMILY-PROFESSIONAL PARTNERSHIPS

Family Interview Protocol
10-10-09

Participants in the in-depth qualitative family interviews will be drawn from among a convenient sample and use of snowball sampling. Families will be given initial recruitment information and if they are interested can respond verbally, or by mail or email and indicate their interest in participation. We will then contact the selected participants by phone and ask for their continued interest. If they are interested, we will arrange an initial interview.

Introduction (Interviewer script)

My name is ______ and I want to thank you for giving us this time for an interview with you (and your family). [Describe your role on this project].
The interview will take about 45-60 minutes and everything you share is confidential. We are talking with you as a parent of a young child with special needs.

The purpose of this interview is to gather information about what families think about how best to encourage their child’s learning and development. We want to learn more about how parents support and build their child’s development of skills to make choices, to learn how to pay attention for longer periods of time, or how to problem solve or deal with frustrations they encounter. We want to know your family’s beliefs about the kinds of things you do that you feel are important for your child’s future success. We want to hear your family’s story, understand your child and his or her needs, and get your ideas about what families could really use to enhance their ability to work with their child.

[Start by reviewing and signing the consent form.] Purpose, all answers confidential, withdraw at anytime, payment for your time. If you want more information about this study or about the researchers, please call -Dr. Mary Jane Brotherson at 294-3677 or Dr. Susan Maude at 294-2370 (or researchers at your site, Yuzhu Zheng at 86-023-68667883).

Finally, please know that we understand the many demands on your time and that we truly appreciate the time you are giving us. Your ideas and knowledge are important to us.

Interviewer Instructions: Qualitative interviews are emergent in nature. Our main goal for these interviews is to gather information from the interviewees in each of the sections below. The probes provided are suggestions only; clearly, if you ask them all, you will never finish in an hour. Pick probes that help the respondent understand better what we want to know, and probes that fit an individual family circumstance. We hope that each interview will provide information in each of the large categories below.
Interview Questions

A. Understanding the Family –
   Objectives:
   • To understand beliefs and values of the family related to how the family perceives
disability, what it means to have a child with a disability, expectations for the future.
   • To gain insight into how the family perceives services - what are the roles of the schools,
and how are family members involved, (fathers, mothers, grandparents, and siblings))?

Grand Tour questions:
Tell me about your family.
Tell me about your child with the disability in your family?

More specific questions/probes:
   ○ How many children (ages) and adults do you have in your family?
   ○ Where and with whom does your child spend most of her/his time?
   ○ Describe your beliefs and values that you would want teachers to know about your
family.
   ○ Describe any special traditions or customs you use when parenting.
   ○ How long have you lived in the United States and what has been your experience?
   ○ Describe your own educational experiences.
   ○ Describe family functions – what do you do for fun?
   ○ What activities in the community are you involved in (library story hour, child care,
music classes, church school). Describe. (Also describe your neighborhood).
   ○ Tell me about your expectations for your child’s development
      ○ What do you want to see in his/her development?
      ○ What dreams do you have for your child’s future? (to get at family priorities)

B. Choice making
   Objectives:
   • To understand the parents’ ideas about their child’s autonomy and rights and abilities to
make their own choices and decisions

Grand Tour Questions:
What choices does your child make on his/her own?
How does your child make choices or decisions?

More specific questions/probes:
   ○ Tell us about what your child might choose if given the opportunity.
   ○ How does your child let you know what he/she wants?
   ○ How do you know when he/she likes or doesn’t like something?
   ○ Does your child use any assistive devices or do you make any adaptations or changes that
help him or her make choices or decisions?
   ○ What would you find helpful in teaching your child to make his or her own choices? Not
helpful?
   ○ Are there certain routines, times or places that helps him/her make choices or decisions?
o How do you think your family values might influence your child’s opportunity to make choices or decisions or to problem solve?

o Are there certain strategies or activities that you feel have been very helpful to you and to your child to make choices or decision?

o What advice or ideas would you have to give other parents who wanted to help their child make choices or decisions

C. Self-regulation and control

Objectives:

• To gain insight into how the child self-regulates

• To understand the parents’ attitudes about self-regulation and what they do to encourage/teach/model/facilitate it

Grand Tour Questions:

How does s/he manage or control his/her emotions, behavior, and attention?
Describe a time when your child was upset or frustrated about something then was able to calm herself/himself down or not able to calm themselves down.

More specific questions/probes:

o How does he/she let you know when he/she needs help?

o Are there certain routines, times, people or places that help your child to self-regulate?

o Can you describe any ways that you have helped your child to regulate his or her behaviors and emotions?

o What kinds of things do you do to help him or her comfort themselves?

o Does your child use any assistive device that helps him or her regulate?

o What would you like teachers to know about how your child regulates emotions and activities (behaviors)?

o Have you changed/adapted your home environment (in any way, physical emotional or otherwise) to help your child self-regulate or reduce frustrations? (For example, reduce auditory noise or visual clutter, have comfort items easily accessible for your child, or offer a quite space for your child to go when he/she wants/needs it.)

o Are there certain strategies or activities you feel have been very helpful to you and to your child to reduce frustrations?

o What advice or ideas would you have to give other parents who wanted to help their child to be able to regulate their behaviors and emotions?

D. Engagement—

Objectives:

• To understand how the child engages with his/her environment.

• To gain insight in the parents’ beliefs about their child’s ability to engage

• To ascertain what the parents currently do/believe to encourage the child to engage
Grand Tour Questions:
How does your child get involved with the people and things around him or her?
How do you know when your child is really connecting to or engaged with these people or objects?

More specific questions/probes:
- What kinds of toys or activities really capture your child's attention?
- When does your child show the greatest level of interest at home? (Why? What is he doing?)
- Does your child use any assistive device that helps him or her be more engaged or have you made any changes or adaptations that help him/her be more engaged?
- Are there certain routines, times, people or places that helps your child to be engaged?
- Can you describe any ways that you have helped your child to be more involved and pay attention with things and people in their lives?
- What would you want teachers to know about how your child gets engaged with people and things?
- Are there certain strategies or activities that have been helpful to you and your child to get engaged? Where did you learn about them?
- What advice or ideas would you have to give other parents who wanted to help their child to be more engaged?

E. Parent–Professional Partnerships
Objectives:
- To understand the parents' perceptions about working with professionals
- To gain insight into how families think professionals can help them and their child

Grand Tour Question:
What do you think would be the best way for the school and other programs in the community to work most effectively with you and your family?

More specific questions/probes:
- How do you like to share/receive information with teachers and other people who provide support and assistance?
- How important do you think it is for you to be involved with the school in the education of your child?
- What would you like to see in a partnership with teachers? What would an ideal partnership between you and the teacher look like?
- What ways do you think would hinder or prevent an effective partnership between teacher and parent?
- What can a person from the school do to assist your family in promoting your child's self-regulation and active involvement in activities within your home? How should that process work in your opinion?
- What advice or ideas would you have to give other parents who wanted to build a solid relationship or partnership with teachers?
为促进有障碍儿童的自决定能力发展而建立基础：家庭与专业人员之间的合作关系

家庭采访草案

参与这次深入家庭采访的人员是从方便的样本中抽取的并使用了雪球抽样的方法。
对家庭将提供初步的招聘信息，如果他们有兴趣的话，可以口头答复，或者通过邮寄或电子邮件表示他们有兴趣参与。我们将通过电话联系选定的参与者，询问他们是否继续对我们的研究有兴趣。如果他们有兴趣，我们会安排初步面试。

导言（采访脚本）
我的名字叫_____，我要感谢您抽出时间让我们采访您（和您的家庭）。[说明你对这个项目中的作用。]
访谈约需45-60分钟，你与我在这里分享一切都是保密的。
我们现在和你交谈，是因为你是一个有特殊需要的幼儿的父母。
这个访谈的目的是收集有关家庭认为如何才能更好地鼓励孩子的学习和发展的信息。我们希望更多地了解家长如何支持和帮助孩子的发展技能去做出选择，学会如何较长时间地集中精力，或者如何解决和处理他们遇到的挫折。我们想知道你觉得什么对孩子未来成功是重要的。我们想知道你们家的故事，了解你的孩子和他/她的需要，并了解你对如何才能真正提高孩子的能力的想法。

[通过审查并签署同意书。]目的，所有的内容都保密，任何时候都可以退出，报酬。如果你想了解更多有关这项研究和研究者，请联系玛丽.简.布罗瑟森电话是1-515-294-3677或苏珊.莫德博士电话是1-515-294-2370（或您所在的研究人员,郑宇珠电话是86-023-68667883）。

最后，请相信，我们理解您为这次采访所付出的时间，我们真正感谢您所付出的时间。您的想法和知识对我们非常重要。

调查者指导说明：定性访谈本质上是自然发生的。我们访谈的主要目的是收集有关以下各节中的受访者的信
息。我们只是询问了一些可能问到的问题；很明显，如果你要在一小时内问所有的问题，那绝对是不可能的。根据家庭的情况，选择一些我们想知道的问题。我们希望每个访谈将为以下几个部分提供信息。
采访问题

A. 了解家庭

目的：

- 了解有关家庭如何看待残疾，有一个残疾孩子意味着什么，以及对未来的期望。
- 能够深入了解家庭如何看待所接受的服务----学校的作用是什么，以及家庭成员如何参与，（父亲，母亲，祖父母，兄弟姐妹）？

总括问题：

说说你的家庭情况。

- 告诉我你家庭中的残疾儿童的情况？

更具体的问题/探讨：

Ø 在你的家里有多少儿童（年龄）和成年人？
Ø 你的孩子在哪里与谁度过她/他的大部分时间？
Ø 描述你希望老师了解的你的信念和价值观。
Ø 描述任何你在养育小孩方面所使用的特殊的传统或习俗。
Ø 你住在美国有多久，你经历了些什么？
Ø 描述你自己的教育背景情况。
Ø 描述家庭功能，你是如何找到乐趣的？
Ø 你参与了什么样的社区活动，（如图书馆故事时，幼儿园，音乐班，教会学校）。请描述。（也描述您的所生活的小区情况）。
Ø 告诉我你对孩子发展的期待。
Ø 你想看到他/她有什么样的发展？
Ø 你对孩子的未来有什么梦想呢？（在家庭得到优先考虑）

B. 作出选择

目的：

了解父母对孩子的做出自己的选择和决定的自主性，权利和能力的想法。

总括问题：

你的孩子自己选择什么？

你的孩子是如何做出选择或决定的？

更具体的问题/探讨：

Ø 告诉我们，如果有机会你的孩子可能会选择什么。
Ø 你的孩子如何让你知道他/她想要的？
Ø 当他/她喜欢或不喜欢什么的时候，你是怎么知道这些的？
Ø 您的孩子是否使用任何辅助设备，或你做任何改变以帮助他或她作出选择或决定？
Ø 你发现哪些方法能够有效教会他或她做选择和决定呢？哪些方法没有什么用？
Ø 日常生活中哪些事情，或哪些时间或地点，帮助他/她作出的选择或决定？
Ø 你觉得你的家庭价值观可能会如何影响你孩子做选择或决定或解决问题的机会？
Ø 您觉得有特别有用的一些方法，技巧或者活动能帮助你和您的孩子做出选择或决定的？
Ø 在帮助他们的孩子做出选择或决定，你给其他家长有什么的建议？

C. 三自我调控
目标：
• 能够深入了解孩子如何自我调节
• 了解父母如何看待自我规管的，以及他们如何鼓励/教/示范/促进自我规管的。

总结问题：
他/她如何管理和控制他/她的情绪，行为和注意的？
描述一下当您的孩子对某事感到不满或沮丧的时间，他们能够自己平静/下来或无法自己冷静下来的情况。

更具体的问题：
Ø 当他/她需要帮助的时候，他/她是怎么让你知道的？
Ø 日常生活中有哪些事情，时间，人物或地点，能帮助孩子自我调节？
Ø 你如何描述一下任何你用来帮助你的孩子规范他或她的行为和情绪的方法？
Ø 你做些什么来帮助他或她安慰自己呢？
Ø 您的孩子是否使用任何辅助设备来帮助他或她的规管？
Ø 老师想了解你的孩子用了哪些来调节情绪和活动（行为）的？
Ø 你改变/调整过您的家庭环境（以任何方面，物理的，情绪的或其他方式），以帮助孩子自我调节或减少挫折？（例如，减少噪音的听觉或视觉混乱，提供一些东西让孩子毫不费力地得到用来自我安慰，或者为您的孩子提供一个安静的空间避免他/她想要/需要的去的时候去。）
Ø 您觉得有哪些特别有用的一些方法，技巧或者活动能帮助你和您的孩子自我规管？
Ø 在帮助他们的孩子自我规管方面，你给其他家长有什么的建议？

D. 参与
目标：
• 了解孩子如何融入参与到他/她所在环境中
• 了解父母对他们的孩子参与的能力的观点
• 确定父母目前认为怎么做的去鼓励儿童参与

总结问题
如何让您的孩子融入参与到周围的人或者环境中？
你怎么知道您的孩子是真的融入或者融入和参与到这些人或事情中？
更具体的问题/探讨：
Ø 什么样的玩具或活动能够吸引你孩子的注意力？
Ø 在家里，你的孩子什么时候显示出最大程度的兴趣？（为什么？他在做什么？）
Ø 你的孩子使用任何辅助设备，或者你改变/调整过你的家庭环境，以帮助他或她是更多地参与？
Ø 每日生活中有哪些事情，时间，人物或地点，能帮助孩子参与？
Ø 你能描述一下任何你用来帮助你的孩子更多地参与或集中注意力的方法？
Ø 你想让老师知道哪些能帮助你孩子参与和集中注意力的方法？
Ø 在帮助他们的孩子参与和集中注意力方面，你给其他家长有什么的建议？

E. 家长-专业从业人员的伙伴关系

目标：
• 了解家长对与专业人士合作的看法
• 深入理解家庭如何看待专业人士帮助他们和他们的孩子的工作

总括问题：
你认为对于学校和社区的其他项目来讲，与你和你的家庭合作的最好的方式是什么？

更具体的问题/探讨：
○ 你喜欢怎么和教师以及其他为你提供服务和帮助的人分享和接受信息？
○ 你认为参与到你孩子的学校教育中有多重要？
○ 你想与教师建立什么样的伙伴关系？你和老师之间理想的伙伴关系是怎样的？
○ 你认为哪些会妨碍或阻止老师和家长之间有效的伙伴关系的形成？
○ 学校里哪个人能帮助促进你的孩子在家里的自我规管与积极参与活动？你觉得这一过程是如何起作用的？
○ 在家庭与教师之间建立一个稳定的伙伴关系，你给其他家长有何建议？
# APPENDIX F. INTERVIEW SUMMARY SHEET

## Interview Summary Sheet

<table>
<thead>
<tr>
<th>Name of person being interviewed:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Data of interview:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Brief description of setting:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Describe general impression from the interview:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What went well in the interview:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>What was difficulty about the interview?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Are there any questions to add/delete/modify in the next interview?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is there anything to be address?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
## APPENDIX G. DATA ANALYSIS EXAMPLES

**Paper 1: EARLY CHILDHOOD INTERVENTION IN PEOPLE’S REPUBLIC OF CHINA (PRC)**

FROM THE FAMILIES’ PERSPECTIVE

1. **Family**

<table>
<thead>
<tr>
<th>Family</th>
<th>Place</th>
<th>Extended Family (Yes/NO)</th>
<th>Who are they?</th>
<th>How work Together?</th>
<th>Caused Problem</th>
<th>Financial Situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>F 1</td>
<td>Countryside</td>
<td>Y</td>
<td>Parents and grandparents</td>
<td>Father plays the main role (taking to school and accompanying in school), and the rest play roles in daily life</td>
<td>Cannot work out of town and influence family’s income</td>
<td>Heavy loans</td>
</tr>
<tr>
<td>F 2</td>
<td>Countryside</td>
<td>Y</td>
<td>Parents and grandparents</td>
<td>Mother---the main role (including taking to school and accompany in school) Others--help</td>
<td></td>
<td>No money, and loans</td>
</tr>
<tr>
<td>F 3</td>
<td>Big City</td>
<td>N</td>
<td>Parents</td>
<td>Mom quit her job and mainly plays the main role including taking to school and accompanying</td>
<td>Cannot afford better private intervention center</td>
<td>Medium-level</td>
</tr>
<tr>
<td>F 4</td>
<td>Countryside</td>
<td>Y</td>
<td>Parents and</td>
<td>Mom plays the main role</td>
<td>Spend a lot of money on</td>
<td>Bad</td>
</tr>
</tbody>
</table>
grandparents included taking to school and accompanying in school. Except daily care, grandparents support money too.

<table>
<thead>
<tr>
<th>Child</th>
<th>Age</th>
<th>Disabilities</th>
<th>When to start intervention</th>
<th>Experience</th>
<th>Intervention place</th>
<th>Daily intervention time</th>
<th>Intervention fee</th>
</tr>
</thead>
<tbody>
<tr>
<td>F5</td>
<td>Big city</td>
<td>Y</td>
<td>Parents and grandparents</td>
<td>Parents care about study and grandparents are in charge of daily care.</td>
<td>Spent a lot of money on hospitals.</td>
<td>Medium-level</td>
<td></td>
</tr>
<tr>
<td>F6</td>
<td>Big City</td>
<td>Y</td>
<td>Parents and grandparents</td>
<td>Grandparents play main role in studying and daily life.</td>
<td>No mentioned</td>
<td>Medium-level</td>
<td></td>
</tr>
</tbody>
</table>

2. Children

C1: Near to 6 years old | Cerebral palsy | Around 5 years old | 1.5 years old—diagnosis 3-near 5: hospitals Around5-now: Interventio n | Disabled People’s Federatio n | Around 2 hours | Free
<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
| C2 | 4 years old | Cerebral palsy | Around 3 years old | 1 year old—diagnosis
1-3: no treatment or intervention, stay at home.
3—now: intervention | Disabled People’s Federation | Around 2 hours | Free |
| C3 | 3 years old | Hearing Loss | Several months old | 2 months old-diagnosis
Several month—now: intervention | Disabled People’s Federation | 1 hour | Free |
| C4 | 3 years old | Hearing Loss | Around 1 year old | Around 1 --diagnosis
Around 1--Intervention | Disabled People’s Federation | 1 hour | Free |
| C5 | 4 years old | Cerebral palsy | Around 4 years old | 4 months old—diagnosis
4 months old---3, 4 years: Hospitals
4 years old—now: Special education | Private | Full-day | Charged |
<table>
<thead>
<tr>
<th>Family</th>
<th>Diagnosis time</th>
<th>Diagnosis Process</th>
<th>Responses</th>
<th>Results</th>
<th>New Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>1.5 years old</td>
<td>Not paying attention—self-doubt—not want to face the reality—hospital diagnosis</td>
<td>Turned to different hospitals for a cure.</td>
<td>In heavy loans, but not many improvements</td>
<td>To get free training; Planning to borrow money and have a last another try a surgery.</td>
</tr>
<tr>
<td>F2</td>
<td>1 year old</td>
<td>Self-discovery abnormality --- hospital diagnosis</td>
<td>Crying (very sad) and cannot believe; Cannot afford medical treatment, and take the child home</td>
<td>Stay at home</td>
<td>To get free intervention training</td>
</tr>
<tr>
<td>F3</td>
<td>2 months old</td>
<td>Hearing Screening in hospital and did not pass</td>
<td>Do not believe; renting hearing aids; start the free intervention; waiting for free hearing aids; got free two pairs;</td>
<td>Good improvement and the child has started to go to normal kindergarten.</td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td>Older than 1 year old</td>
<td>Self-discovery of abnormality---hospital diagnosis</td>
<td>Cannot accept the reality; Diagnose</td>
<td>Improvement is not very successful</td>
<td></td>
</tr>
</tbody>
</table>
several times;
Early intervention;
Waited for free surgery;
Self-paid surgery

<table>
<thead>
<tr>
<th>F 5</th>
<th>4 months</th>
<th>Doubt—Diagnosis by hospital</th>
<th>Angry; Try different hospitals around the country; “Full expectations of hospitals in a desperate situation.”</th>
<th>Spent a lot of money; No much improvements</th>
<th>Go to the private special education center</th>
</tr>
</thead>
</table>

| F6  | 3 years old | No information | Stay at home with grandparents | No information | To private special education center for one hour intervention |

Memo (11-17-2011): Family 3 started early intervention very early, and the intervention is very successful and now the child is in normal kindergarten with hearing aids. It shows how early intervention is. And the success is due to the early diagnosis by the hospital. The family is in the big city and the hospital offers free hearing screen and the family got information more easily.

From all the families, we can see that diagnoses were finally conducted by hospital. Why cannot hospital advocate or early screen for the families?
### 4. Disability

<table>
<thead>
<tr>
<th>Family</th>
<th>Knowledge about Disability Before Diagnosis</th>
<th>Old Understanding of Disability</th>
<th>Response to Disabilities</th>
<th>Present Understanding</th>
<th>Attitude towards Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>No</td>
<td>Illness</td>
<td>Hospitals, medicine, surgery “It is to give medicine to a dead horse.”</td>
<td>“No cure, only rehabilitation”</td>
<td>No mentioned</td>
</tr>
<tr>
<td>F2</td>
<td>No</td>
<td></td>
<td>No money for hospital</td>
<td>To have a child with disability is troublesome;</td>
<td></td>
</tr>
<tr>
<td>F3</td>
<td>No</td>
<td></td>
<td></td>
<td>A burden to family and society</td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F5</td>
<td>No</td>
<td>Disease</td>
<td>Disease</td>
<td>Do not give up after birth and live happily Avoid if possible before birth; A burden to family and family</td>
<td></td>
</tr>
<tr>
<td>F6</td>
<td>Not mentioned</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Memo (11-18-2011): From the table, we can see that families do not necessary knowledge about the normal development of a child and disabilities. Some of them regard it as illness and depended on medicine or surgery, which consumes the families a lot of money and make them have serious financial problem. Or some of them have little understanding and they did
not try effective intervention strategies. For example, one mom thinks autism can be got ridden of if she takes her child to play and study with other children. Beside, most families think it is quite hard to have a child with disabilities. If possible, we should try to avoid it before birth because it will be a burden to the country, society, family and the child. Why this happens is because of the not efficient policy in the PRC.

5. Expectations of children

<table>
<thead>
<tr>
<th>Family</th>
<th>Physical</th>
<th>Living Skills</th>
<th>Education after intervention</th>
<th>Future after growing up</th>
<th>Focus of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Walk; dress</td>
<td>Self-care; simple living skills</td>
<td>Go to normal school</td>
<td>Too far to think about (Remote future)</td>
<td>Walk</td>
</tr>
<tr>
<td>F2</td>
<td>Eat himself walk</td>
<td>Independent living skills</td>
<td>Go to normal school; Study well</td>
<td>Make a living on his own</td>
<td>Walk,</td>
</tr>
<tr>
<td>F3</td>
<td>Ability to live; live independently; Full development</td>
<td>Normal kindergarten and school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td>Be able to hear and speak</td>
<td>Live like normal child</td>
<td>Study like a normal child</td>
<td>Good future</td>
<td>Hear and Speech</td>
</tr>
<tr>
<td>F5</td>
<td>Walk</td>
<td>Independence; Make a living Self-care; “自力更生，能自立”，“自己维持到自己。“</td>
<td>To normal school; Get higher education; Learn knowledge</td>
<td>Integrate into society; Develop potential with help</td>
<td>Walk</td>
</tr>
<tr>
<td>F7</td>
<td>Speak properly</td>
<td>Independence in daily life</td>
<td>No high expectation in studying Normal</td>
<td>Independence in daily life</td>
<td>No clear idea about future</td>
</tr>
</tbody>
</table>
Memo: All the families expectation their children to be able to be independent. Here, independence mostly means self-care such as taking care of one’s daily life and making a living to support one’s own life. From all the family, we can see that their goals and expectations mainly target at very near goals such as being able to walk, speak or communicate if they cannot now. All the families hope that their children can go to normal school and study with normal children even they do not have expect high expectation in their academic achievements. But, on the other hand, it shows that inclusion does not really work in the PRC even there is a law which requires it. This reality influence families’ expectations of their children and intervention. But I cannot understand why the families or teachers do not think of other ways to compensation the children’s lack of abilities. For example, if the child cannot walk independently, why cannot they use wheelchairs? The key point is that inclusion does not really work there. There is no physic access for them to go to school, and no teachers who will help the child use the bathrooms.

6. Inclusion

<table>
<thead>
<tr>
<th>Child</th>
<th>Barrier to Normal School</th>
<th>Preconditioned to school</th>
</tr>
</thead>
<tbody>
<tr>
<td>C1</td>
<td>Unable to walk;</td>
<td>Be able to walk;</td>
</tr>
<tr>
<td></td>
<td>School does not accept;</td>
<td>Be able to use bathroom</td>
</tr>
<tr>
<td></td>
<td>Teachers will not take care;</td>
<td>himself;</td>
</tr>
<tr>
<td></td>
<td>Family cannot continue to accompany all the time</td>
<td></td>
</tr>
<tr>
<td>C2</td>
<td>“Going to school is impossible for him now.”</td>
<td></td>
</tr>
<tr>
<td>C3</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>C4</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>C5</td>
<td>Not mentioned</td>
<td>Not mentioned</td>
</tr>
<tr>
<td>C6</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Memo: Three out of 6 families mentioned that it is impossible for their children with disabilities to go to normal school because the dependence caused by their disabilities prevent them from doing so such as being unable to walk, use the bathroom. Besides, there are too many children for teachers to handle in normal school. It is hard to take care of these children. The last reason is the normal school focuses on cognitive learning and academic achievements. But these children may slow down in studying.
### 7. Public policy

<table>
<thead>
<tr>
<th>Family</th>
<th>Knowledge of Public Policy about Disabilities</th>
<th>Knowledge of Disabilities</th>
<th>Information Resource</th>
<th>Evaluation</th>
<th>Problems related to policy</th>
<th>Attitude</th>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Did not know before diagnosis--little understanding</td>
<td>Not knowing; Not been told; No information resource</td>
<td>Tv; Friends; Disabled People’s Federation; Teachers; Hospitals</td>
<td>No advocate; Application for support is annoying which takes forever</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F2</td>
<td></td>
<td>Neighbor; Teachers; Disabled People’s Federation;</td>
<td>Policy is good now</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F3</td>
<td>A little knowledge</td>
<td>Doctor;</td>
<td></td>
<td>No subsidize maintenance fee</td>
<td>Hopes are killed by government;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td></td>
<td></td>
<td></td>
<td>Limited intervention providing centers;</td>
<td>Higher salary for teachers; Better</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F 5</td>
<td>Never heard</td>
<td>No guaranteed employment;</td>
<td>No policy practically effective;</td>
<td>Not effective;</td>
<td>Do not guarantee the rights of people with disabilities;</td>
<td>Policy is formalism;</td>
<td>People with disabilities do not really have legal rights;</td>
</tr>
<tr>
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<td>---------------------------------</td>
<td>----------------</td>
<td>------------------------------------------------</td>
<td>---------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>F 6</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Memo: From the families I know that families do not know much about disabilities and the public of policies. They are not provided adequate information about the typical development of children. They were not provided information about how they should handle disabilities after diagnosis. However, the policy is better than before now. There is free and short intervention for children with disabilities such as cerebral palsy. However, families expressed their dissatisfaction of the public policy. This is because the law is not really effective and the people with disabilities do not really enjoy the rights given by the law. Families call for more support.
### 8. Present intervention or education

<table>
<thead>
<tr>
<th>Family</th>
<th>When to start Intervention</th>
<th>Provider of Early Intervention</th>
<th>Teacher’s Major(s)</th>
<th>Daily Duration of EI</th>
<th>Fee for EI</th>
<th>EI Form</th>
<th>Main Contents</th>
<th>Evaluation of EI</th>
<th>Suggestions to EI</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Around 5 years old</td>
<td>Disabled People’s Federation</td>
<td>Medicine; Education</td>
<td>2 hours</td>
<td>Free</td>
<td>Parent-Participation</td>
<td>Mainly Physical Therapy; Training Based on child’s needs; Physical training is primarily, and learning knowledge is secondary</td>
<td>No mention</td>
<td></td>
</tr>
<tr>
<td>F2</td>
<td>Around 3 years old</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>The same as the above one</td>
<td>No mention</td>
<td></td>
</tr>
<tr>
<td>F3</td>
<td>Several months old</td>
<td>Disabled People’s Federation</td>
<td>No information</td>
<td>1 hour</td>
<td>Free</td>
<td>Parent-Participation</td>
<td>Listening and speaking training</td>
<td>Not very good; The</td>
<td>Teach more than listening and</td>
</tr>
<tr>
<td>on</td>
<td>g</td>
<td>child dislikes it;</td>
<td>Evaluation of performance is not accurate;</td>
<td>Teachers are not passionate, snobbish and do not do good jobs, do not treat students equally;</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Parents hopes are killed by teachers;</td>
<td>Teachers teach very badly;</td>
<td>Look down upon;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Teachers;</td>
<td>Have no faith in language;</td>
<td>Improve teacher’s quality</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td>Around 1 year old</td>
<td>Disabled People’s Federation</td>
<td>No information</td>
<td>1 hour</td>
<td>Free</td>
<td>Parent-Participation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Listening and speaking training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Not effective;</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mainly depends on parents;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Too many students;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Teachers don’t care the child learns or not;</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Teachers are not good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Better teachers; Better salary for teachers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F5</td>
<td>2 years old</td>
<td>Private Special Education Center</td>
<td>No information</td>
<td>Full time</td>
<td>Charged</td>
<td>No parents accompany in school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Language, cognition based on IEP, and games “</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Important and effective</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F6</td>
<td>Around 4 years old</td>
<td>Private Special Education Center</td>
<td>No</td>
<td>One hour a day</td>
<td>Charged</td>
<td>No parents accompany in school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Language training</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Effective; Teacher’s responsible</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Memo: From the families, we can see that the PRC has made some great improvements in early intervention. It has started to offer free early intervention for families. One child started early intervention very early and now she is in normal kindergarten now. From this child, we can see the efficiency of early intervention if it can be conducted. Early intervention is also provided by some private agencies now. However, there are still many important issues in early intervention. First, when compared to the families who send their children to private center, free intervention is too brief, and most families think it is not effective. The teachers there teach badly, and they are not passionate or responsible. There are too many children for them to handle every day. Second, their intervention only focuses on physical therapy. However, the private center runs more like a normal kindergarten and the teaching content is more diverse. And it implemented IEP.

9. Financial issues related to disabilities

<table>
<thead>
<tr>
<th>Family</th>
<th>Where to spend money related to disabilities?</th>
<th>Some issues related to disabilities</th>
<th>The present financial situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1</td>
<td>Hospitals; Higher fee for entering normal kindergarten</td>
<td>The father accompanies the child at school, cannot earn money outside to support the whole family</td>
<td>Borrowed a lot of money</td>
</tr>
<tr>
<td>F2</td>
<td></td>
<td>The mom accompanies the child at school, cannot earn money outside to support the whole family</td>
<td>No money</td>
</tr>
<tr>
<td>F3</td>
<td></td>
<td>The mom quit her job and accompany the child at school</td>
<td>Medium-level</td>
</tr>
<tr>
<td>F4</td>
<td>Surgery</td>
<td>The mom quit her job and accompany the child at school</td>
<td>Given money by the grandparents; Not good</td>
</tr>
<tr>
<td>F5</td>
<td>Hospitals; Costly Early intervention</td>
<td>Use all the saved money</td>
<td>Not good</td>
</tr>
<tr>
<td>F7</td>
<td>Costly Early intervention</td>
<td></td>
<td>Medium level</td>
</tr>
</tbody>
</table>
Memo: Due to lack of information about early intervention, many families first chose hospitals, which consumed them a lot of money and make them in bad financial problems especially families from countryside. Besides, the free intervention requires the parents accompany their children at school, which needs one important bread-winner and influence the family’s income. Due to the limited number of free intervention, the families need to travel long distances to get the intervention.

**Paper 2: EARLY CHILDHOOD INTERVENTION IN PEOPLE’S REPUBLIC OF CHINA (PRC) FROM THE FAMILIES’ PERSPECTIVE**

<table>
<thead>
<tr>
<th>Family</th>
<th>Making-choice</th>
<th>Self-regulation</th>
<th>Engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Practice</td>
<td>Under standing</td>
<td>Barriers</td>
</tr>
<tr>
<td></td>
<td>Understand</td>
<td>Things to choose</td>
<td>Practice</td>
</tr>
<tr>
<td></td>
<td>Food, clothes</td>
<td>Adult regulate</td>
<td>Reason;</td>
</tr>
<tr>
<td>F1</td>
<td>Teach to make right choices; Letting make choice or satisfy choices means spoiling</td>
<td>Do not have money to satisfy choices</td>
<td>coax; beat, scare, ignore</td>
</tr>
<tr>
<td></td>
<td>The child does not listen to adults</td>
<td>ignore</td>
<td>Take part in what is good for the child</td>
</tr>
<tr>
<td></td>
<td>Force, coax, beat, scare, ignore objections</td>
<td></td>
<td>Reason, coax, beat, scare, ignore objections</td>
</tr>
<tr>
<td>F2</td>
<td>Did not teach how to make choice</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Take care to comfort; ignore</td>
<td></td>
<td>Use child’s interest</td>
</tr>
<tr>
<td>F3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4</td>
<td>Did not provide chances purposively</td>
<td>Ignore; take out for a walk; distract his attention</td>
<td>No ways</td>
</tr>
<tr>
<td>----</td>
<td>----------------------------------</td>
<td>-----------------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>F5</td>
<td>Making choice means following one’s interest</td>
<td>It is impossible for children with disabilities to self-regulate</td>
<td>Beat; threaten</td>
</tr>
<tr>
<td>F6</td>
<td>Support to make choice within parent s’ plan and no choices in studying; Child is able to make choices</td>
<td>Comfort; Hug; Touch; distract attention</td>
<td>Reason, change home environment; force</td>
</tr>
<tr>
<td>F7</td>
<td>Support choice making and be against forcing</td>
<td>Reason, Ignore</td>
<td>Too young to learn</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

As a non-native English speaker, it was truly a demanding and long journey to finish this dissertation and receive my Ph.D. in the United States. Without the strongest of encouragement and the warmest support from so many great people, I would have never succeeded in finishing this journey. I want to sincerely extend my deepest appreciation to all of them in this acknowledgement.

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