FAMILY NEEDS OF CHINESE FAMILIES WITH CHILDREN WITH INTELLECTUAL
AND DEVELOPMENTAL DISABILITIES:
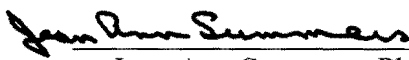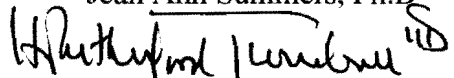A QUALITATIVE INQUIRY

By

Xiaoyi Hu

Submitted to the Department of Special Education and the
Faculty of the Graduate School of the University of Kansas
In partial fulfillment of the requirements for the degree of
Doctor of Philosophy
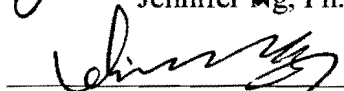
Dissertation Committee:

_____
Ann P. Turnbull, Ed.D., Chairperson

_____
Jean Ann Summers, Ph.D.

_____
H. Rutherford Turnbull, LLM

_____
Jennifer Ng, Ph.D.

_____
Mian Wang, Ph.D.

Dissertation defended: June, 24th, 2011

Copyright 2011

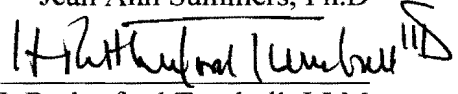The Dissertation Committee for Xiaoyi Hu certifies
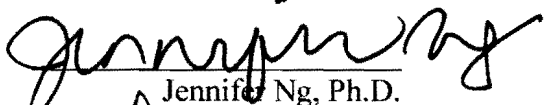that this is the approved version of the following dissertation:

FAMILY NEEDS OF CHINESE FAMILIES WITH CHILDREN WITH INTELLECTUAL
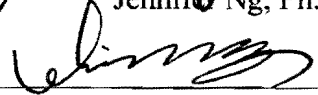AND DEVELOPMENTAL DISABILITIES:
A QUALITATIVE INQUIRY

Dissertation Committee:

Chair, Ann P. Turnbull, Ed.D.

Jean Ann Summers, Ph.D

H. Rutherford Turnbull, LLM

Jennifer Ng, Ph.D.

Mian Wang, Ph.D

Date approved: _____

ABSTRACT

This dissertation presents the findings of a qualitative study examining needs of Chinese families with children with intellectual and developmental disabilities. The purpose of this dissertation is to inform the process of further developing the family support programs and opportunities that already exist in China and to assist in establishing best practices, as authorized by existing or proposed policy, through a qualitative explication of the family needs of Chinese families of children with IDD. Through focus group discussions and interviews, Chinese families expressed a vast array of needs. Three types of family needs emerged: (a) survival needs, (b) sufficiency needs, and (c) enhancement needs. Overall, this study develops a conceptual framework explaining the relationship among factors influencing family perceptions of their needs, family needs, and the resulting types of family support that are aligned with family needs and, ultimately, the delivery of family support to families. A discussion of the findings is provided and implications for practice, policy, and future research are discussed.

ACKNOWLEDGEMENTS

First and foremost, I would like to thank my parents, Baolan Li and Lianhua Hu for four years of constant support, patience, and encouragement. I could not have done this without them. I would also like to thank my sister, Xiaodong Hu. I thank her for her taking care of my parents and my son while I worked. I also thank my husband Frank and my son, Kevin. Kevin is two years old now. Thank you for your independence and patience while I was writing my dissertation.

I would like to thank my committee members: Ann and Rud Turnbull, Jean Ann Summers, Mian Wang, and Jennifer Ng. I was fortunate to have Ann and Rud as my advisers. The Beach Center on disability is my American home and Lawrence is my second hometown. They gave me my second home in the United States. In addition to admiration for their professional knowledge and commitment to the disability field, I respect their working spirit. Having Ann and Rud on my side has changed the course of my future. I owe an incredible amount of gratitude to Jean Ann Summers. She has been there with every step with my dissertation and was instrumental in the completion of my program. Also I have been fortunate to have Main Wang for my committee. He gave me practical advice on learning and living in the U.S. He also he encouraged me to apply what I learned from special education in the U.S to China. I thank Mian for his continued and unwavering support of my decisions and studies. He has been a mentor and a friend. I thank Jennifer Ng. for her willingness to serve on my committee across the miles. I was so fortunate to be one

of her students in her several qualitative courses. I know I have much more to learn but I thank Jennifer Ng for setting me on this path of qualitative studies.

I valued the friendship with Angel Chou and her husband and Lei Guo. I am so happy to be your friends in Lawrence. I look forward to our continued friendship as we move into the next phase of our careers.

Also my colleagues from Beijing Union University, including Professor Xu, Professor Liu, Chuanping Hao, and Xu Zhang, and my advisor at Beijing Normal University, Professor Xiao, gave me constant support and guidance on my data collection and analysis in China. Especially, I want to thank a number of colleagues from the Harvard project on disability in China and the local school teachers, working staff from the local associations for persons with disabilities, and students from master programs from Xinan Universities. Finally, I would like to dedicate my dissertation to the whole group of Family Needs Assessment group formed by my colleagues from the Beach Center and in Spain. They gave me much support and kept me on the track of exploration of the needs of families with children with disabilities.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER 1 LITERATURE REVIEW

Over the past decade, special education professionals and disability service providers have recognized that meeting needs of families who have children with disabilities affects not only the child's quality of life but also the families' overall quality of life (Bailey et al., 1998, 2006; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010). For at least that one reason, families themselves as consumers of support have been the foci of research and practice related to family-oriented approaches (Turnbull et al., 2010). Although it is one thing to understand the needs of families who traditionally have been the targets of and respondents in family support research, especially in the United States of America, it is altogether another matter to understand the meaning of family support to families in other countries. Because I myself am Chinese and have considerable experience in working with and researching about the quality of life of Chinese families who have a member with an intellectual disability (Hu, Wang, & Xiao, in press), I conducted this dissertation study about family needs as they affect Chinese families in mainland China. Accordingly, in this chapter, I (a) explain the purpose of my dissertation; (b) provide a brief review of family needs research; (c) describe Chinese literature on family needs related to children with intellectual and developmental disabilities (IDD); and (d) describe the current status of support for families with children with IDD in China.

Study Purpose and Research Questions

In this section, I provide (a) the description of IDD and family support in China, (b) the statement of my research questions, and (c) the definition of key terms used throughout this dissertation.

Study Background

IDD is one of the five high-incidence disabilities in China. For that reason, individuals with IDD have received a considerable amount of attention in China among researchers, practitioners, and policy makers. Demographic data justify that attention. The IDD population is estimated to be approximately 5,540,000, accounting for 6.68 % of all people with disabilities in China (China Disabled Persons' Federation, 2006). Approximately 50% of this population consists of children under age 18 (The Central People's Government of the People's Republic of China, 2011). Policy makers are acutely aware of the significance of these demographic data. Indeed, children with IDD were the first disability category to be included in special education programs and rehabilitation services after the formation of the People's Republic of China (Gu, Piao & Liu, 2010).

Beyond the special education and rehabilitation initiatives, there has been, in recent years, a growing awareness across Chinese social welfare policy, theory, and educational research that it is important to provide services and supports to families, the overarching purpose being to target families in order to benefit the children with disabilities (Hu, Wang, & Xiao, in press). Thus, family-oriented services and supports are instrumental to the children's development, as is the case in the U.S. (Turnbull et al., 2010; Dunst & Trivette, 2009). Meanwhile, U.S. scholars have introduced the concept of family support into China (Xu, 2002). Introducing the term is appropriate because, although special education and school systems have

been established in China, the system of support for families with children with IDD across the life span is still an area relatively undeveloped and weakly established (Jiang & Huang, 2005). Yet some development and establishment of family support is underway (Huang & Liu, 2006), justifying my research to explore the family needs of Chinese families of children with IDD by a qualitative inquiry. The purpose of this dissertation is to inform the process of further developing the family support programs and opportunities that already exist and to assist in establishing best practices as authorized by policy through a qualitative explication of the family needs of Chinese families of children with IDD.

Research Questions

Specifically, this dissertation explores the following questions: (a) What are the needs of Chinese families with children with IDD?; (b) What is the nature of family support that is aligned with the preferences and needs of Chinese families of children with IDD?; and (c) What are the contextual factors contributing to the accomplishment of the family support they desire to meet their needs?

Definition of Key Concepts

Having briefly described the context and purpose for my dissertation, it is appropriate for me to define and explain the key terms. This study is a qualitative inquiry of family needs. These are the needs that families of children with IDD perceive they have; thus, family needs refer to the needs for support that a family regards as necessary in order for family members to participate in activities linked with normative family functioning.

The definition of family support was based on the Consensus Statement on Family Support, National Family Support Summit held at Beach Center on Disability in 2006 (Beach Center on Disability, 2006). Family support consists of various resources, including cash

3

assistance, professionally provided services, in-kind support from other individuals or entities, goods or products, or any combination of them that are provided to families who have minor or adult members with disabilities living in the family's home. This definition is in consistent with the family support paradigm developed by Turnbull & Turnbull (2002), which emphasizes supporting and accommodating individuals with disabilities and their families across all environmental levels in the ecological systems, instead of only fixing the individual with disability by providing support and resources. More importantly, family support includes both formal and informal sources of support. Formal support refers to an organized means for delivering formal instructional, social, and health-related activities or other forms of paid assistance. Informal support includes assistance provided from the informal social sources (e.g., spouse, extended family, and friends) to the family or the individual. Formal support is usually provided by professionals and informal support is provided by non-professionals.

Finally, the term intellectual disability (ID) has the same meaning as described by American Association on Intellectual and Development Disabilities (AAIDD): "a significant limitation both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills, originating before the age of 18" (Schalock et al., 2010, p. 1). According to the U. S. Developmental Disabilities Assistance and Bill of Rights Act, the term developmental disabilities means a severe, chronic disability that (a) originated at birth or during childhood, (b) is expected to continue indefinitely, and (c) substantially restricts the individual's functioning in several major life activities (Developmental Disabilities Assistance and Bill of Rights Act , Public Law No. 106-402, 114 Stat. 1683). I use the term intellectual and developmental disabilities (IDD) to refer to this combined population.

Research on Needs of Families of Children with Disabilities

In this section, I provide a review on English-language research on family needs of children with disabilities. To retrieve articles, I conducted a key word search in the following social science databases: Psych-INFO, ERIC, Educational Abstracts, and Wilson Web. The key words and combination of key words used to search all databases included family and parents, paired with needs and disab*, (* denotes disabled, disabling, disability, or disabilities). Below I describe the (a) the general characteristics and trends, (b) methodological issues, (c) conceptual framework, and (d) application issues of family needs research.

General Research Characteristics and Trends

The available literature on family needs dates back to the 1950's. As a mother of a child with ID, Murray (1959) explained six basic needs faced by families: (a) difficulties in initially accepting the child's diagnosis of mental retardation; (b) stress from the child's daily care needs; (c) theological conflicts concerning acceptance of the child with disabilities; (d) financial concerns; (e) anxiety over lifetime care for the child; and (f) inept, inaccurate, and ill-timed professional advice.

In the 1980s, researchers began to define and assess the needs of families of children with disabilities in order to effectively develop interventions to support families. One of the contributing factors to an emphasis on needs assessment was the U.S. Public Law 99-457, which requires early intervention professionals to write an individualized family service plan (IFSP), including a family-directed assessment of the family's resources, priorities, and concerns and the identification of the support needed to enhance a family's capacities to meet the needs of the family's infant or toddler with disabilities (Education of the Handicapped Act Amendments of 1986, Pub. L. No. 99-457, 100 Stat. 1145). An early initiative to identify family support needs

was Bailey's and Simeonsson's (1988) Family Needs Survey (FNS). The FNS is a 35-item parent-completed assessment tool to evaluate the needs of parents with young children with disabilities irrespective of services. Items are grouped by type of needs: (a) needs for information, (b) needs for supports, (c) explaining to others, (d) community services, (e) financial needs, and (f) family functioning. In the 1990's, several assessment checklists were developed to measure family needs, such as the Parent Needs Survey (Seligman & Darling, 1997), Family Information Preference Inventory (Turnbull & Turnbull, 1986), and Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988). These checklists (See Table 1) enable families to rate how items from the checklists apply to their situations. In general, families have reported needs in various areas such as information, communication, services, respite, education, and assistive technology devices and services.

The specific needs assessment for respite care of families with children with IDD has been recently recognized and investigated by several researchers in the U.S. and the United Kingdom (e.g., Robinson, Jackson, & Townsley, 2001; Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002). A consistent finding of these studies has been the presence of emotional strain as the primary reason for needing respite care. Additionally, the more severe the degree of the disability a child experienced, the more the families expressed a need for respite care.

Table 1

Descriptive Characteristics of Family Needs Assessment

Instrument	Reference	Domain Assessed	Response Option	Number of items
Family Needs Scale	Dunst, Cooper, Weeldreyer, Snyder, & Chase, (1988)	1. Basic Resources 2. Specialized Child Care 3. Personal/Family Growth 4. Financial & Medical Resources 5. Child Education/Therapy 6. Meal Preparation & Adapted Equipment 7. Care of Child in Future 8. Household Support	5 point: 1=almost never, 3= sometimes, 5=almost always and N/A	41 items
Family Needs Survey	Bailey & Simeonsson, (1988)	1. Needs for Information 2. Needs for Support 3. Explaining to Others 4. Community Services 5. Financial Needs	3-point: 1=No, 2= Not sure, 3=Yes, and N/A	35 items

		6. Family Functioning		
Family Resource Scale	Dunst, Vance, & Cooper (1986)	1. Growth & Support 2. Health & Necessities 3. Nutrition & Protection 4. Physical Shelter 5. Intrafamily Support 6. Communication & Employment 7. Child Care 8. Income	5 point: 1=Not at all adequate, 3= sometimes adequate, 5= almost always adequate, and N/A	30 items
Parent Needs Survey	Seligman & Darling (1989)	1.Information 2. Intervention 3. Formal Support 4. Informal Support 5. Material Support 6. Competing Needs	Check at three categories: I really need help in this area; I need some help in this area; and I don't need any help in this area	24 items

Prioritizing Family Needs Scale	Finn, Vadasy, Snyder & Calamas (1990)	1. Basic Needs 2. Health & Safety 3. Social Needs 4. Personal Needs 5. Needs for Self-fulfillment	checklist	
Family Support Scale	Dunst, Jenkins, & Trivette, (1984)	Individual item scores are sum up in five sources (kinship, spouse/partner support, informal support, programs/ organizations, professional supports)	5 point: 1=not at all helpful, 3= generally helpful, 5 =extremely helpful, and N/A	21 items
Family Information Preference Inventory.	Turnbull & Turnbull (1986)	1. Teaching Child at Home 2. Advocacy and Working with Professionals 3. Planning for the Future 4. Family Relaxation and Using More Support	3 point: 1= no interest in this information, and 3= information is a high priority	37 items

Another trend in family needs assessment has focused on emotional and social support needs. Emotional supports needs expressed by families include parent to parent programs (Santelli, Turnbull, Marquis, & Lerner, 1997; Singer et al., 1999), counseling and psychotherapy (e.g., cognitive coping strategies, and stress management training) (Singer, 2006), and spousal support (Konstantareas & Homatidis, 1989). Moreover, studies have identified that parents' well-being is also affected by the resources available to them and by families' utilization of resources. One important resource is social support (Beresofod, 1994; Dunst, Trivette, & Cross, 1986). In particular, social support influences the successful adaptation of families to stress and mental health problems (Singer et al., 1999). Moreover, research demonstrate that families' social support needs are multi-dimensional, including spousal support or satisfaction (e.g., Herman & Thompson, 1995), support from extended family members, especially grandparents, to help parents to cope with the demands of a child with IDD (e.g., Hastings, 1997), and support from friends and religious groups (e.g., Salovita, Italinna, & Leinonen, 2003; Smith, Oliver, & Innocenti, 2001). In addition to these social support from informal sources, researchers have found that professional and related social support are directly associated with family needs. For instance, Affleck, Tennen, Rowe, Roscher, and Walker (1989) found that the formal parenting skills training in response to mothers' indicated needs for assistance was associated with positive outcomes, whereas the formal support in the absence of an indicated need for support had negative consequences. This study also articulated the necessity to identify family concerns and priorities as the first step in designing and developing family-needs-based intervention and support, with the overarching purpose to meet their unmet needs.

In addition to research into specific types of needs families experience, family needs assessment studies have focused on specific ethnic populations in the U.S., a trend that can be

attributed to the fast growth rate of the Latino-American and African-American populations (U.S. Census Bureau Population Division, 2005). The needs of families of children with disabilities reflect values and beliefs unique to each ethnic population (Buysse, Castro, West, & Skinner, 2005; Darling & Gallagher, 2004). For instance, research for family needs targeting the African-American population largely focuses on health needs of young children as well as educational services directly related to children (Darling & Gallagher, 2004; Marcenko, Keller, & Delaney, 2001). The Latino-American families of children with IDD perceived family needs in the areas of English proficiency, bilingual special educators, health rehabilitation, information, and support groups (Buysse, Castro, West, & Skinner, 2005; Gannotti, Kaplan, Handwerker, & Groce, 2004).

In summary, the family needs literature is ripe with different (a) assessment tools and procedures, (b) family member respondents, (c) needs focus, and (d) results. In addition, the variety of family situations and mixture of diverse family characteristics render it difficult to make unequivocal statements about the characteristics of family needs based on this research. The following three sections will consider issues in current research by addressing three major questions:

What are some of the methodological issues related to family needs research?

What are the theoretical bases of research on family needs?

What are some of the application issues related to the process of family needs assessment among professionals?

Methodological Issues

Although numerous assessment tools and strategies have been developed to analyze family needs, concerns, and priorities in order to better provide support to families, there are few

11

reviews and studies focused on the methodological issues. The literature of family needs assessment reviewed in the earlier section demonstrated that the research tradition has been driven by the desire to understand the general nature of family needs in a convenient and efficient way (Henderson, Aydlett & Bailey, 1993). However, very little research on family needs has focused on the actual preferences of families for the type of research they would find most appropriate. A few discussions of this issue include Summers et al. (1990) and Davis and Gettinger (1995). One key finding of their research was that family members generally preferred informal approaches, self-reported measures, and/or interviews. Furthermore, Bailey and Blasco (1990) found considerable variability in family members' preferences for needs assessment to be carried out using surveys instead of interviews. In their survey of more than 200 parents, 60% of fathers preferred a survey, whereas 60% of mothers preferred an interview. As Bailey (1991) later explained, the issue of explorative interviews versus surveys on family needs is not an either-or question; however, it is a fundamental research-appropriateness issue for both families and professionals. Bank, Santos, and Roff (2003) further provided early intervention practitioners with interview and survey strategies for conducting family needs assessments. In a nutshell, this research teaches that researchers and practitioners should carefully select needs assessment tools according to family preferences, rather than using them in a singular fashion.

A second methodological consideration focuses on the psychometric properties of family needs assessment tools. McGrew, Gilman, and Johnson (1992) reviewed 15 scales designed to assess family needs of families with children with disabilities in terms of administration format, content validity, and psychometric characteristics. The review found these scales typically list potential needs followed by a response format on which respondents can indicate the extent to which the item reflects a perceived need, concern, priority, and/or strength. There was limited

evidence in support of the psychometric characteristics of measurement tools, including insufficient reliability and criterion-related validity information, lack of response and scoring variability, and small sample sizes. The authors called for a more thorough investigation of psychometric properties when using these instruments to assess family needs in the broader context of family-centered, collaborative processes.

Henderson, Aydlett, and Bailey (1993) further illustrated the difficulty in applying classical standardized testing theory to evaluate family needs measurement tools in light of the facts that family members' perceived needs are individualized, change over time, and can be fully captured only when the respondent is truly willing to be candid in needs identification. They suggested using social validity methods (e.g., collecting evaluative feedback from family members or service providers; providing families with choices to choose from two or more surveys; or conducting a focus group in combination with surveys) to enhance the accuracy utility of family needs assessment.

Most of the research and reviews by these authors was conducted in the early 1990s. However, there has been no more recent research to determine whether these methodological problems are still valid or any refinements have been achieved in family needs assessment tool development. It is certainly possible that there may be inadequate assumptions and limited theoretical focus on family need, which may exclude other possible needs and perhaps fail to address concerns of the whole family unit. The following section will address the theoretical basis of family needs research.

Conceptual Framework

A conceptual framework or theory is essential to build the construct domains and indicators of an assessment measure (Bengston et al., 2005). To date, the majority of empirical

investigations of family needs have followed a relatively simple pattern. Typically, the types of family needs are first dependent upon the authors' definition of family needs (Henderson, Aydlett, & Bailey, 1993); families then have then been asked to rate how these items apply to their situations. In the review of 15 family needs measurements, McGrew and colleagues (1992) chose first to explore the content of family needs and then to determine the extent to which each scale measured the content. The authors identified 17 categories of family needs and then classified all the survey items on each scale into one or more of the 17 need categories. These categories included: Food/Clothing, Physical/Housing, Economic/Financial, Vocational/Employment, Medical/Dental/Health, Transportation/Communication, Social Network within Family, Social Network outside Family, Cultural/Social, Recreation/Leisure, Emotional/Mental Health, Religious/Spiritual, Child Care, Child Education/Intervention, Adult Education/Enrichment, Legal, and Future Planning.

Their review demonstrated considerable differences across and within measurement tools in terms of coverage of these 17 categories. No one scale provided all these categories. Although some assessment tools were designed specifically to measure certain categories of family needs (e.g., mental health), none of instruments originated from a well-defined conceptual framework or theoretical bases of family needs.

In addition, empirical family needs research has failed to emphasize the whole family's strengths, priorities, and supports as they focus on the needs due to the disability of the child (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010). The purpose of these family needs studies was to understand the nature of family functioning in order to design or evaluate the effectiveness of interventions. Accordingly, although the assumption that family as the unit of support and support has been explicitly stated in family needs research, concerns and strengths of

family members, including siblings and grandparents have been neglected. Dunst and Trivette, 2009) made the argument that family-identified needs, in turn, could be best met by empowering families to address their needs by leveraging their family strengths. To be more specific, professionals and service providers can help families use their strengths and capabilities to obtain the necessary resources and supports to meet needs and become more competent. Therefore, identifying and building on family strengths works as a way of family support to families with children with disabilities.

A positive quality of life for families with children with disabilities, referred to as family quality of life (FQOL), has emerged as an important family outcome and disability-related policy indicator (Wang & Brown, 2009) and is, as I have stated above, the core of my dissertation study. The FQOL theory also includes family needs research into its conceptual framework, thereby providing a new theoretical perspective to family needs research and assessment. Zuna, Summers, Turnbull, Hu, and Xu (2010) described the unified theory as follows:

> Systems, policies, and programs indirectly impact individual and family-level supports, services, and practices; individual demographics, characteristics, and beliefs and family-unit dynamics and characteristics are direct predictors of FQOL and also interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family strengths, needs, and priorities. These re-enter the model as new inputs, resulting in a continuous feedback loop throughout the life course (p. 269).

Concepts

Systems
Policies
Programs

Systemic

Individual Member Concepts

Family Unit
Concepts

Family Level
Performance
Concepts

Individual Level
Performance
Concepts

Services
Supports
Practices

Services
Supports
Practices

Family
Quality of
Life

New Family Strengths,
Needs, and Priorities
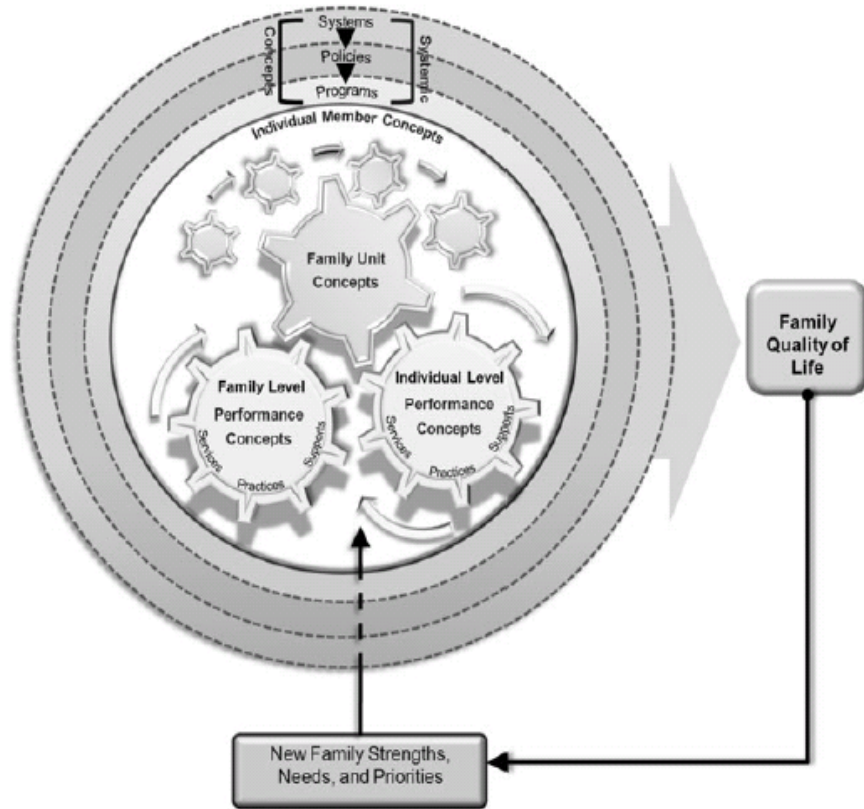
Figure 1. Unified theory of family quality of life

The unified theory of FQOL (see Figure 1) proposes the identification of family needs,

strengths, and priorities as the beginning point for determining how family support systems,

policies, and programs may impact individual family members and the family unit. My

dissertation study focuses on the input component of the unified theory of FQOL. In particular,

my research concentrates on family needs by exploring these three research questions: (a) What

are the needs of Chinese families with children with IDD?; (b) What is the nature of family

support that is aligned with the preferences and needs of Chinese families of children with IDD?;

and (c) What are the contextual factors contributing to the accomplishment of the family support

they desire to meet their needs? Thus, needs, utilization, and context of family support are the

three core components of my research, consistent with the FQOL unified theory.

It is fair to conclude, based on the literature I have briefly cited above, that the next natural progression in understanding and implementing the family support paradigm is to conduct research that assesses family needs based on the families' expressed strengths, needs, and priorities at the family unit level. Inasmuch as the ultimate outcome of research is enhanced family support to increase families' quality of life, it is now appropriate to address the application issues that have emerged from family needs research.

Application Issues

Application issues are practical issues that may limit the ability of a program to provide support to families while simultaneously addressing the health, educational, and social needs of the individual with IDD. For example, a dilemma for professionals is how to prioritize limited time and resources for families who may have unlimited needs (Bailey, 1991). Furthermore, on the one hand, family members may perceive that a needs assessment is an intrusion into their family life. They may even be concerned that they may lose their support after they share their information with professionals. On the other hand, agencies or programs may identify family needs but then not have the staff, expertise, or financial resources to address needs to create solutions for need attainment.

As I noted above, the current family support paradigm calls for adjusting the social, policy, and physical environment to ensure the adequate family support, services, and accommodations to meet family needs. Therefore, the solution to these application issues for professionals is to (a) focus on family-expressed needs, (b) support families in providing solutions, and (c) secure resources through a trustful partnership (Turnbull et al., 2010). Families interact with professionals because of specific needs related to their child with a disability and/or the family unit as a whole as it is impacted by the child with a disability. Although families

typically desire assistance for their child and family, the family support paradigm makes no assumption that it is the practitioner's role to "fix" families. Rather, the role of professionals is to serve as a resource and to be supportive partners for families, working with families to help them identify their needs and priorities and to achieve goals they have either for their children or themselves (Turnbull & Turnbull, 2002).

<center>Family Needs of Chinese Families with Children with IDD</center>

Culture is an important ecological factor in the family support paradigm. Although there are differences in families' cultural contexts, it is doubtful whether the differences contribute to the existence of particular or unique needs of Chinese families. In this section, I will review the literature of family needs of Chinese families with IDD.

Article Location and Retrieval

I conducted a literature search for studies on family needs of children with IDD in China. The search included the following key words: needs, family and parents. I conducted the search on China Academic Journals Full-text Database, the Chinese only social science database. In addition, I conducted a similar literature search on Psych-INFO, ERIC, Educational Abstracts, and Wilson Web, adding "Chinese" and "China" as key words. In order to obtain a comprehensive review of family needs research trends in China, including those on family needs of children with disabilities (i.e., disabilities may include IDD as one disability category), I purposely excluded the date range and disability categories as my selection criteria. After my initial search, I reviewed the list and included only those articles on children with IDD and those general disabilities that included IDD as the specific subcategories.

General Study Characteristics

   A total of 14 articles met the inclusion criteria for the review. Table 2 lists the studies categorized by author, publication year, research design, and title. The studies included in the review were all published in refereed journals. The earliest studies date back to 1994 and the most recent were published in 2010.

Table 2

Reference for the Sample Studies Included in the Review (N=14)

Study	Reference	Research Design	Title
1	Chen (2007)	Survey	Rehabilitation needs of families with children with disabilities
2	Chen & Simeonsson (1994)	Survey	Child disability and family needs in the People's Republic of China
3	Gu et al. (2010)	Survey	Needs of families with children with disabilities in Beijing
4	Huang & Liu (2007)	Survey	Social support of families with children with disabilities
5	Huang, Zhang, & Xing (2009)	Survey	Needs of 71 families of children with autism
6	Lin, Qin, & Zhang (2007)	Survey	Needs of parents who have children with autism in rehabilitation agencies in Chongqing
7	Luo & Lei	Survey	Family needs of children in special education

	(1999)		schools
8	Lv & Gao (2005)	Survey	Support needs of mothers with children with autism
9	Mao & Jiang (2010)	Survey	Parents desire for the placement of their children with ID after graduating from elementary vocational and technical schools
10	Mu (1995)	Survey	Parent needs whose children with ID attending special schools
11	Wong, Wong, Martinson, Lai, Chen, & He (2004)	Focus group interviews	Needs of Chinese parents of children with developmental disability
12	Xuan (2007)	Survey	Psychological needs of parents with children with autism
13	Zeng (2006)	Survey	Needs of families with adult child with intellectual disabilities in Shanghai
14	Zhang & Liu (2010)	Survey	Learning needs and its influential factors of the parents of children with mild intellectual disabilities

Five studies focusing on family needs of children with ID and five studies on DD met the review criteria. The remaining four studies included families of children with multiple disabilities. Eight of the 14 studies (57%) investigated general family needs. In some studies,

measures included sources of support for families to rate (e.g., educational agencies, professional

support), whereas other studies included measures that asked families to identify specific needs

that they perceived to be most important. The remaining six studies focused on specific family

needs, including information needs, psychological needs, and family rehabilitation needs.

Thirteen of these studies used quantitative measures, and all of them used a rating or

Likert-scale response format. These studies were conducted by mainland Chinese researchers,

except one study was carried out by researchers who were from China and the United States.

Only one of the 14 studies, conducted by Hong Kong researchers, used qualitative focus group

interview inquiry.

Key Findings

In the following section, I report relevant findings of the studies organized by types of

family needs (See Table 3). I begin with a description of the findings related to the sample

characteristics; I then report the findings related to research method as well as psychometric

properties.

Table 3

Studies Categorized by Need Types

Need Categories (examples)	% (n) Studies	Study
Professional services: attend rehabilitation services for the child, and locating services	57%(8)	1,3, 4,5,6,7,8, 11,
Parenting: manage the child's behavior, provide care or supervision for children	43% (6)	4,5,7, 11,12,14
Information: know information on intellectual and developmental disabilities, or of child development	43% (6)	2, 3, 4,5,7, 11

Financial assistance: need money for necessities or for special needs; pay for therapy/special services	43% (6)	2,3,4,5,7,8
Mental Health: cope with stress or a sense of being stigmatized	22%(3)	7, 11,12
Financial assistance: need money for necessities or for special needs; pay for therapy/special services	43% (6)	2,3,4,5,7,8
Employment: have employment for their children, need vocational training	22%(3)	9,13,14
Future planning: plan for future of child, worry about future of child	7%(1)	10
Working with professionals: build partnership with professionals	7%(1)	10
Attitude towards children: have a realistic expectation for the child	7%(1)	11

Fifty-seven percent of studies reflected the lack of professional services as the highest concern of families surveyed. These professional services included locating and accessing rehabilitation services (Chen, 2007; Huang & Liu, 2006) and other professional services (Gu et al., 2010), agencies or programs to accept their children (Huang, Zhang, & Xing, 2009), professional guidance (Lin, Qin, & Zhang, 2007; Luo & Lei, 1999), and early diagnosis and evaluation services (Lv & Gao, 2005). Forty-three percent of studies highlighted financial assistance, information on child disability, and parenting skills as the other three priorities. Twenty-two percent of studies found mental health and emotional support as a problem faced by

parents, especially parents with children with autism (e.g., Zeng, 2006). Seven percent of these studies found three major family concerns, including developing a realistic expectation for the child, building partnerships with professionals, and planning for the future of the child.

Interestingly, Chen and her colleagues (1994) conducted an exploratory comparison of needs using the Family Needs Survey (Bailey & Simeonsson, 1988) for Chinese and American families with children with disabilities. In comparing the ten priority needs expressed by Chinese and American families, only two items differed in magnitude between the two countries. Specifically, a greater proportion of American families expressed a need to find more time for themselves and a need to talk to other parents with a similar child. A greater proportion of Chinese families expressed the need for help to locate a doctor and the need for financial assistance for therapy and special service. Thus, there appears to be some similarity in the pattern of what families consider to be priority needs across cultures. This study concluded that informal support could be a mediator of family needs, a finding that was consistent with American studies (Beckman, 1991; Zigler & Black, 1989). In the end, the authors called for more direct evidence required to determine specifically which kinds of support are differently beneficial in Chinese and Western cultures.

With the increasing number of children with autism being identified in the past decade but a low rate of their being accepted into professional services (McCabe, 2008), home-based intervention research has emerged as a new field of study in the field of developmental disabilities (Lei, Yang, & Liu, 2010). Twenty-eight percent of the Chinese studies identified in this review focused on needs of parents of children with autism. Compared with studies on families of children with ID and general disabilities, families of children with autism expressed greater needs for professional guidance as well as emotional support (Huang, Zhang, & Xing ,

2009; Xuan, 2007). However, no studies conducted family needs assessment of children with other types of developmental disabilities, including cerebral palsy and various genetic and chromosomal disorders. It is possible that this variety in research is caused by the fact there was no specific category of developmental disabilities and limited research on other developmental disabilities. Interestingly, families with children with ID are more focused on employment opportunities, vocational training, and future planning issues of their children (e.g., Mao & Jiang, 2010; Zeng, 2006). This may be due to the fact that educational services for children with ID have been well established in China, although transition and adult services are still lacking in most cities and rural areas.

With regards to the sample characteristics, all studies utilized a sample recruited through a hospital, rehabilitation agency, or school system. Four of the 14 studies (29%) identified the composition of respondent information (i.e., percentage of fathers, mothers, and other family members). Among these four studies, mothers were the dominant respondents. A surprisingly large number of studies did not include descriptions regarding the ethnic distribution or social economic status of respondents. Seventy-nine percent of studies (n=11) described their sample as living in urban areas. Only one study chose families from a rural area as respondents (i.e., Chen & Simeonsson, 1994). (Urban was defined as an area whose population is greater than 50,000; suburban was defined as an area in which the population was between 10,000 and 50,000; and rural was defined as a population less than 10,000.). Two of the 14 studies did not provide demographic-related information.

Only one study asked parents' preferences for approaches to conducting needs assessment. Luo and Lei (1999) found 71.4% of their 276 respondents preferred interviews, while 21% of the respondents preferred surveys. Luo and her colleagues found that parents' lack

of communication opportunities with professionals, as well as low literacy levels, were the two primary reasons for parents' preferences for interviews. Additionally, only one study explored factors to predict family needs. Zhang and Liu (2006) found that, in terms of social support, mothers demonstrated significantly greater needs than fathers. In this study, Zhang and her colleague also found that factors predicting family needs of children with ID were social economic status, educational background, geographic differences, gender, and severity of disability.

Nine studies (64%) used self-made questionnaires to assess family needs, and three studies (21%) used the Family Needs Questionnaire developed by researchers from Taiwan (Wang, 1993). Only one study used the Family Needs Survey (Bailey & Simeonsson, 1988). None of the studies that used self-made questionnaires reported data on validity and reliability of the measures developed and/or adapted from existing surveys or questionnaires.

Discussion of Findings

One obvious feature of Chinese family needs studies was that families expressed their needs more at the child level. To be more specific, research studies demonstrated that families expressed various types of needs; however, most of these needs were closely related to their children. Moreover, no studies attempted to explore family strengths. Similar to empirical family needs research in the U.S. in 1990s, researchers failed to explore family needs as well as strengths expressed at the family unit level. It was also possible that Chinese families are accustomed to facing discrimination because of their children's disabilities and oftentimes have had to solve the problems of raising their children with disabilities by themselves. These social attitudes towards Chinese families of children with disabilities become barriers that impede parents' ability to recognize their strengths (McCabe, 2008).

25

If one is to understand Chinese families' needs, it is necessary to be aware of the fact that Chinese culture and traditional perspectives of disability, as well as family values, will make some needs culturally specific. However, as Chen and Simeonsson (1994) found, the patterns of needs of Chinese families were consistent with American culture as well. Unfortunately, there were limited current studies to gain a more expansive understanding of family needs in the context of Chinese culture and society, especially in rural areas where traditional culture still plays a dominant role in family lives (Liu, 2005). Therefore, it is clear that additional research is needed to gain a deeper understanding of the top priorities as well as identification of strengths of Chinese families in both urban and rural areas. In addition, future research agendas should focus on gaining a deeper understanding of needs and strengths expressed not only by mothers, but also by fathers and other caregivers or family members of children with IDD.

Finally, none of the studies asked the families' perception of the nature of family support. This is because family supports in China has only focused on children with disabilities, and the support needs of family members has long been ignored (Hu, Wang, & Xiao, in press). In the following section, I provide an introduction to family support in China by focusing on issues emerging from policy development, research initiatives, and application issues.

Family Support in China

In this section, I introduce the background and status of family support in China. Throughout this section, I describe (a) policy issues, (b) research initiatives, and (c) service-delivery issues related to family support in China.

Policy Issues

Families are the core social unit of society. Through the ages, JIA TIAN XIA (i.e., family as the world), which occurred in the Five Classics of Chinese Confucian literature, has become the dominant family value in China (Liu, 2005). However, national laws do not directly acknowledge the significant roles and responsibilities of families in raising and being partners with educators. Nevertheless, since the period of Reform and Opening, children with intellectual disabilities, hearing impairments, and visual impairments have had opportunities to enroll in special schools. By 2008, there were 1040 special schools for children with intellectual and developmental disabilities, along with 5640 special classrooms serving 205,803 students (National Education Commission, 2008). Official policy beginning in the mid-1980s has formalized early efforts for this education and demonstrated government commitment to developing special education.

Three important policies established a segregated special education system in China. They were Compulsory Education Law (National People's Congress, 1986), the Law of the People's Republic of China on Protection of Persons with Disabilities (National People's Congress, 1990), and the Regulations on Education for Persons with Disabilities (State Council, 1994). In fact, state policies have emphasized the education responsibilities of parents by stating that families are responsible for sending their children with disabilities to schools at the age of six (e.g., Compulsory Education Law), providing family-based rehabilitation services (e.g., the Law of the People's Republic of China on Protection of Persons with Disabilities), and ensuring preschool education (e.g., the Regulations on Education for Persons with Disabilities). However, there were no other references to families in laws or regulations. Considering the language of these laws about holding parents responsible to ensure education for their children with

27

disabilities, and considering the roles of families as the core unit of the society, the Chinese government has not recognized that families must be supported to meet the special needs of their children with disabilities. Instead, the rights of children with disabilities have been the only focus of government concern (Deng, Poon-Mcbrayer, & Farnswoth, 2001).

The segregated special education system, as well as all related services developed under these laws, has affected the lives of families with children with disabilities from different aspects. Led by this landmark legislation, children with disabilities have had access to an educational system that addresses their individual needs, and parents have been partially relieved of the burden of caretaking. From 1990, principles of western special education systems, especially inclusion, have made great impacts on China's traditional system for developing special education (Deng, Poon-Mcbrayer, & Farnswoth, 2001). The driving force in the inclusion movement in China has been referred to as Learning in Regular Classrooms (LRC). LRC is fully articulated in the Regulations on Education for Persons with Disabilities (State Council, 1994), a Work Program for Disabled Persons (State Council, 2000), and the Twelfth Five Year National Developmental Plan (2010-2015). One key catalyst for LRC has been parents' advocacy for providing special education to children with disabilities in neighborhood schools in classrooms with their peers without disabilities, especially for children in small towns or poor rural areas that do not have special education schools (Liu, 2001).The purpose of LRC has been to expand enrollment of children with disabilities into the school system in response to its compulsory education mandate (Deng & Manset, 2000). This led to a quick increase in school enrollment of children with disabilities. In 2003, LRC programs served approximately 67% of all students identified with disabilities (364,700) in regular schools (Ministry of Education of China, 2003).

In fact, experiments and implementation of LRC have been major contributors to the growing provision of educational opportunity for children with disabilities. However, this combined contribution has not been implemented fully because the emphasis in the LRC has been teaching students in general classroom, which has more to do with providing access to public education than ensuring the right to be educated effectively in regular education. The goal of LRC, unlike inclusion, is to give the majority of children with disabilities who have been excluded from any education the opportunity to attend school (Deng, M. & Poon-McBrayer, 2004). Unlike the Individuals with Disabilities Education Act, the American federal special education law, 20 U.S.C. Sec. 1400 et seq., there is no guaranteed right to an appropriate education, individualized education program (IEP), or parent involvement once students with disabilities are enrolled in general classrooms.

Although efforts of parents have stimulated the practice of LRC in rural areas, small towns, and urban cities nationwide, there has been no clear direction for parent participation in general education classrooms with general education teachers and professionals. For example, the Ninth 5-Year Work Program for Implementing Compulsory Education for Children with Disabilities (State Council, 1996) encouraged special schools to play a key role as resource and rehabilitation centers for local communities and families and to provide parents with consultation and other resources, training materials, and methods. However, consultation and training to parents has been primarily carried out in large and midsize cities; similar practices are virtually nonexistent in rural areas (Gu et al., 2010). To further complicate things, due to the large disparities in the ethnic, economic and geographic conditions between rural and urban areas and between western and eastern regions of the country, parents from various regions advocated for

specific issues of interest, making it hard for parents to have a unified voice (Mao & Jiang, 2010).

Because there are large numbers of children needing to be educated and not enough government-sponsored schools and organizations to provide this education, the non-governmental sector is beginning to play an important role in providing special education and rehabilitation services, especially to children with autism, severe disabilities, and multiple disabilities. As the government found itself "unable to meet all of the education and other welfare needs of its population…. during the reform period," government "encouraged non-government sectors to provide services" to children as well as their parents (Zhang, Chen, Wang, & Li, 2009, p. 36). By 2010, more than 2300 private non-profit non-enterprise units had been created to either provide training and guidance to parents or provide education and therapies to children (Zhang, Chen, Wang, & Li, 2009). A large number of these organizations had been established by parents beginning in the late 1980s (Mu, Yang, & Armfield, 1993). However, due to the many standards related to registering non-government organizations or agencies, many organizations have been improving slowly (McCabe, 2004). Lin and her colleagues found that "almost two thirds of these initiatives failed…for poor management, unqualified personnel…or (being) unable to provide training tailored at parents' unmet needs" (Lin, Qin, & Zhang, 2007).

Although LRC and non-government initiatives helped parents of children with disabilities developed a common goal around their struggle to obtain education opportunities for their children, family support has been long neglected in state laws and practices. Moreover, passive or negative social attitudes towards Chinese families of children with disabilities have become barriers to the design and development of services and supports for families, even though great progress has been made in Chinese social policy for people with disabilities (Hu, Wang, & Xiao,

in press). The primary issues around which families feel unsatisfied with current policies and regulations are as follows:

   • The Compulsory Education Law has led to efforts to universalize basic education for typically developing children, as well as efforts for children with three basic disability conditions (i.e., intellectual disabilities, hearing impairments, and visual impairments) to receive basic education. However, there are no mandates for this implementation for children with autism and learning disabilities, leading many schools to reject these children. Educating and caring children with these disabilities still occurs by families at home (McCabe, 2007).

   • Because diagnosis and evaluation of children with disabilities are not included in laws, and given the fact the evaluation is conducted only by medical staff at hospitals, families cannot get access to evaluation process. Thus, many families may not understand their children's needs and strengths (Hu, 2005a).

   • Parents are not members of the IEP teams and have no right to be educational decision makers for their children or effective partners with professionals. As recipients of unchallenged authority, parents follow educators' or professional advice about the nature of special education and the child's placement (Deng & Poon-McBrayer, 2004).

   • Preschool special education and early intervention are not required, although they are "encouraged" by laws and policies. Families lack the right to protest preschool educators' actions to exclude their children with disabilities (Huang & Liu, 2006).

   • Policies articulate the employment rights of adults with disabilities under the Regulation on the Employment of the Disabled (State Council, 2007). However, according to 2008 Annual Disability Status Report published by China Disabled Persons' Association, of all working-age

people with disabilities (age 21 to 60), only 1% are employed full or part time; 96% of adults stayed at home after graduation from school system (National Education Commission, 2008).

• Adults with disabilities are entitled to welfare benefits and medical services under the Law of the People's Republic of China on Protection of Persons with Disabilities. However, parents often report significant difficulty navigating the complex system of welfare to obtain needed medical, mental health, educational, and social services for their adult children (Lv & Gao, 2005).

Currently, federal policies have not authorized any family support programs. In considering families' increasing needs for support to meet their needs, the justification for family support for children with disabilities as a public policy is self-evident. Acknowledgment of its necessity may lead to future incorporation into policy. Fortunately, Chinese scholars have recognized the significant role of families in raising and educating children with disabilities. Further, some research initiatives on family support have demonstrated effective family support models, especially when family support is tailored to meeting the unique unmet needs of each family and is done so through partnership between professionals and families (e.g., Liu, 2009; Qiu & Wang, 2010).

Research Initiatives

While researchers have long focused on parents' needs of children with IDD, little research has focused on developing and providing family support. A few discussions of this issue include Huang and Liu's (2006) study on the effectiveness of home-based parent training programs; Xu and Zhang's (2009) case study on the self-determination intervention to a child with ID by a family support program; and Liu's (2009) thesis on providing parent counseling and parenting skills to young children with ID and autism. One consistent finding of these studies is that family support interventions improve family functioning and emotional well-being.

32

Moreover, individual variability within a family indicated the critical need for addressing

individualization when providing family support.

Delivery Issues

One reason for the limited family support research targeting families and children with

disabilities in Chinese literature is that, as noted in the description of policies, Chinese polices do

not authorize any specific family support. Thus, educational agencies and researchers are

reluctant to conduct family support interventions due to funding and resources constraints. Also,

family support intervention programs are located in a few major cities and are short term. As Lei

and her colleagues (2010) described the failure for providing parent training at a non-government

agency for children with autism in Beijing:

> Parent training for children with autism is outside of the public education
>
> system…parents and children attend usually for a few weeks or a few months, and then
>
> return to their hometown, where there may be no services at all to help them to continue
>
> their training…This means that parents, recipients of training today, have often to be the
>
> only teachers for children at home tomorrow…. (p. 45)

Another reason for limited family support is that educational practitioners or service

providers have lacked experience and expertise in working with families (Hu, 2005b). Instead,

professional development programs often place too much emphasis on instilling the knowledge

of special education theories, practices, as well as technical skills of therapies, as opposed to

enhancing participation of families as well as building an effective partnership with families. To

further complicate this issue, the negative social attitudes towards Chinese families of children

with disabilities render it possible that families become passive recipients of interventions. In this

sense, they do not have enough courage to speak out concerning what they desire from

professionals to meet their unique and unmet need, thus impeding the delivery of family support.

Because of the concerns raised by the process of family support, however, further studies and

interventions are needed to improve the effectiveness for applying and delivering families

support according to family needs and priorities.

In China, as I have noted, there is, on the one hand, growing interest in studying and

developing family support, guiding organization and service delivery system changes, and

evaluating quality family outcomes under the theoretical underpinnings of FQOL (Xiang, Xu, &

Wang, 2007; Xu, Wang, Xiang, & Hu, 2005). Yet, as I have also noted, research is necessary to

understand what "family support" means to Chinese families who have children with IDD, and

in turn, to understand more fully the likely effects, if any, of those support on the FQOL of those

families. On the other hand, research needs to inform and facilitate policy makers in the process

of developing the family support that already exists and to provide best practices as authorized

by policy. Based on my experience in conducting research on FQOL among Chinese families

who have children with IDD (Hu, Wang, & Xiao, in press) and in light of the observations of

other researchers (e.g., Mao & Jiang, 2010; Zeng, 2006), I anticipate that family needs of

Chinese families will be broad and comprehensive and will depend not only upon how they

characterize their needs but also on whether they believe the local policymakers and government

can remedy any mismatch between desired family outcomes and demanding needs, especially

given the diversity of available resources and professional service providers. In a word, "gaps"

and "context" are factors that I believe will influence families' needs for support and the

availability of those support and, in turn, their effect on FQOL. When knowledge about gaps and

contexts is grounded in careful research, Chinese policy makers, practitioners, and researchers

will be more effective in developing and establishing family support and thus contributing to the

enhancement of FQOL of Chinese families whose members have IDD. Therefore, the purpose

of my study is to inform the process of further developing the family support programs and

opportunities that already exist and assist in establishing best practices as authorized by policy

through a qualitative explication of the family needs of Chinese families of children with IDD.

CHAPTER 2 METHOD

The nature of the research purpose lends itself to qualitative inquiry as its grounding methodology to explore in depth families' subjective perceptions of their needs in various aspects of family life. According to Creswell (2005a), qualitative inquiry is most appropriate in research in which the research "seeks to establish the overall tendency of responses from individuals and to note how this tendency varies among people" (p. 45). More specifically, this dissertation study is an attempt to derive inductively the subjective perceptions of family needs from constructivist and interpretivist perspectives with the overarching purpose of better developing and providing family support.

In addition, qualitative inquiry incorporates an iterative and rigorous process of data collection and analysis (Creswell, 2005a). This process entails gathering primary data, making multiple visits to the field, conducting comparative analyses, developing and interrelating categories of information, and developing propositions. It is an ideal design when the researcher's purpose is to generate predictions, explanations, interpretations, and applications (Creswell, 2009). This design seems to be particularly appropriate for my research because I will study multiple families with children with IDD from both urban and rural areas in order to explore common themes related to family support needs.

The current dissertation study is a derivative of a larger project on *Inclusive Education Rights of Children with Disabilities in China* in collaboration between Beijing Union University and Harvard Law School. This project has three primary components: (a) support to individuals with disabilities in inclusive settings, (b) family support to families with children with disabilities, and (c) policy development of inclusive education rights of children with disabilities. The methods used for the dissertation study will be consistent with those in the larger study. The

research questions, research sites and participants, sampling procedure, data collection strategies, analysis plan, and techniques for trustworthiness will be described in this section.

Research Questions

The purpose of this dissertation is to inform the process of further developing the family support programs and opportunities that already exist and to establish best practices as authorized by policy through a qualitative explication of the family needs of Chinese families of children with IDD. The research questions guiding this study are: (a) What are the needs of Chinese families with children with IDD?; (b) What is the nature of family support that is aligned with the preferences and needs of Chinese families of children with IDD?; and (c) How do Chinese families perceive contextual factors contributing to the accomplishment of the family support they desire to meet their needs? The first question seeks to explore the types of family needs at the family unit level. The second question intends to explore the available family support families have and prefer that is aligned with their needs. The last question aims to examine the role of related policymakers in developing family support to meet family needs, again from the families' viewpoints.

Research Sites

Qualitative inquiry calls for homogeneous respondents from dispersed areas to provide contextual information useful in the axial coding phase of data analysis (Creswell, 2009). A team of seven researchers conducted focus groups followed by individual interviews and home visit observations across four geographical regions: east, south, north, and central China. Among the four areas, two are urban and two are rural areas. In each rural area, two sites were involved. In each urban area, one site was selected. Therefore, in this study, I collected data from a total of six research sites in China. These sites were selected because they provided a balance between

several criteria including: (a) variation in family demographics, (b) variation in geographic locations, (c) involvement with the larger project, and (d) travel costs and logistics. Table 4 describes the characteristics of the six research sites that comprised the sample for this study.

Table 4

Research Sites

Research Sites	Geographic locations	Family demographics	SES (per captia income/month)	Member of the larger project
Sichuan (Rural Area)	South			
Shifang		53 minority	$180	Yes
Pixian		ethnic groups,	$150	Yes
		more than 10		
		dialects		
Hubei (Rural Area)	Central			
Qianjiang		Han Nationality	$80	No
Yichang		Tujia Nationality	$120	No
Beijing(Urban City)	North	Han Nationality	$555	Yes
Shanghai(Urban City)	East	Han Nationality	$532	No

The research team included six local peer researchers and me. The peer researchers were masters' students majoring in special education from the local colleges or universities. Three research sites established a partnership with the larger project. More specifically, three schools and agencies participated in the *Inclusive Education Rights of Children with Disabilities in China.* With the agreement of the supervisors of schools and agencies, they are involved in this dissertation study. Sichuan is the strongest province in western China in terms of overall

economic strength. In the Sichuan province, I selected Shifang, which was designated as a disaster area in the 2008 earthquake (magnitude 8.0). I chose the only (as well as newly established) special education school as my research site because I attempted to explore family needs and their perceptions of family support after such a catastrophe. In addition, I selected an early intervention agency in Pixian as my second research site. Pixian is one of strongest economical counties in the Sichuan province. In Beijing, I selected Haidian special education school, one of the top schools for providing special education and rehabilitation to children with disabilities as my third research site.

Additionally, I purposefully selected three other research sites that were not part of the larger project. In these three sites, we contacted the special education office in the local education agencies. We asked office administrators to assist us with the identification of schools, agencies, and programs, including special education schools, inclusive schools with general education or special education classrooms, and rehabilitative service centers. In each research site, I selected one target school/program/agency based on the degree to which these programs were representative of the region's demographic characteristics. The Hubei province is a conservative agricultural province. I selected one rural inclusive school operating in Qianjiang (an impoverished mountainous area) and a special education school in Yichang (a major transit port along Yangtze River). Finally, I selected a transition program for adults with IDD in Shanghai as my sixth research site. Studying both rural and urban schools/programs/agencies allowed me to develop common themes across differentiated economically developed areas and permitted a comprehensive investigation of family needs of Chinese families with children with IDD.

Research Participants

I used purposive sampling to select participants. Maxwell (2009) has explained that in small samples, purposive sampling allows for researchers to achieve maximum variation of the focus population. I purposefully chose participants based on their potential contribution to this study. In each research site, four or five individuals participated in a focus group. A total of 26 parents participated in this study across all six sites. Once the school/program/agency was selected, we asked professionals within each school/agency/program to nominate families with a range of variables in terms of: (a) ethnicity, (b) severity of children's disability, (c) child age, (d) SES, and (e) relationship to the child with IDD. Using these criteria, professionals from the local school/program/agency provided us with brief demographic information of potential participants. We selected family members who most fit our criteria and spoke Mandarin. With the assistance of the professionals, I sent a consent form with the introduction of the project to the selected family members. Table 5 describes the characteristics of focus group participants. The majority of participants were female (65%), Han (70%), and from rural areas (70%). Approximately three quarters of the participants' total household income per month was below average level (i.e., less than $250) (National Bureau of Statistics of China, 2011). The majority of children were aged between six and16 (62%) and have mild IDD (51%).

Table 5

Characteristics of Focus Group Participants

Characteristics	Frequency	Percent
Gender		
Male	9	35
Female	17	65

Ethnicity		
Han	18	70
Minority	8	30
Relationship to individual with disability		
Mother	13	50
Father	7	27
Grandparent	5	20
Aunt or uncle	1	3
Geographic Location		
Urban	8	30
Rural	18	70
Total Household Income		
Low (Less than $100)	9	35
Average (between $100 and $250)	9	35
High (over $250)	8	30
Age of child with disability		
Birth to 5	4	15
6-16	16	62
Over 16	6	15
Disability of the child		
ID	14	52
DD	13	48
Severity of disability		

Severe	5	19
Moderate	8	30
Mild	14	51

I used convenience sampling for my individual interview participants' selection. Specifically, after each focus group discussion, I asked participants their interest in participating in the follow-up home visit and individual interview. Based on their indication of interest and availability of time, I purposefully selected a total of 12 participants who were out-spoken from the focus group discussions and volunteered for further interviews. For individual interviews with the 12 participants, I interviewed the same participants without including their spouse, other family members, or children with IDD. Table 6 identifies the demographic data of these families.

Table 6

Characteristics of Interview Participants

Characteristics	Frequency
Gender	
Male	4
Female	8
Ethnicity	
Han	9
Minority	3
Relationship to individual with disability	
Mother	5
Father	3

Grandparent	3
Aunt or uncle	1
Geographic Location	
Urban	8
Rural	4
Total Household Income	
Low (Less than $100)	4
Average (between $100 and $250)	4
High (over $250)	4
Age of child with disability	
Birth to 5	3
6-16	5
Over 16	4
Disability of the child	
ID	6
DD	6
Severity of disability	
Severe	2
Moderate	4
Mild	6

Protocols

Two researchers, including myself and a local peer researcher, were assigned to each site. There were four or five participants in each research site for a total number of 26 family members across all six sites. In this section, I describe the following data collection methods used: (a) consent form and demographic questionnaire, (b) focus group protocol, (c) individual interview protocol, and (d) home visit observation protocol.

Consent Form and Demographic Information

Professionals from the local schools/programs/agencies obtained written consent for participation from all participants before starting data collection according to the University of Kansas Human Subjects requirements. In addition, each participant completed a demographic questionnaire and was notified of the time and site for interview. Each participant received a monetary compensation of $30 for their time and contribution.

Focus Group Protocol

In this study, the focus group protocol centered around the three research questions: (a) What are the needs of Chinese families with children with IDD?; (b) What is the nature of family support that is aligned with the preferences and needs of Chinese families of children with IDD? and (c) What are the contextual factors contributing to the accomplishment of the family support they desire to meet their needs? While focus groups should be as open-ended and flexible as possible, they also need to be focused (Barbour, 2008). The focus group questions are grounded in existing theory, literature, and empirical research regarding family support needs. They serve as a tentative analytic frame to identify the broad areas of support needs. Questions that explored these issues included: (a) How does your child with ID affect your daily life?; (b) What concerns or worries do you have now?; (c) What types of support do you need to take care of your child?; and (d) How can local policies be implemented to support for you to meet the needs? These four

broad questions served as the framework within which the peer researchers and I asked follow-up probes and elicited more detailed responses and examples from the participants.

The purpose of the focus group was to encourage interactions among the participants in order to expand and explore their answers as much as possible (Creswell, 2009). After each focus group, I conducted debriefing with the local peer researcher to develop themes. Then I went back to Beijing and discussed with other three researchers from the Harvard Law School Chinese Disability Project to develop new directions for the protocol for future groups (Rubin & Rubin, 2005). A copy of the initial focus group protocol is found in Appendix A.

Individual Interview Protocol

Unlike the focus group protocol, the follow-up individual interview protocol was developed to explore families' need for specific family support (including unpaid support from the informal social network) and services items (including paid services from the formal or professional system). The individual interview protocol was intended as an opportunity to further explore issues raised in the focus groups. The protocol was part of the iterative research based on the debriefing and reflection of former focus group participation. However, the interview questions still centered on the study's overall research questions (Maxwell, 2009). To be more specific, the broad areas of support needs identified in the focus groups worked as guiding questions for the interviews. Under each of the guiding questions, I developed a series of sub-questions to further clarify and probe for more detail. Not all the probe questions were used; the probes were intended to guide the interviewers in possible ways to rephrase or follow-up on respondents' comments.

I used the framework of the *Family Needs Assessment (FNA)* to develop the initial individual interview protocol (Kyzar & Chiu, 2011). The FNA is a tool intended to assess the

types and intensity of family support needs. It consists of nine categories pertinent to family life routines and activities: home and daily living, emotional well-being and mental health, financial well-being, health, advocacy, vocational self-sufficiency, social interaction, parenting, and community and neighborhood participation. I used these nine categories as broad areas of support needs in the interview protocol and developed sub-questions centering around the three research questions. For example in terms of home and daily living, interview questions included: (a) For carrying out daily life and home living activities, what concerns or worries do you have now? What do you need most?; (b) To meet your needs, what kind of support do you want?; (c) What support do you have now for carrying out daily life activities?; and (e) From whom do you think you can support or who should be responsible for providing these support? A copy of the initial in-depth individual interview protocol is in Appendix B.

Home Visit Observation Protocol

During the home visits, I used the observation protocol to document: (a) home environment and (b) neighborhood/community environment. Home environment included physical home setting, family structure, housing situation, and family members living in the home. Neighborhood/community environment included community disability-related services/agencies/programs, related professionals, and rehabilitation or therapy resources. The purpose of the home visit was twofold: (a) to observe the context in which the family support is delivered or will be delivered and (b) to build rapport with family members for the individual interview process. I did not use the observation to examine available resources and supports that families currently had, because one home visit likely would not capture the whole picture of family support utilization. A copy of the home visit observation protocol is in Appendix C. If parents agreed, I conducted the individual interview during the home visit.

46

Data Collection

Focus Groups

In each research site, the local peer researcher and I conducted a focus group with four or five families. A focus group is a type of interview with a group of people, typically four to six, with specific common characteristics related to the research topic in order to collect shared understanding as well as to state perspectives about an issue (Creswell, 2009). Focus groups are advantageous when the interactions will stimulate participants' desire to yield the best information, as well as when participants perceive they are similar to and cooperative with each other. Another advantage is when the time to collect information is limited and the participants are hesitant to provide information (Krueger & Casey, 2009), focus groups can enable them, especially participants who have been marginalized, to express their opinions in a supportive environment. I audio recorded focus groups after obtaining participants' consent.

At each research site, the local peer researcher and I presented a 30-minute presentation on family support to the focus group participants nominated by the local school/program/agency. I decided this presentation was necessary to be able to obtain opinions from families who may have no prior knowledge about the nature of family support. The presentation began with sharing family experiences on parenting a child with IDD to provide a context for open sharing of information. A brief description of family support and family needs followed, including an overview of family support policy (i.e., background, purpose, benefits) and a brief introduction to the FQOL concept. I selected a presentation format, including didactic and interactive elements, because it was particularly amenable to creating a responsive learning environment in order to enhance parents' awareness and understanding of family support concepts. At the end of the presentation, the focus group portion of the meeting began when the peer researcher and I

facilitated a relaxed conversation and interaction among parents. Following the presentation, we conducted a 2-hour focus group about their family needs.

Home Visits

Observation is a qualitative inquiry process of gathering open-ended, firsthand information by observing people and places at a research site (Creswell, 2005b). I chose families for a home visit and interview after the focus group. In each research site, with the assistance of the professional from the local school/program/agency, I made one home visit to each of two families. The professional from the local school/program/agency was the special education teacher of the class or the assistant or coordinator who provides educational services to the child. In order to facilitate the observation and build rapport with participants, the professional and peer researcher accompanied me to the home setting. I conducted a total of eight home visits in this study. In addition, I conducted observations during the home visits using the home visit observation protocol to document home environment (i.e., physical home setting, family structure, housing situation, and family members living in the home) and neighborhood/community environment (i.e., community disability-related services/agencies/programs, related professionals, and rehabilitation or therapy resources). The observation and interview occurred at the same time unless the family indicated a preference for the interview to occur at a later time (e.g., by phone). Four participants chose either the school/program/agency or a coffee shop; thus I did a total of eight home visits. Finally, I used contact summary sheets, conversations with peer researchers, and reflective notes based on the observation protocol as qualitative data for analysis. All these served as data sources in addition to the audio recordings of the interviews.

Individual Interviews

In-depth individual interviews are an important qualitative inquiry method allowing participants to report their own perceptions and experiences to the interviewer (Kvale & Brinkmann, 2008). At each research site, I conducted two individual interviews with the same families who attended the focus group and who agreed to participate in the home visit observation with the local professional, peer researcher, and me. If it was inconvenient for the family to conduct the interview at the same time as the home visit, I scheduled the interview at a location and time of the family's choosing. I conducted a total of 12 interviews across the six research sites of the study.

The local peer researcher and I conducted interviews. As the primary interviewer, I began each interview by introducing my purpose for conducting the follow-up in-depth interview, which was to further explore their need for specific supports. Together, we explained the informed consent process, and I asked for permission to record the interview, assuring the participants that this will be for purpose of accuracy only. In using the interview protocol, I began the interview by summarizing main points from the focus group and sought participants' feedback about the accuracy of those points. During the interview, the peer researcher and I elicited the participants' insights about their family needs and support to be provided and the meaning and role of family support in their lives. Furthermore, I probed for their experiences with the available disability-related support as well as their perception of policy factors contributing to the accomplishment of family support they desired to meet their needs. The second interviewer, the peer researcher, was the note-taker and made necessary clarifications to the interview questions in order to obtain more accurate data. At the end of each interview, I summarized the main points and asked participants to check for accuracy.

After each interview, the peer researcher and I debriefed about our main impressions from the interview and developed the primary themes that emerged from the interview. We used a contact summary sheet to document first impressions, emergent themes, and any suggestions for modification of the interview questions for future use. Based on the contact summary sheet, we discussed the emergent themes and interview protocol modifications following individual interviews at each research site. I transcribed the audio tapes of the interviews.

<div align="center">**Data Analysis**</div>

Due to the nature of the iterative process of qualitative research and its emphasis on the interaction between data collection and analysis, data analysis is an on-going process that begins as the first focus group starts. More importantly, each step of the data analysis process directed the next step (Maxwell, 2009). I conducted analyses of various data sources, including (a) observation field notes, (b) transcripts of both the focus groups and interviews, and (c) contact summary sheets. I organized and analyzed the data using the management techniques recommended by Creswell (2002) including three phases: (a) preparing and organizing the data; (b) describing and developing themes; and (c) interpreting the data and reporting the findings. Although these three phases were in successive linear order, I revisited phases for further checking and analysis to ensure accuracy and trustworthiness.

Preparing and Organizing the Data

Along with the observation field notes and contact summary sheet, I transcribed audio recordings from the focus groups and individual interviews in full. I then imported the transcription to the Qualitative Solutions and Research International Nvivo software (version 8) to maintain an electronic database of the consensus analysis of transcripts, information about each code, and a detailed log about the process of developing the codebook (QSR, 2010).

Currently, Nvivo 8 is the only qualitative research software possessing the capability to recognize and analyze Chinese.

To be more specific, I created document folders for the various types of data sources and cases for each participant. Based on debriefings and discussions with members of the research team, I developed categorical themes as initial tree nodes (i.e., Nvivo terminology analogous to an outline or developing category framework) in order to categorize the resulting family needs schemes into the three research questions of this study.

Moreover, I used free nodes and memos to document trends in the data as I began my analysis. Free nodes are the "containers" in Nvivo 8 terminology, referring to any amount or kind of data, including concepts, processes, abstract ideas, people, places, or any other categories in the study about which the researcher has not yet made a decision about their logical or conceptual relationships to other nodes. I used memos as a means of recording my ideas and thoughts during the data analysis process. Memos are stored in a separate area in Nvivo 8 so that they can be edited, coded, searched, and linked as needed. I modified the tree nodes as I went through my analysis of the more detailed transcripts creating branches based on the tree nodes. Finally, in this way, I modified family needs by deleting, adding, or reorganizing the categories of support needs desired by families. This analysis procedure enabled me to visualize how the data supported my interpretations. Once I completed my analysis, I then went into the literature and made memos where my tree node branches reinforced or challenged the existing constructs of family need (Charmaz, 2006).

Describing and Developing Themes

I used the constant comparison method for code and theme development from the data. The constant comparison method is an inductive data analysis procedure in qualitative research which involves generating and connecting categories by comparing incidents in the data to other incidents, incidents to codes, codes to categories, and categories to other categories (Creswell, 2005a). The overall intent was to develop or ground the themes in the data. In Nvivo software context, incident, codes, and categories refer to free nodes, tree nodes and branches, respectively. Throughout the data collection and analysis process, I constantly compared the free codes to free codes, tree codes to tree codes, and branches to branches especially after conducting interviews and observations at each research site. Moreover, through a continuous process of discussions, the research team in the larger project and I developed the themes by using the constant comparison method (Creswell, 2005a). The function of the broader research team was to generate, question, and review the identified categories (e.g., types of family support) and relationships (e.g., the sources of family support and the types of family support). This process occurred throughout the analysis until the team and I reviewed all interview data and created a final theme and category framework.

Interpreting the Data and Reporting the Findings

Relationships of Nvivo are a special kind of node that enables researchers to define the connection among items such as a relationship between two cases or between two nodes. By using the Relationship function of Nvivo 8, I completed the following steps: (a) re-read all the coded data by tree nodes and branches to make initial interpretations; (b) built connections between branches with tree nodes and nodes underneath each branch; and (c) integrated the developed branches into the existing nine-domain model of the FNA imported before the data analysis began. During this process, I continued to utilize the constant comparison strategy to

check the plausibility and accuracy of the final themes that emerged and the relationships built within.

I generated a report in the text file format containing all the related raw transcripts and free nodes and tree nodes as well memos through Nvivo 8. A peer researcher cross-checked 20% of the codes for the report answering the three research questions. After selecting quotes to use in the dissertation, I made the translations into English by myself.

Establishing Trustworthiness

Although qualitative research is a creative process, it is imperative that the analysis be rigorous and systematic so that the findings are accurate and justified (Marshall & Rossman, 1999). Lincoln and Guba (1985) have described four constructs of trustworthiness by which qualitative research is to be judged: (a) credibility, (b) confirmability, (c) dependability, and (d) transferability. In this section, I discuss these four constructs.

Credibility

Credibility in qualitative research is most related to internal validity in quantitative research in describing the extent to which the findings accurately represent the the participants' realities (Anfara, Brown, & Mangione, 2002). I used three techniques to establish credibility: (a) triangulation of data, (b) peer debriefing, and (c) member checks.

Triangulation of data calls for using multiple types and sources of data from multiple participants by multiple collection methods and multiple researchers with the overarching purpose of creating rich data and themes (Maxwell, 2009). In this study, researchers from the Harvard Law School Chinese Disability Project engaged in this study to ensure the iterative process of data collection and data analysis. To be more specific, three faculty researchers who are specialists in children with IDD or disability policy studies from the Department of Special

53

Education of Beijing Union University, engaged in data analysis. After collecting data at each site, these researchers and I discussed the data in Beijing to review copies of all focus group and interview notes, observation notes, and contact summary sheets. Moreover, we further discussed emergent themes, cross-case differences and similarities, and revisions to the focus group and interview protocol for next research sites. There were multiple sources of data including focus groups, individual interviews, home visits observation field notes, and contact summary sheets. Based on each discussion, I documented the emergent themes and modified my focus group and interview protocols. The discussion provided me with new directions or needs for follow-up or clarification questions (Rubin & Rubin, 2005). In order to facilitate my follow-up studies, one researcher assisted me by collecting the background information about my next research site by online checking and document review. The background information included the local economic status, ethnicity and minority status, and the family and disability-related supports and policies. Finally, to ensure credibility, I gained information from multiple participants with different characteristics from the six research sites.

Peer debriefing is a strategy of enlisting a peer who is not immersed in the research but has some general understanding of the study. The local peer researchers from the special education master programs served as the peer debriefers. To be more specific, after each focus group and individual interview, peer researchers worked with me to read portions of the data or reports, listen to my ideas, and discuss the findings that emerged from the data and cross-case similarities and differences. In each research site, there was one peer researcher so a total of six peer researchers provided multiple perspectives on data analyses to ensure credibility. Peer debriefing occurred immediately after the data collection, as described earlier, between the local

peer researcher and myself. In addition, I conducted weekly conference calls with other

members of the team to discuss ongoing coding and emergent themes.

Another strategy to enhance credibility is the member check which decreases

misinterpretation by asking participants to check for accuracy of data (Creswell, 2002). I

conducted member checks by (a) explaining my biases and expectations before each focus group,

home visit, and individual interview so the participants could have a better understanding of the

purpose of the study and the impact of my values on the study's findings; (b) consistently asking

for clarification from the participants to ensure their opinions are accurately recorded; (c)

summarizing the main points of the focus groups and interviews and asking participants to

highlight, correct, and/or clarify my interpretations at the end of the interview; (d) describing

initial themes identified in initial sites and asking respondents in subsequent sites whether they

have experienced the same things; (e) sending a summary of findings to all participants to seek

their confirmation that the emerging themes accurately reflected their comments at the six

research sites; and (f) seeking discrepant evidence and negative cases to determine if the

conclusions should be modified or retained.

Confirmability

Confirmability is the equivalent of objectivity in quantitative research (Anfara, Brown, &

Mangione, 2002). However unlike quantitative research, the qualitative paradigm supports the

possibility of multiple potential interpretations and explanations for "reality." Therefore,

confirmability in qualitative inquiry calls for determining whether the researchers' conclusions

are reasonably traceable to the rich data sources presented in the study. In this study,

confirmability was ensured by (a) triangulation of data, (b) peer debriefing, and (c) reflective

practice and search for bias (Creswell, 2007; Creswell & Miller, 2000). A peer researcher from

the Harvard Law School Chinese Disability Project reviewed 20% of the raw data including (a) raw data (transcripts/field notes) and (b) memos and notes for data analysis in Nvivo 8. Using this process, the peer researcher validated whether good decisions were made during the research process (Anfara, Brown, & Mangione., 2002). Meanwhile, the peer researchers and I actively and continually searched for any bias and make any such research bias visible for further inspection to ensure conformability (Creswell, 2007).

Dependability

Dependability in qualitative studies is equivalent to reliability in quantitative studies (Anfara, Brown, & Mangione, 2002). I ensured the dependability by (a) triangulation of data, (b) close cooperation with a team of researchers and local peer researchers, and (c) constant comparison analysis to detect any discrepant evidence and negative cases. I have previously described the methods I used for these three dependability strategies. Moreover, as I noted above, a peer research review reviewed 20% of the raw data.

Transferability

Transferability refers to the extent to which the findings of the study can be applied to another context or other participants. It is most related to external validity in quantitative research (Anfara, Brown, & Mangione, 2002; Lincoln & Guba, 1985). In qualitative studies, researchers should provide sufficient information so that readers may be able to recognize the potential for transfer to other contexts or build applicability judgments (Lincoln & Guba, 1985). In this study, I provided thick descriptions with rich details to enable readers to obtain a clear picture of the data (Anfara, Brown, & Mangione, 2002). In addition, purposive sampling enhanced transferability by including data from multiple geographic areas and ethnic populations.

Limitations

The purpose of this dissertation is to inform the process of further developing the family support programs and opportunities that already exists and to establish best practices as authorized by policy through a qualitative explication of the family needs of Chinese families of children with IDD. However, in interpreting the findings of this study, there are several limitations that could contribute to validity threats. First, this study lacked long-term involvement or observation with the participants or study sites. The data were collected in a short period of time—approximately three months. Second, I purposefully selected 12 volunteer participants who I considered to be more out-spoken for the interviews. Their views may not represent the full range of parents. In addition, I purposefully selected families who speak Mandarin as my research participants. After 51 efforts to popularize Mandarin by Chinese government, Mandarin is widely used as the communication medium during public activities while people use the dialect native to their area or province when communicating within their family or with other native speakers. According to the survey of language use in China, 53% of the population, about 700 million people, communicate in Mandarin (Liu, 2004). Among those who do not speak Mandarin, most are 60 years old or older. Due to the limitation of my language used, I did not include those who do not speak Mandarin. However, sometimes participants used their dialects to communicate their ideas during the focus groups and home visits, especially when they exchanged ideas or debriefed among participants themselves or among family members. Third, the Chinese style of communication might limit the utility of focus group. For example, families naturally talk simultaneously about a particular topic instead of talking one at a time, which impeded my progress in comprehending and documenting their ideas and thoughts.

Ethical Assurances

I carefully considered ethical issues, as described in The Belmont Report (U. S. Department of Health, Education and Welfare, 1979), that involved multiple levels of consent. First, I collected appropriate consent on the purpose of this study from participants before beginning any data collection. Once individuals had agreed to participate in the study, I thoroughly explained their rights and obtained a signed written consent form. Moreover, I assigned all participants code names/numbers for data collection and processing, as well as for the written report. Finally, I did not make the focus group recordings available to other parties for any use.

I made it clear to participants that the purpose of this study is to inform the process of further developing the family support programs and opportunities that already exists and to establish best practices as authorized by policy through a qualitative explication of the family needs of Chinese families of children with IDD. Participants had the freedom to decline to participate at any time. They had the opportunity to review the focus group interview transcripts for accuracy and the option to contact me if further information was desired.

CHAPTER THREE   FINDINGS

To better understand family needs of Chinese families with children with IDD, I

developed Figure 2, a framework linking all the three research questions: (a) What are the needs

of Chinese families with children with IDD?; (b) What is the nature of family support that is

aligned with the preferences and needs of Chinese families of children with IDD?; and (c) What

are the contextual factors contributing to the accomplishment of the family support they desire to

meet their needs? Consistent with this framework, I will present in the following section the

results for each research question. Moreover, in the summary of findings, I will further explain

how the framework illustrates the interactional process among the components and features.

Research Question 1: What Are the Needs of Families with Children with IDD?

The first research question asked Chinese families about their needs. Two major

categories emerged including: (a) factors influencing perceptions of family needs, and (b) types

of family needs. Table 8 in Appendix E summarizes each category and subcategory and provides

a sample quotation from the data to illustrate each question.

Factors Influencing Perceptions of Family Needs

Chinese families held perceptions concerning their needs. These perceptions were

formed, in part, by (a) Chinese cultural values, (b) family characteristics, (c) families' previous

experiences, (d) current family support, and (e) family awareness and expectations.

Chinese cultural values.   The first obvious emergent category from transcript analysis,

Chinese traditional cultural values about the family, plays a critical role in family's perception of

their needs. Chinese cultural values are manifested in terms of (a) needs of family unit first and

(b) emphasis on education.
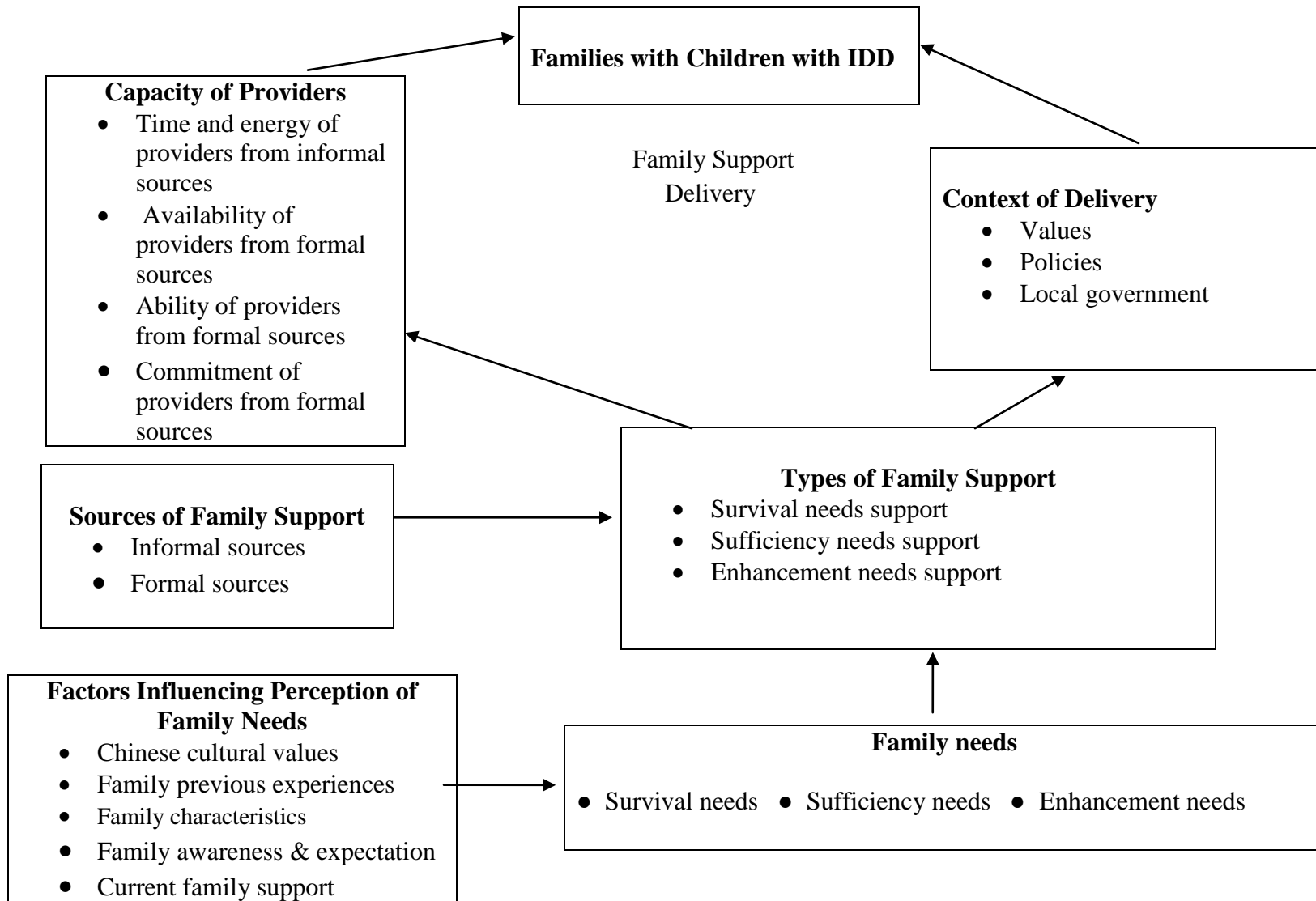
Figure 2 Framework for Family Needs of Chinese Families

Needs of family unit first. An important Chinese cultural ideology is Confucianism, which stresses one unique family value system that places the family above individual and personal needs (Chan & Lee, 2004). Under this ideology, families pay attention to not only the needs of the child with IDD but also the interests and needs of grandparents and other family members. Therefore, promoting family integrity, rather than individual interests and needs, is families' primary priority. For example, one young mother refused to move to Chengdu, the capital of Sichuan province, to have better rehabilitation and services for her child even though her husband worked there. Instead, she chose the local agency in her hometown and lived with her parents, both in their 70s, to provide caregiving for them. She further explained:

> Before, I would go to Chengdu with my son for sure. Now I have to consider my parents here. They helped me so much when QiuQiu (the son's name) was so young and no kindergarten accepted him…I cannot be so selfish...On the other hand, my parents did not like the idea that QiuQiu might leave them to move far away…[they] love him so much…my son would not either [I bet]…

Usually, parents still live with their parents in the same household to show filial piety, which is the most significant virtue to be held in Chinese culture. Nineteen of 26 focus group participants (73%) and eight of 12 interview participants (67%) lived with their parents in the same household. As the "sandwich generation," parents doubled their responsibilities to provide daily care to their parents as well as their children. They viewed themselves as integral to the whole family unit and strived to promote the family's oneness and harmony. Additionally, some grandparents played a significant role in maintaining home and daily living activities. During my home-visits, when parents were with me conducting the interviews, grandparents were either preparing meals or doing laundry, which parents reported made them feel guilty. For example,

61

due to the fact that the local school did not provide lunch, a grandfather around 80 years of age

had to deliver the child back home. This grandfather made a total of four roundtrips with his

electric bicycle, or a total of 40 miles a day, to take the granddaughter back and forth to school.

The father said with tears: "It should be the time that I need to take care of my father after my

mother died two years ago …However…I have to ask for his help…although [my father] said he

loved to do so."

    Emphasis on education. Traditional cultural factors can also affect how families value

various needs for their children with IDD. Chinese families uphold a cultural value that their

primary responsibility is to provide their children with the best attainable education. Respondents

expressed the belief that their primary need was to provide an education to their children. They

assumed that their critical responsibility as parents was to ensure their children are successful in

education. In this sense, training on cognitive development was regarded as the primary task of

schools. In contrast, parents regarded behavior training and social skills to be their

responsibilities to teach in home settings. This was evident in discussions in which respondents

focused on children's math education, speech development, and reading performance at schools.

They never regarded behavior modification and social skills training as teachers' tasks. This was

evident in one participant's family when the mother talked about her son's behavior problem of

carrying classmates' and friends' things back home:

    I never thought that[behavior] training can be done in the classroom…Instead, I thought,

    or his father always said 'give birth to you but not teach your behavior, it is father's fault'

    (one credo of Confucianism from San Zi Jing, one of the Chinese classic texts, which was

    thought to have been written in the 13th century). So we moved from town to the farm

    and built the house here [to] avoid [others'] accusations…we tried what we can do to train

his behavior and made detailed plan…but we never talked about it with his teachers…on the other hand, the teacher always blamed me in terms of his stealing [behaviors] at school.

Family characteristics. Family characteristics are defined as the families' geographic location, social economic status, educational background, and the type and severity of disability of the child with IDD. Table 7 provides a detailed comparison of families in this study on these key characteristics.

Table 7

Differences in Family Characteristics in Rural and Urban Area

Families from rural areas	Families from urban areas
• Parents live apart to work for money	• Family members live together and work in the same city
• Extended family members live nearby	• Extended family members live apart
• Safe neighborhood and community	• Unsafe neighborhood and community
• Grandparents live in the same household	• Grandparents live in the same household or live nearby
• More than two children	• One child
• Limited family support	• Limited family support
Families from low SES	Families from average and high SES
• Unemployed or at risk of unemployment	• Stable and adequate income
• Limited medical insurance	• Access to several options of medical insurance
• Limited living space and live in poverty	• Adequate living space

Families with low education	Families with high education
• Incorrect beliefs towards disability of child, e.g., belief that the child can be recovered from Down Syndrome	• Realistic expectations towards disability, e.g., expectation that the child be independent living with supports
Families with children with ID	Families with children with DD
• Adequate information provided on ID • Available support	• Limited support on DD • Limited accessibility and availability of education options
Families with children with severe/moderate IDD	Families with children with mild IDD
• Limited information on children's disability • Stress due to dealing with negative social attitudes	• Adequate information on mild IDD • Less stress due to dealing with negative social attitudes

Geographic location. Families demonstrated all the characteristics in Table 7. Eighteen of 26 focus group participants (70%) and eight of 12 interview participants (67%) were from rural areas. Many geographic factors are associated with their perceptions of family needs. For example, rural husbands often had to leave the family and farms and to go to big cities to work for more money. The left-behind children lived with their mother, grandparents, or other relatives. For example, a 24-year-old mother lived with one twin boy with cerebral palsy and her mother in their hometown. The mother's other twin boy, who has no disability, lived with grandparents in the east of China, which is the father's hometown. The father worked in Tibet as a migrant laborer. The mother had one opportunity to see her husband and her son without a

disability during the spring festival. However, the father has not seen his son with cerebral palsy

for three years. She vocalized her wishes to me:

> I hope to have family union, which is really a dream to me. I am sick of the life here
>
> without a job and taking care of my son 24 hours a day…I have cried everyday for the last
>
> half of year [because] I cannot find one way out…I told my husband I can only have one
>
> more year to see the progress of my son. [If he] cannot walk, I have to give up
>
> [rehabilitation]. I have to be with my other son…[who] did not like his brother here… I
>
> am afraid if I am away him so long, he would not like me either.

Family SES and educational background. Families from low SES and education

backgrounds expressed needs for basic financial support, employment, their own health issues,

and health insurance, as well as concerns about their future of their child with IDD and how they

were developing. In contrast, families from average and high SES and education backgrounds

considered needs beyond basic supports. For instance, respondents from Beijing and Shanghai

asked me about the possibility of having aquatic therapy and swimming training for their

children with autism. Furthermore, respondents with higher education more often shared their

insights on social exclusion, which resulted in low employment rates and lack of friendships for

their children with IDD.

Disability of child. The children's disability influenced families' perception of needs. One

distinct finding was that families with children with autism, cerebral palsy, and Fragile X

syndrome were lacking in professional services, knowledge about the disability, and knowledge

about child development. As I noted in the Chapter 1, education for children with developmental

disabilities was not mentioned directly in any policies, making it difficult for children with

autism and other developmental disabilities to attend schools, whether general education schools

or special education schools. While there are "cultivate intelligence schools" (i.e., schools for children with intellectual disability) and adequate professionals specialized at educating and rehabilitating children with intellectual disability, families of a child with autism have met more difficulties in locating doctors for diagnosis and advocating for their child's right to an education. Finally, families with children with severe and moderate IDD experienced more stress than those with mild IDD. Needs expressed by respondents with children with severe and moderate IDD were more focused on social inclusion. This is evident in the story of one mother with a daughter with cerebral palsy:

> Xinxin wants to play with neighborhood peers, but no one would love to. One day, I insisted on inviting one neighbor to my house...Their daughter only wants to play with Xinrui (Xinxin's younger sister without disability)… I can see the parents staring at Xinxin, then Xinxin kept crying…no one would love to make friend of Xinxin, which is not what I want. However it is the fact. Xinxin's friends are her classmates. This is the reason she loves school. Xinxin likes her classmate Jin very much and is always with her at school…I once invited Jin and her parents to my home but got refusal. Jin has mild intellectual disability and good independent living skills…When I brought Xinxin out, I felt great pressure [because] people around felt she was a monster…so I always have to pull my and her hat down a little bit…

Family previous experiences. Families also had experiences with other social service agencies and family support programs. All of these experiences, whether positive or negative, impacted their perceptions of family needs. Many respondents who had older children have participated in parent training and counseling. Some respondents found them very helpful in that the agencies provided the parents with useful information on child disability. However, some

parents regarded the parent education workshops as useless because the training content is difficult to apply in home settings.

In addition to parent training, respondents had experiences with child services that tended to complicate family assumptions towards not only types of support, but also the quality of support. One family moved back to Chengdu (the capital of Sichuan province), their original hometown, because they could not afford the high rehabilitation fee for their daughter with cerebral palsy, although the physical therapy promoted her ability to move and walk. In order to continue the therapy, her grandparents made simple equipment and trained her at home. However, without prompt and adequate professional guidance from her current school, the girl developed avascular necrosis of the femoral head. Because this family had experienced negative encounters with rehabilitation services, they were more reluctant to ask for guidance from schools for their child's home program.

The most valued aspect of parents' work with the parent training and child services related to the friendships they developed with other families who are in similar circumstances. One mother expressed the value-added of friendship as a resource that "helped me avoid many detours." Respondents obtained emotional support and information about their child's disability and development and about the availability of services from peer families.

Current family support. Except for education and services to children with IDD, most families in the sample did not have professional support for themselves. Some respondents had local government benefits (e.g., monthly subsidy), regular check-up services for children, and sporadic parent training and counseling from schools, as well as volunteers from community colleges to provide tutoring to the child with disability and housework support. Respondents who received government benefits expressed concern that these benefits were not enough, and they

worried that these benefits would be reduced or stopped altogether. One single father explained "every month, my family can get a $13 allowance. [But] our expense was $130…still now; I owed the tuition fee for this semester…if you can call $13 family support."

In contrast, families said they were benefiting from support from informal sources. Support from grandparents, relatives, friends, and other peer families through normal daily routines as well as crises made many families feel satisfied with daily lives. As one mother noted, "I don't have any needs on home daily living [because] my parents take care of everything." This was because, as I noted above, Chinese people value family as the central focus of an individual's life, the foundation to generate obligation and loyalty, build trust, and experience interdependence. They like to devote more energy to maintaining their families; consequently, they tend to get more support and attention from their families (Chan & Lee, 2004). Therefore, families were more likely to make assumptions about their needs for formal support provided by professionals in terms of types of support programs to meet the needs of their child. As the mother continued " what I need is the future of the child… to be independent …government should think about it too [as] it is a social problem….I think my son needs supported accommodations or work after graduation…[which] is my most primary need."

Family awareness and expectation. A need is generally considered to be a discrepancy or gap between "what is," or the present state, and "what should be," or a desired state of affairs (Witkin & Altschuld, 1995). But before we can explore family needs for support, one focal point is families' awareness and expectations about the nature and extent of the family support they prefer to have. Therefore, family awareness and expectations are precursors to "needs" --- without awareness and expectations, a need would not exist. The first consideration when looking at family support in the community or program/school/agency is the simple question:

"Have families ever thought about service XYZ?" For example, after my presentation on family support in one focus group discussion, respondents expressed surprise about respite care, which is a new service provided only in Beijing area. As one mother noted, "I never thought about it…yes! That's what I need…I need a person take care of my son twice a week [which] will make me feel very content." Clearly, if respite services exist but are not known to the family, then the family may not vocalize their needs.

Types of Family Needs

The factors influencing families' perceptions of needs described in the previous section influenced their understanding of the meaning of "needs" and whether they wanted those needs to be satisfied by policy or practice. I identified seven categories of needs, subsumed under three thematic areas: (a) survival needs, (b) sufficiency needs, and (c) enhancement needs. These seven categories included: (a) financial needs, (b) physical health, (c) child education/therapy, (d) teaching child at home, (e) social inclusion, (f) mental health, and (g) future planning.

Survival needs. Survival needs refer to families' necessities to maintain family existence, including money, food, house, medical insurance. Families mentioned a variety of needs which clustered in two primary survival need areas: (a) financial needs and (b) physical health needs.

Financial Needs. Most respondents emphasized the incredibly pressing needs for financial support for a better family life and described the intense demands on them to meet their financial obligations. First, they expressed concern over the accessibility and costs of medical insurance. Children with IDD from Sichuan and Hubei were not included in the rural medicare system, in which the government covers the medical expenditures via reimbursement. Respondents had to purchase medical insurance from private insurance companies. In Beijing

and Shanghai, only children with severe ID meet the medical eligibility criteria regulated by insurers. However, these private insurance companies either reduced the reimbursement level or established complicated and strict eligibility criteria as a condition of offering coverage. Respondents in Beijing expressed concern that the eligibility criteria were difficult to meet:

The medicare issue was huge issue…I read the 30 pages of eligibility criteria and made one conclusion: they do not let my child in their coverage…[second respondent] Yes. The most important [policy] was for outpatient, you can have reimbursement for 50%, for inpatient, you have nothing [to be reimbursed]… [third respondent] You cannot tell them your child has a disability… [in fact]…I did not and have the insurance [for my daughter]…but it is still very expensive…not enough to really care [for my daughter]. For example, if she develops a chronic illness, they will not reimburse.

Respondents with older children with IDD expressed concern about the social security insurance for their children, which was not "an efficient way to work everything out." Only some children in urban areas met the eligibility criteria for social security insurance. In contrast, rural adult children above 16 did not have unemployment compensation and disability benefits. They asked for the same government benefits. Even families in urban areas expressed concern about social security insurance. A mother in Shanghai further explained:

I did a thorough study on it. First, the benefit is for those aged from 16 to 55. [The insurance] only covers 15 years. If my son gets it, then he will not have it when he is 31. Second, only persons with severe IDD can benefit from it with 100% …my son has mild autism, so he can have 50% benefit from the lowest pension [standard of Shanghai].

Later in the interview with this mother, she told me she had a new diagnosis related to her son's autism and, after her "clamor for change," her son eventually got the severe disability on

70

his Disability Certificate. She expressed enormous guilt but said in the end "this is the only way for my son… [which] I hate so much."

In addition to insurance and disability benefits, low-income and rural families vocalized a need for cash assistance to purchase necessary equipment or assistive technology devices, an allowance for necessary rehabilitation and therapy fees, and reduced tuition and transportation expense subsidy. This was particularly true for some families because of the severe shortage of specialized services. Some rural families had to relocate to a city temporarily to have rehabilitation and therapies. This meant those families had to spend a significant portion of their financial resources or borrow money from relatives and friends. This also meant that parents had to be separated because one parent migrated to wealthy urban areas to work. A stay-at-home mother was worried about loss of income and the negative impact it would have on her family:

> [The daughter's] father has a good job before so we can rent the house nearby school. We are doing fine right now, but [you know] if something happened to my husband…he fainted from his office desk three times last year…I cannot think more about it….

Even families with high SES complained about being unable to pay for the high cost of some services, all of which had to be accessed from private agencies and non-profit units. Many urban respondents indicated that they had to make sacrifices and adjustments in order to pay school tuition. Some urban families and families with high educational backgrounds expressed needs for money management strategies in order to save more money for their child's future.

Housing-related issues were another financial assistance need that families expressed and I observed during home visits. Some respondents rented an apartment nearby schools or in the areas where they worked. Respondents with limited financial resources who lived in particularly crowded conditions especially commented on their needs for enough space. One boy with Fragile

X Syndrome lived with his grandparents on two boats in the Yangtze River. The living space was 107 square feet. The grandma shared how such a crowded housing situation negatively affects their home daily lives:

> [He and his grandpa] live in one boat and I live in another. We are retired and have no money to buy an apartment. Before it was fine but now I felt he is already 14 years old. He may need his own space…Last time he told me he wanted a dog I said 'oh, no!' …I saw him very upset and he needed a friend but our home environment…

> ***Physical health.*** In addition to financial needs, families placed a high value on physical health needs*.* Many respondents spoke about their health problems, including diabetes, high blood pressure, heart disease, and insomnia. In addition, respondents complained that they either had no time to have regular check-ups and treatment for themselves, or limited energy to take care of the senior members (e.g., grandparents) in the family. The issues of greatest concern for families were related to the health condition of their child with IDD. One mother spoke at length about an accident her daughter had recently experienced, in which she fell down and broke three teeth. Most respondents shared their negative experiences locating a doctor to diagnose their children's disability and treat disability-related health problems:

> I went to Town Hospital A, the doctor said she never had this kind of case before and maybe Hospital B in Wuhan had similar children. We went there and Hospital B notified me Hospital C in Wuhan could provide a diagnosis… [second respondent] I remembered you [first respondent] told me your son had an intellectual disability…[first respondent] yes. But now specialists from Hospital D said it was autism and only they had the right to issue Disability Certificate…yesterday, the teacher told me my daughter might have some hearing problems…I was really frustrated.

Respondents demonstrated a pressing need for information about their child's disability, child development, and related health conditions. One father strongly believed that modern medicine could cure his son's Down syndrome and repeated his belief several times during both the home visit and focus group discussions. Several families in the sample who had children with autism still had no knowledge about autism and related characteristics. One mother asked me:

Would you love to see my daughter later [after this discussion]? She has cerebral palsy…But recently, she has very weird behaviors, such as talking to herself and pinching others and herself…

Parents with children with IDD related that they often utilized Traditional Chinese Medicine (TCM) and related therapies, including acupuncture, cupping, and chiropractics to improve children's movement, muscle strength and functional independence. However, they expressed the need for accessing high quality TCM services, lest any other therapies or poorly executed TCM would harm their child. . Usually, these families had previous learning experiences from professionals that enabled them to perform medical procedures or physical therapy for their child with severe IDD. Some parents held different perspectives about using TCM and thought they needed more information on its effectiveness.

Sufficiency needs. Sufficiency needs refer to families' needs for being included in the society and having relationships with others, seeking and providing education to their family members, and developing skills to deal emotionally with challenges. Usually, with families' survival needs relatively satisfied, sufficiency needs take precedence, including (a) the child's education and therapy, (b) home-based education, and (c) social inclusion.

Child's education and therapy.   Most comments about sufficiency needs concentrated on children. Although other areas of sufficiency needs were important, respondents expressed the

child's education and therapy as their major need. Additionally, families expressed various needs related to education and therapy services for their children. Indeed, these needs could be further explored in terms of (a) adequacy of the supply of services, (b) accessing services, and (c) accepting services.

Respondents needed information on adequacy of the supply of education and therapy services for their children. For example, they knew that special education schools and agencies were for their children, and even knew that some regular schools have inclusive programs or schools with resource rooms existing within their community. However, they did not know much about their availability because their children have never enrolled in these schools/programs/agencies. Many respondents expressed their needs for vocational training to benefit their adult children, intervention with behavior modification, social skills training, and PT and OT services by professionals. Even some respondents vocalized their wishes to have new therapies (e.g., dolphin assisted therapy, aquatic therapy, and play therapy) for their children:

I need more aquatic therapy to my daughter. She spent wonderful time with dolphins and professionals there and she loved swimming…[second respondent] Where did you have that? I knew it from Ocean Heaven (a new film on a father with a son with autism working with dolphins). [third respondent] Beijing Aquarium. I heard about it. But it should be very expensive...[first respondent] Yes. we can have discount in winter seasons and children like ours can have a double discount…

Accessing education and therapy services was a significant problem that families experienced, regardless of their SES and educational background. Some parents were preparing a proposal to LEAs to provide dining services in Hubei. One mother in Shanghai felt frustrated that she had to be with her son with cerebral palsy at an acupuncture clinic every weekend, when

74

she hoped to have some of her own time. One grandmother in Sichuan could not bring her grandson to the nearby park simply because the park did not accommodate wheelchairs. One father in Sichuan needed specialized services provided to his son with severe IDD so he would not need to wait outside the classroom on teachers' call to help his son with toileting, walking, and eating. One mother in Beijing asked for help from special education professors in higher education institutions to conduct a comprehensive assessment of her child's disability because she did not accept the fact that her son had ID.

Some families perceived services for their children were unacceptable or viewed them as being nonexistent when, in fact, they were available and accessible for various reasons. Among the reasons families regarded the services as unacceptable were the high tuition or service fee, professionals' unfriendly attitudes towards parents or negative relationships with parents, limited classroom accessibility and adequacy, long waiting lists for enrollment and low enrollment rates, or unsafe school environments. One parent leader in Shanghai shared her story with me. She actively advocated for inclusive education for her son with autism and made every effort to have him enrolled in the regular elementary school in the community. However, the school expelled him because of his language and behavior problems. Having earned her Ph.D. in education policy, she published an article in a well-known newspaper, triggering a hot debate on a local talk show program. However, the conclusion from the debate was that the school did nothing wrong. We interviewed her when she got the news:

> I was so depressed… [crying]…Maybe it was ok… anyway, Xiaojun (son's name) did not like that school [because] the teachers did not like him…also they know nothing about intervention…But they cannot refuse my son because of their own fault…

Teaching the child at home. In addition to having education and therapy services for children with IDD, families expressed a strong need to receive instructional guidance at home. Compared to needs expressed for child education and therapies from professionals, respondents focused on parenting training needs to learn how to teach their child about independent living skills, behavior management skills, social skills, sexuality issues, and safety issues. Indeed, respondents believed they shoulder responsibility to teach them to be a "good" socialized person. Parents shared that they had already instilled these strategies in their children directly or indirectly within their home environment. Among these, teaching behavior management skills was an important component contributing to most of the comments. "Spare the rod and spoil the child" is an old Chinese saying and also one of the dominant "hidden rules" of parenting in China, although families knew the negative impact on child development. Families with children with problem behavior were especially concerned about using effective and appropriate discipline and behavior support strategies. One grandfather explained:

> I want them just to perform "right" and be able to discipline better. I know of the word for 'corporal punishment,' but my friends, neighbors all use this method and it worked. Also [you know] how hard it is to teach her [who is so] strong willed. I am not sure whether I am right or not. If I can have some other ways out [for her behavior issues], I would not punish her in that way…

Families with more than one child especially spoke about the need to teach siblings without disabilities to interact and assist the child with IDD. Usually these families were from rural areas where the law permitted them to have another child if the first child has disabilities. Indeed, they did not expect the younger children without disabilities to take care of the older ones for their entire life. Instead, their intention in having another child was to have a peer with

76

whom their child with IDD could play. However, these families were lacking in appropriate parenting skills in dealing with two children, especially when the child with IDD was demonstrating aggression.

> Yuchen felt shocked when Yuxin ran around at home, hitting herself and shouting. I still did not understand why Yuxin could not accept Yuchen by her side. Then Yuchen began crying…But I cannot do anything about it. Even their father and I cannot…

Social inclusion. Respondents vocalized the importance of a sense of social acceptance and belonging in their lives. In fact, generally most respondents expressed their desire to feel accepted by people or to participate in social activities as with all family members. Moreover, respondents had significantly more needs concerning acceptance for children with disabilities than with other family members. "I can sense the discrimination to her when we go out." Some respondents became very emotional when they shared their experiences about people who had shown discrimination: "The bus driver eventually let us in. It is not wholeheartedly accepted. I should say it is a feeling of mercy because I had to use a basket to carry [my son] on my back."

Some respondents desired to develop friendships; however, they found their friendships were limited to parents with similar conditions, usually parents of children in the same classroom. Many respondents expressed needs to maintain friendships which could provide emotional support. They also described being far away from friends due to relocation and reported a feeling of loss.

Some respondents expressed needs to participate in community activities, but due to residency limitations, the neighborhood committee (i.e., the community agency in charge of all community affairs) refused to include them. One mother related:

I never had them [persons from neighborhood committee] knock at my door to ask what help we want…when my son wanted to work as the newspaper delivery guy for some apartments nearby, I went there. They told me because my husband, the owner of my apartment had no Beijing residence, they are not responsible for providing any services or assistance.

Enhancement needs. Enhancement needs refer to families' needs to realize family growth and development for a better family life. Respondents expressed two types of enhancement needs: (a) emotional health and (b) future planning.

Emotional health. Emotional health needs related to the mental health, feeling, and affective conditions of family members. Emotional health needs were regarded by most respondents as "not so important compared to other needs" because they believed emotional support was an excessive desire for a better quality of life. In fact, respondents expressed various needs in terms of accepting the fact that their child had IDD, fearing that their child might have other possible disabilities, using coping strategies to manage stress, getting support from a marriage partner and other family members, and feeling hope for the future. One mother talked about her emotional journey:

I used five years to accept Xufeng had cerebral palsy. Xufeng was very healthy and normal at birth. If not for that accident [the child fell out of bed when she was six-months old], she would be just like other peers. However up till now [the daughter's] father never brings her out for parties, weddings, or recreation activities with Xulin [twin brother without disability]… I used to go to a psychiatrist once a week…also my sister, brother, and mother helped me out…. After that, I never went out for job, shopping, or travelling. I had great pressure to do training [i.e., rehabilitation and therapies] because I changed

78

my life focus to Xufeng and indeed, [she was] my job…Now I feel kind of separated

from my husband because of my joblessness. We have less and less to talk about and

communicate…[I think] he has a normal life, going to work every day, but I stay at home

and feel exhausted to take care of two children…Neighbors always say that I am a strong

woman to shoulder such great responsibility. And I am also such an easy-going person.

But indeed no, I am very weak inside because except myself and my family, no one

would love to help me…that's true [crying]…Now I recently found he has some

characteristics of autism…if so, it will kill me…that's true [crying]…what if, [Xufeng] is

8 years old, and I cannot carry him on my back to the sixth floor [to my apartment]?

Future planning. Respondents from all groups and interviews spoke about the needs

related to what would happen to children and families when the children became adults or when

parents died before their children. The overall orientation was towards children's future planning

needs with regard to (a) opportunities for employment, (b) medical and health issues, and (c)

support for living independently. These quotes recurred many times:

I want him be independent…independent!

I hope government can have some ways to help us to manage the money [which we saved

for him] after I am no longer around.

I am fine with her current status. All our family members love her. What I am worried

about is her future….[actually] all children of the parents at present here today…Who

brings her to the hospital and who pays for the medicine?

If he can have a job, no matter how much he gets paid or what kind of work, that would

be a great relief. [By this way] he will have a meaningful life, instead of being a burden

to the society.

I hope those children will be able to live on their own in the future.

In addition to future needs related to children, respondents expressed their vision of family as a whole. They vocalized their needs for personal career development, financial management strategies, and especially family union. Some respondents spoke about the necessity to be strong enough to "keep their dreams alive in the face of never-ending difficulties":

I told my husband…three years…my son will be walking without any assistance…by then, he will move back [from Tibet to the hometown in Sichuan] and we will have saved enough money…we will have our own business…maybe in the future, my son can work for us [smiling]…

The first research question asked what the family needs of Chinese families with children with IDD are and how those needs are shaped by their perceptions of family needs. Chinese families developed their perceptions or made assumptions about their needs based upon (a) Chinese cultural values, (b) family characteristics, (c) family previous experiences, (d) current family support, and (e) family awareness and expectations. These perceptions framed three primary types of family needs, including (a) survival needs (e.g., financial need and physical health needs), (b) sufficiency needs (e.g., child education/therapy, teaching child at home, and social inclusion), and (c) enhancement needs (e.g., mental health and future planning). In accordance with these three primary types of family needs, respondents expressed preferences for family support from informal and formal sources. The next section explores the family supports that Chinese families with children with IDD prefer that are aligned with their needs.

Research Question 2: What is the nature of family support that is aligned with the preferences and needs of Chinese families of children with IDD?

The second research question explored family support that Chinese families prefer that are aligned with their needs, namely, survival needs, sufficiency needs, and enhancement needs. Types of family support emerged in three broad categories including: (a) survival needs support, (b) sufficiency needs support, and (c) enhancement needs support. Additionally, two primary sources of family support emerged as (a) informal sources and (b) formal sources. Table 9 in Appendix E provides a summary of each category and subcategory, along with a sample quotation from the data to illustrate them.

Types of Family Support

As the core of my second research question, families expressed the scope of family support they need. There were eight types of family support identified: (a) financial support, (b) in-home support for caregiver, (c) child education and services, (d) parent training, (e) social support, (f) emotional support, and (g) future planning support. These subcategories were subsumed under three primary categories: (a) survival needs support, (b) sufficiency needs support, and (c) enhancement needs support. The following sections present each of these categories, together with examples of the respondents' comments giving rise to the respective categories.

Survival needs support. Families expressed their survival needs with regard to financial and physical health. When asking them about any resources or support they would like to have in terms of their financial assistance and physical health, respondents spoke about two major categories: (a) financial assistance and (b) in-home support for caregiver.

Financial assistance. Respondents generally found it embarrassing to speak about their needs for financial support, which was indeed a critically important priority of families, no matter what their demographic background. As a mother explained:

> You know the system here…or you can call [it a] cultural or social phenomena…Chinese …. I mean [in which] everybody values money and needs money…I feel so embarrassed to say that I need money, but indeed I really need…I have created a burden to the society, can I ask for more from the society?

According to the remarks of respondents, financial assistance included a multitude of programs, ranging from housing assistance, home improvement programs, income support, and government benefits to cash subsidies, both to the family and to the child with IDD. With regard to current financial assistance they have, many of the respondents from urban areas complained about the child's disability benefit being inadequate to pay for the high cost of some services which had to be accessed privately. A small minority of respondents needed cash assistance to purchase equipment and assistive technology devices. Some responses from rural families indicated there was a perception of inequitable and reduced allocation of allowances and limited types of benefits to the farmers. Among these, increasing the reimbursement of medicare was the most important financial assistance, contributing most to the comments.

In addition, many of these respondents spoke about the government's responsibility to develop financial assistance programs, types, and delivery methods. They expressed extreme frustration coming from the fact that "there is no financial help for which their children were eligible." One mother did a thorough research on that and shared her suggestions on the financial assistance items which received applause of other respondents in a focus group discussion:

In terms of financial aid, I think, or I should say, improving the medicare insurance or

disability benefits is not enough at all. It is the first step. Direct cash assistance on

diagnosis to young children; (then) free tuition, reduced therapies and rehabilitation fee to

school-age children. Then full social security insurance to adult children. If the child has

no job, then [he or she should have] the minimum level of income necessary to have an

adequate standard of living locally. All these should be timely and appropriate to the

child and family and consider the location differences in terms of the economic status and

consumption level. Finally, we can see in what degree these programs solve our

problems…All in a word, better than nothing…If, I say if, the government wants to,

would love to [provide one or two of these], the family would not feel such pressure and

isolation.

In-home support for the caregiver. Respondents with children with moderate and severe

disabilities expressed a strong hope to have in-home support for the caregiver who takes primary

responsibility to take care of the child with IDD. In-home support included physical help,

assistance with general household chores, and personal care. Most respondents, including

families from high SES and urban areas, described their support needs generally in terms of

"respite care services" as the term is understood in the United States and said that their need for

such care was totally unmet. These support items included summer and winter holiday care for

the child, after school care for the child, and companion services at home.

Sufficiency needs support. Family support around respondents' sufficiency needs was

the strongest theme coming from qualitative data, based on the emphasis given to this theme by

the respondents. In the first research question, families expressed various categories concerning

their sufficiency needs. Accordingly, there were various support items which respondents

identified as possible supports to meet those needs: (a) child education and related services, (b) parent training, and (c) social support.

Child education and related services. Interestingly, all respondents focused on the accessibility and availability of child education and related services as the primary type of family support they needed. With regard to child education, respondents highlighted the importance of having special education schools or programs to accept their children. In Shifang, families felt extremely happy to have a brand new special education school one year after the Sichuan earthquake in 2008:

> Before, we did not have a special education school...you can see how beautiful this campus is. This is the gift of the earthquake [smiling]…[the second respondent said quietly, covering her month] The school only accepted children with mild [disability] condition…[third respondent] So we feel very lucky. I live far away; 220 miles away…there is no [special education] school in my hometown. I rented an apartment near the school…

Later in the interview the third respondent further explained that "indeed, there is no other better choice." She wanted to have her daughter enrolled in "the best special education school' in Chengdu, the capital of Sichuan province. However, the daughter could not meet the eligibility criteria due to the local residence policy that out-of-Chengdu residents had to pay a high tuition fee and sponsorship fee. She continued: "What you can sense [from the discussion with all the respondents you met yesterday] is we feel so lucky and happy that we can have a place to have them. I do not really care about the teaching quality or the school having other blind and deaf students... otherwise, my child will be like my neighbors' [child with ID], wandering around the field."

Most of the urban respondents said there were no professionals available to provide speech therapy, sensory integration training, and vocational training to children with IDD. In one focus group discussion in Beijing, respondents expressed this conclusion in these words:

> The new school is much better than the old one…but it seems the teachers who provide speech therapy left the school. [the second respondent] The school had several sources of sponsorship. There is lots of training materials here but the doors [are] locked. You can only see from outside…[the third respondent] The vocational training classroom has cooking utensils, simple knitting tools, drawing and ikebana materials…and no more. After some basic training, teachers work as keepers.

Additionally, a minority of respondents complained about the services provided by professionals, including no specialized personal care for children with severe IDD, insufficient information on child development, inappropriate diagnosis of disability, and unreasonably large teacher-student ratios.

Parent training. Parent training programs, operated through parent education workshops offered by schools, is the primary family support that respondents had; which unfortunately, respondents described as "empty formalism." In fact, only respondents from urban areas have parent training programs focused on brief introduction and characteristics of child with IDD, parenting skills, and family-professional partnership strategies. Instead, respondents articulated various programs they are eager to have, including parent management training to reduce behavior problems; parenting skills training; social skills training; and training on basic physical therapy, speech therapy, sensory integration, and psychological counseling. Furthermore, they expressed strong willingness to learn these skills:

> "I need to know how to train my child to become independent."

"I want to know more about my child's violent behaviors."

"If with basic training, I think I am able to some physical therapy at home. It should be [provided] step by step. My parents can also learn them and use them in everyday life."

Social support. Respondents expressed a strong desire to meet and talk with others who have children with disabilities. In some focus groups, respondents felt it was a great opportunity for them to get know each other to discuss their needs and preferences for support. As noted above, most families relied on their support inside their homes. Some respondents were benefiting from religious groups. For instance, one family participated in rehabilitation activities sponsored by a Catholic charity organization. Moreover, respondents also hoped to participate in community activities and be a member of their community:

> I really want my child and myself to be a member of the community, but I am fearful of
>
> rejection of my child by the neighborhood. Now I have a sense of isolation, or we are
>
> living on the edge of the society.

Enhancement needs support. Respondents focused their enhancement support needs related to future planning for their children with IDD and emotional support for themselves. They considered these two family supports as critical ways to improve their current family status, advance their family functioning, and enhance the individual family member's growth. A mother further explained the reason that she sent her son to her relative's company to work as a porter twice a week: "I had to drive [my son] 80miles by motorcycle, well…we feel it is worth doing. Only by this way, can he be more independent and have jobs in the future. If so, we will have more free time, maybe travel around the country [smiling]… Surely his father and I had made plan for our next five years and prepared for it."

86

Future planning support. Many expressed anxiety with regard to the future care of their

son or daughter with IDD should their son or daughter outlive the parents. They expressed a need

for local government to provide group homes, nursing homes, or support to help them live

independently. Also they hoped to teach job-related skills to their children based on their

children's preferences. In one interview with a mother with a 16-year-old son with autism, she

suddenly recognized she might find some potential jobs:

> Yes. You are right. He loves gardening. He could spend the whole afternoon taking care
>
> of the flowers he had. But we never realized it. Maybe his father's working unit or our
>
> community can provide some part-time jobs for him. No matter whether they can have
>
> [jobs] for him or not, I will do something on this…maybe this is a way to change his life
>
> and ours.

Some urban respondents expressed a need for communities to provide various day

programs to adults with IDD after their children left school. Beginning in 2005, neighborhood

committees in urban areas have taken the responsibility to provide welfare and information on

job opportunities to the persons with disabilities in its community. Respondents hoped that day

programs would be included in neighborhood committees' agenda and provide life skills

training, vocational training, and leisure activities and facilities to their children with IDD.

In addition to future planning support to children with IDD, some respondents also said

they needed support for their own career development. One mother shared her story:

> I know her father did much for the whole family. He left the Aigo company last year and
>
> opened the new company with his friends. He told me he worked so hard for having a
>
> better life for Xinxin. But I had to be stay at home to take care of her and Xinrui. It was

horrible to be jobless. If her father's company fails, we will have no income. I need to

learn new job skills and have to have jobs.

Emotional support. In focus group discussions, only a minority of respondents were

willing to speak about their support needs for emotional health. In in-depth interviews, however,

most respondents were more willing to share their emotional journeys and vocalized their needs

for emotional support. Some mothers talked about the great assistance they had received from

psychologists. Some respondents pointed out they sought support from grandparents and other

family members. Nevertheless, most respondents claimed that they had to accept the disability of

their child and cope with stress by themselves. Some responses showed the pressure of full-time

caring and the need for emotional support in these circumstances:

> I feel…although I did not admit yesterday…I really need to have some support for
>
> myself. I seem to have lost friends, co-workers, my parents, and even my husband. I am
>
> extremely alone [crying].

Sources of Family Support

With regards to who is able to provide family support, respondents spoke about various

providers. Two primary sources emerged as (a) informal sources and (b) formal sources.

Informal sources. Respondents indicated that most of support they currently have is

from grandparents, spouse, friends, spouse's friends, extended family members, other parents of

children with IDD, and co-workers. A minority of respondents from urban areas said friends

from church groups were a "very helpful support."

Several respondents said that they did not have much support from extended family or

friends, either because they lived too far way or because respondents themselves concealed the

disability of the child. But parents who did have support from grandparents, extended family

members, and friends described their support as a "powerful and secure backing." One mother further explained: "My mom is my extra hand. She gives me not only physical or emotional relief; it is more than beyond that. I should say her presence at my side, is an extraordinary support for me!"

Most respondents spoke about the experiential information they received from other "experienced parents" or parents with children with similar disabilities as "invaluable." In my visit to schools or agencies, I found several parents gathering together and sharing their experiences with parenting their children and information related to their children. In most cases, these parents were accompanying their children to provide toileting, walking, and eating services. In addition to group settings, parents gathered "first-hand" information through e-mail and telephone conversations. One father said:

> She (the other mother with a child with IDD) always called my wife about the epilepsies. We really supported each other. If my child was having an emergency and went to the hospital, she would come over and make meals for us. It was one of the most supportive things for us.

Formal sources. Responses from families with children with IDD demonstrated their needs for services provided by professionals, including those from disability-specializing entities, educational agencies, communities, and government bodies. In addition, respondents perceived that segregated special education schools still work as the fundamental place where children benefit. Namely, educators from special education schools/programs/agencies are the primary formal family support providers. Specifically, most respondents pointed out that schools need to have professional therapists who can provide PT, OT, and speech therapy. Some

respondents vocalized the need to have additional teachers to work with children with severe IDD:

> My child needs a professional teacher urgently. The classroom has only two teachers with 18 students ranging from mild to severe IDD... [the second respondent] I had to have a nanny to accompany her in the class. Otherwise, the school will refuse my child [the third respondent] When a student with severe IDD was lying on the ground crying, two teachers had to go to her. Then my child and others learned from the student and would lie on the ground too. The teachers cannot stop it. Everything is chaos. I do not want my child to learn this…he needs systematic treatment and education, experienced professionals, and qualified therapists.

In addition to having more professionals to work with children with IDD, respondents pointed out additional training should be provided for existing professionals. One mother said:

> When I told the teacher of my child that she might consider floor time training, she said she knew nothing about it. When I wanted to have a look at my child's IEP, she said no need because IEPs for each student look the same. When I asked her to pay more attention to my child's behaviors, she said she had no time…I know she is tired dealing with many students, and she wanted to do as I said above…we talked about it several times. It did not mean she did not really want to. She is just lacking training. As she told me, she was 'finding her way in the darkness without any guidance from others.'

The second research question explored family support that Chinese families prefer that is aligned with their needs. Accordingly, types of family support organized into three broad categories: (a) survival needs support, (b) sufficiency needs support, and (c) enhancement needs support. Additionally, qualitative data showed these three primary types of family support come

from two primary sources, including informal sources and formal sources. With regard to how families can benefit from various family support from both formal and informal sources, respondents shared their viewpoints on how the context of delivery and capacity of providers impact the accomplishment of support they desire to meet their needs. The next section will explore families' perception of the contextual factors in delivering family support.

Research Question 3: What are the contextual factors contributing to the accomplishment of the family support they desire to meet their needs?

The third research question explored families' perceptions of the contextual factors contributing to the ability of the family to receive support they desire to meet their needs. Qualitative data analysis identified two inseparable factors affecting supports received by Chinese families with children with IDD: (a) context of delivery and (b) capacity of providers. Table 10 in Appendix E provides a summary of each category and subcategory, along with a sample quotation from the data to illustrate them.

Context of Delivery

All kinds of family support have to be delivered to families with children with IDD in Chinese social and cultural contexts. Three contextual factors emerged as (a) values, (b) policies, and (c) local government. The following sections present each of these categories, together with examples of the respondents' comments giving rise to the respective categories.

Values. Values are defined as broad preferences concerning appropriate courses of action or outcomes which are an integral part of every culture (Kluckhohn, 1951). The values of a society are largely shared by their members. Therefore, the values of Chinese culture and society can influence the development and delivery of family support. Qualitative data

91

demonstrated that families expressed two value factors including (a) social attitudes and (b) family values.

Social attitude. According to families, social attitudes towards people with disabilities had a great deal to do with the accomplishment of support they desired to meet their needs. The Chinese traditional perspective of disability as a stigma or shame made many families face discrimination against their children's IDD from the society (Wong et al., 2004). As one mother shared with tears, "I don't want my child to have autism, but I am really concerned about it. But nobody wants to play with her. Even in this community [which is so close to the special education school and considered as a safe one], some children wanted to bully her. She just wanted to stay at home then and talk to herself…"

In addition, some respondents were worried about social attitudes towards family support. After one presentation on family support to a focus group, respondents vocalized their concerns:

> We surely want this kind of support for my family; I just question whether our society is ready for that. For example, I need vocational training for my son. And I think our government knows the importance [of providing vocational training to persons with disabilities]. But other people will argue that they need vocational training too, especially those who are jobless. [the second respondent] Yes. You are so right on this point. Others will argue society should focus on those with disabilities first, instead of their families. [the third respondent] Many people do not have such awareness like those in U.S. Even now, most people still believe it is useless to provide vocational training to my son because of his disability.

Family values. As I noted in the first research question, many respondents put family

unit needs above their individual and personal needs. Therefore, promoting family integrity,

rather than individual interests and needs, is the primary priority that families consider in terms

of their desires for better family quality of life. With regard to how family support can be

delivered to them, respondents spoke about the importance of having all family members get

involved:

> If [I can have] parent training on behavior modification [provided] to me, I think not only
>
> me, but also my parents, my husband can have a chance to attend some workshops. [the
>
> second respondent] Yes. I agree. If the support is to family, then all of the family
>
> members living together with my son should benefit from it. [the third respondent]
>
> Although my husband is far away in Guangyuan, I think he would love to come here
>
> every weekend to attend this training because we both have to deal with the aggressive
>
> behavior of my daughter.

Some respondents believe in karma, the concept that the each person is rewarded or

punished in present life according to that person's deeds in the previous life. These respondents

were very cautious about utilizing family support at home. As one mother shared her story:

> I have to admit it is I and my family that delayed my daughter's [intervention for her]
>
> disability. We actually found she has some delays in communication and behavior
>
> development when she was only one year old. However, my parents-in-law did not agree
>
> to bring her to hospital and let outsiders know she had problems. They felt it was a huge
>
> shame. And also they thought my daughter was a punishment for their wrong-doings
>
> before. Her grandpa is a faithful follower of Buddhist beliefs. So she did not go to
>
> daycare and stayed at home with them. Even today, they have not told their relatives that

93

my daughter has ID. Also they did lots of good things after they knew my daughter had

disability to better change her life and help her alleviate or overcome her

disability….They probably will not [accept] any kind of services or support by outsiders

to my family…They will close the door to them.

Policies. All respondents touched on the policy issue in terms of how to design, develop,

and deliver family supports to meet their family needs. They spoke about how policies could

play a more significant role in providing family support programs by (a) refining the existing

policies related to children with disabilities and (b) authorizing public policy on family support

to children with disabilities.

Refining the existing policies. Some respondents expressed their disappointment with

current policies related to children with disabilities. A minority of respondents complained that

they are not fully informed about disability benefit polices which had complicated eligibility

criteria and application procedures. Most respondents thought the existing policies, including

local policies and regulations, are too general and vague. For instance, some respondents

described local policies to provide financial support to families with children with severe

disabilities. However, the policies did not specify the method, the amount, and the duration of

financial support. One mother from Yichang shared her story:

> Our family felt shameful when we got to know that my daughter had autism because we
>
> gave the society a big burden, also for myself. So I did a long struggle about whether I
>
> should ask help from the government….after a long time, my husband began to check
>
> online for any policies, state or local, concerning rights and benefits of my daughter. The
>
> only one is some state regulations on including autism into mental disability. Also some
>
> [regulations are] on including children with autism into special education for children

with ID. Then there is no more beyond that. He printed them out and brought it to the local special education school. Believe it or not! The school staff said that they never heard of this regulation. Then I checked the regulation carefully and found out it says 'local schools should make attempt to accept children with autism based on their condition and capacity.' I went to the local court and found that I could not file a lawsuit because the school is not wrong [to refuse my daughter]

Authorizing new policies. Most respondents vocalized that they never heard of any policies or regulations on providing support to their families. In fact, the policies with which they were familiar are those related to providing education to their children with IDD. However, none of them can articulate the name of the state law (e.g., Law of the People's Republic of China on Protection of Persons with Disabilities). Some urban respondents with a good education background actively vocalized the necessity to establish new policies on providing necessary support to their families. As one father said:

We cannot compare ourselves with Americans or any other [families] in developed countries. But the Chinese government must have new polices for those with disabilities and us because it is a huge population. The most important thing to be on the law is providing the necessary assistance we need badly and urgently, like financial help. Also the law has to be clear and the items have to be specific enough…This is a social problem and also the issue that government needs to pay more attention.

Local government. Local government played a unique role in the implementation of policies and execution of support for children with IDD. Families identified three areas in which local government most impacted the achievement of family support: (a) leadership, (b) partnership, and (c) execution.

Leadership. According to respondents, leaders of local government bodies in charge of disability affairs have decision-making power to support or impede the accomplishment of family support. In general, respondents spoke about two leadership entities from which they needed to have family support: the local education agencies and the Local Association of Persons with Disabilities (LAPD). In some rural areas in poverty such as Qianjiang, the leader of the school with one inclusive program for children with IDD met with me to explain how he took families into consideration when providing special education services and his willingness to work with me to design and deliver family support programs in his school. He also shared with me his efforts and difficulties he had experienced in opening the only local inclusive program. Meanwhile, respondents felt very supportive of this leader:

> The school leader really cares about us. He knows us and made home visits to each of us. He asked us whenever he saw us what we needed and what he can do…He will be very happy with trying some family support programs here.

In addition, respondents expressed concerns about leadership changes. One mother recalled her experiences:

> For us, our first need is the therapy for children, such as OT, PT, and speech therapy. We had them before and our children had specific periods of time to have these services. But now after the new leader came, all therapies stopped. And the teachers here did not provide any specific training anymore; instead, they said they integrated training into everyday teaching activities and tasks, which are more natural. But I don't think my son benefits from that and his speech [ability] has lagged behind…

Partnership. Respondents perceived that segregated special education schools still work as the fundamental place where children benefit. Therefore, most respondents expressed strong

wishes to work with school or program professionals and would love to "do anything to be partner with them for the child." In general, they needed professional guidance to teach their children at home. However, they felt shameful about asking for additional help from the professionals. One father said:

> The teacher is already very busy with these children with IDD. So I did not want to ask her to do more after class. My son really wants some athletic training to make his muscles stronger …I want to ask her to make a detailed plan for me to follow at home, not only just in class…But she is so busy with other students who will participate in the Special Olympics. I think if I have an opportunity to work with her [on my daughter's training], that will be a great support for my whole family.

Some rural respondents spoke about professionals as "doctors" who have absolute power to have prescriptions and themselves as "patients" to absolutely accept and have the medicine. They complained about the lack of specialized services for children with IDD; however, they were afraid to ask for it from schools. As one grandfather said: "Who dares to speak [that] out? They will expel my grandchildren then. They have done a lot to accept my two grandchildren with ID." Some urban respondents established good partnerships with professionals and felt it was a truly invaluable support. As one mother said: "Yuan (the teacher's name) will surely work with me. She is just like my close friend. She will love any support for my family and work with me." To this mother, partnership with a professional includes a collective effort and experience and will facilitate family support design and delivery.

Execution. Respondents expressed time and time again the importance of local government being willing to "work with" them and "fully execute" family support programs.

97

Here respondents spoke about the execution ability of family support providers and leaders. One mother emailed me after the interview and further expressed her thoughts on family support:

> I think family support is a great idea and should be put into policy agenda urgently. However, it is not enough. Direct providers from the LAPD have to have that awareness and the ability of executing and implementing the services to us effectively. They have to be clear about how to do it, and if they cannot, then what methods to compensate [for not being able to provide family support] and who should shoulder that responsibility. All is the execution ability of LAPD indeed.

Capacity of Providers

In terms of who should take the responsibility for providing family support to families with children with IDD, respondents identified four factors related to formal and informal sources facilitating or impeding family support in China. These four factors included: (a) time and energy of providers from informal sources, (b) availability of providers from formal sources, (c) ability of providers from formal sources, and (d) commitment of providers from formal sources.

Time and energy of providers from informal sources. Respondents indicated that most of the support they currently have is from informal sources, including grandparents, spouse, friends, spouse's friends, extended family members, other parents of children with IDD, volunteers, and co-workers. In addition, they believed that they were very comfortable with having family support programs together with them and needed their ongoing support to implement training or instruction to their children with IDD at home. For instance, one mother said that she would much more love to work with her parents to carry out the behavior management training at home.

However, respondents expressed concerns about "endlessly asking help" from their family to provide any support or services because they also had to consider their needs and availability. In one home visit to a Beijing mother, I encountered a mother whose mother was leaving her family to take care of her brother, instead of her sick child with ID. Then the mother explained:

> I have already asked so much help from her [my mother], and I felt shameful and guilty. On the one hand, I have my own family and grew up. So I should not ask her help. On the other hand, I really have to have her because I cannot find a way out. She had been helping me take care of Xinxin for nine years. Now she has a chronic illness which needs long-term acupuncture. She had no time to go to hospital. Also I have a young brother who now lives in hospital. So these days my mother has to go to see him every afternoon. What's the life of her own? She told me she does not want to help me anymore and wants to have some free time to find a partner for the rest of her life. She needs to be taken care of and be loved too…[crying] do you think I am too selfish?

Availability of providers from formal sources. Respondents vocalized time and time again they needed professionals who can work with their children and themselves. In fact, the shortage of special education teachers, related services providers, therapists, nursing staff, and doctors is very dominant in each research site, even in Beijing and Shanghai. These quotes recurred several times in focus group discussions and interviews:

> My son needs a professional teacher urgently.

> Here we do not have physical therapist. Actually, we do not even have any professionals specialized in therapy or rehabilitation.

> Two teachers for one class with 25 students like my daughter. Nobody can do that job.

Some respondents paid high service fees for private agencies to have therapy and rehabilitation. They believed that the training to the child and parent training programs provided by private agencies are systematic in terms of content design and curriculum delivery. However, according to the respondents, these newly established agencies could not keep the service providers for the long term. One mother shared her experiences with an agency in Beijing. The agency was established by a mother with a child with autism. The respondent's son has been in that agency for three years to have applied behavior analysis (ABA) training:

> The professionals are fine, but unfortunately they left one after another. I thought the establisher [of the agency] has her own beliefs on educating children with autism and trained some graduates majoring in special education or therapy. The first generation of these [professionals] was really good, but the following generations are not good and [the numbers of them] decreased much. The establisher's belief does not attract [them] to work for the agency any more. So I gave up.

Later at my home visit, the respondent had a tutor coming for her son. She quickly guided the tutor to her son's room and returned to me for our interview. After a deep exchange of her thoughts, she admitted that she had to find an experienced professional from that agency to continue ABA training. She also told me she paid high for that tutor. She was afraid that if our project [i.e, the in the larger project of *Inclusive Education Rights of Children with Disabilities in China* which I worked for] provided ABA training to her son, she will not have such an experienced tutor any more.

Ability of providers from formal sources. Another issue that concerned respondents was the ability and quality of providers from formal sources. In rural areas, special education professionals were mostly from general education schools or at the age of retirement. Although

they had some in-service training, they might not be fully aware of the significance of providing

supports to the whole family and lack of the professional skills to implement services such as

behavior modification and speech therapy. Some professionals were nearly 50 years old, and

according to respondents, they did not truly love their jobs; rather, they were doing it to "kill

time until they could retire at the age of 55."

Some respondents were disappointed with the staff from the LAPD. According to them,

the direct service providers did not really understand their condition, needs, and priorities. A

rural father shared his experiences with staff from his LAPD.

Every Spring Festival, some staff from LAPD will come to my house to give me oils and

rice to show how they are concerned about me. But I need more beyond that…On other

days if I look to them to ask for help or any information, it would be very hard. They

were either not at LAPD or in the meeting room. One time I told them my son needs

rehabilitation. They said 'rehabilitation, like medicine, is useless when you do not have it.

If you had rehabilitation once a week, which is what we can do, it is useless. You'd better

not have it.'…Another time, my wife asked about a job for my son after he graduates.

They said 'job?! Are you kidding? What kind of job can he [with ID] do? You have to

have a clear understanding of your son and solve it by yourself.

Commitment of providers from formal sources. The final, but the most important

issue families addressed, is commitment of providers from formal sources. One mother

characterized commitment as "the basic precepts, the most important attitude of professionals

when providing family supports [to us], and how faithfully they carry them out." To respondents,

providers had to have a sound set of beliefs. These beliefs included that they understand the

unique needs of the child with IDD and the family, take actions for their needs, design and

implement services, and work with them for achieving desired outcomes. One mother shared her story with a professional:

> She [the professional] is great. She knows my son and me. She made home visits once a week to provide speech therapy at my house. Four years! You cannot believe that even in heavily rainy days or windy days, she walked 20 miles [to my house]. In summer or winter holiday, she would have assignment for us to train my son. She told me she simply believed that my son can talk one day….I would love to say her persistence is not blind, but with definite purpose.

Summary of Findings

Overall, this study develops a conceptual framework explaining the relationship among factoring influencing family perceptions of their needs, family needs, and the resulting types of family support which are aligned with family needs and ultimately, the delivery of family support to families with children with IDD in China. The framework shown in Figure 2 (p.60) illustrates first that the family's perception of their needs shapes their tangible needs. The three primary types of family needs are survival needs, sufficiency needs, and enhancement needs.

Furthermore, the framework depicts how family needs determine the support families prefer that are aligned with their needs. Specifically, three types of family support emerged in accordance with the three types of family needs: survival needs support, sufficiency needs support, and enhancement needs support. Figure 2 also illustrates the sources of the family support.

Finally, Figure 2 demonstrates that the family's perceptions of various family supports can be accomplished through two inseparable factors, namely, context of delivery and capacity of providers. These two factors work together to influence the practices and outcomes of family

support programs to families with children with IDD provided by both formal and informal sources. For example, a grandmother's previous negative experiences with physical therapy training provided by a service agency shaped her desire for high quality physical therapy and related parent training provided by professionals. The grandmother might have distrust of the professionals and concern about the ability of the physical therapist. Meanwhile, she and her family might feel that professionals conducting therapy at her home is intrusive. Instead, she prefers to transport her granddaughter to an agency or school to receive therapy, and she wants to participate in the program with her granddaughter to learn any related skills so that she can work with her granddaughter in her home setting. Therefore, family support providers need to take family needs into careful consideration when designing and delivering physical therapy and related parent training programs.

In the following chapter, I will further explain this framework as it relates to literature and the findings. In particular, I will explore how the components interact with each other and moreover, how the types of family need relate to each other and work together within the family unit. I will also address implications for research, policy and practice.

CHAPTER FOUR: DISCUSSION

The families who participated in this study assisted me as I investigated the needs of

Chinese families with children with IDD and informed me as I explored the process of

developing family support programs within the unique cultural and social context of China. I

answered each research question by identifying the themes that developed from the qualitative

data analysis. In this chapter, I discuss each research question as it relates to the findings and

relevant research. I also identify the limitations of this study and implications for research,

policy, and practice.

Key Findings

Overall, from this study I have developed a conceptual framework explaining the

relationship among factors influencing family perceptions of their needs, family needs, and the

degree to which family support is aligned with family needs and, ultimately, the delivery of

family support to families with children with IDD in China. The qualitative data suggest that

Chinese families demonstrated both unique and universal unmet family needs as shaped by their

perceptions of needs. Contextual factors and the providers' capacities may impact how family

support is delivered to and accomplished with families with children with IDD. In this section,

using the theory framework to analyze the dynamics I observed, I discuss each research question

as it relates to the findings and relevant research.

Research Question 1: Family Needs

The first research question asked what types of needs Chinese families with children with

IDD perceive they have. The following section will explore family needs from (a) factors

influencing perceptions of family needs, (b) types of family needs, and (c) dynamic nature of

family needs. I provide a case story of a rural Chinese family from my participants as an example to better illustrate the dynamic nature of family needs.

Factors Influencing Perceptions of family needs. This study found that family needs are shaped by Chinese families' perceptions. Furthermore, this study found these family perceptions are determined by the family's current condition and their family quality of life preferences. In fact, needs assessments generally require identifying the discrepancy between two conditions: the current states and desired states (Altschuld & Witkin, 2000; Kaufman, 1988). According to the needs assessment framework developed by Kaufman (1982), the current states (i.e., what is) and the desired states (i.e., what should be) determine a person's perceptions about his or her needs (i.e., the gap). Consistent with Kaufman (1982), this study found families' current condition as involving three important elements: family characteristics, Chinese cultural values, and family support they currently have.

First, families' perceptions about their needs for desired family life are shaped by their current family characteristics. Family characteristics refer to the traits or descriptors of each family as a whole, including each family's geographic location, social economic status, educational background, religious preference, ethnicity, family form, size of the family, and the disability of the child with IDD (Zuna, Summers, Turnbull, Hu, & Xu, 2010). Particularly important characteristics influencing family perceptions of needs in this study were families' geographic location, SES and educational background, and disability of the child. Consider, for example, the case of Xing. She lives in a poor rural Sichuan area. She has twin boys, and one of them has severe cerebral palsy. For Xufeng, the boy with disability, Xing's family has made huge adjustments and sacrifices. Xing lived with her parents and the Xufeng in her hometown in Sichuan. Xing's husband, Zhenxuan, works in Tibet as immigrant worker. In order to make more

money for the whole family, Zhenxuan shared his rented apartment with others. Xing's parents-in-law and Xulin (i.e., the boy without disability) live in Zhejiang, the east of China. To save money, Xing carries Xufeng on a basket on her back downhill from her home, and then takes the bus to the local early intervention program, a trip that takes 1½ hours. She could not afford a motorcycle. In general, families from rural areas with a low SES and education background who have children with IDD have more demands and desire to have family support, especially financial support, physical health supports for themselves, and professional services to their child. This finding offers support to the findings of earlier studies done in China and U.S that predicting factors of family needs were severity of disability of the child and socioeconomic status (Abelson, 1999; McConkey, 2003; Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002; Zhang & Liu, 2006).

Second, in the traditional Chinese family value system, which puts family unit needs above individual member needs, families with children with IDD are more likely to take the interests and needs of grandparents and other family members into careful consideration and express the needs of the whole family based on the current condition of all the family members. This is particularly evident in Xing's family. As she said : "My parents give me strong support to take care of him. Also they make me strong enough….I know there is better school for my son in Chengdu. I still want to be in my hometown to take care of my parents." Moreover, respondents, especially grandparents, viewed themselves as integral to the whole family unit and strived to promote the family's oneness and harmony. In addition, Chinese families uphold the cultural value that their primary responsibility is to provide their children with the best education (Chan & Lee, 2004). Therefore, families utilize this value system as one of the criteria to prioritize their needs. Specifically, families express their priority needs to be their children's cognitive

development based on current academic performance, and to put behavior support and social skills training as less urgent demands. Chinese literature also suggests that Chinese parents underscore accomplishments, hold high expectations for achievements, control the behavior of their children, and consider schooling very important (Chao, 1996; Sue & Sue, 2003; Zhang & Carraquillo, 1995). Interestingly, these beliefs may affect parents' views of their children and related family support program and intervention preferences.

Finally, the quality of current family support they are receiving is another aspect of families' current condition. Some respondents expressed satisfaction with parent training workshops and current partnership with professionals from special education schools. However, when I asked families for suggestions for program improvement, these families indicated many unmet needs. The needs varied from dining services at school to needing material items. For example, Xing attended some parent training workshops related to Xufeng's disability characteristics and found them to be very helpful. She also expressed needs for more parent training on other related topics, especially parenting skills on basic speech therapy because Xufeng still could not communicate. This finding is consistent with literature from U.S that families express satisfaction even when they continue to need more support (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005). The possible reason for this finding is that Chinese parents do not have available family support (Gu et al., 2010). Indeed, most respondents expressed strong dissatisfaction with the current professional support they have because of their various unmet needs, including needs of the child and of the whole family. In contrast, families reported benefiting more from support and resources from informal sources. Therefore, they were more likely to express their needs from professionals in formal sources. However, some families

expressed concern about the stability and future availability of support from grandparents, friends, extended family members, and other parents of children with IDD.

Families' desire for a better family quality of life is another determining factor for shaping their perceptions of family needs. This study found two factors influenced families' desired family condition. Families' previous experiences with family support programs or other social service agencies, whether positive or negative, shaped their hope for their desired family life. This finding is echoed in Heller and her colleagues' studies that families who have had little family support in the past have low expectations for support (Heller, Miller, & Hsieh, 1999; Heller & Schindler, in press). A second factor is family's awareness and expectation for a better family life, which leads to their perceptions of family needs. As Rettig and Leichtenritt (1999) note, an individual's experience of family life will "depend upon the extent to which personal needs are met, as judged by the personal values, standards, and aspirations one has for an ideal family life" (p. 310). In this study, this concept is best addressed by Xing's words:

> I hope to have family union (i.e., parents and children live together), which is really a dream to me. I was sick of the life here without job and taking care of my son 24 hours a day…He is only six years old. What will I do when he is 16 years old? I almost cannot carry him now. I cried every day for the last half of year [because] I cannot find one way out …I have to be with my other son…[who] did not like his brother with disability… I am afraid if I am away from him so long, he would not like me either.

Indeed, families' aspiration for better family quality of life and their awareness of possible family support that might benefit them shapt their needs to advocate for and develop new support programs to improve their current family life (McConnell, Llewellyn, 1997; Hess, Molina, & Kozleski, 2006).

108

Types of family needs. This study identifies various needs that might be generally expected of the larger population of individuals and families in China. These needs emerged as three primary categories: survival needs, sufficiency needs, and enhancement needs.

Survival needs. Survival needs refer to family necessities to maintain family existence, including money, food, house, and medical insurance. One survival need expressed by most respondents is financial needs, which is echoed in Chinese literature on family needs of children with IDD (e.g., Chen & Simeonsson, 1994; Gu et al., 2010; Huang & Liu, 2007). Overall, respondents' comments identified various financial needs, including medical insurance, social security insurance, disability benefits, cash assistance for rehabilitation and therapy/special services, and income stability. In comparison to the Chinese literature documenting family financial needs (Gu et al., 2010; Lv & Gao, 2005), this study found that families' financial needs are not limited to only cash assistance for necessities or for therapy/special services. Instead, participants in this study expressed primary financial needs related to welfare issues varying from medical insurance to income stability. Because of the severe lack of possible services for their children, they often had to relocate to urban areas. Relocating also meant that one of the parents (usually mothers) had to quit a job to accompany the child to receive services or education. This then further strained their financial resources and even alienated families from available social support from which they benefited in their home community (Xuan, 2007). This is true in Xing's example. Xing quit her full-time job and now has some part-time jobs such as collecting garbage. Indeed, Zhenxuan's income is the main source of income for the family. In order to have more income, Zhenxuan went to Tibet as an immigrant worker; thus, they have not been together as a family for three years. She reported needing financial support urgently to purchase assistive devices and acupuncture:

I need money to buy a wheelchair or pay someone who can bring my son back home up

the hill. I really need it…but I cannot afford it…I can only afford acupuncture for my son

for two weeks now.

Respondents also expressed physical health needs as one of the survival need. Consistent

with findings by Chen and Simeonsson (1994), locating a doctor and needs for information on

the child's disability and development are primary physical health needs. Additionally, this study

found that respondents and family members are encountering several chronic health problems

due to taking care of the child with IDD, a finding that has not been documented in Chinese

literature. Xing explained that she could not afford the medical fee and time to treat her

premature heart beat in the past several months: "if I can have one free afternoon, just one

afternoon, I would love to go to the doctor. But I do not…I know I have to be with my sons so I

have to be healthy."

One reason for chronic health problems might be that parents shoulder tremendous

responsibility and stress related to taking care of their child by themselves. Another possible

reason is that there is a significant absence of health services for children with IDD; therefore,

parents may prioritize their child's physical health needs over the family's physical health needs.

Interestingly, families were seeking new treatment methods for their children. They especially

expressed needs for surgery, medicine, cell transplantation, and acupuncture. They believed

these treatments will at least have functional improvement for their children. Clearly, families

needed correct information on the child's disability, typical and atypical growth, treatment and

development, and more importantly, a realistic expectation for the child having independent

living in the society (Wong et al., 2004).

Sufficiency needs. Sufficiency needs refer to families' needs for being included into the society, having relationships with others, and seeking and providing education to their family members. Usually, with families' survival needs relatively satisfied, sufficiency needs take precedence. The first sufficiency need is for child education/therapy. Respondents strongly expressed various needs for information on adequacy of the supply of services, accessing services, and accepting services. Indeed, the limited existing Chinese literature has addressed the lack of professional support as the highest concern of families surveyed. Professional services that are lacking include rehabilitation services (Chen, 2007; Huang & Liu, 2006), other professional services (Gu et al., 2010), agencies or programs providing services to their children (Huang, Zhang, & Xing, 2009), professional guidance (Lin, Qin, & Zhang, 2007; Luo & Lei, 1999), and early diagnosis and evaluation services (Lv & Gao, 2005). In Xing's case, she urgently needs speech therapy for Xufeng because his speech regressed significantly this semester. Her need for specialized assistance for Xufeng is clear in her description of her everyday life:

> I brought my son [here] on 7:30 a.m. That means I got up around 5:30 a.m…I carried my son down the hill for half an hour and took a bus here for an hour. The school asks parents to be with their children with severe disabilities, like my son. I had to quit my job and [I] wait outside the classroom until 3 p.m. On teachers' call, I would go into the class and bring him out to toilet, assist him walking and eating…Then I brought him to the acupuncture clinic around 5p.m. by bus…we usually got back home around 8 p.m. and had dinner and everything done…I usually went to bed near midnight. My life is always the same."

A second type of sufficiency need was the need for instruction on how to teach the child at home. Compared to needs expressed on child education and therapies from professionals, respondents focused on parenting needs in terms of independent living skills, behavior management skills, social skills, sexuality issues, and safety issues. Interestingly, in comparison to U.S literature that schools and families coordinate together to provide independent living skills, behavior support, and social skills to children (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010), Chinese families believed they should shoulder primary responsibility, instead of professionals, to teach these skills to their child as a "good" socialized person (Xuan, 2007, Zhang & Liu, 2010).

Finally, the third sufficiency need expressed by Chinese respondents was for social inclusion. This has not previously been explicitly documented in Chinese literature. Although some studies highlighted the cultural stigma and discriminatory beliefs towards families with children with disabilities as their one of the primary stressors in raising their children by themselves (e.g., Deng & Harris, 2008; Wong et al., 2004), they ignored families' strong needs to be accepted by the society and develop friendship with families with and without children with disabilities. Therefore, families reported having no social inclusion programs and strategies to assist them with inclusion into social and community activities.

Enhancement needs. Enhancement needs refer to families' needs to realize family growth and development for a better family life. Interestingly, in comparison to U.S literature that addresses the emotional health needs as one of the primary needs of families (Brotherson et al., 2011), Chinese families held the view that emotional support as an excessive desire or beyond their expectations for a better quality of life. Only three studies found mental health and emotional support as a problem faced by Chinese parents, especially parents with children with

autism (Luo & Lei, 1999; Wong et al., 2004; Zeng, 2006). To be more specific, these studies found coping with stress or a sense of being stigmatized as the primary emotional stressor of families with children with IDD. In contrast, in this study, families expressed various emotional needs in terms of accepting the fact that their child had IDD. One possible reason for a lower emphasis on emotional needs in the Chinese literature might be that emotional health has long been ignored in education, health care, and social welfare research (Zeng, 2006). Another possible reason is Chinese families with children with disabilities have to meet their survival and sufficiency needs (e.g., financial needs); therefore, they are more likely to ignore their emotional support needs even though they are experiencing various emotional concerns and problems.

Another enhancement need is future planning for the whole family. Mu (1995) pointed out that families were most worried about what would happen to children and families when the children became adults or when parents died. This was due to the poorly established social support and welfare systems in China (Huang & Liu, 2007). It may also be due to dominant Chinese cultural values that emphasize future prevention and avoidance of any unnecessary troubles (Gu, 2002). In the end of the interview with Xing, she expressed her wishes with tears:

> in three years…my son will be walking without any assistance…by then, my husband will move back with enough money…we will have our own business…maybe in the future, my son can work for us [smiling].

Dynamic nature of family needs. Maslow (1943) proposed a theory pertaining to a hierarchy of human needs. Maslow's hierarchy conjectured that the most basic level of needs must be met before individuals express a strong desire for the higher-level needs. The complexities of the needs expressed by Chinese families in this study demonstrate, however, that more than one type of need may occur in one family. Also, more than one need may motivate

113

families' desire for enhanced family quality of life. In Xing's family, all three primary categories of needs occurred. Moreover, the findings indicate that the order of needs can be different for different families. For example, Xing prioritized financial needs first and put emotional support needs least. However, for one family with good SES status in Beijing, the mother might place her emotional support needs (e.g., coping with stress) above those of survival needs.

Additionally, further analysis of the interviews revealed a notably dynamic nature of family needs. The findings indicate the families' perception of needs impacts the variation of family needs. Specifically, any change in the current family condition will influence how family needs change. For example, if the Local Association of Persons with Disabilities (LAPD) assists Zhenxuan in finding a self-employment opportunity and provided funds, Xing's family life would experience a fundamental change and her survival, sufficiency, and enhancement needs would vary accordingly. Similarity, if Zhenxuan expects to work more than three years in Tibet, Xing will likely continue to be feeling frustrated, and her future planning needs may regress to meeting her needs at the lower-order which is easier to satisfy, for instance, Zhenxuan can rent an apartment by himself and Xing will bring two sons there for holidays.

Research Question 2: Family Support

The second research question explored family support and its alignment with families' preference. The following section will discuss (a) types of family support and (b) sources of family support.

Types of family support. In comparison to the vast array of family support, both formal and informal, the types of family support that Chinese families desire are more focused on the child, which is consistent with findings of other family needs studies conducted in China (Huang & Liu, 2007; Mao & Jiang, 2010, Zhang & Liu, 2010). Additionally, as noted in Chapter 1, very

limited intervention research has targeted the effectiveness of family support on families and children with disabilities in China. Only Xu & Zhang (2009) indicated a need for addressing individualization of family support according to variability within a family. In this study, initial focus group discussions indicated a promising interest and desire for family support. However, further in-depth interview and observation with family members found that families held a strong passive attitude towards its development and implementation in China. As one mother said, "I have been interviewed several times by doctoral students, educators or whoever they might be about the future implementation of very exciting programs [benefiting] us. But never, never, a follow-up research or update with me…I really hope you are not one of them."

One possible reason is that due to long-term self-blame, stigma, and stress, many families made no attempt to expect more from society or make any future plans for the whole family. Survival or keeping the current family condition is their desire now. As discussed by Monsen (1999), families who lost confidence and hope for the future might keep a negative perspective and low expectation for the future of the child and the family. Therefore, it is critically important for support providers to work with families to cope with stress and stigma, sustain confidence, and discover their resilience when providing family support (Wong et al., 2004). However, the needs for emotional support and social inclusion were not highlighted in family needs assessment studies in the 1990's conducted by Bailey et al., (1992), Dunst et al., (1998), Kreutzer, Serio, & Berguist, (1994) , and Seligman & Darling (1997). Perhaps it may relate to the level of stress experienced by Chinese parents, which might be higher than is perceived by U.S mothers (Huang, Rubin, & Zhang, 1998). This study contributes to existing knowledge on social and emotion support for families in China.

Sources of family support. Given the lack of support provided outside family and schools, it is also not surprising those Chinese families rely primarily on their child's school, their spouse, and their extended family members for social support. These results are consistent with existing literature (Baxter & Kahn, 1999; Chen & Tang, 1997, McCabe, 2007; Wong & Wong, 2003; Wong et al., 2004). It is also not surprising families expressed strong needs for support provided by professionals, including those from healthcare, disability-specializing entities, educational agencies, communities, and government bodies. This finding is somewhat different from Chinese studies that identified families as being reluctant to seek assistance outside of the family (Gu et al., 2010; Huang & Liu, 2007; Huang, Zhang & Xing, 2007). As data reported earlier indicate, in 2008 approximately 36% of the school-age children with disabilities were not in school, but instead were in homes, orphanages, or child welfare centers (China Disabled Persons' Federation, Beijing University, & National Bureau of Statistics of China, 2009). Based on conversations with families, some schools are refusing children with severe disabilities, especially severe IDD. Some families are even abandoning their children eventually at the hospital or in the field. Since the recruitment of participants for this study involved contacts through schools, this study might not reflect the perceptions of families with children with severe disabilities in China whose children were not receiving formal education or rehabilitation services.

Research Question 3: Family Support Delivery

The delivery of family supports did not occur in a vacuum. Instead, they occurred within particular Chinese contexts. The third research question focused on the contextual factors that supported or impeded the accomplishment of desired family support to meet the vast array of family needs. Qualitative data analysis identified two inter-related factors affecting family

support received by Chinese families with children with IDD: (a) context of delivery and (b) capacity of providers.

Context of delivery. In this study, family descriptions of the delivery of family support included characteristics of the systematic variables, including the cultural values, policies, local governments, and agencies from which they accessed support. The findings demonstrated that Chinese families have to face discrimination against their children's disabilities from the society and oftentimes have to solve problems of raising their children with disabilities by themselves. These passive or negative social attitudes towards Chinese families of children with disabilities become barriers to the design and development of support for families, even though great progress has been made in Chinese social policy for people with disabilities (Wong et al., 2004). Again, findings about attitudes indicate an urgent need to include the whole family as the target receiver of family support (Hu, Wang, & Xiao, in press). Interestingly, families reported that local policy entities, especially the professionals and leaders from LAPD and schools, were instrumental in efforts to create an environment that promoted family support programs. Yet, none of the relevant Chinese articles that I found addressed the impact of leadership on the development and implementation of family support.

Capacity of providers. Just as the literature has a void in addressing the impact of leadership, there is also a void in addressing the providers' capacity in meeting family needs. Specifically, families identified availability, ability, and commitment as other critical elements that impacted the delivery of family support to them. Families also noted that partnerships were another element of the context facilitative of their desired outcomes. For some, partnerships with school professionals were overwhelmingly positive. Others found an absence of partnerships with working staff from LAPD. For these families, negative experiences with support providers

117

and professionals may have led them to give up on education and rehabilitation to their children. In the existing Chinese literature, only Mu (1995) noted that building partnerships with professionals significantly impacted the ability to meet family support needs. There were, however, no other studies on the role service providers can play either as a barrier or facilitator. Instead, U.S. literature addressed the role of strong family-professionals partnership in meeting family needs and enhancing FQOL (e.g., Turnbull, Blue-Banning, Turbiville, & Park, 1999).

Limitations of the Study

The dissertation study sought the perspectives of Chinese families towards family needs, development and delivery of family support through focus group discussions and in-depth interviews. There are several limitations to this investigation that warrant attention. First, I translated all the quotations from respondents by myself and did not adopt any translation technique (e.g., back-translation technique) to examine and ensure the translation accuracy. This may have limited translation accuracy. Second, respondents included only those whose children attended formal education or rehabilitation services. This study might not reflect the perceptions of families with children with severe disabilities in China whose children were not receiving formal education or rehabilitation services. In focus groups, 51% of the children are with mild IDD and 16% of children of interview respondents are with severe IDD. Further research should examine responses of those families in order to achieve a broader understanding the needs of Chinese families and the family support they desire. Moreover, most of the respondents were mothers: 50% of focus group respondents and 40% of interview respondents were mothers. Future research should obtain input from fathers, grandparents, and extended family members. Finally, a limitation exists regarding the age of the children with IDD. Although I was interested in the needs of families with children of different life span, due to the school-age children at

118

schools/agencies/programs, more than 62% of children of focus group respondents are aged six to 16. Future research is needed to explore needs of families of children with younger and older children.

<div align="center">**Implications for Research**</div>

There are several next steps in this line of research. In this section I recommend two areas of future research: (a) more in-depth research into family needs as an input related to the overall framework of the unified theory of FQOL, and (b) more in-depth research into Family Needs Assessment (FNA) tool development.

Implication for the Unified Theory of FQOL

Zuna and her colleagues (2010) offered a unified theory of FQOL. It proposes the identification of family needs, strengths, and priorities as the beginning point for determining how family support systems, policies, and programs may impact individual family members and the family unit (i.e., see Figure 1, p. 16). This theory defined FQOL as "a dynamic sense of well-being of the family…in which individual and family-level needs interact" (Zuna et al., 2010, p. 262). Meeting the needs of the individual family member and the whole family unit is a fairly obvious purpose of developing the unified theory of FQOL. Therefore, it is self-explanatory that family needs work as the input component of the unified theory of FQOL. As Zuna et al., stated:

> Systems, policies, and programs indirectly impact individual and family-level supports, services, and practices; individual demographics, characteristics, and beliefs and family-unit dynamics and characteristics are direct predictors of FQOL and also interact with individual and family-level supports, services, and practices to predict FQOL. Singly or combined, the model predictors result in a FQOL outcome that produces new family

<div align="center">119</div>

strengths, needs, and priorities which re-enter the model as new input resulting in a

continuous feedback loop throughout the life course. (p. 269)

In this study, qualitative data indicated that family needs are the foundations for

developing and designing family support programs to Chinese families. The results of this study

fit within the overall conceptualization of the unified theory of FQOL. As the arrow in the

bottom of Figure 1 (p. 16) illustrated, family needs are conceptualized as the input component

determining how family-related support can be developed and delivered to families with children

with disabilities to enhance FQOL as an outcome.

Moreover, this study found that family needs are shaped by families' perceptions of their

current family condition and desired family lives. Specifically, current family conditions include

Chinese cultural values, family characteristics, and current family support that families have.

These three components are equivalent to the components of the model (Figure 1), including

systemic variables, family unit/individual member variables, and family/individual level

performance variables respectively. For example, unique Chinese values that address filial piety

and family harmony are implicit systematic and contextual concepts may shape families'

perceptions that family unit needs are prioritized over individual member needs. As another

example, some families who are benefiting from local government benefits are not satisfied with

the current financial support they have and are worried that these benefits would be reduced or

stopped altogether. In this sense, systems, policies, and programs impact families' perception of

their family needs.

Additionally, individual and family unit characteristics as well as family/individual

supports, services, and practices also impact families' assumptions of their current unmet family

needs. Earlier studies conducted in China and U.S suggest that predictive factors of family needs

were severity of disability of the child and social economic status (Abelson, 1999; McConkey; Chadwick, Beecham, Piroth, Bernard, & Taylor, 2002; Zhang & Liu, 2006). The implication of this finding is that family needs do not only work as an input, but are a determining component that is also impacted directly or indirectly by the complicated interaction of systemic concepts and family/individual level concepts and performance. This study needs to be replicated to determine the impact of the systemic concepts as well as family/individual level performance (e.g., family support) to family needs. As noted by Zuna et al. (2010), more recent research has begun to investigate the impact of performance factors (e.g., family support) on FQOL outcomes. More research is needed along these lines to explore the impact of performance factors on the variation of family needs, as well as the nature of specific performance factors (e.g., the support providers) as they relate to family needs. Another research agenda recommendation is that the dynamic nature of family needs, namely, the variation of needs under three primary needs areas (i.e., survival, sufficiency, and enhancement needs) require additional research to validate the construct suggested by the results of this study.

Additionally, families' expectations for a desired FQOL impacts their family needs. Families' aspiration for better family quality of life and their awareness of possible family support that might benefit them determines their needs to advocate for and develop new support programs to improve their current family life. Bailey and colleagues (1999) found that Latino parents with children with severe disabilities are likely to have more specific and apparent needs when they have greater awareness of the services available to them, and, therefore, greater use of family services. Future research is needed to examine the impact of enhanced Chinese families' awareness and desire to utilize family support on the variation of family needs and their satisfaction with family support.

With regard to family support that families prefer to have, this study found informal sources of family support contribute critically to Chinese families. Indeed, families indicated that most of support they currently have is from informal sources. Future research should focus on identifying and building social support for Chinese families with children with IDD. Furthermore, Chinese families expressed strong needs for formal support provided by professionals. The findings demonstrated that the sources of family support are the primary issue that families addressed, which is not explicitly specified in the unified theory of FQOL. Therefore, I recommend the next iteration of the unified theory of FQOL would address the sources of family support, especially informal sources (Kyzar, 2010).

This dissertation study contributes to the field of FQOL study by supplementing the research that focuses on family needs and its relationship to family support and to the FQOL outcome. To be more specific, this study provides a framework for understanding (a) the dynamic process of how families develop their assumptions about family needs, (b) the alignment of family needs with specific types of family support, and (c) ways to deliver family support Chinese families with children with IDD (See Figure 2, p. 60). In terms of family support delivery, future research could determine if the framework and factors found in this study are interchangeable with those found in the U.S., especially the contextual factors due to the discrepancy of cultural and value systems (Hu, Wang, & Xiao, in press). The contextual factors may include the family values, social attitudes towards family support, legislation system, and the capacity of family support providers. Moreover, the dynamic nature and order of three types of family needs should be explored in the U.S. context in terms of its transferability.

With respect to the unified theory of FQOL, these findings suggest that the addition of cultural values as one element of the systems component. Zuna et al. (2010) define systems as

"as a collection of interrelated networks organized to meet the various needs of society, such as health care, education, and legal systems" (p.266). To make the unified theory of FQOL more culturally applicable and responsive to other countries and populations, future research needs to examine how cultural values impact the family needs as well as the design and delivery of family support.

One of the un-stated premises of the unified FQOL theory is that culture affects the systems, policies, and programs that, in turn, affect the families and their interactions and their quality of life. Culture refers to the "customary beliefs, social forms, and material traits of a racial, religious, or social group; also, the characteristic features of everyday existence … shared by people in a place or time" (Merriam-Webster's Collegiate Dictionary, p. 304). Culture is an implicit understanding of "who we are" and "what shapes us." And culture is one model for understanding the meaning of disability and the response of society and governments to disability (Turnbull & Stowe, 2001). The unified theory does not explicitly illustrate that culture is a powerful influence, arguably the most powerful, in affecting systems, policies, and programs that ultimately affect families' quality of life. As other research, including my own, elaborates on the findings I have set out here, it seems essential that it probe explicitly into the effects of "Chinese culture" on the unified theory and its components, and, even more, that it take into account ancient and still influential Chinese culture about families and the role of government and, simultaneously, the more recent culture articulated for China by modernist, Communist doctrine. It may also be useful for research to determine the extent, if any, to which the ancient culture is more or less prevalent in rural China and the modernist culture is more or less prevalent in urban China.

Implications for Family Needs Assessment

As noted in Chapter 1, FNA is a measurement tool that researchers affiliated with the Beach Center on Disability in the U.S. and Universitat Rmon Llull in Spain are developing to assess family needs under the framework of the unified theory of FQOL (Kyzar & Chiu, 2011). Currently, this assessment tool is in the process of pilot study in U.S, Spain, and China. I suggest that this study on family needs in China has implications for FNA development and application in terms of (a) design of the domains, (b) cultural adaptation, and (c) response format.

The findings of this study found seven areas of family needs, most of which are covered in the eight domains of the FNA. This demonstrates that the FNA assesses a relatively comprehensive range of family needs. In addition to examining family needs, another overarching purpose of FNA is to explore family prioritization of needs to effectively design and use family support to meet their needs. Because decisions about priorities require the allocation of resources and can seriously impact how the providers and organizations deliver support (Altschuld & White, 2010), future research is needed to determine what basis and criteria families use to select some needs and not others. The findings of this study indicate that families would be more likely to prioritize their domains of needs from the hierarchical order of survival needs, sufficiency needs, and enhancement needs. Further research is needed to continue the effort to test the method that families use to prioritize their identified needs.

Additionally, the finding of this study demonstrate unique family needs expressed by Chinese families as well as their attitudes towards the sources and means of delivery of family supports they prefer within the context of Chinese culture, systems, policies and programs. In view of the FNA developed by an international group of researchers (Kyzar & Chiu, 2011), it is

essential for researchers to examine cultural appropriateness and adaptation when applying the FNA to other populations and cultures.

Finally, to advance the response format and administrative effectiveness of FNA, I suggest adding open-ended questions to the FNA. Also, observation checklists can be used as supplements to provide a different window into family needs (Peterson, 2002; Banks, Santos, & Roff, 2003).

In general, the needs expressed by Chinese families in this study provide critical information on design and development of family support in China. The value of this study is that it identifies a range of needs that might be generally expected of the larger population of individuals and families in China. Since generalization is not possible using qualitative research, the next step would be to develop a Chinese version of the FNA and conduct a pilot study to test it with other families in China. This sample includes a unique demographic of families with children with IDD receiving formal services from school/agency/programs. Most of the parents interviewed are from rural areas and have school-age children. Future research could determine how other families who are outside of the current study's demographic express their needs and preferences for family support. A comparison of the outcomes might provide additional information on how to better develop family support in China to meet its described purpose.

Implications for Policy

Findings of this study recognize that issues of children with IDD necessarily involve the whole family as the focus of support. However, disability-related supports in China have only focused on children with disabilities; involvement of families and specialized family support to family members has long been ignored. It is clear from this study that there is an urgent need and that efforts must be made at national policy levels to improve the FQOL and situations of the

families described in this dissertation study. Namely, national-level policies addressing family support will provide educational, rehabilitative, and other social supports to all Chinese families, regardless of their locations (McCabe, 2007).

More important, given the critical role of informal support to Chinese families, policy makers needs to reauthorize the Law of the People's Republic of China on Protection of Persons with Disabilities and expressly endorse family support practices provided by informal support providers (i.e., grandparents, spouse, friends, spouse's friends, extended family members, other parents of children with IDD, and co-workers). Additionally, the Regulations on Education for Persons with Disabilities should be refined in terms of educators' involving informal support providers when they implement training or instruction to children at home and community settings. Policy makers also need to articulate the responsibility of LAPD, local universities, healthcare organizations to collaborate with informal support providers to assure that both formal and informal family support can be delivered to families with children with IDD.

In the remainder of this section, I elaborate on the political implications of this study based on the three components of policy and services: education, human and social services, and health care.

Education Effort

This study found that a primary issue related to Chinese families' needs is for professional educational and related services. Here, I elaborate key implications of these findings for what, who, where, and how policy change in educational services for families and their children are needed.

The beginning step is to develop different programs to meet the educational needs of children with IDD. Given the lack of other options for educating the children with IDD, the

families in this study perceived that segregated special education schools still work as the fundamental place where children benefit. As noted in Chapter 1, segregated special education is still the primary education system for children with disabilities and has been accepted by Chinese families. Therefore, Chinese educators would need to work with families to identify critical learning competencies and program structures necessary to prepare students to be more productive members of society. The findings show a strong need for schools to provide various programs to advance inclusion and productivity, including behavior support, speech therapy, social skills, and vocational training. Along with providing effective training and courses to students, it is equally important to recruit paraprofessionals and related services providers, as well as to provide on-going in-service training to educators to prepare them to implement these programs to meet children's needs.

Then educators and service providers need to take the family needs and preferences into careful consideration and provide family support where families feel most comfortable in a natural way. For instance, if the local education agency creates a policy to support families with behavior support, the natural way would be providing the support with therapists visiting the homes because those families might feel behavior training is their responsibility as parents to teach in home settings. Also, therapists might need to communicate with grandparents and obtain their support to ensure the effectiveness of behavior support within home settings.

Moreover, findings highlight the critical role of informal sources of family support in meeting their various needs as well as families' strong concern about its instability and availability. The implications of this finding are clear: educational policy makers need to include provisions to encourage and involve informal support providers into family support programs provided by formal sources. Also educators and related service providers to work with families

to expand their informal sources and social networks. Finally, given the fact that families need information about disability-related services for their children, educators are encouraged to refer families to formal sources of support, such as clinics, hospitals, and rehabilitation agencies.

Human and Social Services Effort

Due to the huge impact of disability on the whole family, families are experiencing a great stress for survival financially and emotionally, especially those families where one parent leaves to work in the city while the others stay behind. Although this kind of family break-up has been the general trend in Chinese society since the period of Reform and Opening in the 1980's, it is clear that families experience an extraordinary financial burden due to the disabilities of their children (China Disabled Persons' Federation, 2007). My first recommendation is that community-based efforts and financial allowances should give priority to families of children with IDD who are in poverty (Huang & Liu 2006; Lei,2001). In this regard, support providers from the local government in charge of human and social affairs for the persons with disabilities (i.e., LAPD) are playing a critical role to cooperate with other related social identities to solve the prioritized concerns families have. As one mother said: "One home visiting in Spring Festival (i.e., the Chinese Lunar New Year) is not enough. What I want is to solve my most urgent concerns, which are not so many indeed."

Secondly, more available housing options and transportation assistance should be created and provided to families, especially those living some distance from schools. For instance, policies on home rental or purchasing reimbursement allowances for families of children with disabilities could substantially affect the lives of children with disabilities and their families.

Finally, policy makers should consider improving medical insurance policies to meet the urgent needs expressed by families. Specific recommendations include raising the

128

reimbursement level, providing more flexible medical eligibility criteria, and developing various insurance types.

Heathcare Effort

The finding of physical health needs has strong implications for healthcare policy. Not all families have qualified and professional disability diagnosis for their children. Only families in big cities have the opportunities to benefit from disability diagnosis services from specialists at hospital. However, respondents from rural areas have to go to these cities to conduct diagnosis. Child identification needs to be well-funded to give families access to a quality heathcare system. In addition, it is important to consider providing services to families with children with severe IDD. These services might include therapeutic day time support, respite care, companionship and outings, and personal care. Several cities have conducted initiatives to provide nursing services to the senior family members (Jin & Liu, 2001; Liu, Han, Huang, & Peng, 2004). Next steps might be including children with severe IDD. Finally, families expressed a general need for information about the nature of their child's disability and medical services that are available to them. Healthcare policy makers should make more effort to provide information to families. More important, policy makers need to consider the most helpful method and format of providing information according to families' unique needs and characteristics.

<div align="center">

Implications for Practice

</div>

In order to develop family support for Chinese families, support providers must on the one hand expand their knowledge and strategies with the intention of providing support to meet family needs. On the other hand, families have to empower themselves to work as partners with support providers, including professionals and nonprofessionals. From this research,

recommendations for practices include: (a) professional development for educators, (b) professional development for other practitioners, (c) parent training, and (d) support groups.

Professional Development for Educators

Pre-service programs must do more to inform teachers about family needs and instill teachers with needed knowledge, skills, and attitudes to serve families, highlighting the unique needs of each family with children with IDD. Moreover, these programs must include specific family support components that prepare future teachers as family support providers to take family needs into consideration and work with families with the overarching purpose of enhancing their overall FQOL (Hu, Wang, Xiao, in press). In-service teacher training programs also need to include family support component. Currently, most in-service professional development programs are still focusing on teaching strategies and curriculum development to address the needs of children with specific disabilities (e.g., autism) (Wang & Lei, 2007). Families are playing an important role to generalize these strategies into home settings. This may be the first step for professionals to build active partnership with families.

Professional Development for Other Practitioners

In addition to specialized instruction or curriculum on family issues, effective professional development programs on preparing paraprofessionals, physical therapists, speech therapists, rehabilitation professionals, and social workers are critical to achieve long-term and fundamental change for families. The findings of this study demonstrated strong family needs for professionals from a broad array of disciplines and special assistants to work with professionals in both classrooms and home settings. For instance, paraprofessionals might be an effective strategy to relieve the burden of families as well as professionals to provide specialized assistance to children with severe IDD in the classroom, such as toileting, eating, and walking.

Itinerant teachers might be sent to suburban areas of the cities as well as rural areas to provide

guidance and training regarding parenting skills, family counseling, and the provision of family

support to parents at home settings.

Parent Training

Parent training is another strategy for meeting the needs of families in terms of providing

them with information and enhancing their awareness and ability to advocate for family support.

The findings indicate that parents need to have a thorough understanding of the child's

development and condition. Moreover, as there is a fundamental lack of access to appropriate

rehabilitation and therapy services, training parents becomes a critical task (Wong et al., 2004).

However, as noted above, accurate identification and prioritization of family needs is necessary

for professionals to develop training programs. The findings demonstrate several potential topics,

including (a) understanding the characteristics of IDD, (b) strategies to cope with challenging

behaviors and speech problems, (c) knowledge about home rehabilitation therapy, (d) seeking

and utilizing available resources and support mechanisms, and (e) promoting family awareness

and resilience.

Support Groups

Finally, support groups, especially parent-to-parent programs, should be encouraged to

meet families' information, emotional, and social support needs. It was found that families

generally lack opportunities to be socially included in mainstream society. Indeed, several

grassroots initiatives have been launched in China to provide counseling, disseminate

knowledge, share resources, and educate parents about entitlements of their children's services

and means to access community services such as transportation, housing, education, employment

and recreation (McCabe 2007; Hu, Wang, & Xiao, in press). One more important

recommendation is for professionals to encourage families to talk with and share their stories with other family members. This may be the first step for families in evoking their awareness to establish a family advocacy network in China.

Conclusion

Family support for families with children with IDD is both a young and broad field of study in China. Efforts must be made at policy levels to improve the situations of the families described in this dissertation study. There is much to be considered, particularly with regards to how the policy can best address the long ignored needs for effective family support and how best to design programs to meet that needs. International cooperation is one approach to address the efforts; and this study, within the larger project of *Inclusive Education Rights of Children with Disabilities in China,* provides a foundation upon which such cooperation may be built. The next steps of the larger project are to develop family support program to the families participating in this project based on their family need and evaluate their overall FQOL outcome. The conceptual framework developed in this study provides researchers with a frame of reference when exploring family needs. For my next step in the larger project, I will focus on the individual analysis of families' needs in order to design and implement individual family support programs.

At a more basic level, awareness of needs in families who have a member with a disability is the first step to understand families with children with disabilities. In the pursuit of rigorous research, an essential next step is the refinement of the Beach Center Family Needs Assessment tool to assess the quantity, intensity, and prioritization of family needs so that we may begin to identify the specific design elements of family support programs in China. In terms of practice, service providers need to take the family needs into careful consideration when working with families to design family support programs. As Luther W. Youngdahl (1950) said,

132

"Our great democracy can be measured best by what it does for the least of its little citizens." This is also applicable in China. It is self-explanatory that everyone, irrespective of skin color, income, educational background or family structure, has the most basic and fundamental right to pursue better family quality of life. The findings of this study are the first step in the development of truly needs-based practice with regard to family support program design in China for families who have children with IDD.

REFERENCES

Abelson, G. A. (1999). Respite care needs of parents of children with developmental disabilities, *Focus on Autism and Other Developmental Disabilities, 14*(2), 96-100.

Affleck, G., Tennen, H., Rowe, J., Roscher, B., & Walker, L. (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high risk infants: The benefits and costs of helping. *Child Development, 60,* 488-601.

Altschuld, J.W., & White, J.L. (2010). *Needs assessment: Analysis and prioritization.* Thousand Oaks, CA: Sage.

Altschuld, J.W., & Witkin, B.R. (2000). *From needs assessment to action: Transforming needs into solution strategies.* Thousand Oaks, CA: Sage.

Anfara, V.A., Brwon, J.K.M., & Mangione, T.L. (2002). Qualitative analysis on stage: Making the research process more public. *Educational Researcher, 31*(7), 28-38.

Banks, R.A., Santos, R.M., & Roff, V. (2003). Discovering family concerns, priorities, and resources: Sensitive family information gathering. *Young Exceptional Children, 6(2),* 11-19.

Bailey, D. B. (1991). Issues and perspectives on family assessment. *Infants and Young Children,* 4, 26-34.

Bailey, D.B., & Blasco, P.M. (1990). Parents' perspectives on a written survey of family needs. *Journal of Early Intervention, 14,* 196-203.

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

Bailey, D. B., Bruder, M. B., Hebbeler, K., Carta, J., Defosset, M., Greenwood, C. et al. (2006). Recommended outcomes for families of young children with disabilities. *Journal of Early Intervention, 28*(6), 227-251.

Bailey, D. B., McWilliam, R. A., Darkes, L. A., Hebbeler, K., Simeonsson, R. J., & Spiker, D., et al. (1998). Family outcomes in early intervention: A framework for program evaluation and efficacy research. *Exceptional Children, 64*(3), 313-328.

Baily, D.B., & Simeonsson, R.J. (1988). Assessing needs of families with handicapped infants. *The Journal of Special Education, 22*(1), 117-127.

Barbour, R. (2008). *Doing focus group*. Thousand Oaks, CA: Sage.

Baxter, A., & Kahn, J.V. (1999). Social support, needs, and stress in urban families with children enrolled in an early intervention program. *Infant Toddler Intervention, 9*(3), 239-257.

Beach Center on Disability. (2006). *the Consensus Statement on Family Support.* Lawrence, KS: Beach Center on Disability, University of Kansas.

Beckman, P. J. (1991). Comparison of mothers' and fathers' perceptions of the effect of young children with and without disabilities. *American Journal on Mental Retardation 95,* 585-595.

Bengtson, V. L., Acock, A.C., Allen, K.R., Dilworth-Anderson, P., & Klein, D. M. (Eds.). (2005). *Sourcebook of family theory & research*. Thousand Oaks, CA: Sage.

Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry and Allied Disciplines, 35,* 171–209.

Brotherson, M.J., Summers, J.A., Naig, L.A., Kyzar, K., Friend, A., Epley, P., Gotto, G.S., &

Turnbull, A.P. (2010). Partnership patterns: Addressing emotional needs in early intervention. *Topics in Early Childhood Special Education, 30*(1), 32-45.

Buysse, V., Castro, D.C., West, T., & Skinner, M. (2005). Addressing the needs of Latino children: a national survey of state administrators of early childhood programs. *Early Childhood Research Quarterly, 20*, 146-163.

Chadwick, O., Beecham, J. Piroth, N., Bernard, S., & Taylor, E. (2002). Respite care for children with severe intellectual disability and their families: Who needs it? Who receives it? *Child and Adolescent Mental Health, 7*(2), 66-72.

Chan, S., & Lee, E. (2004). Families with Asian roots. In E.W. Lynch & M.J. Hanson (Eds.), *Developing cross-cultural competence: A guide for working with children with families* (pp. 219-298). Baltimore: Brookes.

Chao, R. K. (1996). Chinese and European American mothers' beliefs about the role of parenting in children's school success. *Journal of Cross-Cultural Psychology, 27,* 403-423.

Chen, Y.H. (2007). Rehabilitation needs of families with children with disabilities. *Chinese Journal of Special Educati*on, *87*(9), 15-20.

Chen, J.H., & Simeonsson, R. J. (1994) Child disability and family needs in the People's Republic of China. *International Journal of Rehabilitation Research, 17,* 25-37

Chen, T.Y., & Tang, C.S. (1997). Stress appraisal and social support of Chinese mothers of adult children with mental retardation. *American Journal of Mental Retardation, 101,* 473-482.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

China Disabled Persons' Federation. (2006). *Report on numbers of persons with disabilities in China.* Retrieved from http://news.xinhuanet.com/politics/2006-

136

12/01/content_5419388.htm

China Disabled Persons' Federation, Beijing University, & National Bureau of Statistics of

China. (2009). Report on the status of persons with disabilities in China in year 2008.

Retrieved from http://www.gov.cn/fwxx/cjr/content_1315535.htm.

Creswell, J. (2002). *Educational research: Planning, conducting, and evaluating quantitative*

and qualitative research. Upper Saddle River, NJ: Merrill Prentice Hall.

Creswell, J. (2005a). *Qualitative inquiry and research design: Choosing among five traditions.*

Thousand Oaks, CA: Sage.

Creswell, J. (2005b). *Educational research: Planning, conducting, and evaluating quantitative*

and qualitative research (2nd ed.). Upper Saddle River, NJ: Merrill Prentice Hall.

Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five traditions*

(2nd ed.). Thousand Oaks, CA: Sage.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches.*

Thousand Oaks, CA: Sage.

Creswell, J., & Miller, D. (2000). Determining validity in qualitative inquiry. *Theory Into*

Practice, 39(3), 124-130.

Darling, S.M., & Gallagher, P. A. (2004). Needs of and supports for African Americans

and European Americans caregivers of young children with special needs in

urban and rural settings. *Topics in Early Childhood Special Education, 24*(2),

98-109.

Davis, S.K. & Gettinger, (1995). Family-focused assessment for identifying family resources and

concerns: parent preferences, assessment information and evaluation across three

methods. *Journal of School Psychology, 33*(2), 99-121.

Deng, M., & Harris, K. (2008). Meeting the needs of students with disabilities in general
education classrooms in China. *Teacher Education and Special Education, 31*(3), 195-
209.

Deng, M. & Poon-McBrayer, K. F. (2004). Inclusive education in China: conceptualization and
realization, *Asia-Pacific Journal of Education, 24*(2), 143–157.

Deng, M., Poon-McBrayer, K.F., & Farnsworth, E.B. (2001). The development of special
education in China. *Remedial and Special Education. 22*(5), 288-300.

Deng, M., & Manset, G. (2000). Analysis of the "Learn in Regular Classroom" movement in
China. *Mental Retardation, 38*(2), 124-130.

Developmental Disabilities Assistance and Bill of Rights of 2000. Pub. L. No. 106-402

Dunst, C. J., Bruder, M. B., & Trivette, C. M. (2001). Characteristics and consequences of
everyday natural learning opportunities. *Topics in Early Childhood Special Education,
21*(2), 68-92.

Dunst, C.J., Cooper, C.S., Weedldreyer, J.C., Snyder, K.D., & Chase, J.H. (1998). Families
needs scale. In C.J. Dunst, C.M. Trivette, & A.G. Deal (Eds.), *Enabling and empowering
families: Principles and guidelines for practice.* Cambridge, MA: Brookline.

Dunst, C. J., Jenkins, V., & Trivette, C. M. (1984). Family Support Scale: Reliability and
validity. *Journal of Individual, Family and Community Wellness,1,* 45-52

Dunst, C., Trivette, C., & Cross, A. (1986). Mediating influences of social support: Personal,
family, and child outcomes. *American Journal of Mental Deficiency, 90,* 403–417.

Dunst, C.J., Trivetter, C.M. (2009). Capacity-building family-systems intervention practices.
Journal of Family Social Work. 12(2), 119-143.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering*

families: Principles and guidelines for practice. Cambridge, MA: Brookline Books.

Dunst, C. J., Trivette, C. M., & Deal, A. G. (Eds.). (1994). *Supporting and strengthening families: Methods, strategies and practices.* Cambridge, MA: Brookline Books.

Dunst, C. J., Vance, S. D., & Cooper, C. S. (1986). A social systems perspective of adolescent pregnancy: Determinants of parent and parent-child behavior. *Infants Mental Health Journal,* 7, 34-48.

Education of the Handicapped Act of 1986, Pub. L. No. 98-199, 99-457, 101-476, U.S.C., Secs. 1400-1485.

Finn, D. M., Vadasy, P. F., Snyder, S., & Calamas, M. L. (1990). *A pilot study on the content validity of the Prioritizing Family Needs Scale.* Unpublished manuscript, University of Alabama, Birmingham.

Gannotti, M. E., Kaplan, L. C., Handwerker, W. P., & Groce, N. E. (2004). Cultural influences on health care use: differences in perceived unmet needs and expectations of providers by Latino and Euro-American parents of children with special health care needs. *Developmental and Behavioral Pediatrics, 25*(3), 156-165.

Gu, C.F., Chen, Y.H., Wang, R., Cao, Y., Mu, G., & Li, Y.Y. (2010). Needs of families with children with disabilities in Beijing *Chinese Journal of Special Educati*on, *124*(10), 7-12.

Gu, D.Q., Piao, Y.X. & Liu, Y.H. (2010). *History of Special Education in China.* Beijing: Beijing Normal University Press.

Hastings R. P. (1997). Grandparents of children with disabilities: A review. *International Journal of Disability, Development and Education 44,* 329–340.

Heller, T., Miller, A. B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with developmental disabilities and their family caregivers. *Family Relations, 48 (4)*, 419-427.

Heller, T., & Scchindler, A. (in press). Family support interventions for families of adults with intellectual and developmental disabilities. *International Review of Research in Mental Retardation.*

Henderson, L., Aydlett, L. & Bailey, D. (1993). Evaluating Family Needs Surveys: Do standard measures of reliability and validity tell us what we want to know? *Journal of Psychoeducational Assessment, 11* (3), 208-219.

Herman S. E. & Thompson L. (1995). Families' perceptions of their resources for caring for children with developmental disabilities. *Mental Retardation 33,* 73–83.

Hess, R.S., Molina, A.M., & Kozleski, E.B. (2006). Until somebody hears me: parent voice and advocacy in special educational decision making. *British Journal of Special Education, 33*(3), 148-157.

Hu, X.Y. (2005a). Implications of nondiscriminatory evaluation principle to China. *Chinese Journal of Special Educati*on*, 61*(5), 13-17.

Hu, X.Y. (2005b). Core issues of family-professional partnership. *Chinese Journal of Special Educati*on*, 68*(12), 7-11.

Hu, X.Y., Wang, M., & Xiao, F. (in press). Family Quality of life of Chinese Families of Children with Intellectual Disabilities. *Journal of Intellectual Disability Research.*

Huang, J.J. & Liu, Y.H. (2006). Social support of families of children with disabilities*. Chinese Journal of Special Educati*on*, 70*(4), 3-11..

Huang, W., Rubin, S.E., & Zhang, f. (1998). Correlates of stress level of Chinese mothers of a

    child with mental retardation. *International Journal of Rehabilitation Research, 21*(2),

    237-240.

Huang, X.Y., Zhang, R., & Xing, Y.Q. (2009). Needs of 71 families of children with autism.

    C*hinese Journal of Special Educati*on, *113*(11), 43-49.

Jiang, X.Y. & Huang, Y. (2005). Families of children with disabilities in China*. Chinese Journal*

    *of Special Educati*on*, 61*(7), 86-92.

Jin, X., & Liu, Z.Y. (2001). Perspectives on community nursing services to the elderly in China.

    Journal of Chinese Nurses Training, 16(8), 5-8.

Kaufman, R. (1982). *Identifying and solving problems: A system approach.* San Diego:

    University Associates

Kaufman, R. (1988). *Planning educational systems: A results-based approach.* Lancaster, PA:

    Technomic.

Konstantareas, M. M. & Homatidis, S. (1989). Assessing child symptom severity and stress in

    parents of autistic children. *Journal of Child Psychology and Psychiatry, 30,* 459–470.

Kluckhohn, C. (1951). "Values and value-orientations in the theory of action: An exploration

    in definition and classification." In T. Parsons & E. Shils (Eds.), *Toward a general theory*

    of action. Cambridge, MA: Harvard University Press

Kreutzer, J.S., Serio, C.D., & Berguist, S. (1994). Family needs after brain injury: A quantitative

    analysis. *Journal of Head Trauma Rehabilitation, 9*(3), 104-115.

Krueger, R. & Casey, M.A. (2009). *Focus groups: A practical guide for applied research.*

    Thousand Oaks, CA: Sage

Kvale, S. & Brinkmann, S. (2008). *InterViews: Learning the craft of qualitative research interviewing.* Thousand Oaks, CA: Sage

Kyzar, K. (2010). *The relationship of perceptions of service and support adequacy to family quality of life for families of children with deafblindness.* (Doctoral dissertation). Retrieved from ProQuest Dissertations and Theses. (3412876)

Kyzar, K., & Chiu, C. (2011). *Development and research plan for Family Needs Assessment.* Paper presented at the third conference of the International Society on Early Intervention. New York.

Lei, J. H. (2001), Review and analysis of quality standard of special education *Chinese Journal of Special Educati*on, *36*(3), 7-11.

Lei, X. Y., Yang, Z., & Liu, S. (2010). The impact of parenting efficacy to rehabilitation of children with autism. *Chinese Journal of Special Educati*on, *118*(4), 33-36.

Lin, Y.Q., Qin, W., & Zhang, F.J. (2007). Needs of parents who have children with autism in rehabilitation agencies in Chongqing. *Chinese Journal of Special Educati*on, *90*(12), 51-59.

Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry.* Beverly Hills, CA: Sage.

Liu, A.M. (2009*). Counseling needs of families with children with disabilities.* (Unpublished master's thesis) HuaDong Normal University, Wuhan, China.

Liu, H.O. (2005). *From tradition to enlightenment: Change of Chinese traditional family value.* Beijing: China Social Science Publishing.

Liu, S. S. (2001). *Theory and practice for integrated education in China.* Wuhan, China: Wuhan Press.

Liu, X.X. (2004, 12 26). China Daily. Retrieved from http://www.chinadaily.com.cn/english/doc/

2004-12/26/content_403419.htm

Liu, B., Han, J.F., Huang, L.J., & Peng, Y.G. (2004). Nursing intervention to the elderly heath improvement in the community of China. *Nan Fang Journal of Nursing, 11*(12), 5-14.

Luo, Y.C., & Lei, J.H. (1999). Family needs of children in special education schools. *Education Research and Experiments*, *4*, 31-39.

Lv, X.T., & Gao, Q.Z. (2005). Support needs of mothers with children with autism. *Chinese Journal of Special Educati*on, *61*(7), 41-50.

Mao, P.P., & Jiang, Q.D. (2010). Parents' desire for the placement of children with intellectual disabilities after graduation from elementary vocational and technical school. *Chinese Journal of Special Educati*on, *115*(`), 9-14.

Marcenko, M. O., Keller, T. E., & Delaney, M. A. (2001). Children with SED and their families in an urban public metal health system: Characteristics, needs, and expectation. *Journal of Child and Family Studies, 10*(2), 213-226.

Marshall, C., & Rossman, G.(1999). *Designing qualitative research*. Thousand Oaks, CA: Sage

Maslow, A. H. (1943). A theory of human motivation. *Psychological Review, 50*, 370-396.

Maxwell, C. (2009). *Qualitative research: A guide to design and implementation*. New York: Jossy-Bass. Publishing Inc.

McCabe, H. (2004). *State, society, and disability: Supporting families of children with autism in the People's Republic of China.* Doctoral dissertation. Retrieved from ProQuest Digital Dissertation. (3133975).

McCabe, H. (2007). Parent advocacy in the face of adversity: Autism and families in the People's Republic of China. *Focus on Autism and Other Developmental Disabilities, 22,* 39-50.

McCabe, H. (2008). Autism and family in the Peoples' Republic of China: Learning from parent' perspectives. *Research and Practice for Persons with Severe Disabilities, 33,* 27-47.

McConkey, R. (2003). Information needs of parents about learning disabilities. *Journal of Learning Disabilities, 7*(3), 211-219.

McConnell, D., & Llewellyn, G. (1997). Providing services for parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual & Development Disability, 22*(1), 5-13.

McGrew, K. S., Gilman, C.J., & Johnson, S. (1992). A review of scales to assess family needs. *Journal of Psychoeducational Assessment, 10, 4-25.*

Merriam-Webster. (2008). Merriam-Webster's Collegiate Dictionary. Merriam-Webster, Inc.

Ministry of Education of China. (2003). *The major statistics of the national education development in 2003.* Retrieved from www.edu.cn/20040527/3106677.html

Monsen, R.B. (1999). Mothers' expectations of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing, 14*(3), 157-163.

Mu, K.L. (1995). Parent needs whose children with ID attending special schools. *Exceptional Children and Special Education Professionals Research, 7* (3), 17-23

Mu, K., Yang, H., & Armfield, A (1993, April). *China's special education: A comparative analysis.* Paper presented at Annual Convention of Council for Exceptional Children, Bloomington

Murry. A. M. (1959). Needs of parents of mentally retarded children. In. J.B Balcher & B.L. Baker (Eds.), *The best of AAMR: Families and mental retardation* (pp. 48-56). Washington D.C.: American Association on Intellectual and Developmental Disabilities.

National Bureau of Statistics of China. (2011). Report on 2010 China's economic and social

development. Retrieved from http://www.stats.gov.cn/tjgb/ndtjgb/qgndtjgb/

t20110228_402705692.htm

National Education Commission. (2008). Basic statistics of special education. Retrieved from

http://www.edu.cn/tsjy_9348/

National People's Congress. (1986). *Compulsory Education Law,* Retrieved from

http://edu.people.com.cn/GB/4547065.html

National People's Congress. (1990). *the Law of the People's Republic of China on Protection of*

Persons with Disabilities. Retrieved from http://news.xinhuanet.com/newscenter/2008-

04/24/content_8044571.htm

Peterson, C.A., (2002). Reflections on the challenges of program evaluation. *Topics*

in Early Childhood Special Education, 22(2), 82-85.

Qiu, X.J., & Wang, L,X. (2010). Family involvement in early intervention programs of children

with autism in Beijing. *Chinese Journal of Special Educati*on, *118(4*), 37-42.

QSR (2010). *NVivo 8 research software for analysis and insight.* Reviewed 18 June 2010,

http://www.qsrinternational.com/products_nvivo.aspx

Rettig, K. D., & Leichtentritt, R. D. (1999). A general theory for perceptual indicators of family

life quality. *Social Indicators Research, 47*(3), 307-342.

Robinson, C., Jackson, P., & Townsley, R. (2001). Short breaks for families caring for a

disabled child with complex health needs. *Child and Family Social Work, 6*, 67-75.

Rubin, H.J., & Rubin, I.S. (2005). *Qualitative interviewing: the art of hearing data.* Thousand

Oaks, CA: Sage.

Salovita T., Italinna M. & Leinonen E. (2003). Explaining the parental stress of fathers and

mothers caring for a child with intellectual disability: a double ABCX model. *Journal of Intellectual Disability Research 47,* 300–312.

Santelli, B., Turnbull.A., Marquis, J., & Lerner, E. (1997). Parent-to-parent programs: A resource for parents and professionals. *Journal of Early Intervention, 21*(1), *73-83.*

Schalock, R.L., Borthwick-Duffy, S., Bradley, V., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., Gomez, S.C., et al., (2010). *Intellectual Disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.

Seligman, M., & Dariling, R.B. (1989). *Ordinary families, special children: A systems approach to childhood disability.* New York: Guilford Press.

Seligman, M., & Darling, R.B. (1997). *Ordinary families, special children.* (2nd ed.). New York, Guilford Press.

Singer, G.H. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American journal of mental retardation. 111*(3), 155-169.

Singer G. H. S., Marquis J., Powers L. K., Blanchard L., Divenere N., Santelli B., Ainbinder J. G. & Sharp M. (1999). A multi-site evaluation of parent to parent programs for parents of children with disabilities. *Journal of Early Intervention 22,* 217–229.

Smith T. B., Oliver M. N. I. & Innocenti M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry 71,* 257–261.

State Council. (1994). *Regulations on education for persons with disabilities.* Beijing: Huaxia Publishing.

State Council. (1996*). The nine 5-year work program for implementing compulsory*

education for children with disabilities. Beijing: Huaxia Publishing.

State Council. (2000). *Work program for disabled persons.* Beijing: Huaxia Publishing

State Council. (2007). *Regulation on the employment of the disabled.* Beijing: Huaxia Publishing

State Council. (2009). *Regulation on the employment of the disabled.* Beijing: Huaxia Publishing

State Council. (2010). *The twelve 5-year work program for implementing compulsory*

   education for children with disabilities. Beijing: Huaxia Publishing.

Sue, D., & Sue, D. (2003). *Counseling the culturally diverse*. New York: Wiley

Summers, J. A., Dell'Oliver, C., Turnbull, A. P., Benson, H. A., Santelli, E., Campbell,

   M., & Siegel-Causey, E. (1990). Examining the Individualized Family Service

   Plan process: What are family and practitioner preferences? *Topics in Early Childhood*

   Special Education, 10, 78-99.

Summers, J.A., Hoffman, L., Marquis, J., Turnbull, A., & Poston, D. (2005).

   Relationship between parent satisfaction regarding partnerships with

   professionals and age of child. *Topics in Early Childhood Special Education,*

   25(1), 48-58.

The Central People's Government of the People's Republic of China. (2011). *2011 report on*

   persons with disabilities in China. Retrieved from http://www.gov.cn/fwxx/cjr/

   content_1839338.htm.

Turnbull, A.P., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent

   education to partnership education: A call for a transformed focus. *Topics in*

   Early Childhood Special Education, 19(3), 164-172.

Turnbull, A. P., & Turnbull, H. R. (1986*). Families, professionals, and exceptionality: A special*

   partnership. Columbus, OH: Merrill.

Turnbull, A.P. & Turnbull, R.H. (2002). From the old to the new paradigm of disability and

  families: Research to enhance family quality of life outcomes. In J.L. Paul, et al.(Eds.).

  Rethinking professional issues in special education (pp. 83-118). London: Ablex

  Publishing.

Turnbull, A.P. Turnbull, H.R., Erwin, E., Soodak, L., and Shogren, K.A. (2010). *Families,*

  professionals and exceptionality (6th ed). Upper Saddle River, NJ: Merrill/Prentice Hall.

Turnbull, H. R., Beegle, G., & Stowe, M. J. (2001). The core concepts of disability policy

  affecting families who have children with disabilities. *Journal of Disability Policy*

  Studies, 12(3), 133-143.

Turnbull, H. R. & Stowe, M. J. (2001). Five models for understanding how professionals, policy

  leaders, researchers, families, and individuals with disabilities think about the meaning of

  and about societal and policy responses to disability. *Journal of Disability Policy*

  Studies,1 2(3), 198-205.

U.S. Census Bureau Population Division. (2005). *2005 Americans with Disabilities*

  Retrieved from http://www.census.gov

U. S. Department of Health, Education & Welfare. (1979). *The Belmont report.* Retrieved

  Jun, 11 ,2010, from http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.htm

Wang, M. & Brown, R. (2009). Family quality of life: A framework for policy and social service

  provisions to support families with children with disabilities. *Journal of Family Social*

  Work, 12(4), 144-167.

Wang, T.M. (1993). Family needs of children with disabilities. *Special Education Research. 9,*

  73-90.

Wang, S.S. & Lei, J.H. (2007). Comparison study of s pecial education professional development between China and U.S. *Modern Special Education of China, 6,* 2-9.

Witkin, R. and J. *Altschuld (1995). Planning and conducting needs assessments.* Thousand Oaks, CA: Sage Publications.

Wong, S. Y., Wong, T.K.S., Martinson, I., Lai, A.C., Chen, W.J., & He, Y.E. (2004). Needs of Chinese parents of children with developmental disability. *Journal of Learning Disabilities, 8,* 141-158.

Xiang, Y.Y., Xu, J., & Wang, M. (2007) Research on core indicators for Chinese individuals with Mental Retardation. *Chinese Journal of Special Education*, *89*(4), 41-48.

Xu, J. (2002). On the evolvement of the new definition of mental retardation: the new tendency oriented by function, support and quality of life. *Chinese Journal of Special Educati*on, *40*(1), 19–23.

Xu, J., Wang, M., Xiang, Y., & Hu, X. (2005). Quality of life for people with intellectual disabilities in China: a cross-culture perspectives study. *Journal of Intellectual Disability Research, 49*(2), 745-749

Xu.S., & Zhang, F.J. (2009). A case study on the family support to advance the self – determination development for student with intellectual disability. *Chinese Journal of Special Educati*on, *109*(7), 39–43.

Xuan, J.R. (2007). Psychological needs of parents with children with autism, *Chinese Journal of Practical Nursing. 23*(2), 53-57.

Zeng, F.L. (2006). Needs of families with adult child with intellectual disabilities in Shanghai. *Chinese Journal of Practical Nursing. 75*(9), 21-26.

Zhang, M.L., Chen, H., Wang, H., & Li, X.Q. (2009). Diagnosis of children with autism in

    rehabilitation agencies in China. . *Chinese Journal of Practical Nursing. 99* (83), 35-38.

Zhang, S.Y., & Carrasquillo, A.L. (1995). Chinese parents' influence on academic performace.

    New York State Association of Bilingual Education Journal, 10, 46-53.

Zhang, H.C.. & Liu, L. (2010). Learning needs and its influential factors of the parents of

    children with mild intellectual disabilities. *Chinese Journal of Practical Nursing. 69* (3),

    3-9.

Zigler, E. and Black, K. B. (1989). America's family support movement: strengths and

    limitations. *American Journal of Orthopsychiatry* 59, 6-19.

Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Xu, S. (2009). Theorizing about family

    quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with*

    intellectual disability: From theory to practice. Dordrecht, The Netherlands: Springer.

Appendix A: Focus Group Discussion Guide

Create a relaxed environment. Ask each participant to introduce him or herself.

A predetermined set of three questions pertaining to family support will be used, with follow up

questions at the discretion of the facilitator. All predetermined questions will be the same for all

three focus groups. Follow up questions will be introduced to stimulate richer in-depth

information.

Informed Consent:

- *Explain the purpose of the interview.* Thank you all for coming to this group interview.

  The purpose of this research project is to explore family needs of children with intellectual

  disability (ID). As I said earlier, we do not have family support that has as its goal the

  improvement of quality of life of children with ID and their families. However, our federal

  government has begun to aware of the impact of family on development, education, and

  health care of children with ID. Your insight on family support as well as your family story

will add richness to the overall findings of the study. The overarching purpose of this study is to develop a family needs assessment tool for the future policy design and implementation related to education, medical services, and social welfare for your children with ID.

- *Ask for Consent.* We want to assure you that the information you share with me in this group interview will remain confidential. Your name will not be associated with any of the reports of the findings. You may participate in this interview as you feel comfortable; if any question makes you uncomfortable, please let me know and we will adjust the topics accordingly. Your participation is voluntary and at any time during the interview, you can ask to stop the interview as well as asking to remove yourself from the study. Before we continue, I ask that you read the consent letter I have given you. Are you comfortable with continuing with the interview? If so, please sign one of the forms. You may keep the other copy for your records.

- *Ask permission to record interview.* With your authorization, I would like to videotape our discussion to get an inclusive record of what is said. No one outside of this room will listen to or see anything you say. Only the researchers will have access to the records and end results that you and others have said. No responses will be ascribed to you by name. Is this ok with you?

Discussion Guide:

- I want to begin by learning a little bit about how your child with intellectual disability affects your daily life? what concerns or worries do you have now?

(Probes): --When did you find out your child has some special concern? Who did you consult for help?

    --How did your life change after you learned your child has an intellectual delay?

--How did it impact you and your husband/wife/your other kids? What would you be doing if your child did not have a disability?

- Let's talk about the needs you have for your family. Given your situation, what kinds of support do you need to take care of your child and family?

(Probes)   --Can you tell me who works with your child and your family?

  --What are the most urgent support you need for your child?

  --What support would be most useful to help you to carry out daily activities and why?

   -- How often do you expect for that support, if you are receiving that service/support?

- How can local policies be implemented to provide support for you to carry out daily activities?

 (Probes)-- Given your situation, for better family life, what can local government or associations of people with disabilities do for providing service/support you need as said above?

Appendix B: Family Interviews Protocol

Create a relaxed environment. Begin by introducing the participant in the room connected to the collection of data. Ask each participant to introduce him or herself. A predetermined set of interview questions pertaining to 9 areas of family support needs will be used, with follow-up questions at the discretion of the facilitator. Follow-up questions will be introduced to stimulate richer in-depth information. Modification to the interview questions will be conducted based on the past interview and peer-debriefing discussion.

Informed Consent

- *Explain the purpose of the interview.* Thank you for all of you for allowing us to conduct this interview. As the same for the group discussion, the purpose of this research project is to explore family needs of children with ID.

- *Ask for Consent.* We want to assure you that the information you share with me in this interview will remain confidential. Your name will not be associated with any of the reports

of the findings. You may participate in this interview as you feel comfortable; if any question

makes you uncomfortable, please let me know and we will adjust the topics accordingly.

Your participation is voluntary and at any time during the interview, you can ask to stop the

interview as well as asking to remove yourself from the study. This interview was described

in the consent form that you signed when you participated in the focus group. If you need a

new copy of that form, I have additional copies available for you. Are you comfortable with

continuing with the interview?

- *Ask permission to record interview.* With your authorization, I would like to audiotape

our discussion to get an inclusive record of what is said. No one in the outside this room will

listen to or see anything you say. Only the researchers will have access to the records and end

results that you and others have said. No responses will be ascribed to you by name. Is this

ok with you?

Interview Questions

Follow-up questions about specific support items in each broad area will be developed as

individual interview questions. There are two sections in this demographic survey including (a)

Getting to know you and your child, and (b) Exploration of family support needs.

I. Getting to know you and your child

Is this child your first child?

How would you describe the extent of your child's disability?

What federal-state benefits does your child/your family currently receive?

2. Exploration of family support needs

Terms need to be explained to participants:

- Family support refers to either formal, professional services provided by school, agency,
  program, hospital, local government, or other forms of paid assistance. Family support

also refers to social network, informal supports provided by your friends, relatives, and other people who would love to help you.

Area 1: Home Living and Daily Life

--For carrying out daily life and home living activities, what concerns or worries do you have now? what do you need most?

--To meet your needs, what kind of support do you want?

--Do you have any support now for carrying out daily life activities? If so, what are they? Who provide support?

--Who do you think you can get the support from or who should be responsible for providing this support?

Area 2: Emotional Well-Being and Mental Health

--What's your emotional burden or pressure now due to your parenting of your son/daughter?

--What can you do to deal with this emotional stress?

-- To meet your needs, what kind of support do you want?

----Do you have any support now can help relieve your stress? If so, what are they? Who provide support?

--Who do you think you can get the support from or should be responsible for providing this support?

Area 3: Financial Well-being

--In terms of financial issues, what concerns you most due to the disability of your child?

-- To meet your needs, what kind of support do you want?

--Who do you think you can get the support from or should be responsible for providing this support?

--In terms of housing conditions, what kind of support/benefits do you need most for your child and your family?

Area 4: Health

--In terms of health of your child/your family, what types of concerns and needs do you have now?

--What do you want most for better medical care or medical benefits for your child and your family?

--What physical and mental health problems does your child have? Are there any safety concerns for your child and your family?

--To meet your needs, what kind of support do you want?

--Who do you think you can get the support from or who should be responsible for providing this support?

Area 5: Advocacy

--I know advocacy is a new word to you, let me introduce you first. Here advocacy refers to families assist your child or adult child in communicating with authority figures, institutions, or community agencies concerning their rights and interests. Advocacy can be with the informal network of family and friends, as well as with authority figures. If you do not advocate for your child and yourself, no one knows what you need. So what will you need to help you advocate for your child's rights for disability-related supports?

--Can you think of any supports you may need help you advocate for your child and family? Whom do you think you should advocate to?

--Where or from whom can you get resources/information about your child's disability and rights? Will you consider legal services?

--To be more specific, what information do you need most about your child? Where will you get the information from?

----Do you have any support or services now can help you advocate your child's right and benefits? If so, what are they? Who provide support?

--Who do you think you can get the support from or who should be responsible for providing this support?

Area 6: Vocational self-sufficiency

--What are your needs for support to learn job or career skills?

-- To meet your needs, what kind of support do you want?

----Do you have any support now can help you learn career skills? If so, what are they? Who provide support?

--Who do you think you can get the support from or who should be responsible for providing this support?

Area 7: Community and Neighborhood Participation

--What would be helpful to your child and your family to engage in non-vocational activities outside the home?

--What kind of non-vocational activities do your child and your family need most? Such as recreation activities, outdoor activities, community activities?

--What kind of support do you want for your child and family?

--Who do you think you can get the support from or who should be responsible for providing this support?

Area 8: Social Interaction

--What worries do you have when it comes to your family participating in social activities or engaging in social interactions? Social interaction activities may include attending family reunion parties, playing sports, and going out for a dinner with friends.

--To meet the needs of your child and family, what kind of support do you want?

-- Who do you think you can get the support from or who should be responsible for providing this support?

Area 9: Parenting

--How do you support your child's academic learning? What do you need most or what worries do you have now?

--To meet your needs, what kind of support do you want? --Do you have any support/services now can help you promote your child's academic learning? If so, what are they?

--Who do you think you can get the support/service from or who should be responsible for providing this?

--In terms of child's behaviors, what worries you most? What do you need most to address that?

--Do you have any support now can address your child's behavior? If so, what are they?

--Who do you think you can get the support from or who should be responsible for providing this?

--How about the child's social skills? What do you need most?

--Do you have any support now can address your social development? If so, what are they?

--In terms of your communicating with your child and other family members, do you have any concerns? What kind of support do you need?

-- Do you have any support now can address your social development? If so, what are they?

--In terms of taking care of needs of other family members, especially your spouse, do you have any concerns?

--Do you have enough time for yourself in terms of personal habit and leisure activity?

--Do you have any support now can help you pursue your habit or interest? If so, what are they?

Appendix C: Home Visit Observation Protocol

1. A description of the home physical environment and persons who are living in the home.

Participant code:	Date:	Time:
Place:	Interviewers:	
Categories and Indicators	Observation Notes	Reflective Notes

Family structure:		
- The number of family members - The siblings - The extended family members, such as grandparents, or relatives		

Housing situation: • The number of rooms or the housing space per person • The property of housing, such as rented apartments, purchased homes, or low-rent housing from local government.		
Home settings: • The home appliance • The furniture • The decoration • The play and study place for the child with ID • The living room settings		

2. A description of neighborhood and community environment.

Participant code:	Date: Time:	
Place:	Interviewers:	
Categories and Indicators	Observation Notes	Reflective Notes
Neighborhood environment: • demographics • housing • economics • public safety		
Community environment: • transportation access • community services to children • community services to family		

6/18/2010

HSCL #18770

Xiaoyi Hu
Beach Center
3136 Haworth Hall

The Human Subjects Committee Lawrence Campus (HSCL) has received your response to its expedited review of your research project

18770 Hu/Turnbull (BEACH CENTER) Family Support Needs of Chinese Families with Children with Intellectual
        Disability: A Qualitative Inquiry

and approved this project under the expedited procedure provided in 45 CFR 46.110 (f) (7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. As described, the project complies with all the requirements and policies established by the University for protection of human subjects in research. Unless renewed, approval lapses one year after approval date.

The Office for Human Research Protections requires that your consent form must include the note of HSCL approval and expiration date, which has been entered on the consent form(s) sent back to you with this approval.

1. At designated intervals until the project is completed, a Project Status Report must be returned to the HSCL office.
2. Any significant change in the experimental procedure as described should be reviewed by this Committee prior to altering the project.
3. Notify HSCL about any new investigators not named in original application. Note that new investigators must take
    the online tutorial at http://www.rcr.ku.edu/hscl/hsp_tutorial/000.shtml.
4. Any injury to a subject because of the research procedure must be reported to the Committee immediately.
5. When signed consent documents are required, the primary investigator must retain the signed consent documents for at least three years past completion of the research activity. If you use a signed consent form, provide a copy of
    the consent form to subjects at the time of consent.
6. If this is a funded project, keep a copy of this approval letter with your proposal/grant file.

Please inform HSCL when this project is terminated. You must also provide HSCL with an annual status report to maintain HSCL approval. Unless renewed, approval lapses one year after approval date. If your project receives funding which requests an annual update approval, you must request this from HSCL one month prior to the annual update. Thanks for your cooperation. If you have any questions, please contact me.

Sincerely,

Mary Denning

Coordinator
Human Subjects Committee Lawrence

CONSENT FORM

Beach Center on Disabilities, University of Kansas, USA

Research Consent Form

Thank you for your participation in our Family Support Study for Chinese families with children
with intellectual disabilities. If you are interested, we would like to invite you to take part in
focus group discussions and individual interviews.

What is the purpose of this study?

Family support to children with disabilities is a new research area in China. The purpose of this
study to understand the perceptions of family support needs of Chinese families with children
with intellectual disability in rural and urban areas. To be more specific, this study will use focus
groups, home visits and individual interviews to determine (a) the types and intensity of family
support needs of families with children with intellectual disability, and (b) the contextual and
political factors contributing to the accomplishment of support desired by Chinese families with
children with intellectual disability.

What does this study involve?

If you agree to be in this study, we will ask you to take part in a focus group discussion. The
meeting will last approximately 1 to 1½ hours. In addition, you may if you choose be among the
two families we will invite from your focus group to have a more in-depth interview, either in
your home or in a place where you feel comfortable.

Are there any risks in this research?

We don't believe this study will involve any risks. If you would like to stop participating at any
time, you have the right to do that.

What are the benefits of being in this study?

You may not benefit from this study. However, we do hope you will recognize that sharing your
experiences with us may enable your child's service providers, schools, agencies, or policy
makers to understand your needs, and better provide the supports you and your family needs.

What information will we ask for?

We are interested in your opinions about the types and frequency of family support you believe
families of children with intellectual disabilities need. We will need to ask you how your child
with intellectual disabilities affects your daily life, and how local policies might be implemented
to provide support for you to carry out daily activities. To provide an accurate record of opinions

and comments, we will video-tape and make a written transcript of the discussion. If you participate in the follow-up interviews, those interviews will be audio-taped and transcribed. If it is possible, we will do home visit to your family and make notes for observation of your home life and services you and your child have.

How will we protect your privacy?

Everything we learn from you and your program is 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 and your program 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 will be used by me, a doctoral student from the Beach Center on Disability at the University of Kansas. Information also may be reviewed by officials at the University of Kansas who ensure that research is done in an ethical and legal way, and that participants are treated fairly.

If you agree to participate, can you change your mind later?

Yes. You are always free to choose whether or not you want to be in this study, and your decision will not affect your relationship with your early intervention program or the state of Kansas. If you change your mind at any time, you have the right to stop being in the study, without any type of penalty. You don't have to answer any questions that you would rather not answer.

We will do our best to answer any questions you might have now or at any time during the study -- even after the study is finished. So, please feel free to call us at the numbers listed below. In addition, if you have additional questions about your rights as a research participant or feel you have suffered an injury as a result of your participation in this research, you may contact Mary Denning, Coordinator of the Human Subjects Committee at KU, 785-864-7429, available via e-mail at mdenning@ku.edu.

We hope you will decide to participate in this part of the study and that it will be a good experience for you. If you would like to participate, please sign below and keep one copy for yourself. Thanks very much.

Sincerely,

Xiaoyi Hu
Doctoral Candidate
Beach Center on Disability
1200 Sunnyside Ave, Haworth Hall Rm, 3136
Lawrence, KS, 66045
huxiaoyi@ku.edu

China Address:

Department of Special Education
Pu Huang Yu Er Xiang Jia Yi Hao,
Special Education College, Beijing Union University,
Beijing, China, 100066
Tele: 86-10--67612188
Fax: 86-10-67622798

==

I have read the information in this form (or, it has been read to me), and have had a chance to ask questions. I have received answers to any questions I had about information that will be used and shared in this study. I know that the information about me and my program will be kept private.

I give permission to be part of this study, knowing that I can drop out of the study if I decide to. I also agree to the use and sharing of my information as described above. By signing this, I verify that I have received a copy of this consent form to keep.

_____
Name of Participant (Please print clearly)

_____   Date signed _____
Participant's Signature

Appendix E: Results Summary Tables

Table 8

A Summary of Findings Based on Research Question 1-Family Needs of Chinese Families with Children with IDD

Primary Categories	Categories	Subcategories	Sample Quotes
Factors Influencing Perception of Family Needs	Chinese cultural values	Needs of family unit first	Before, I would go to Chengdu with my son for sure. Now I have to consider my parents here. They helped me so much when QiuQiu (the son's name) was so young and no kindergarten accepted him…I cannot be so selfish...On the other hand, my parents did not like the idea that QiuQiu left them to move far away…[they] loved him so much…my son would not either [I bet]…
		Emphasis on education	I never thought about [behavior] training can be done in the classroom…Instead, I thought, or his father always said 'give birth to you but not teach your behavior, it is father's fault' (one credo of Confucianism from San Zi Jing, one of the Chinese classic texts, which was probably written in the 13th century). So we moved from town to the farm and built the house here [to] avoid [others'] accuse…we tried what we can do to train his behavior and made detailed plan…but we never talked about it with his teachers…on the other hand, the teacher always blamed me in terms of his stealing [behaviors] at school.
	Family characteristics	Geographic location	I hope to have family union, which is really a dream to me. I was sick of the life here without job and taking care of my son 24 hours a day…I cried everyday for the last half of year [because] I cannot find one way out…I told my husband I can only had one more year to see the progress of my son. [If he] cannot walk, I had to give up [rehabilitation]. I have to be with my another son…[who] did not like his brother here… I am afraid if I am away him so long, he would not like me either.
		Family SES and educational background	As a Ph.D in education, I know what the so-called sensory integration is…[the agency] bought the materials but no one really know how to use them…they (i.e., agency staff) let children in for playing, like children playground
		Disability of child	Xinxin wants to play with neighborhood peers but no one would love to. One day, I insisted inviting one neighborhood to my house...Their daughter only wants to play with Xinrui (Xinxin's younger sister without disability)… I can see the

			parents staring at Xinxin, then Xinxin kept crying…no one would love to make friend of Xinxin, which is not I want. However it is the fact. Xinxin's friends are her classmates. This is the reason she loves school. Xinxin likes her classmate Jin very much and is always with her at school…I once invited Jin and her parents to my home but got refusal. Jin has mild ID and good independent living skills…When I brought Xinxin out, I felt great pressure [because] people around felt she was a monster…so I always have to pull my and her hat down a litter bit…
	Family previous experiences		We used to go to agency XYZ for therapies…[you know] how famous it is…but it is not what I expected… apple of Sodom…was the word to describe it…they have floor time, RDI (relationship development intervention)…I think the establisher (i.e., the mother who had autism and opened the agency) was doing right with the whole interventions for her son…maybe not for my son…
	Current family support		"I do not have family support, any kind of family support, to me." "every month, my family can get $13 allowance. [But] our expense was $130…still now; I owed the tuition fee for this semester…if you can call $13 was family support." " I don't have any needs on home daily living [because] my parents take care of everything".
	Family awareness and expectation		"Have families ever thought about service XYZ?" "I never thought about it…yes! That's what I need…I need a person take care of my son twice a week [which] will make feel very content"
Types of Family Needs	Survival needs	Financial needs	• **Medical insurance:** The medicare issue was huge issue…I read the 30 pages of eligibility criteria and made one conclusion: they do not let me child in their coverage…[second respondent] Yes. the most important [policy] was for outpatient, you can have reimbursement for 50%, for inpatient, you have nothing [to be reimbursed]…[third respondent] You cannot tell them your child have disability…[in fact]..I did not and have the insurance [for my daughter]…but it is still very expensive…not enough to really care [for my daughter]. For example,

<table>
<tr>
<td></td>
<td></td>
<td></td>
<td>

if she got chronic illness, they will not reimburse.

- **Social security insurance and disability benefit:**

I did a thorough study on it. First, the benefit is for those aged from 16 to 55. [The insurance] only cover 15 years. If my son gets it and he will not have it when he is 31. Second, only persons with severe IDD can benefit from it with 100% …my son has mild autism, so he can have 50% benefit from the lowest pension [standard of Shanghai].

- **Cash assistance:**

I need money to buy a wheelchair or pay someone who can bring my son on back to my apartment in the sixth floor. I really need it…but I cannot afford it…

- **Income stability:**

[The daughter's] father had a good job before so we can rent the house nearby school. We are doing fine right not, but [you know] if something happened to my husband…he had fainted from his office desk three times last year…I cannot think more about it….

- **Housing-related issues:**

[He and his grandpa] lived in one boat and I lived in another. We were retired and had no money to buy an apartment. Before it was fine but now I felt he is already 14 years old. He may need his own space…Last time he told me he wanted a dog I said 'oh, no!' …I saw him very upset and he needed a friend but our home environment…

</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Physical health</td>
<td>

- **Locate a doctor:**

I went to Town Hospital A, the doctor told she never had this kind of case before and maybe Hospital B in Wuhan had the similar children. We went there and Hospital B notified me Hospital C in Wuhan can provide diagnosis… [second respondent] I remembered you [first respondent] told me you son had intellectual disability…[first respondent] yes. But now specialists from Hospital D said it was autism and only they had the right to issue Disability Certificate…yesterday, the teacher told me my daughter might have some hearing problems…I was really frustrated..

- **Information about child's disability and health conditions:**

Would you love to see my daughter later [after this discussion]? She had cerebral palsy…But recently, she had very weird behaviors, such as talking to herself and

</td>
</tr>
</table>

			pinched others and herself… • **Accessing to high quality TCM services:** The school did not want us to use acupuncture, however, I think it really helps…the point is to get good one and would love to treat my son.
	Sufficiency needs	Child education	• **Adequacy of supply of services:** I need more aquatic therapy to my daughter. She spent wonderful time with dolphins and professional there and she loved swimming…[second respondent] Where did you have that? I knew it from Ocean Heaven (a new film on a father with a son with autism working with dolphins). [third respondent] Beijing Aquarium. I heard about it. But it should be very expensive...[first respondent] yes. we can have discount in winter seasons and children like ours can have double discount… • **Accessing to services:** The school asked parents to be with their children with severe disabilities, like my son. I had to quit my job and waited outside the classroom from 8am to 3pm. On teachers' call, I would go into and bring him out to toilet, assist him walking and eating… • **Accepting services:** I was so depressed… [crying]…Maybe it was ok… anyway, Xiaojun (son's name) did not like that school [because] the teachers did not like her…also they know nothing about intervention…But they cannot refuse my son because of their own fault…
		Teaching child at home	• **Teaching behavior management skills:** I want them just to perform "right" and be able to discipline better. I know the word of 'corporal punishment', but my friends, neighbor all use this method and it worked. Also [you know] how hard to teach her [who is so] strong willed. I am not sure whether I am right or not. If I can have some other ways out [for her behavior issues], I would not punish her in that way… • **Teaching siblings to interact and assist child with IDD:** Yuchen felt shocked when Yuxin run around at home, hitting herself and shouting. I still did not understand why Yuxin could not accept Yuchen by her side. Then Yuchen began crying…But I cannot do anything about it. Even their father with I cannot…

		Social inclusion	• **Social acceptance:** "I can sense the discrimination to her/him when we go out." "The bus driver eventually let us in. It is not whole-heartedly accepted. I should say it is a feeling of mercy because I had to use basket to carry [my son] on back." • **Develop and keep friendship:** I have not contacted with my friend after I moved to Beijing…she knew my son had autism…maybe she did not like to be my friends or…we had nothing common anymore… • **Participate in community activities:** I never had them [persons from neighborhood committee] knocked at my door to ask what help we want…when my son wanted to work as the newspaper delivery guy for some apartments nearby, I went there. They told me because my husband, the owner of my apartment had no Beijing Residence, they are not responsible for providing any services or assistance.
	Enhancement needs	Emotional health	I used five years to accept Xufeng had cerebral palsy. Xufeng was very healthy and normal at born. If not was that accident [that she fell down from bed when she was six-months]. However up till now [the daughter's] father never brings her out for parties, weddings, or recreation activities with Xulin [twin brother without disability]… I used to go to psychiatrist once a week…also my sister, brother and mother helped me out…. From then, I never went out for job, shopping, travelling. I had a great pressure to do training [i.e., rehabilitation and therapies] because I changed my life focus to Xufeng and indeed, [he was] my job…now I feel kind of separation from my husband because of my jobless. We had less and less to talk, communicate…[I thought] he had a normal life, going work every day but I, stayed at home and feel exhausted to take care of two children…Neighborhood always say that I am a strong woman shoulder such great responsibility and I am also such an easy-going person. But indeed no, I am very weak inside because except myself and my family, no one would love to help me…that's true[crying]…Now I found he recently had some characteristics of autism…if

			so, it will kill me…that's true [crying]…what if, [Xufeng] is 8 years old, I cannot carry him on my back to the sixth floor [to my apartment]?
		Future planning	• **Future planning for children:** "I want him be independent…independent!" "I hope government can have some ways to help us to manage the money [which we saved for him] after I am no longer around." "I am fine with current statues. All our family members loved her. What I are worried is her future….[actually] all children of the parents at present here today…Who bring her to the hospital and who paid for the medicine?" "If he can have a job, no matter how much he get paid or what kind of work, that would be a great relief [by this way] he will have a meaning life, instead of a burden to the society." "I hope those children will be able to live on their own in the future." • **Family vision for the whole:** I told to my husband…three years…my son will be walking without any assistance…by then, he will move back and saved enough money…we will have our own business…maybe in the future, my son can work for us [smiling]I am fine with current statues. All our family members loved her. What I are worried is her future….[actually] all children of the parents at present here today…Who bring her to the hospital and who paid for the medicine? If he can have a job, no matter how much he get paid or what kind of work, that would be a great relief [by this way] he will have a meaning life, instead of a burden to the society. I hope those children will be able to live on their own in the future.

Table 9

A Summary of Findings Based on Research Question 2-Family Support of Chinese Families with Children with IDD

Primary Categories	Categories	Subcategories	Sample Quotes
Types of Family Support	Survival needs support	Financial needs	In terms of financial aid, I think, or I should say, improving the medicare insurance or disability benefits are not enough at all. It is the first step. Direct cash assistance on diagnosis to young children; free tuition, reduced therapies and rehabilitation fee to school age children. Then full social security insurance to adult children. If the child has no job, then [he or she should have] the minimum level of income necessary to have an adequate standard of living locally. All these should be timely and appropriate to the child, family and consider the location differences. Finally, we can see in what degree these programs solve our problems…All in a word, Better than nothing…If, I say if, the government wants to, would love to do [provide one or two of these], the family would not feel such pressure, and isolated.
		In-home support for the carer	I never thought about it…yes! That's what I need…I need a person take care of my son twice a week [which] will make feel very content"
	Sufficiency needs support	Child education and related services	Before, we did not have special education school...you can see the how beautiful this campus is. This is the gift of the earthquake [smiling]…[the second respondent said quietly, covering her month] the school only accepted children with mild [disability] condition…[third respondent] so we feel very lucky. I live far away; 220 miles away…there is no [special education] school in my hometown. I rented an apartment near the school… The new school is much better than the old one…but it seems the teachers who provide speech therapy left the school. [the second respondent] the school had several sources of sponsorship. There is lots of training materials here but the doors locked. You can only see from outside…[the third respondent] the vocational training classroom has cooking utensils, simple knitting tools, drawing and ikebana materials…and no more. After some basic training, teachers work as keepers.

		Parent training	"I need to know how to train my child to become independent." "I want to know more about my child's violent behaviors." "If with basic training, I think I am able to some physical therapy at home. It should be [provided] step by step. My parents can also learn them and use then into everyday life."
		Social support	I really want my child and myself be a member of the community but I am fearful of rejection of my child by the neighborhood. Now I have a sense of isolation, or we are living on the edge of the society.
	Enhancement needs support	Future planning support	Yes. You are right. He loves gardening. He could spend the whole afternoon taking care of the flowers he had. But we never realized it. Maybe his father's working unit or our community can provide some part-time jobs for him. No matter they can have [jobs] for him or not, I will do something on this…maybe this is a way to change his life and ours. I know her father did much for the whole family. He left the Aigo company last year and opened the new company with his friends. He told me he worked so hard for having a better life for Xinxin. But I had to be stay at home to take care of her and Xinrui. It was horrible to be jobless. If her father's company failed we will have no income. I need to learn new job skills and have to have jobs.
		Emotional support	I feel…although I did not admit yesterday…I really need to have some support for myself. I seems to have lost friends, co-workers, my parents, and even my husband. I am extremely alone [crying].
Sources of Family Support	Informal sources		She (the other mother with a child with ID) always called to my wife about the epilepsies. We really supported each other. If my child is having an emergency and went to the hospital, she would come over and make meals for us. It was one of the most supportive things for us.

| | Formal sources | | My child needs a professional teacher urgently. The classroom has only two teachers with 18 students ranging from mild to severe IDD... [the second respondent] I had to have a nanny to accompany her in the class. Otherwise, the school will refuse my child [the third respondent] when a student with severe IDD lying on the ground crying, two teachers had to go to her. Then my child and others would learn the student and lied on the ground too. The teachers cannot stop it. Everything is chaos. I do not want my child learn this…he needs systematic treatment and education, experienced professionals, and qualified therapists.

When I told the teacher of my child that she might consider floor time training, she said she knew nothing about it. When I wanted to have a look at my child's IEP, she said no need because IEPs for each student looks like the same. When I asked her to pay more attention to my child's behaviors, she said she had no time…I know she is tired dealing with many students and she wanted to do as I said above…we talked about it for several times. It did not mean she did not really want to. She is just lacking of training. As she told me, she was 'find her way in the darkness without any guidance from others". |
|---|---|---|---|

Table 10

A Summary of Findings Based on Research Question 3- Contextual Factors of Family Support Delivery

Primary Categories	Categories	Subcategories	Sample Quotes
Context of delivery	Values	Social attitudes	We surely want this kind of support to my family; I just feel whether our society is ready for that. For example, I need vocational training to my son. And I think our government knows the importance [for providing vocational training to persons with disabilities]. But other people will argue that they need vocational training too, especially those jobless. [the second respondent] Yes. You are so right on this point. Others will argue society should focus on those with disabilities first, instead of their families. [the third respondent] Many people do not have such awareness like those in U.S. Even now, most people still believe it is useless to provide vocational training to my son because of his disability.
		Family values	If [I can have] parent training on behavior modification [provided] to me, I think not only me, but also my parents, my husband can have a chance to attend some workshops. [the second respondent]Yes. I agree. If the support is to family, then all of the family members living together with my son should benefit from it. [the third respondent] Although my husband is far away in Guangyuan, I think he would love to come here every weekend to attend this training because we both have to deal with the aggressive behavior of my daughter. I have to admit it is I and my families delayed my daughter's [intervention to] disability. We actually found she has some delays in communication and behavior development when she was only one year old. However, my parents-in-law did not agree to bring her to hospital and let outsiders know she had problems. They felt it was a huge shame. And also they thought my daughter was a punishment for their wrong-dongs before. Her grandpa is a faithful follower of Buddhist beliefs. So she did not go to daycare and stayed at home with them. Even until today, they did not tell their relatives that my daughter had ID. Also they did lots of good things after they knew my daughter had disability to better change her life and help her alleviate or overcome her disability⋯.They probably will not [accept] any kind of services or support by outsiders to my family…They will close the door to them.

	Policies	Refining the existing policies	Our family felt shameful when we got to know that my daughter had autism because we gave the society a big burden, also for myself. So I did a long struggle that whether I should ask help from the government….after a long time, my husband began to check online on any policies, state or local, to rights and benefits of my daughter. The only one is some state regulations on including autism into Mental Disability. Also some [regulations are] on including children with autism into special education for children with ID. Then there is no more beyond that. He printed them out and brought it to the local special education school. Believe it or not! The school staff said that they never heard of this regulation. Then I checked the regulation carefully and found out it says 'local schools should make attempt to accept children with autism based on their condition and capacity.' I went to the local court and found that I could not file a lawsuit because the school is not wrong [to refuse my daughter]
		Authorizing new policies	We cannot compare ourselves with Americans, or any other [families] in developed countries. But Chinese government must have to have new polices for those with disabilities and us because it is a huge population. The most important thing to be on the law is providing those necessary assistance we need badly and urgently, like financial help. Also the law has to be clear and the items have to be specific enough…This is social problem and also the issue that government needs to pay more attention.
	Local government	Leadership	The school leader really cares about us. He knows us and made home visits to each of us. He asked us whenever he saw us what we needed and what he can do…He will be very happy with trying some family support programs here. For us, we needed first is the therapy for children, such as OT, PT, and speech therapy. We had them before and our children had specific period of time to have these services. But now as the new leader comes, all therapies stopped. And the teachers here did not provide any specified training anymore; instead, they said they integrated training into everyday teaching activities and tasks, which are more natural. But I don't think my son benefits from that and his speech [ability] got lagged behind…

		Partnership	The teacher is already very busy with these children with IDD. So I did not want to ask her do more after class. My son really wants some athletic training to make his muscle more strong…I want to ask her make some detailed plan for me to follow at home, not only just in class…But she is so busy with other students who will participate in the Special Olympics. I think if I have some opportunity to work with her [on my daughter's training], that will be a great support for my whole family.
		Execution	I think the family support is a great idea and should be put into policy agenda urgently. However, it is not enough. Direct providers from the LAPD have to have that awareness and the ability of executing and implementing the services to us effectively. They have to be clear about how to do it, and if cannot, then what methods to compensate [for not able to provide family support] and who should shoulder that responsibility. All is the execution ability of LAPD indeed.
Capacity of providers	Time and energy of providers from informal sources		I have already asked so much help from her [my mother] and I felt shameful and guilty. On the one hand, I have my own family and grew up. So I should not ask her help. One the other hand, I really have to have her because I cannot find a way out. She had been helping me take care of Xinxin for nine years. Now she had some chronic illness which needs long-term acupuncture. She had no time to go to hospital. Also I have a young brother and now lives in hospital. So these days my mother had to go to see him every afternoon. What's the life for her own? She told me she does want to help me anymore and have some her free time and find a partner for her rest of life. She needs to be taken care of and be loved too…[crying] do you think I am too selfish?
	Availability of providers from formal sources		The professionals are fine but unfortunately they left one after another. I thought the establisher [of the agency] has her own beliefs on educating children with autism and trained some graduates majoring in special education or therapy. The first generation of these [professionals] is really good but the following generations are not good and [the numbers of them] decreased much. The establisher's belief does not attract [them] to work for the agency any more. So I gave up. "My son needs a professional teacher urgently." "Here we do not have physical therapist. Actually, we do not even have any

			professionals specialized in therapy or rehabilitation." "Two teachers for one class with 25 students like my daughter. Nobody can do that job."
	Ability of providers from formal sources		Every Spring Festival, some staff from LAPD will come to my house to give me oils and rice to show how they are concerned with me. But I need more beyond that…Others days if I look for them to ask for help or any information, it would be very hard. They were either not at LAPD, or in the meeting room. One time I told them my son needs rehabilitation. They said 'rehabilitation, like medicine, is useless when you do not have it. If you had rehabilitation once a week, which is what we can do, it is useless. You'd better not have it.'…Another time, my wife asked about the job for my son after he gets graduates. They said 'job?! Are you kidding? What kind of job can he [with ID] do? You have to have a clear understanding of your son and solve it by yourself.'…
	Commitment of providers from formal sources		She [the professional] is great. She knows my son and me. She made home visits once a week to provide speech therapy at my house. Four year! You cannot believe that even in heavily rainy day or windy day, she walked 20 miles [to my house]. In summer or winter holiday, she would have assignment for us to train my son. She told me she simple believed that my son can talk in one day….I would love to say her persistence is not blind, but with definite purpose.