PALACKÝ UNIVERSITY OLOMOUC

Faculty of Education

Institute of Special Education Studies

NEEDS AND SUPPORTS PERCEIVED BY CHINESE FAMILIES OF CHILDREN WITH DISABILITIES

A dissertation presented to the Faculty of Education
In partial fulfillment of the requirements for the degree of
Doctor of Philosophy

By

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Olomouc, Czech Republic

2017

ABSTRACT

The purpose of this study was to examine the perceived needs and supports of Chinese families of children with disabilities by conducting a questionnaire survey. A total of 430 parents of children with disabilities enrolled in early intervention programs participated in the survey. Results revealed that the most priority needs of families of children with disabilities in the western China were needs for information, child care, and community services; the perceived supports of these families were at the medium level, the most priority items of supports were mainly emotional and informational support, and came from spouses, professionals or teachers; fewer supports came from religious groups, social welfare agencies, relatives and friends, and social workers. In addition, the predictor factors influencing family needs or supports were child's age, whether the child is the only child, whether the child has a disability certificate, disability category, parents' educational status, family income, geographical location and so on.

This dissertation consists of five related chapters including an introduction of research background, aims and questions; a literature review; research methodology and results. Finally, implications of this study for future research and service provision are discussed.

ACKNOWLEDGEMENTS

Foremost, I would like to express my sincerest gratitude to my supervisor prof. PhDr. PaedDr. Miloň Potměšil, Ph.D. for his continuous support of my doctoral study and related research, for his excellent guidance, patience, motivation, and for providing me with an excellent atmosphere for doing my research.

I would like to thank my committee members doc. Mgr. Dita Finková, Ph.D., doc. PhDr. Lea Květoňová, Ph.D., doc. Mgr. Kateřina Vitásková, Ph.D., doc. Mgr. Jiří Langer, Ph.D., PhDr. Jana Kvintová, Ph.D., doc. PhDr. Lea Květoňová, Ph.D., and prof. PaedDr. Alica Vančová, CSc., who have provided me with their expert assistance and valuable feedback.

Special thanks to doc. Mgr. Kateřina Vitásková, doc. PaedDr. Milan Valenta, Ph.D., and PhDr. Jana Kvintová, Ph.D. for guiding my research for the past several years, and helping me to develop my background in philosophy, pathopsychology, and research methodology.

In addition, special thanks to all the faculty and staff members of department of special education for their continued support.

I would like to thank my colleagues from early intervention institutions in Ningxia, Guangxi, Sichuan and Chongqing for all of the opportunities I was given to conduct my research and their wonderful collaboration. Furthermore, I would like to thank the parents of children with disabilities who generously filled all the questionnaires. The research would not have been possible without their significant contributions.

I would like to express the deepest appreciation to my parents and my family. They were always supporting me and encouraging me with their best wishes. And always they're cheering me up and stood by me through pain and pleasure.

Last but not the least, there are my closest friends who encouraged and believed in me. Thanks for being by my side, and always giving me reasons to cheer.

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CHAPTER 1 INTRODUCTION

China is a developing country with the largest population in the world and also has the most populous disabled people. According to the Second National Sample Survey of Disabled People in 2006, the number of children with disabilities aged from 0 to 6 is 1.678 million in mainland China, accounting for 2.02% of the total number of disabled people, with the prevalence rate up to 1.69%. In other words, 0.8-1.2 million disabled children born each year and an annual increase of 199,000 children. The number of these disabled children consists of 97,000 in Visual Disability, 137,000 in Hearing Disability, 540,000 in Speech Disability, 314,000 in Physical Disability, 1,188,000 in Intellectual Disability and 111,000 in Mental Disability (China Disabled Persons' Federation, 2006). If detected early with early intervention services as soon as possible, combined with medical care, special education, rehabilitation and other professional services team, they can alleviate the phenomenon of developmental delay, and even catch up with the development of normal children, or decrease the degree of disability. Thus, early intervention is crucial for the children and their families; the concept of early detection and early intervention services has attracted increasing attention.

Early childhood is the most and the rapid period of development in a human life, children usher their key developmental period from birth to 6 years. From the perspective of family system, individuals cannot be understood in isolation from one another, but rather as a part of their family. Among families of children with disabilities, the interaction between the children and family members has mutual influence on not just the children having an impact on the family, and relatively the family will also have an impact on the development of children. In taking care of children with disabilities, the family support is of vital importance for caregivers. Family is the first and the most effective placement for the child; due to their physical or mental defects, disabled infants must rely on their families not only in daily life care, but also receiving education and rehabilitation. Therefore, family plays a very important role in taking care of children with disabilities, and the involvement of parents and the whole family is the most lasting.

Early intervention should not only attach importance to the development of children, but also pay attention to the needs of parents and their families. Because of the particularity of the families of children with disabilities, the specific family needs are emerged. Also, different predictor factors such as child, family and social environment backgrounds may make family put forward different requirements. Thus, it is necessary to conduct the individualized family needs assessment for determining appropriate support services. Only when the support services met the family needs, the needs of children's rehabilitation and development can be met.

The trend of early intervention emphasizes the implementation of individualized family service, and the needs of children and their families should be evaluated from the perspective of ecological standards. P. McWilliam (1996) considered that early intervention should respect individual differences of families. Bailey et al. (1998) also proposed that early intervention services should focus on the family, enhancing the development of children and the ability of parenting, and reducing dependence on the external environment. They put forward several key points on family work: Firstly, the required family resources are very different, as well as priorities and cultural background that should be paid attention to. So it's necessary to respect the individual needs and expectations. Secondly, families and professionals cooperate as partners to make plans and provide services. Therefore, professionals play the role of support and partnership, with timely advice and suggestion, and the family is the final decision maker in the early intervention services.

Taking the United States as an example, the rights and interests of families with children with disabilities are clearly guaranteed, from a large number programs to promote the comprehensive early childhood education since 1970s, as well as ideas of Individualized Education Plan (IEP) in the Education for All Handicapped

Children Act of 1975 (Public Law 94-142) and Individualized Family Service Plan (IFSP) in the Public Law 99-457. Among them, the Public Law 99-457 defines early intervention from 0 to 3 years old should provide IFSP which is set up to identify individualized supports and services. Part C of the Individuals with Disabilities Education Improvement Act (IDEIA) promulgated in 2004 awards grants to every state in the United States to provide early intervention services to children from birth to age 3 who have disabilities and to their families. A statewide system described in section 633 of IDEA (As amended through P.L. 114-95, enacted December 10, 2015) shall provide for each infant or toddler with disability and their family to receive (a) a multidisciplinary assessment of the unique strengths and needs of the infant or toddler and the identification of services appropriate to meet such needs; (b) a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler; and (c) a written individualized family service plan developed by a multidisciplinary team.

However, early intervention services for children with disabilities in mainland China are facing challenges. How to provide appropriate support to meet the needs of children with disabilities and their families is an important issue that needs to be studied. But in contrast to the existing studies, there is less comprehensive investigation into the early intervention stage. Therefore, this study sought to examine the characteristics of children with disabilities and their families participated in the early intervention programs, and the perceived needs and family supports of these families.

Purpose of the Research

The purpose of this study was to examine the perceived needs and supports of Chinese families, as well as the predictor factors influencing family needs and supports. The overall objective was accomplished by the following specific aims: (a) to identify the characteristics of children with disabilities and their families; (b) to examine the perceived needs and supports of Chinese families of children with disabilities; and (c) to analyze the differences in family needs and supports for children and their families' characteristics.

Research Questions

Specifically, the following questions were raised and guided this study: (a) what are the characteristics of Chinese families of children with disabilities? (b) What are the perceived needs of these families? (c) Is there any difference in family needs for child and family characteristics? (d) What are the perceived supports for Chinese families of children with disabilities? (e) Is there any difference in family supports for child and family characteristics?

Definition of Key Terms

Child with a Disability

The Law of the People's Republic of China on the Protection of Disabled Persons (2008) states that "A disabled person refers to one who suffers from abnormalities or loss of a certain organ or function, psychologically or physiologically, or in anatomical structure and who has lost wholly or in part the ability to engage in activities in a normal way. Disabled persons refer to those with visual, hearing, speech or physical disabilities, mental retardation, mental disorder, multiple disabilities and/or other disabilities" (State Council of the People's Republic of China, 2008).

In this study, ***Child with a disability*** means a child with intellectual disability, hearing impairment, visual impairment, physical disability, speech and language disorder, emotional and behavior disorders, autism spectrum disorder, and multiple disabilities.

Early Intervention Services

Early intervention is a kind of comprehensive services that aims to serve children and their families timely, including children with developmental disabilities or developmental delay and high-risk infants. Most of them are between 0 and 3, as well as preschool children from 3-6. Early intervention services include early detection, early diagnosis, medical treatment, healthcare, rehabilitation, education, and community service, according to the particular needs of children and their families. In practice, a multidisciplinary team provides individual guidance and actual services (F. Zhang & Yang, 2011).

Family Needs

According to Bailey and Blasco (1990), family needs refers to a family's expressed desire for services to be obtained or outcomes to be achieved. Family needs of children with disabilities contains understanding the situation of disability, financial support, understanding and application of social resources such as children's education or welfare, solution to the problem of child care and maintaining family function (Bailey & Simeonsson, 1988). In this study, ***family needs*** are divided into seven categories, namely needs for (a) information; (b) family and social support; (c) financial; (d) explaining to others; (e) child care; (f) professional support; (g) community services.

Family Supports

In the disability field, *Support* refers to "resources and strategies that aim to promote the development, education, interests and personal well-being of a person and that enhance individual functioning" (Schalock et al., 2010, P. 224).

Family supports are services, resources and other types of assistance that enable individuals with disabilities of any age and their families to live together, and to be welcomed, contributing members of their communities (Freedman & Boyer, 2000). A wide range of family supports includes a variety of family oriented professional services, parent training, family rehabilitation, social support, psychological counselling, resources and products, financial subsidies and other forms of help.

The term of ***Family Supports*** in this study refers to a comprehensive and integrated set of services, including “emotional supports” (such as comfort and assistance from spouse, relatives or friends, neighbour, social worker, and professionals); “informational supports” (such as providing parents with medical, educational, and rehabilitation information, available social resources, and knowledge, skills or precaution on taking care of disabled children); and “instrumental supports” (such as parenting education, health and mental health services, resource and referral services, social welfare services, and leisure or parent-child activities).

CHAPTER 2 LITERATURE REVIEW

The purpose of this study was to examine the perceived needs and family supports of Chinese families of children with disabilities enrolled in early intervention programs. This chapter is a review of early intervention services and the extant literature relate to this study. This chapter includes a discussion of (a) early intervention services in mainland China, (b) theoretical foundation, and (c) literature on family needs and supports, and specific related to Chinese families of children with disabilities.

Overview of Early Intervention in China

Demographic Background

China has the biggest population in the world. According to the National Bureau of Statistics of the People's Republic of China (2010), the number of the mainland population reached 13.3 billion. Large population and high risk of disability in children had put great pressure on early intervention services (National Bureau of Statistics of the People's Republic of China, 2010). According to the proportion of disabled people to the total population of the country and the proportion of the total number of disabled people in the Second National Sampling Survey on Disability in 2006, it can be calculated that the number of Chinese disabled people will reach 85 million, involving 260 million family populations (China Disabled Persons' Federation, 2012).

According to the Sampling Survey on Disability in 0-6 year-old in 2001, it was estimated that the total number was about 1,395,000. Among that, 1,071,000 had single disability and 324,000 had comprehensive disability (China Disabled Persons' Federation, 2003). Due to the differences in the definition, classification and identification of disability between China and the Occident, the survey aimed at five kinds of disabilities. There are 158,000 of hearing impairment, 109,000 of visual impairment, 954,000 of intellectual disability, 434,000 of physical disability and 104,000 of mental disability. It can be calculated accordingly that the national annual increase of disabled children from 0-6 is about 199,000. Regardless of the exact number of disabled children in China, it is a huge challenge to provide education and rehabilitation and related supports services for these children and their families, due to Chinese broad population base (Chiang & Hadadian, 2010).

Development of Early Intervention

In 1980s, Gesell Development Schedule and the Denver Development Screening Test has been translated and revised for screening and identifying infants with high risks. Since then, early detection, early diagnosis and early intervention has been widely accepted by parents, teachers and relevant professionals. In 1983, China Rehabilitation and Research Center for Deaf Children was established in Beijing. It was the first language and hearing rehabilitation agency that served children with hearing impairment. After that, similar agencies were gradually established in other cities or provinces. In 1993, there were 1356 hearing-speech rehabilitation institutions, and 38,771 children received or had received rehabilitative training. 12% of the trained children went to general kindergarten or schools after training (Deng, Poon-Mcbrayer, & Farnsworth, 2001).

In 1988, China Disabled Persons' Federation (CDPF) was established in Beijing, aiming to represent and safeguard the rights and interests of disabled people, and to provide comprehensive services to persons with disabilities. It had branches across the whole country, covering all kinds of communities in counties and cities, directly carrying out many kinds of activities and serving for the disabled and their families, including rehabilitation, special education, employment, social security, poverty alleviation, propaganda, sports, human rights and service facilities construction. At same time, it was the main agency that promoted and advocated early intervention services for children with disabilities. Statistical Communiqué on the Development of the Work for Persons with Disabilities shows that the country has 7858 rehabilitation institutions for the disabled persons at the end of 2016. Among that, China Disabled Persons' Federation held 3049 institutions. Through implementation of some key projects, a number of 150,000 of disabled children from 0-6 years old received rehabilitation services at different levels, and 1,322,000 disabled children received various assistive devices, such as white cane, typoscope, artificial limb, prosthetics, cochlear implants and hearing aids. Through the implement of special lottery welfare programs for the disabled, more than 14,000 disabled children whose families had economic difficulties received financial support to get inclusive pre-school special education (China Disabled Persons' Federation, 2016b).

On the other side, with the increasing needs of early intervention service in China, public rehabilitation agencies cannot meet the rapid needs. Due to the constant increasing awareness of importance of early intervention and governmental financial support for the early intervention services, a large number of non-governmental, non-profit organizations and private-operated agencies also start to carry out early intervention service programs in developed cities and regions, such as Beijing, Shanghai and Guangzhou (X. Hu & Yang, 2013). It can be seen that early intervention services develop rapidly in quantity and dimension; China has gradually set up a model of early intervention focused on medical treatment, special education, and rehabilitation for children with disabilities.

Medical treatment-focused early intervention emphasizes carrying out medical treatment and rehabilitation training activities. The service institutions are composed of hospitals and maternal and child health hospitals. Through the mutual cooperation of the staff members of hospitals, health-care centers, special education institutions, and rehabilitation centers, it offers early prevention, early detection, early identification, and early treatment, mainly in the form of medical treatment, healthcare, and rehabilitation, through outpatient treatment. After a period of intervention, children with disabilities will be given a referral to other agencies, such as special educational institutions or rehabilitation institutions.

Education-focused early intervention is mainly composed of preschool classes in special education schools, special classes additionally established by general kindergartens, and privately run children's development centers. Preschool classes provide group and individual teaching for promoting the children's physical and mental development. In the early days, the main targets were deaf children, gradually expanding to children with visual impairment, mental retardation, physical handicaps, autism spectrum disorders, and other developmental disabilities, and most of the providers are special education teachers and social workers. In recent years, preschool education in inclusive settings has gained popularity in China, and experiment practices have been carried out in developed regions such as Beijing, Shanghai, Guangzhou, Shenzhen, Hangzhou, Chengdu, and Zhengzhou, with some achievements accomplished. Inclusive preschool education offers a chance to children with disabilities to receive preschool education in a general kindergarten.

Rehabilitation-focused early intervention The management of rehabilitation services is organized by the China Disabled Persons' Federation (CDPF) and local disabled persons' federations at all levels, which have rehabilitation centers or stations with dedicated spaces, teaching equipment, rehabilitation training equipment, and a variety of professional teachers and rehabilitation professionals, to provide organized and planned rehabilitation services for children with disabilities. Early services involved speech and language therapy for children with hearing impairment, and the project was gradually expanded to include children with visual impairment, mental retardation, autism spectrum disorder, and cerebral palsy. Most of the providers are special educators, speech therapists, physical therapists, occupational therapists and so on. Services include direct rehabilitation training to children in-group and one-to-one training. On the one hand, it creates a collective learning environment for children and promotes their social development. On the other hand, in order to meet children's individual rehabilitation needs, it provides individualized and one-to-one remedial rehabilitation training. Rehabilitation centers also provide counseling and parenting training services for parents or the primary caregivers through the brochures, workshops and seminars. In the poverty areas, especially those in dispersed rural and inaccessible remote mountainous areas, this approach mainly relies on community rehabilitation stations to provide healthcare, medical treatment, special education, rehabilitation training and other comprehensive services for children and their families.

Policies and Legislations related to Early Intervention

Chinese government has promulgated a series of laws and regulations to protect the rights and interests of people with disabilities, such as Compulsory Education Law, Law on the Protection of Persons with Disabilities, Regulation on Improving Education for the Disabled and Regulations on Disability Prevention and the Rehabilitation of the Disabled. Early intervention services for children with disabilities have been paid more and more attention and guarantee on laws and regulations.

Compulsory Education Law. Chinese education system includes childcare and education (under 6), primary education (6-12) and secondary education (13-15). Beyond that, it’s three-year high school or vocational school (from 16-18). Then, it’s higher education (19-23). Special education has become an important part of the formal education system in China. Compulsory Education Law stipulates that primary schools shall accept the disabled school-age children and adolescents, who are able to receive general education, to study along with the primary classes and shall help them to study and recover (State Council of the People's Republic of China, 2006).

Law on the Protection of Persons with Disabilities. In the field of preschool education for children with disabilities, Article 26 stipulates that preschool education institutions for disabled children, special classes for disabled children attached to ordinary preschool education institutions, preschool classes of special education institutions, welfare institutions for disabled children, and families of disabled children should provide preschool education for disabled children. Article 25 also stipulates that ordinary preschool education institutions should accept disabled children who are able to adapt themselves to life there (China Disabled Persons' Federation, 2008). It shows that educational placement of children with disabilities is both isolated and inclusive. Most of the isolated placement is preschool special education institutions and classes, including special preschool institutions, rehabilitation institutions and preschool classes in special schools, while inclusive placement is still in its infancy (He, 2012). The development of preschool special education in mainland China is relatively backward, but it has gradually occupied its place in special education system.

Regulation on Improving Education for the Disabled (revised in 2017). In order to protect the equal rights to receive education of persons with disabilities, the State Council of the People's Republic of China revised the Regulation on Education for Persons with Disabilities in 2017, according to Compulsory Education Law and Law on the Protection of Persons with Disabilities. The initial regulation was promulgated in 1994, the revision further strengthened the support and guarantee on education for children with disabilities and made three specific provisions (State Council of the People's Republic of China, 2017a).

Firstly, guarantee financial input. Educational funds for the disabled children and all necessary costs should be included in the budget of all levels of people’s government, the government at the county level should set up special subsidies for developing education for persons with disabilities as needed. In addition, employment security fund for the disabled can be used for vocational education in special schools. Secondly, strengthen the construction of special schools. The government at the county level or above should make overall plans and rational arrangements base on the developing educational needs. The government should set up special schools and allot necessary equipment and facilities for schooling, rehabilitation assessments, and training, in accordance with relevant national provisions. Thirdly, remit fees. Schools should reduce tuition and other costs for students with disabilities and give priority to subsidies for students facing financial hardship in accordance with relevant provisions of the state.

As for preschool education, the regulation requires that all levels of government should actively raise the proportion of young children with disabilities receiving preschool education, and support general kindergartens in creating conditions to recruit young children with disabilities. Besides, support special schools, welfare organizations and rehabilitation institutions for children with disabilities that are qualified to offer special preschool education. Education on young children with disabilities should be combined with child care and rehabilitation. Preschool education institutions that recruit children with disabilities should be equipped with necessary rehabilitation facilities, equipment and professional personnel, or cooperate with other special education and rehabilitation agencies that have relevant specialized facilities and conditions to carry out rehabilitation training for young children with disabilities. Article 33 clearly puts forward that health care organizations, preschool education and rehabilitation institutions should provide consultation and guidance on early detection, early rehabilitation and preschool education for children with disabilities.

The regulation has emphasized that take family as an important part of early intervention. The revision and implementation of the regulation has provided a more solid legal guarantee for the education of the disabled children. It will promote the development of education with further promotion on education equity for disabled people. But it’s undeniable that China now has no specialized law on special education. Among existing laws and regulations, it lacks of laws and regulations that are more detailed, specific and operational, which is conducive to the realization of high quality development of early education and early rehabilitation.

Regulations on the Prevention and Rehabilitation of Persons with Disabilities. In order to prevent the occurrence of disability, reduce the degree of disability and help disabled people to restore or compensate the functions, promote equal and full participation in social life and develop the disability prevention and rehabilitation of disabled persons, the State Council of the People's Republic of China has promulgated Regulations on the Prevention and Rehabilitation of Disabled Persons according to the Law on the Protection of Persons with disabilities (State Council of the People's Republic of China, 2017b). It is formally promulgated in 2017, and for the first time clearly put forward the responsibility of the state, society and citizens in the prevention and rehabilitation work for disabled persons in the form of laws and regulations. This will provide a strong guarantee for the realization of the goal of everyone enjoying the rehabilitation services.

This regulation has required that disability prevention work should cover the whole population and the whole life cycle, and take targeted preventive measures according to different periods of one’s life, including prenatal and postnatal, early childhood, adulthood and old age. Aiming at infancy and early childhood, the regulation states that the department of health and family planning should carry out pre-pregnancy and maternity care, prenatal screening, prenatal diagnosis and neonatal screening, infectious diseases, endemic diseases, chronic diseases and mental illnesses screening. And take appropriate measures of prevention to eliminate or reduce the risk of disability, to strengthen early clinical intervention and reduce the occurrence of disability. Meanwhile, on the side of safeguard measures, the State should establish a rehabilitation and relief system for the children with disabilities, and gradually realize the goal of children between 0-6 with disabilities in vision, hearing, speech, body, intelligence and autism being able to get free services of operation, auxiliary equipment and rehabilitation training. This system is for all children with disabilities between 0-6, covering six kinds of disability. It is the first meaningful and inclusive welfare system in the rehabilitation area for the disabled persons, and it has great significance to promote the development of rehabilitation for children with disabilities in mainland China.

Practical Issues

With the development of related laws and regulations, China has made some progress in early intervention for children with disabilities. According to the Sampling Survey on Disability in 0-6 Years-old Children in 2001, rehabilitation status of children with disabilities between 0-6 has been greatly improved. 67.09% of disabled children have received rehabilitation training. Among the children who are in need of rehabilitation device, 47.31% with hearing impairment, 14.06% with visual impairment and 38.82% with physical disability have rehabilitation device (China Disabled Persons' Federation, 2003). Family-based rehabilitation has the priority in rehabilitation of children with disabilities. But the needs of special education institutions, hospital treatment and rehabilitation institutions increase significantly. There are also differences between the rehabilitation of different types of disability; the rehabilitation for children with visual and mental disability is not optimistic. In the aspect of preschool special education, 43.92% of disabled children have received preschool education. Among that, 61.48% of them are from city, while 26.41% are from rural area, the percentages are still far below the rate of children without disabilities. The survey also found that special institutions that provide preschool education for children with disabilities are in huge shortage and general preschool institutions lack of teachers and corresponding facilities accepting children with disabilities. The situation of preschool education for children with disabilities between 3-6 years needs to be improved, especially in rural areas. Because in these areas, there is a higher prevalence of disability in children under 6 years in families with lower educational level members and divorced families (Hui Zhang et al., 2006).

With the development of early intervention, more and more specialized institutions are providing related services for children with disabilities and their families, including CDPF system, health care centre, non-governmental organizations (NGOs) and educational institutions. Though disabled children and their families have multiple choices to received early intervention services, these services in mainland

China are still isolated. In particular, Health care centre is primarily responsible for early screening, early diagnosis and treatment. CDPF and education institutions are responsible for formulation and implementation of early intervention plans, and private non-governmental organizations are applicable to persons who are not included in the public service system. Thus, early intervention service is lack of systematic and integrated development concept which of vital importance (X. Hu & Yang, 2013).

In recent years, more and more Chinese scholars have conducted studies on early intervention. The research topics contain all kinds of themes of early intervention, including the definition, importance, policy, legislation, practice and challenges (Chiang & Hadadian, 2010; B. Y. Hu, 2010; X. Hu & Yang, 2013; Pang & Richey, 2006; Trube, Li, & Chi, 2013; Zheng, Maude, & Brotherson, 2015). Most recently, X. Hu and Yang (2013) described the present situation of early intervention practices in mainland China, framed around the key components and guiding principles of Guralnick's Developmental Systems Approach (DSA). They found that extensive evidence demonstrated early intervention practices had addressed some of the guiding principles of DSA and made significant progress in developing some important components of DSA. For example, early detection and early diagnosis have been explicitly incorporated into the policy. Individualized service plan that suits the characteristics of children's physical and mental development has been the core of the implementation of early intervention programs. Performance evaluation of early intervention programs is one of key standard when service provider/service institution are getting subsidy funds from the government, together with family partnership as part of the early intervention program.

However, according the guiding principles of DSA, it is necessary to involve the parents and their families into early intervention programs. When it comes to the specific implementation, decision markers, researchers and early intervention professionals need to formulate development framework combined with DSA key components according to national and local conditions. In terms of policy, it also needs the support of national laws and regulations. It’s obvious that there still has a great deal of work to be done to bring practices up to the high-quality standards of DSA for early intervention services in the Chinese context.

Family-centered Tendency and Challenges

The term ***family-centered*** refers to “a particular set of beliefs, principles, values, and practices for supporting and strengthening family capacity to enhance and promote child development and learning, has come to be the most widely used and accepted” (Dunst, 2002). Family plays an important role in their children’s early intervention and future development of children; early intervention service is to enhance the capacity of families to meet the special needs of their children with disabilities. Working with families by providing supports to the child and family impacts not only the child’s development, but also the family functions (Bailey et al., 2006). Research has indicated that when parents are involved in early intervention, better outcomes are realized.

Since the 1980s, early intervention has paid special attention to parents involvement and stressed the need to provide family support or family-centered services. The leading developed countries have carried out family support services for families of children with disabilities as the core and beneficiaries. Professionals need to recognize the importance of the family environment to children, believe that parents are competent, attach importance to families’ strengths and their rights to make decisions, and regard parents or family members as partners and active participants. Since each family's situation will differ and the needs of family are various, professionals should establish cooperative relationships with parents to provide individualized and various support services so as to enable parents to use community resources, have the motivation to deal with crises, enhance their physical and mental health, problem-solving ability and parenting skills.

Specifically, in the planning, decision-making and evaluation process, family members should be involved, and professionals need to share information with parents, so that families can make decisions to choose the appropriate intervention programs for their children. Cooperation and partnership between parents and professionals should be established to provide the necessary resources and supports for families, not just for children, so that children, parents and families can all be benefited (Dunst, 1995).

Bailey et al. (1986) emphasized that family-centered services should focus on the promotion of family functioning and lay emphasis on the outcomes of children and their families. Professionals should have a better understanding of the strengths and resources of families rather than deficiencies, and support families' decisions and choices. Parents and professionals should jointly decide the priorities of services and the way to provide resources and to delivery services. Putti and Brady (2011) also emphasized that the provision of support services should be based on family needs, and as family needs change, flexible adjustment should be needed. Professionals should also understand the strengths of families, and carry out effective interaction with parents. In a word, in the early intervention service system, the family-centered intervention mode requires parents to be the active participants and understand their central and long-term roles, and ultimately to benefit both children with disabilities and their families.

More and more researches have paid attention to the importance of parents in early intervention. The role of parents or families depends on characteristics of families, including educational background, socioeconomic status, and geographical location etc. Families in cities or developed areas with parents having a good educational background, a better understanding of the importance of early intervention, a positive attitude towards disability, good economic conditions to afford the costs of children's education and rehabilitation services are more likely to have access to high-quality early intervention services than families in rural areas where with parents having a poor education background and backward socioeconomic status (Pang & Richey, 2006).

It is foreseeable that the implementation of family-centered early intervention in China is going to face great challenges. China is a big developing country with 56 nationalities, with a land area of 9.6 million square kilometers, almost comparable to that of Europe. In this vast land, natural conditions, social development, traditional culture and economic level vary widely from one region to another. There are not only urban and rural differences, but also differences between the south and the north, featuring imbalance in regional economic development. And such imbalance is more concentrated in the gap between the eastern, central and western regions.

In cities or economically developed regions, there is appropriate funding support for early intervention programs, and there are also good professional services teams providing health care, education, psychological and social support, family members are encouraged to actively participate in individualized early intervention plans for their children. However, in economically backward rural areas, early intervention programs often face inadequate economic support, low levels of professional services, limited facilities and resources, and parents are less involved in education and rehabilitation activities for their children, and instead of discussing with professionals, parents are more dependent on professionals and service agencies to directly provide special education or rehabilitation training for their children.

The reason may be related to the limitations of the parents, such as poor educational background, low socioeconomic status, the geographical location of the family, and parents’ attitude towards disability. The combination of those complex factors hinders the involvement of families and the effective implementation of family-centered early intervention programs. Secondly, though China is currently in a new era of special education and rehabilitation development for children with disabilities, and a series of services including early intervention have been carried out, yet it is far from meeting the huge needs nationwide, especially the western regions, due to economic backwardness and significant differences between urban and rural areas, it is in extreme shortage of relevant resources like funds, high-quality special educators/professionals, and service facilities etc.

Theoretical Perspective

Family System Framework

Family is a complex dynamic system where each family member has the strength to influence each other, individual behavior will also be affected by the reaction of family members, in other words, there is a network relationship featuring interdependence and mutual influence between each family member.

From a functional perspective, Turnbull, Turnbull, Erwin, Soodak, and Shogren (2015) defined Family as “two or more people who regard themselves as a family and who carry out the functions that families typically perform. These people may or may not be related by blood or marriage and may or may not usually live together” (P. 6). They have developed a family systems framework for effectively understating the roles and interactions among family members when a family has individual with disability. As shown in Figure 1, the key components of this model include family characteristics, family interactions, family functions, and family life cycle.

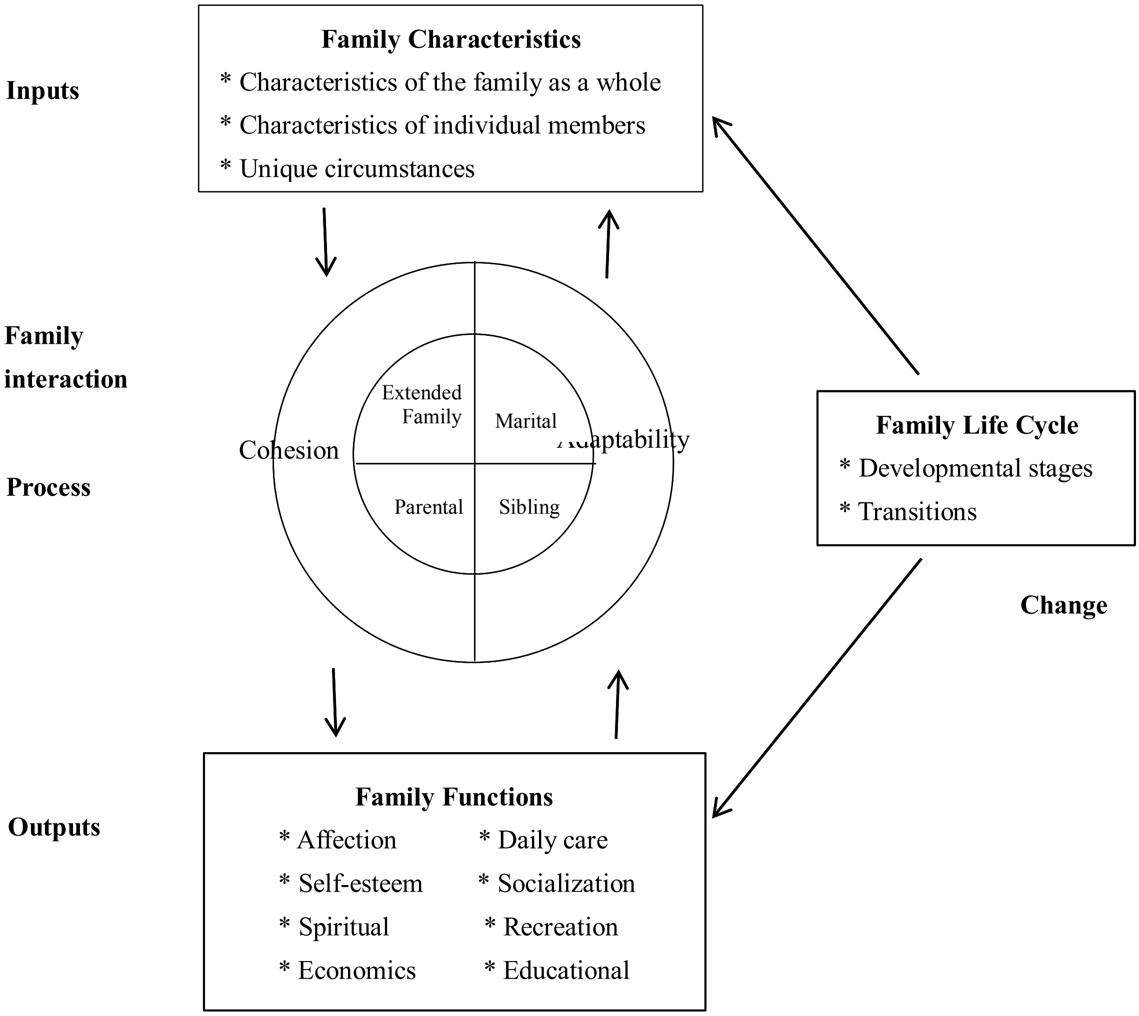

Figure 1. Family system framework (Turnbull et al., 2015)

Family characteristics mainly describe the variables of family background, such as the degree of disability, cultural background etc. These variables will become an input item for family interaction and will affect family interaction; Family interaction refers to the interaction between all family members, including parents, caregivers, siblings and other participants. As a continuous process of family relationships, family interaction will be influenced by the family needs and individual needs of family members, and it is a factor that promotes or suppresses family functions. The family system theory provides more focuses for families because it emphasizes the impact of family on developing children. Family functions refer to the types of individual needs satisfied by families, such as economic or health needs. Finally, the family life cycle represents the order in which family changes are affected, ranging from infancy to school age to adolescence and adulthood.

The above four factors interact with the whole family system and its subsystems. As emphasized by the family system theory, like all families, families of children with disabilities are a complete and unique unit with interaction co-generated by four components, namely marital, parental, sibling, and extended family, so that the internal strength of a family can be gathered and adjusted to respond to various changes brought by family members in various stages of life, and multiple functions of the family can be brought into full play.

Special educators, especially early childhood education and early intervention professionals, have shifted their focus from children or parental subsystems, especially mother-child systems, to a broader focus on the entire family system (R. McWilliam, Snyder, Harbin, Porter, & Munn, 2000). In doing so, the professionals have already realized that every family member is different from each other, and the behavior of any family member will affect the others. Any action related primarily to one member will rearrange the relationship of that person to all of the other family members. In other words, regardless of whether a family has children with disability or not, the family is unique and complex.

Therefore, the family system theory provides a concrete framework for understanding the families of children with disabilities. Since 2000, family system theory has been valued and recognized by special education scholars. The scholars try to explain the influences of disability on the various components of the family from the perspective of the family system theory and how to effectively help the various components of the family to cope with the needs of children with disabilities.

Understanding and identifying the basic characteristics, interactions and functions of families can help provide invaluable insight into how to deliver effective family-centered services in early intervention programs.

Family Quality of Life

Over the past two decades, the trend of intervention programs in disabilities has been changing and developing. The traditional disability intervention targeted the individual's special needs independent of the family and environmental context; however, the development trend is increasing emphasis on supporting individuals with disability and their families and the family quality of life (Samuel, Rillotta, & Brown, 2012). Family quality of life (FQOL) has been increasingly recognized as an important concept in the field of family support for families of children with disabilities, and furthermore, FQOL has emerged as an important outcome of services delivery for children with disabilities and their families.

The definition of FQOL as an outcome is as follows "Family quality of life is a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact" (Zuna, Summers, Turnbull, Hu, & Xu, 2011, P.262). Furthermore, they stated the unified FQOL theory as:

> "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 which re-enter the model as new input resulting in a continuous feedback loop throughout the life course" (P. 269).

In the FQOL theory, the dynamic relationship between FQOL and family support is well summarized. Each individual and family will have different characteristics and beliefs that interact with the provision of services, supports, and practices leading them to make unique decisions about their life and their family's life. These multiple interactive factors are consisted in a dynamic process resulting in unique FQOL outcomes. More specifically, family characteristics and dynamic interact with individual characteristics to influence FQOL outcomes; Family and individual performance factors act as mediating or moderating variables on the effects of family-unit or individual family member factors to predict FQOL; Program quality predicts implementation of best practices, implementation of best practices impacts an individual child factor which in turn impacts FQOL (Zuna et al., 2011, P.267).

C. Chiu et al. (2013) adapted the FQOL theory framework from Zuna et al. (2011) with a focus on systemic factors, family-unit factors, individual-level factors, family and individual support, and outcomes (see Figure 2). They reviewed studies within FQOL theory and discussed the influence factors of FQOL. They proposed that family-unit factors could impact the family members' perceptions toward their FQOL; moreover, family characteristics (e.g., family income, size of family, geographic location, religious preference, and family structure) can impact on FQOL determining the positive outcome. For families of individuals with disabilities, family dynamics can also impact family outcomes. A family member's characteristics (e.g., type of disability, disability severity) can interact with family-unit factors and then impact on FQOL. In addition, systematic factors (including societal values, policies, systems, and programs) directly affect the supports and services gained by individuals with disabilities and their families. As described in the FQOL framework, systemic factors, family-unit factors, individual-level factors, family and individual support factors are constantly influencing and producing the FQOL outcomes. Meanwhile, the FQOL outcomes contribute to new family strengths, needs and priorities.

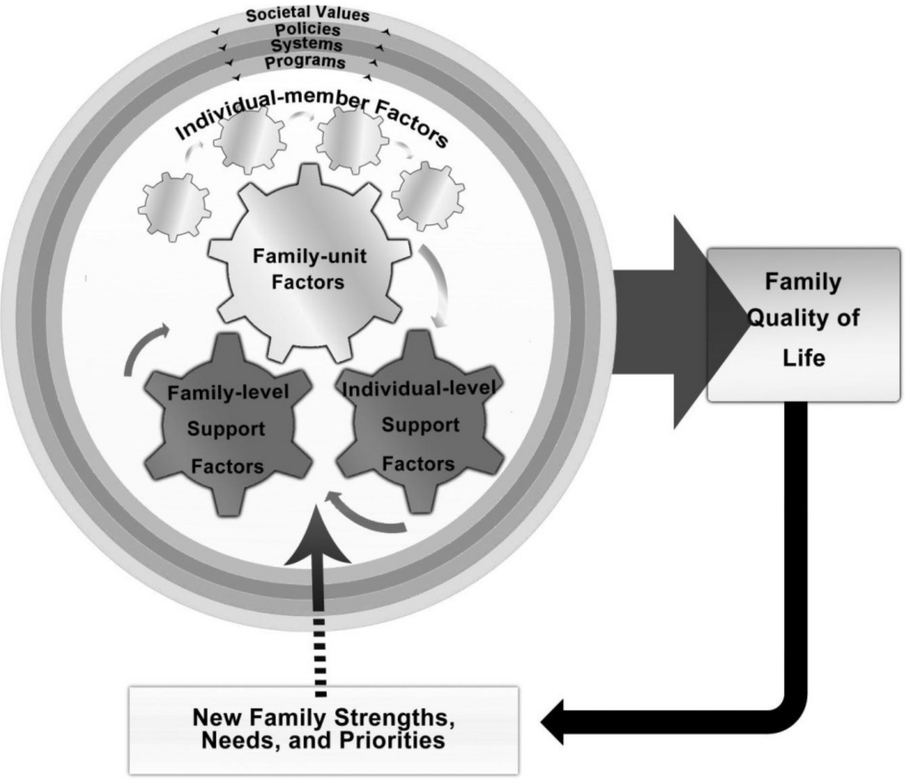

Figure 2. Family quality of life conceptual framework (C. Chiu et al., 2013)

If the family system theory focuses on various influences and impacts disability brings to a family and how families respond to the parenting of children with disabilities, FQOL research focuses more on family supports and quality of services in the field of rehabilitation, special education and social services for children with disabilities and their families (X. Hu, 2015). Brown, Hong, Shearer, Wang, and Wang (2010) pointed out that family needs determined the support services, while the implementation and effectiveness of family support determined family quality of life. The issue is not just a child with a disability but the interaction of disability with the family members as a whole. If there can be a virtuous cycle development among family needs, family supports and family quality of life, the overall family functions will definitely be improved.

Family Assessment in Early Intervention

Families of Children with Disabilities

Having a child with a disability is an unpredictable fact that can affect the vast majority of families, and what this fact has brought to families has always been one of the research focuses. Children with disabilities have profound effects on the entire family-parents, siblings and extended family members, including family structure and all aspects of family functioning. All families expect a healthy and cute child, and it might be difficult to accept the disability and they are less likely to provide necessary care for this child. In this case, children with disabilities may have a negative effect on the family, including negative emotions for disabled children, misunderstanding of disability, potential stress for parents, and the negative interaction between parents and their children. On the other hand, this impact is not necessarily negative, and there may also be a positive impact. If the parents positively recognize and understand the disability, it can increase family members' awareness of their inner strength, the relationship between parents may get closer and family cohesion may also be enhanced.

In studying needs of the parents of children with disabilities, the most logical beginning will be to look at the problems faced by the parents (Murray, 2002). The problems which parents of retarded children face are the acceptance of the fact of disability, financial problems, emotional tension, resolving the theological conflicts, making decisions relative to life-time care for handicapped child, and making choices from the professional advices. Families of children with disabilities face many challenges:

Having a child with disability may increase stress and take a toll on physical and mental health. Hayes (1996) listed the potential emotions that parents of disabled children may experience, such as sadness, guilt, fear, anxiety, resentment, denial, anger etc. Caring for a child with disability imposes high physical, financial, and emotional demands on parents; the tense day-to-day care and assistance can make family members physically and mentally exhausted. The long-term needs for special education and rehabilitation have a lasting and pervasive impact on the family, which at least includes change in the family interaction model and the roles of family members. Apart from the roles of family members that must be re-adjusted, children with disabilities bring great pressure to their parents throughout their life in various aspects like economy, daily routine, emotion, social networking etc. (Oelofsen & Richardson, 2006).

A large number of studies have found that families have undergone varying degrees of pressure during the process of raising children with disabilities. Disabled children need long-term and large-scale care from their parents in daily life, adding a lot of stress to their families, including the heavy work load of caring, the difficulties in upbringing, the repression of psychological emotions, the reduction of economic income, the choice of future placements and the lack of social interaction. A national survey reported more than half parents/caregivers spent more than 40 hours per week providing support for their loved on with intellectual or developmental disabilities, nearly half of parents/caregivers had more caregiving responsibilities than they can handle, and the vast majority of caregivers were suffering from physical fatigue, emotional stress and emotional upset or guilt some or most of the time, people with intellectual or developmental disabilities were still living in the shadows (Anderson, Larson, Wuorio, & Lakin, 2011).

Mothers' parenting pressure has always been the focus of pervious studies. On the other hand, if the main caregiver, such as the mother, is overly involved in the education and rehabilitation of the child while father is less involved, or even immersed in his own work or leisure activities, this pattern will usually affect the marital relations. Due to the change of family system and family life, the primary caregiver may change or give up his or her career planning, and female family members are more likely to be the primary caregiver, and thus give up or change their career planning, especially in Chinese traditional culture.

In recent years, more and more researchers have begun to focus on the pressure of fathers, grandparents and siblings in taking care of disabled individuals. For instance, Davis and Carter (2008) suggested that fathers of very young children present high levels of stress and depressive symptoms, and mothers' parenting stress and depression scores were uniformly higher than fathers' scores.

In sum up, families of children with disabilities are bound to face a lot of pressure, such as emotional stress, parental pressure, financial and time burden. Parents will go through a period of adjustment, during which a lot of problems and specific needs are emerged. Form the family system viewpoint, family's life cycle consists of different stages, in the transition process from one stage to another, the family characteristics, the interaction between family members, and the family functions will change accordingly. For families of children with disabilities, there needs will have different focuses depending on the life stage their children are experiencing. Therefore, only when individualized early intervention services based on the family characteristics and specific family needs, children with disabilities and their families can get more supports and early intervention services can be more effective.

Family Involvement

Family involvement is considered as a key factor in early intervention. Every effort to encourage parental involvement includes offering options that are individualized to reflect each family's own culture and unique set of strengths, values, skills, expectations and service needs (Bailey, 1991). Research on family needs is an important part of family-centered services, parents and family members share their concerns and priorities, and professionals provide relevant information to help them determine what services and supports they need for desired outcomes. A family assessment should be an ongoing and interactive process involving parents and professionals, rather than an activity conducted by the professionals on the family. It should focus on family strengths and family needs.

Who determines the needs of families with disabled children? Bailey and Blasco (1990) believe that when families are aware of stress and tension, they will have expectations for resources and services, and then derives relevant needs. Assessing family needs is an important collaborative process that requires cooperation with family members, the main reasons of which are as follows: First of all, family environment affects the behavior and development of children; second, children with disabilities often bring many challenges; third, the family is a complicated system, different family members may have different understandings of disability and they also have different interactive experience, all these factors will interact and influence each other. In addition, family members may respond to disability very differently.

On the other hand, family needs are based on existing and available early intervention services. The demands decided by existing services may accurately reflect the needs of children with disabilities and their families. The perception of needs may also be related to time, place, the characteristics and beliefs of individuals and their families. It is therefore a complex and important task to accurately determine what is needed for disabled children and their families and to assess the effectiveness of services. It requires early intervention professionals to cooperate with the family members to jointly identify their specific needs (Epley, Summers, & Turnbull, 2011).

Whether early intervention can be successful or not depends on the family's awareness and acceptance of early intervention. Early intervention is no longer just about children education and rehabilitation service, it also includes satisfying the whole family's needs. It should focus on the entire family and be based on the overall family needs. However, studies have shown that Individual Family Service Plan (IFSP) usually does not reflect a family's concerns and priorities (Jung & Baird, 2003; Ridgley & Hallam, 2006). On the contrary, many IFSPs still reflect what professionals think a family needs rather than what the family thinks they need, because early intervention services do not align with family's perceptions of needs and are less likely to have a positive impact on the family outcomes (Epley et al., 2011). As in many countries, early intervention, education and rehabilitation services for children with disabilities have historically focused on supporting disabled children, followed by family needs and priorities in China. In practice, the content of intervention services is usually decided by professionals to implement this plan, but they focus less on family needs and priorities, thus family involvement is particularly important in early intervention services.

Family Needs Assessment

To make sure that children with disabilities can get access to effective early intervention services, the needs of children with disabilities and their families should be considered. While providing early intervention for infants and toddlers with developmental delay or disability, it is necessary to carry out not only child's developmental evaluation and identification of individuals, but also family assessment. The goal of implementing the family assessment is to identify the family strengths, needs and priorities. More specifically, previous researches have confirmed that a comprehensive family assessment roughly includes the following domains: family identified needs or priorities, family characteristics and structure, family life cycle changes, family and home environment, family strength or functioning style, and family social support (McGrew, Gilman, & Johnson, 1992).

In assessing family needs, professionals usually collect information by means of questionnaire surveys, observations and interviews. Among all methods, self-reported questionnaire survey with quantitative information is the most frequently employed in studies for its appropriateness in measuring the subjectively defined construct (i.e., family needs) and its time-efficiency in data collection (Creswell, 2013). Although parents of children with disabilities have different preferences for written surveys as distinguished from face-to-face interviews, they generally consider that self-administered family needs questionnaire is helpful in improving their communication with professionals (Bailey & Blasco, 1990).

Since the 1980s, researchers have developed a number of psychometric tools for assessing family needs. Questionnaire survey is applied in most studies, Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988), Family Needs Survey (Bailey & Simeonsson, 1988), and Family Needs Assessment (Chiu, Turnbull, & Summers, 2013) are the frequently employed measures. Meanwhile, some qualitative researches also obtain information on family needs through focus group or interview. McGrew et al. (1992) reviewed 15 family needs assessment tools and summarized 17 categories of family needs, with most of the assessment tools (93%) containing one to multiple need categories such as economic/financial, social network (within family), social network (outside family), emotional/mental health, and child care. And the relatively less involved category is cultural-social (20%), religious/spiritual and legal （40%）, and food/clothing (47%).

Among them, Family Needs Survey (FNS) is the most frequently employed questionnaire for assessing family needs in early intervention programs. Bailey and Simeonsson (1988) carried out researches on the needs of families with disabled children relatively earlier, by reviewing a large number of research literature, they put forward at least six potential needs (i.e. information needs, supports needs, explaining to others, community service needs, financial needs and family functioning), and designed the FNS scale for identifying family needs. Based on the conceptualization of the need categories, the family needs survey revised in 1990 divided family needs into seven category (Bailey & Simeonsson, 1990), including:

Information includes families' needs for information about the parenting skills, techniques and knowledge of children with disabilities, information about the services needed for disabled children, and information about the future development of children with disabilities, which can help families to make decisions based on the information, enable families to understand their children, better parent their children and cope with problems related to the development of their children.

Family and Social Support refers to the needs to discuss the problems about disabled children with family members and the needs to discuss knowledge about family education and rehabilitation with more friends, parents and relevant professionals.

Financial Need refers to subsidy in material objects and relevant material support and subsidies to assist disabled children. In addition to living expenses, it also refers to the additional cost of taking care of child, the cost for parents to receive counseling and find jobs.

Explaining to Others refers to how to respond to other people's questions, including family members, such as child's siblings, grandparents, neighbors, relatives and friends, and other families with disabled children.

Child Care includes the need for qualified caregivers, day care institutions etc.

Professional Support refers to the need to get counseling from psychological counselors, social workers, therapists and doctors, and can have more time to discuss the practical situation of children and their families with the above people.

Community Service refers to the ability to work with other parents with exceptional children to discuss the parenting skills and methods of raising a child.

Family Needs

Family Needs of Families of Children with Disabilities

Many studies have been conducted to examine family needs of the families in raising and caring for children with disabilities. And needs expressed by families of children with disabilities vary from person to person and from family to family. As indicated by the previous literature on family needs, researches mainly include two aspects, namely the areas of family needs and the predictor factors influencing family needs.

Previous researches have identified several types of family needs of families with children with disabilities. Mahoney, O'Sullivan, and Dennebaum (1990) constructed a Family-Focused Intervention Scale (FFIS) to assess the degree to which mothers received a number of family intervention services. The questionnaire was completed by 503 mothers, the findings indicated that the information they need most was about how to get involved (such as relevant laws, available resources, communication with professionals, participation in parental growth groups etc.) and information about their children (such as children development, disability status, institutional benefits to handicaps children, children's health, assessment results etc.), followed by information related to family guidance (such as books on how to play with children, how to teach them and relevant guiding skills) and external resources (such as doctors, transportation, financial resources etc.), and personal and family assistance was the last thing they need (such as family problems, stress adjustment, family counseling, sharing feelings with other parents etc.)

Sahay et al. (2013) employed Family Needs Survey (Bailey & Simeonsson, 1988) to investigate the needs of parents of children with intellectual disabilities, and found that parents had a higher need for information of current and future service available in society and the community, which was followed by basic expenses, teaching strategies and therapy, day care services. The needs of community services and professional support were at an average level, while they had a relatively low need in aspects like family and social support, explaining to another and child care etc.

As for qualitative research, McConnell, Llewellyn, and Bye (1997) applied focus group or interview and identified six areas of parent needs, including needs for parenting skills, living skills, self-esteem and assertiveness skills, informal social support, access to mainstream services, and advocacy. Redmond and Richardson

(2003) interviewed 17 mothers of children aged 4 years and under with severe/profound intellectual disability, and explored the mothers' views of the usefulness of the financial, practical and emotional supports being offered to them and their suggestions for service improvements. The results revealed that mothers expect to receive services related to children such as comprehensive information services and advocacy support, and services of short home-based respite care; it is necessary to provide counseling and support services for parents, especially when children are found have a disability.

Samuel, Hobden, LeRoy, and Lacey (2012) employed Family Quality of Life Survey (FQOLS-2006) to conduct structured interviews among 149 main caregivers of children with intellectual or developmental disabilities, and found that the majority of families reported that they needed more professional support from disability-related services, among which the need for therapy for the child with intellectual or developmental disabilities was the support service they needed most. Specifically, families were in need of speech therapy, occupational therapy, physical therapy and other therapies such as recreational, art therapy or music therapy. The second support they need most was extra education services, including day care, social skills training, and respite care. The third most needed support was the need for spiritual support.

Factors Influencing Family Needs

The family system theory emphasizes that the individual's development comes from the interaction between the individual and environments, which is a complex interaction with the family system. And the family quality of life conceptual framework constructed by C. Chiu et al. (2013) is mainly applied in families of children with disabilities. It is a systematic view to learn and assess family quality of life, and it puts forward five systemic factors influencing the family quality of life, family strengths and family needs, including societal values, policies, systems, programs, and macro-environment. As indicated by this cyclical model, these five systemic factors affect the family quality of life, endow families with strengths or cause family needs. If family strengths are rationally used and family needs are met, factors in this system may be changed and improved.

C. Chiu et al. (2013) integrated relevant researches and found that the macroeconomic environment of the disabled and their families includes personal factors (demographic information of the family members-age, gender, education background, race, place of residence, work situation; factors about the disabled themselves-demographic information, degree of disability, problematic behavior) and family factors (such as family income, family structure, family location, religion) and so on. These factors reflect information about the disabled children themselves and their families; therefore, factors influencing family needs are also explored by understanding the relationship between family needs and children with disabilities and their family characteristics. While assessing family needs, special attention should be paid to the characteristics of children with disabilities and their family ecosystems, which must be included in the assessment.

Although the impacts of disabled children on their families have a lot in common, and most studies have focused on exploring the needs perceived by families of children with disabilities, yet there are also some studies exploring the characteristics of children and their families, and the influences of these characteristics on family needs. Existing studies have indicated that factors affecting family needs primarily include the age of child, type of disability, severity of disability; and socioeconomic status of the family, geographical location etc. For instance, C.-Y. Chiu et al. (2013) reported the highest expressed needs of the primary caregivers (*N* = 401) are hope (i.e., anticipating and achieving positive outcomes) and disability-related services (i.e., getting services and teaching the child with disabilities); they have relatively lower needs of family resources and caregiving, and it is basically consistent among subgroups with various demographic features. However, for low-income families, the financial need is the highest area of needs. In addition, families of children with severe/profound disabilities have higher needs in all domains and need more support in their daily life.

Child's age: According to a survey conducted by Ellis et al. (2002), age of the child predicts overall family needs. Families of younger children express the greatest overall needs. However, some studies used the same measures (FNS) shows that there is no significant effect of child's age on family needs (Bailey, Blasco, & Simeonsson, 1992; Farmer, Marien, Clark, Sherman, & Selva, 2004; Palisano et al., 2009). Thus, whether the age of children affects family needs is not conclusive.

***Type of Disability*:** According to the study carried out by Bailey et al. (1992), disability types have no clinical significance in terms of family needs. But some studies indicate that when children have multiple disabilities, families also report highest levels of unmet needs (Sloper & Turner, 1992).

Severity of child's disability: Parents expressed lower family needs when their children with less severity of disability (Gu et al., 2010; Palisano et al., 2009).

Family Socioeconomic Conditions**:** Family income is usually the most direct impact on economic needs. Previous researches have consistently found that families with less family resources (such as racial or ethnic diversity or poor socioeconomic status) have more needs (Epley et al., 2011; Farmer et al., 2004; Reyes-Blanes, Correa, & Bailey Jr, 1999). According to a questionnaire survey among 422 parents, mothers express significantly more needs than fathers, and low-income mothers are more likely to indicate financial needs than middle or upper income mothers (Bailey et al., 1992). Samuel, Hobden, et al. (2012) also indicated that financial issues were the most commonly reported a barrier to accessing services, most of the low income families were not likely to have access to affordable health care.

Geographical Location**:** Compared with the urban environment, families in rural areas have higher financial needs in Chinese families (J. Chen & Simeonsson, 1994). Darling and Gallagher (2004) compared needs of and sources of supports for caregivers of young children with disabilities living in urban and rural areas. The results indicated that African American and European American caregivers differed significantly in terms of family needs, while there was also a significantly difference between urban and rural caregivers in the overall support. It is recommended that differences between race and ethnicity should be taken into account when examining family needs.

In summary, family needs related to information, financial, professional, family and social support, emotional, and psychological are specific domains commonly explored by researchers. Additionally, family is a complex system, even if families encounter similar difficulties and challenges; they may also have different needs because of various internal factors (such as the characteristics of children with disabilities and family members, family interaction etc.) and external factors (such as residence, interaction between family members and the environment etc.).

Research on Family Needs of Chinese Families of Children with disabilities

Article Retrieval

The researcher conducted a literature search for extant Chinese literatures on family needs through China National Knowledge Infrastructure (CNKI). The keywords included terms such as needs, parents or family and disability. In addition, the same information retrieval was conducted through Web of Science, EBSCO and ERIC. The search strategy was as follows: (a) Parent OR Caregiver OR Family; (b) AND Needs; (c) AND disab* (to cover terms such as disability, disabled, disabilities) OR handicap OR impairment; (d) AND child OR Infant OR Student; (e) AND China OR Chinese. In order to obtain relevant literature as much as possible, the reference bibliography of key literatures was also examined.

In the end, 19 studies were reviewed, with the earliest literature published in 1994 and the most recent one published in 2016. As shown in Table 1, these references are sorted chronologically, presenting the domains of the author, publication year, research design, participants and family needs dimensions.

Table 1

Summary of Reviewed Studies on Family Needs of Chinese Families (N = 19)

	Author (Year)	**Title**	**Participants**	**Research Design**	**Family Needs**
1	J. Chen and Simeonsson (1994)	Child disability and family needs in the People's Republic of China	*N*=101	Quantitative (Survey)	1. Information; 2. Support; 3. Financial assistance; 4. Explanation to others; 5. Child care; 6. Professional support; 7. Community services.
2	Mu (1995)	A Survey on Parent Needs of Children with Intellectual Disability	*N*=45	Quantitative (Survey) and qualitative questions	1. Parents training; 2Financial assistance; 3. Compassion and assistance; 4. Welfare agency's assistance in raising child; 5. Understand the causes of disability; 6. Medical treatments 7. Collaboration with teachers.
3	Luo and Lei (1999)	The Research on Family Needs of Students in Special Schools	*N*=276	Quantitative (Survey) and two qualitative questions	1. Information; 2. Professional support; 3. Service support; 4. Financial support; 5. Spiritual support.
4	Wong et al. (2004)	Needs of Chinese Parents of Children with Developmental Disability	*N*=23	Qualitative (Focus group interviews)	1. Parental; 2. Informational; 3. Attitude towards the child; 4. Coping; 5. Support.
5	Lv and Gao (2005)	A Survey on the Support Needed by mothers of Autistic Children in China	*N*=200	Mixed methods Quantitative (survey) and Qualitative (observation, interview)	1. Early detection and diagnosis; 2. Information; 3. Childcare institutions; 4. Short-term service; 5. Expert consultation; 6. Parents' association; 7. Medicaid.
6	Zeng (2006)	An Investigation on Needs of Families with Intellectually Disabled Adult Child in Shanghai	*N*=1412	Quantitative (survey)	1. Government assistance; 2. Care organization; 3. Rehabilitative training; 4. Training and job creation.
7	Y. Chen (2007)	A Survey on the Demands of Family Rehabilitation for Disabled Children	*N*=51	Quantitative (Survey) and qualitative questions	1. Professional assistance; 2. Supply of information; 3. Financial support; 4. Psychological support.

	Author (Year)	Title	Participants	Research Design	Family Needs
8	Lin, Qin, and Zhang (2007)	A Research on Parents' Needs of Autistic Children in Rehabilitation Agencies in Chongqing	*N*=60	Mixed methods Survey and interview	1. Long-term help from teachers; 2. More rehabilitation agencies; 3. Medical treatment subsidy and more consultation information.
9	P. Wang and Michaels (2009)	Chinese Families of Children with Severe Disabilities: Family Needs and Available Support	*N*=368	Quantitative (Survey) and one qualitative question	1. Information; 2. Family and social support; 3. Financial; 4. Explaining to others; 5. Child care; 6. Professional support; 7. Community services.
10	X. Huang, Zhang, and Xing (2009)	An Investigation on Needs of Families and Developmental Support of 71 Autistic Children	*N*=71	Quantitative (Survey)	1. Financial; 2. Support in daily life; 3. Professional assistance
11	Gu et al. (2010)	On the Investigation into the Needs of families with Disabled Children in Beijing	*N*=133	Quantitative (Survey) and one qualitative question	1. Information support; 2. Professional support; 3. Financial support; 4. Service support; 5. Spiritual support.
12	Ni and Su (2012)	Needs of Autism Families and Social Work Intervention- From the Report of 120 Shenzhen Autism Families	*N*=120	Mixed methods Survey and interview	1. Psychological and emotional need; 2 Social resources need; 3. Knowledge and information need.
13	Guo, Deng, Zhao, Wen, and Huang (2014)	Investigations and Analysis on the Needs of Parents of Children with Autism	*N*=3867	Mixed methods Survey and interview	1. Social security; 2. Social support; 3. Vocational rehabilitation and Day-care; 4. Education and rehabilitation; 5. Psychological support; 6. Professional training and information; 7. Special support; 8. Social life and property trust.
14	Su, Wu, and Fang (2014)	An Investigation into Parents' Attitudes towards and Demands for Inclusive Education for Children with Autism Spectrum Disorders	*N*=515	Mixed methods Survey and interview	1. Psychological demands; 2. Instructional; 3. Information; 4. Managerial demands; 5. Policy-oriented support; 6. Financial support.

	Author (Year)	Title	Participants	Research Design	Family Needs
15	X. Hu, Turnbull, Summers, and Wang (2015)	Needs of Chinese Families With Children With Developmental Disabilities A Qualitative Inquiry	*N*=26	Qualitative Focus group and in-depth interviews	*Survival needs*: 1. Financial needs; 2. Physical health needs; *Sufficiency needs*: 3. Higher quality education and therapy for the child; 4. Home-based education and information for parents; 5. Social inclusion for both parents and the child; *Enhancement needs*: 6. Emotional health; 7. Future planning.
16	Y. Li (2015)	A Survey on Family Needs of Children with Cerebral Palsy	*N*=50	Quantitative (Survey)	1. Information; 2. Professional; 3. Financial; 4. Service; 5. Spiritual.
17	Y. Xiong, Gao, and Zhang (2015)	Family Needs and Social Support of Children with Autism	*N*=50	Mixed methods Survey and interview	1. Child care; 2. Financial; 3. Psychological; 4. Educational.
18	Jia and Hu (2016)	A Study on Current Situation and Affecting Factors of Family Needs of Students with Visual Handicap	*N*=207	Quantitative (Survey)	1. Disability-related Service; 2; Caregiving; 3. Social connection; 4. Hope; 5; Family resources; 6. Economics; 7. Recreation.
19	X. Hu, Yue, and Jia (2016)	The Status and Relationship between Family Needs and Family Quality of Life of Children with Visual and Hearing Impairment in China	*N*=798	Quantitative (Survey)	1. Disability-related Service; 2; Caregiving; 3. Social connection; 4. Hope; 5; Family resources; 6. Economics; 7. Recreation.

Previous studies on family needs of Chinese families of children with disabilities have the following characteristics:

Research Design

Most of these studies used quantitative research methods. Eleven studies used the questionnaire survey method, five of which added open-ended questions in the questionnaire (Y. Chen, 2007; Gu et al., 2010; Luo & Lei, 1999; Mu, 1995; P. Wang & Michaels, 2009); Two studies used qualitative focus group and interviews (X. Hu et al., 2015; Wong et al., 2004); the remaining six studies used mix methods, in addition to the questionnaire survey, interview and other methods were also used to obtain qualitative data (Guo et al., 2014; Lin et al., 2007; Lv & Gao, 2005; Ni & Su, 2012; Su et al., 2014; Y. Xiong et al., 2015).

In quantitative studies, 53% studies used self-designed questionnaires, and a few studies examined the reliability and validity of questionnaires. The rest of the studies employed questionnaires designed by other scholars; the most frequently used questionnaires were Family Needs Survey (Bailey & Simeonsson, 1988), Family Needs Survey (T.-M. Wang, 1993), and Family Needs Assessment (C.-Y. Chiu et al., 2013)

Description of study samples

The participants were mainly recruited from parents and families of children who received early intervention, special education or rehabilitation and other related services in hospitals, special schools, rehabilitation centers or private special education institutions etc. Children from these families are currently at the pre-school age, school age and the adult stage, most of them are school-age children. In addition, the types of disability include hearing impairment, intellectual disability, cerebral palsy, autism spectrum disorder (ASD), visual impairment etc. Since 2000, ASD children and their families have received more attention (Guo et al., 2014; X. Huang et al., 2009; Lin et al., 2007; Lv & Gao, 2005; Ni & Su, 2012; Su et al., 2014; P. Wang & Michaels, 2009; Y. Xiong et al., 2015).

From the perspective of geographical location, the participants mainly come from the relatively developed eastern region (such as Beijing, Shanghai, Guangdong and Shenzhen) and the central region (such as Hubei, Henan and Anhui), while few participants come from the economically backward western regions. In addition, the participants primarily come from urban areas. And part of the studies considered the geographical distribution (Guo et al., 2014; X. Hu et al., 2015; X. Hu et al., 2016; Jia & Hu, 2016; Lv & Gao, 2005; Mu, 1995; Su et al., 2014) and urban-rural differences (J. Chen & Simeonsson, 1994; X. Hu et al., 2015; Zeng, 2006) during the sampling process.

Key Findings of Family Needs

There are various categories of family needs in mainland China, most of which are classified as need of information, professional, disability-related service, financial, spiritual support. Among them, professional support, information and financial support are the most priority needs of families with children with disabilities. In addition to analyzing the general categories of family needs, some researchers have also studied specific needs, such as parents' learning needs which investigating the needs for specific knowledge and skills of parenting (Haicong Zhang & Liu, 2006); parental education needs (X. Chen & Li, 2011), psychological needs (J. Liu, 2013), and social welfare needs (J. Li et al., 2015) etc.

Due to the different characteristics of participants, family needs are also different in categories and degrees. Parents of children with hearing impairment at the age of 0-13 expressed that information was their most urgent need, followed by financial support (J. Chen & Simeonsson, 1994). Gu et al. (2010) also gained the consistent findings that families of disabled children at the age of 0-7 had the most needs for information, financial support and professional support. Similarly, Y. Chen (2007) surveyed 51 parents of children with intellectual disability and cerebral palsy, 85% families needed professional supports.

As indicated by study on family needs of students in six blind schools in eastern and western China, families have the highest need for hope and disability-related services (Jia & Hu, 2016). And the priority needs for families with mentally retarded adults are government rescue, institutional care, employment training and rehabilitation training successively (Zeng, 2006).

In recent years, more and more attention has been paid to children with ASD. X. Huang et al. (2009) indicated that families of ASD children had the highest need for financial subsidies. However, according to survey and structured interviews among 3,867 parents of autistic children in 30 provinces and autonomous regions nationwide, the needs for social support system are the most intense (Guo et al., 2014).

H. Liu and Zou (2015) used content analysis and bibliometrics to analyze extant literature from 1977 to 2013. The results revealed that the needs of Chinese parents of ASD children from the highest to the lowest were information, professional guidance, child's rehabilitation education, child's society insurance, adequate rehabilitation institutions, psychological support, improving early detection and diagnosis system, improving the quality of diagnosis and treatment, establishing autistic parents associations, social acceptance, property and trust services etc.

In addition, family needs are affected by the characteristics of children and their families. The predictor factors include child’s age, birth order, type of disability, severity of disability, type of placement, family socioeconomic status etc. Examples of the research findings are as follows: the type of child impairment and the placement may be factors related to variability in expressed needs (J. Chen & Simeonsson, 1994). Families of children with autism are more likely to have greater needs for information and supports than parents of children with intellectual disabilities or physical disabilities (P. Wang & Michaels, 2009). Child’s age, birth order, family socioeconomic status have a significant effect on the degree of needs (Y. Li, 2015). Family needs of families with children with visual impairment have significant differences for different household income, parents’ educational status and working conditions (Jia & Hu, 2016). In addition, severity of disability has a significant effect on family needs; parents above the age of 40 have higher spiritual needs than those under the age of 40, and mothers have more needs for information than fathers (Gu et al., 2010).

Family Supports

Caplan (1974) addressed the concept of support systems as an enduring pattern of continuous or intermittent ties and emphasized the types of relationships that constitute a support network, he also identified distinct forms of support activities:

"The significant others help the individual mobilize his psychological resources and master his psychological, emotional burdens; they share his tasks; and they supply him with extra supplies of money, materials, tools, skills, and cognitive guidance to improve his handling of his situation" (P. 6)

Support has been acknowledged as a critical resource for families of children with disabilities. The philosophy and models of service delivery in early intervention can be guided by a concentration on support (R. McWilliam & Scott, 2001). In order to improve family functions and family quality of life, help parents adjust stress, and reduce stress on families and child care, family support services become an integral part of early intervention (Dunst, 2000). Early intervention service emphasizes the family as a whole, and provides family-centered support services, directly or indirectly exerting effects on children with disabilities, their parents and the entire family.

The theoretical basis of family support includes the social support theory, the family system theory, the transactional theory, and the help giving theory (R. McWilliam & Scott, 2001). These four theories discuss family support from different perspectives: the *social support theory* emphasizes the formal or informal support gained by the family social network, and if the family gets strong social support networks, the family well-being will be strengthened as well; the *family system theory* lays emphasis on the experience of family members, and these unique experience will affect the family well-being, that child disability has negative consequences for parents' well-being (e.g., increased stress); the *transactional theory* is based on parent-child interaction which is testimony to the importance of helping families help their children's development and growth; the *help giving theory* primarily focuses on helping individuals to enhance their abilities and promote their independence.

Family support services are designed to help families care for a relative with disability; there are quite diverse ways and contents of support services. Bailey (1991) argued that family strength was the family's perception of support resources that could be used to meet family needs, including personal resources (such as personality, parenting beliefs), family resources (such as spouses, children, parents, parents-in-laws) and external resources (such as neighbors, friends, other relatives, professionals, parent groups). Guralnick (2005) further pointed out that the content of family support services covered the following levels: (a) Information support helps parents understand the causes of disability, effective education and rehabilitation methods etc.; (b) Social support helps parents get formal and informal social support services to reduce interpersonal interaction difficulties and difficulties in family interaction caused by child's disability, such as parent self-help groups, marital counseling services, etc.; (c) Resources support provides compensatory services to make up families' deficiency in resources and ability, such as financial assistance, respite care, parenting education and training etc.; (d) Health support offers parental counseling and health care services to reduce the psychological threat and physical and mental distress parents may have while taking care of their children. Although family support services vary from one to another, the researchers all point out that support services should be provided according to the individual family needs.

Shumaker and Brownell (1984) have divided social support into emotional support, informational support and instrumental support. More specifically, *emotional support* means getting care from others or expressing feelings to others, including positive emotional expression such as intimacy, sense of belonging, trust, care, respect or appreciation; *information support* refers to the provision of ideas, guidance, suggestions or feedback etc. to help individuals solve problems; *informational support* refers to the material help or assistance, such as material and economic assistance, support for social resources, practical help or assistance in domestic affairs. While R. McWilliam and Scott (2001) divided family support into informational support (e.g., the disability or condition of the child, services and resources, child development, and intervention strategies), material support (e.g., finding resources to meet the basic needs, adapting materials or getting needed equipment, and establishing financial support), and emotional support (e.g., emotional support from professionals, parent groups and social networks). Kyzar, Turnbull, Summers, and Gómez (2012) reviewed the measurement of family support in studies published between 1990 and 2010, they found two types of support were most frequently included across measures: emotional support (e.g., someone to talk with, someone with whom to relax and joke, family acceptance of disability) and /or material/

instrumental support (e.g., finding resources to meet basic needs, accessing respite care, providing transportation to appointments). Besides, physical support (e.g., health checks, nutrition, medical care, assistance with daily living skills for the child: toileting, eating, moving…) and informational support (e.g., verbal or written materials related to improving knowledge) were included in some measures or as an independent variable in the studies.

Family Supports of Families of Children with Disabilities

Previous studies have found that there are wide diversities in the category and source of family supports. Freedman and Boyer (2000) conducted focus groups to obtain the perspectives of parents caring for individuals with developmental disabilities and living at home, and sought to examine family needs for services and ways to facilitate family choice and control of supports. The findings indicated that families used diverse family support, which were ranked as follows from the most frequently used to the least frequently used: respite care, case management, support group, flexible financial assistance and others (such as parents training, transportation, leisure, aids, home health care, home adaptation and family or parental counseling), and their study also confirmed that family support services benefit parents and children in education, emotion and economy, and family members in this study also stressed the necessity to maintain the flexibility of family support services. Additionally, they suggested that support services should be tailored to the individual needs. By reviewing relevant literature, Boyd (2002) found that mothers of autistic children received social support mainly from their spouses, the mothers' relatives and other parents of children with disabilities, and informal social supports can reduce the pressure of those mothers more than formal social supports. In addition, parent support groups were most helpful to those mothers. Kyzar et al. (2012) reviewed two decades of family research documenting the relationship of family support and family outcomes (family functioning, family satisfaction, family quality of life, and family stress) for families of children with moderate to severe disabilities. Findings showed that there was wide variability in the types and sources of support assessed, and family support was significantly related to family outcomes.

Additionally, previous studies have indicated that there are differences in family supports among families with different children and family characteristics. For example, according to findings of Mahoney et al. (1990), mothers of handicapped children at the age of 0-3 express higher support needs than mothers of children at the age of 3-6. Gavidia-Payne and Stoneman (1997) conducted a questionnaire survey among 80 two-parent families of 0-5 year-old children with developmental disability, and found that there were significant differences between mothers and fathers in formal social support. Duvdevany and Abboud (2003) found that mothers with higher informal support had lower marital and economic stress, whereas formal support had no significant association with level of stress. However, the results indicated significant differences in the levels of marital and parental stress by the use of formal support; educated mothers from urban areas used the formal support less than less-educated mothers who lived in rural areas. Keller and Honig (2004) reported that there is a significant correlation between socioeconomic status and family social support in families with school-aged children with disabilities, that is, parents with higher socioeconomic status can make better use of community and social support resources.

Research on Family Supports of Chinese Families of Children with Disabilities

Article Retrieval

Similarly, the researcher conducted key word searches through the electronic database by using the same approach conducted on family needs, the keywords included terms such as supports, parents or family and disability. Reviewed 12 related articles are as listed in Table 2, which mainly lists the authors, research themes, participants and research design.

Table 2

Summary of Reviewed Studies on Family Supports of Chinese Families (N = 12)

	Author (Year)	**Title**	**Participants**	**Research Design**
1	J. Huang and Liu (2006)	An Investigation Report on Social Support to the Families with Children of Special Needs	*N*=221	Quantitative (Survey) Self-designed questionnaire
2	P. Wang and Michaels (2009)	Chinese Families of Children with Severe Disabilities: Family Needs and Available Support	*N*=368	Quantitative (Survey) Adapted FSS
3	Qin, Peng, and Chen (2009)	Investigation on Social Supports of Parents of Children with Autism	*N*=205	Quantitative (Survey) SSRS
4	Cai, Li, and Zhou (2011)	On the Investigation into the Social Support of Family Education on Disabled Children	*N*=488	Quantitative (Survey) Self-designed questionnaire
5	Wu (2010)	The Relationship of Parents Social Support and Anxiety from Autism Children	*N*=54	Quantitative (Survey) SSRS
6	X. Liu (2012b)	Investigation on Family Support of Children with Special Needs in Early Intervention	*N*=206	Quantitative (Survey) Self-designed questionnaire & SSRS
7	Ji, Chen, Yi, Wang, and Tang (2013)	Research on Social Support, Coping Behaviors and Family Functioning in Parents of Children with Autism	*N*=194	Quantitative (Survey) MSPSS
8	X. Xiong and Sun (2014)	Study on Social Support and the Influencing Factors of Families with Autism Spectrum Disorder Children	*N* = 246	Quantitative (Survey) Self-designed questionnaire
9	Peng and Chen (2015)	Investigation on Psychological Property and Social Support System of Parents of Children with Autism	*N*=196	Quantitative (Survey) SSRS
10	Zhu, Peng, and Zou (2015)	The effects of the Socioeconomic Status of a Family with Children with Special Needs and Social	*N*=209	Quantitative (Survey) SSRS

		Support on the Parent-Child Relationship		
11	Zhong, Xie, and Chen (2016)	Study on demands of social support and status of parents with autistic child	*N*=303	Quantitative (Survey) SSRS
12	X. Hu (2016b)	Family Quality of Life and Family Support of Children with Disabilities in China	*N*=3198	Quantitative (Survey) FSS

Note. FSS = Family Support Scale (Dunst, Trivette, & Deal, 1988); SSRS = Social Support Rating Scale (Xiao, 1994); MSPSS = Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988).

By reviewing the previous literature, studies on family supports for Chinese families of children with disabilities have the following characteristics:

Research Design. Most of studies used the quantitative questionnaire survey. Family Support Scale (Dunst, Trivette, et al., 1988) and Social Support Rating Scale (Xiao, 1994) were the most frequently employed measures to assess family supports. The *Family Support Scale* is an 18- item self-report scale measuring different sources of support (e.g., spouses, friends) that parents have found useful in raising young child with a disability. In this literature review, six studies (50%) used the Social Support Rating Scale (SSRS) developed by Chinese scholar. The author Xiao (1994) argued that social support can be divided into two categories. The first category is received social support, that is, objective, visible or practical support, including direct material assistance and the existence and participation of social networks and group relations, or it may also refers to stable relationship (such as a marital, family relatives, friends, colleagues etc.) or unstable social connections (such as informal groups, temporary social communication etc.). The other category is perceived social support, which refers to subjectively perceived emotional support, such as individual's emotional experience of being respected, supported and understood and their satisfaction with experience, and it is closely related to individuals' subjective feelings. The questionnaire has ten items in three domains, namely objective support, subjective support and support utilization. The SSRS scale is widely employed in studies on family social support in mainland China.

From the perspective of ***types of disability*** involved, 50% studies take children with ASD as their research objects (Ji et al., 2013; Peng & Chen, 2015; Qin et al., 2009; Wu, 2010; Zhong et al., 2016). Social support for ASD children and their families receive more attention than that of children with visual impairment, hearing impairment, intellectual disability and other disabilities. This may be caused by the importance attached to ASD at home and abroad in recent years. Many researchers believe that autism is a relatively complex type of disorder, and studying family social support for autistic children and their families may provide reference for other types of disability.

In the aspect of ***perceived family supports***, X. Hu (2016a) conducted survey among 3,198 Chinese families of children with disabilities using the Family Support Scale (Dunst, Trivette, et al., 1988). The results indicated the support degree was in the low level, lying between not helping and a little helping. Family support services can significantly improve the overall family quality of life, especially professional support which has the highest correlation with family quality of life, followed by support from relatives, social organizations, friends, and spouse. Support from informal and non-professional staff (such as grandparents, spouses, relatives and friends etc.) was the main source for families of children with disabilities, and support from social organizations, especially family-to-family help organizations were helpful to families. However, parents generally thought that professional support from rehabilitation institutions, schools, and Disabled Persons' Federation and community workers was not helpful.

In terms of ***support types and the differences***, P. Wang and Michaels (2009) examined the available supports to families of children with moderate to severe disabilities. They found that families received more community services, information and family/social support, and their supports primarily relied on the child's school, spouse and their extended families. Additionally, families of children with autism tended to report greater needs for information and supports than parents of children with intellectual disabilities or physical disabilities.

X. Liu (2012a) found that family supports mainly included economic support, emotional support, group support, treatment support, policy support and professional support, which were family-centered and radial. Policy support and professional support were the priority supports perceived by families. Furthermore, the utilization degree of policy support was significantly higher than the degree of group support, professional support and economic support, and their utilization of emotional support was also in the low level. At present, the costs of treatment and intervention are mainly paid by families and dependent on the state assistance. Due to incomplete supporting of early intervention services, families of children with disabilities rarely experience emotional support.

X. Xiong and Sun (2014) revealed that family internal support of children with autism was sufficient, professional rehabilitation information and educational practice support were deficient, and the other social supports were severely deficient; The main influencing factors included parental educational levels, family residence and economic level. In addition, three comparative studies indicate that there are significant differences in family support between groups of families with disabled children and normal children. The total scores indicating objective support, subjective support and social support gained by parents of autistic children are significantly lower than that of parents of normal children, and parents of autistic children are less satisfied with those supports as well (Peng & Chen, 2015; Qin et al., 2009; Zhong et al., 2016). Parents of autistic children bear more life and psychological stress than parents of normal children, and their need for social support is thereby greater. The social support for families of autistic children comes mainly from the government departments, mostly all levels of Disabled Persons' Federation, and non-government organizations, but these supports still cannot meet their family needs.

Previous studies have further found that there are significant regional differences in family social support. For example, policy support is effectively implemented in most developed areas, but it is not ideally carried out in remote areas or economically underdeveloped areas; as for institutional support, there are rehabilitation institutions in capital cities or economic developed cities, while rural areas or remote areas are extremely short of those institutions, and most institutions in rural areas or remote areas are private operated, which lack of professional support, social support and external supervision. Therefore, it is difficult to meet the actual needs of families with children with disabilities in rural or remote areas (H. Liu & Zou, 2015).

To sum up, family support has a solid theoretical and practical foundation. In early intervention services, family support should be family-centered, and not only focus on the child with disability, but also the entire family. Most researchers believe that family support helps relieve the parenting stress of parents, and it helps parents adapt to their particular role and improve their parenting skills, but the current status of the available supports for Chinese families of children with disabilities is still not sufficient enough. In addition, family supports are related to the characteristics of children and their families, such as the gender of child, the primary caregiver, age of parents, education background of parents, and family socioeconomic status. But there is no consensus on the predictor factors influencing family supports.

CHAPTER 3 METHODS

As described in Chapter 1, the purpose of this quantitative study was to examine the characteristics of children with disabilities and their families, the perceived needs and family supports, and to explore the predictor factors influencing family needs and supports. In this study, a self-reported questionnaire survey was carried out among Chinese families of children with disabilities in provinces, autonomous regions and municipalities like Sichuan, Chongqing, Ningxia and Guangxi to obtain relevant information as a reference for planning and implementing early intervention services in the future.

This chapter describes the methods and procedures employed, including the research design, conceptual framework of the research, participants, and instruments. Additionally, this chapter presents the data collection and data analysis process.

Research Design

To answer the research questions, this study applied quantitative method which is the the process of collecting, analysing, interpreting, and writing the results of a study, to investigate the background information, perceived needs and family supports of Chinese families of children with disabilities through questionnaire survey. The differences among groups with different Children and families' background in regard to perceived needs and family supports were explored.

Figure 3 presents a conceptual research framework of this study. The independent variables were the characteristics of children and families (e.g. child's gender, age, disability category, primary caregiver; family type, family composition, relationship to the child, educational status, family income, and geographical location). The dependent variables were the perceived needs (e.g. need of information, family and social support, financial, explaining to others, child care, professional support, and community services), and family supports (e.g. emotional support, informational support, and instrumental support).

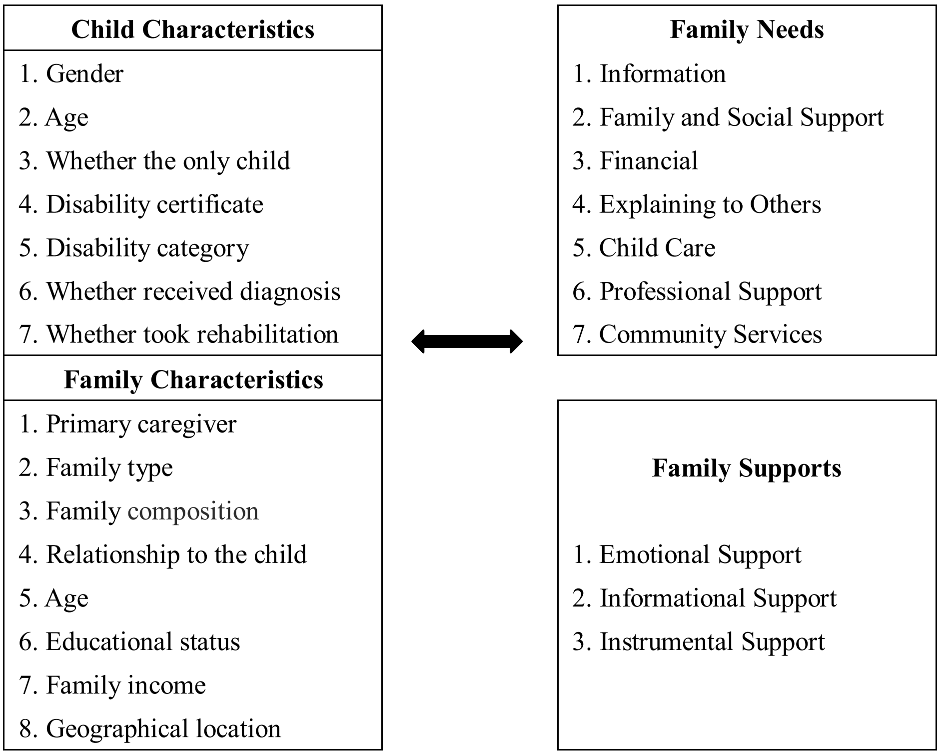

Figure 3. A conceptual research framework

Procedures

After reviewing relevant literature, the researcher planed to employ Family Needs Survey (FNS) as the primary measure. Having been translated into Chinese, this scale has high reliability and validity, it has been used to study family needs in the Chinese context. The original version has two additional items with space for responses in which parents are asked to list other topics or provide any other information that they would like to discuss, and if there is a particular person they would prefer to meet. According to the original author's suggestion, two open-ended questions were added in the revised scale: (a) what services do you currently use to support yourself and your child? (b) Are there any other services you would like to have to support yourself and your child?

The researcher expected to obtain qualitative data through open-ended questions in order to gain a better understanding of the supports those families have perceived and their needs for support. The preliminary draft of questionnaire consists of two parts: first part is a Basic Information Form used to identify the characteristics of children and their families; and the second part is the FNS used to investigate family needs and available supports.

The preliminary draft of the questionnaire was submitted to two persons in charge from early intervention institutions and two parents of children with disabilities who were required to provide advice on the applicability of questionnaire and the appropriateness of statement and wording of questions listed in the questionnaire. According to the two persons from the institutions, few parents will be able to answer the open-ended questions due to the low education level of some parents; the two parents also prefer a closed questionnaire that can be checked directly according to their own ideas. Thus, to meet the preferences of the respondents as well as to further understand the current situation of family supports, the researcher selected the Family Support Survey (FSS) designed by C. Chen (2004) as a supplement, which will be described in the research instruments section in details.

Data collection

In this study, the quantitative data was collected from parents of children with disabilities in western China; and questionnaires were employed to gather information regarding children and families background, parents' perceived needs and family supports.

During initial contacts, the researcher contacted institutions carrying out early intervention programs, such as rehabilitation centers of CDPF, private-operated institutions, kindergartens and so on. The researcher communicated with them on the specific purpose and procedure of this study, including the procedure for informed consent. Eventually, seven institutions agreed to participate in the survey.

After obtaining the consent of those institutions, the researcher sought a responsible person at each institution and delivered the paper questionnaires to them via express, including a cover letter of introduction to parents that completing and returning the questionnaire indicates their consent to participate in this study (see

Appendix A). The persons in charge provided assistance in distributing and collecting the formal questionnaires, and then sent them all back within one month.

Data analysis

After collecting the filled questionnaires, the researcher conducted the coding and raw data input. All data was screening before analyses and the invalid questionnaires were eliminated. Next, all statistical analyses of the quantitative data were conducted with the help of Statistical Package for Social Sciences software (SPSS) version 21.0.

Descriptive statistics were calculated to describe the characteristics of children and their families. Besides, perceived needs and supports were analyzed with percentages, means and standard deviations. The independent samples *t*-test and one-way analysis of variance (ANOVA) were used to compare the difference among groups of families with different children and family backgrounds. If the results of ANOVA presented a significant difference in means, the Fisher's Least Significant Difference (LSD) test was used to determine pairwise differences between groups.

Participants

In this study, the participants consisted the parents of children with disabilities, all their children were enrolled in early intervention programs and received rehabilitations and educational training. The researcher used purposive sampling strategies to recruit participants from seven early intervention institutions in the western regions of China, which were distributed in Ningxia Autonomous Region, Guangxi Zhuang Autonomous Region, Chongqing municipality and Sichuan province. Parents provided demographic and descriptive information, including their child’s age, gender, type of disability, professional diagnosis and rehabilitation status. They also reported on their family type, family composition, educational status, family income, and geographical location.

A total of 600 questionnaires were mailed out, 463 were recollected, 33 invalid questionnaires with incomplete data were eliminated, and finally 430 valid responses were collected, the effective response rate was 71.7%. The current study examined data from 430 Chinese families of children with disabilities, the sample was diverse in terms of child and family characteristics, and specific demographic information about the respondents are presented in Chapter 4.

Instruments

Three instruments were employed to collect quantitative data: (a) the Demographic Information Form; (b) Family Needs Survey (FNS); and (c) Family Support Survey (FSS). A more detailed description of each instrument is provided as follows:

Demographic Information Form

A Demographic Information Form (see Appendix B) was designed for collecting information about children and their families. More specifically, child information included child's gender, age, whether the only child, whether has the disability certificate, disability category, whether once received professional diagnosis (and the diagnosis institutions), whether received the rehabilitation and educational training (and the rehabilitation institutions); Family information included the primary caregiver of child, family type, family composition, respondent's age, educational status, family income, and geographical location).

Family Needs Survey

The initial Family Needs Survey (FNS) was developed by Bailey and Simeonsson (1988) and designed to identify specific family needs and to elicit parents' priorities for early intervention service. The FNS consists of 35 items into six categories: need for information, need for support, explaining to others, community services, financial needs and family functioning. Parents or caregivers of child with disability are asked to respond on a three-point scale with 1 = I definitely do not need help with this, 2 = not sure, and 3 = I definitely need help with this.

Reliability and validity. Previous studies on the psychometric properties and clinical utility have indicated the FNS have high correspondence between ratings of mothers and fathers (*r* = .52); Test-retest stability has also been found over a 6-month period for mothers (*r* = .67, *p* < .001) and fathers (*r* = .81, *p* < .001), with subscale correlations ranging from .53 to .79 (Bailey et al., 1992). This survey has been used in family studies of children with disabilities; at least three forms of the questionnaire are available, with translations in Chinese, Portuguese, Spanish, Swedish, and Egyptian (Touliatos, Perlmutter, & Straus, 2001).

The revised version of FNS (Bailey & Simeonsson, 1990) employed in this study is a 7-factor 35-item measure. Family needs are organized into seven empirically derived clusters, including the needs for: (a) information; (b) family and social support; (c) financial; (d) explaining to others; (e) child care; (f) professional support; and (g) community services. Each item consists of statements about a specific need. Participants are asked to respond on a three-point scale ranging from 1 = No, 2 = Not sure, 3 = Yes.

FNS-revised was slightly modified and adapted to suit the practical situation of parents or primary caregivers living in mainland China in this study (see Appendix C). Two items were deemed to be inappropriate, therefore, Item 29 “Getting appropriate care for my child in a church or synagogue during religious services” was modified to “Getting appropriate welfare care for my child”; and Item 30 “Meeting with a minister, priest, or rabbi ” was revised to “Meeting with officer in government”.

Family Support Survey

Family Support Survey (C. Chen, 2004) is divided into three domains (i.e., emotional support, informational support, and instrumental support) containing a total of 21 items, of which emotional support corresponds to 6 items (Item 1, 2, 5, 6, 11 and 13), informational support is corresponding to 8 items (Item 3, 4, 7, 9, 10, 12, 14 and15), and instrumental corresponds to 7 items (Item 8, 16, 17, 18, 19, 20, and 21) (see Appendix D). Each item has four options, namely None, Some, Many and

A lot, followed by a score from 1 to 4 respectively. The higher the score, the higher degree of family supports.

Reliability. The original author has carried out an internal consistency test of the scale, and the Cronbach's α value is .9390, there is strong reliability within 21-item instrument ($\alpha > 0.7$ indicates a higher reliability coefficient of this questionnaire)

CAPTER 4 RESULTS

This chapter presents the results relate to the research questions in the following three parts: the first part describes the characteristics of children with disabilities and their families in western China; the second part is about the perceived needs of these families, and the difference in family needs among families with different children and family characteristics; the third part focuses on family supports, and the difference among families with different children and family characteristics.

Demographic Characteristics of Participants

The demographic characteristics of children with disabilities and their families are presented in Table 3. A total of 430 respondents from four different regions of the mainland China participated in this study. Overall, there were 299 mothers, 49 fathers and 82 grandparents. The characteristics of children and their family backgrounds will be summarized as follows.

Children Characteristics

Children with disabilities in early intervention programs in this study were primarily 3-6 years of age, taking up a proportion of 58.4%, 26% of them were over 6 years of age, and only 15.6% were under 3 years old. In term of gender, most of them were boys, accounting for 72.1% and girls only took up 27.9%. More than half of the disabled children were single children, reaching a proportion of 52.3%, and the remaining 47.7% were non-only children.

An overwhelming majority of children once received professional diagnosis, accounting for a percentage of 97.4%, most of them were diagnosed in hospitals, reaching a proportion of 71.3%, and 26.8% were diagnosed in rehabilitation institutions. The majority of children had disability certificate, accounting for 69.1%, 40.2% of whom had Multiple Disabilities, followed by Hearing Impairment (19.5%), Intellectual Disability (14.4%), and Autism Spectrum Disorder (13.7%).

In addition, 95.3% children received rehabilitation and educational training, and most of them received services in rehabilitation agencies (78.6%), while some of them gained rehabilitation services in hospitals (18.1%), only minority of them was trained in educational institutions (3.3%).

Family Characteristics

177 families were recruited from Ningxia Autonomous Region, 126 families were from Chongqing municipality, 65 families were from Sichuan province, and 62 families were from Guangxi Zhuang Autonomous Region. The vast majority of families were two-parent families, taking up 90.2%, and single-parent families account for 8.1%. Additionally, more than half were large-sized families of three generations living together under one roof reaching 57.9%, and 38.8% were nuclear families consisting of two parents and their children.

It is important to note that the primary caregivers of these children were mainly mothers (66.9%), followed by the grandparents (21.8%) and fathers (11.3%). Moreover, the majority of respondents in this survey were mothers accounting for 69.5%, followed by grandparents (19.1%) and fathers (11.4%). In terms of age, 44% parents were 31-40 years old, 28.8% were below 30 years of age, 17.4% were more than 50 years old, and about 9.8% were 41-50 years old. When it comes to parents' educational status, 42.1% graduated from middle schools, 34.9% had gone to college, while 21.9% only finished primary school. In terms of household income, the annual per capital income of 54.2% families was less than 20,000 Yuan (€ 2600), 28.1% made an annual per capital income of 20,000 to 40,000 Yuan (€ 2600-5200) and 17.7% were more than 40,000 Yuan (€ 5200).

Table 3

Demographic Characteristics of Participants (N = 430)

Child Characteristics	***n* (%)**	**Family Characteristics**	***n* (%)**
Gender		Primary caregiver	
Boy	310(72.1)	Mother	326(66.9)
Girl	120(27.9)	Father	55(11.3)
Age		Grandparents	106(21.8)
0-3 years	67(15.6)	Nanny	-
3-6 years	251(58.4)	Others	-
Above 6 years	112(26.0)	Family type	
Whether the only child		Two-parent	388(90.2)
Yes	225(52.3)	Single-parent	35(8.1)
No	205(47.7)	Others	7(1.6)
Whether has the disability certificate		Family composition	
Yes	297(69.1)	Small-sized	167(38.8)
No	133(30.9)	Large-sized	249(57.9)
Type of disability		Others	14(3.3)
Intellectual Disability	62(14.4)	Relationship to the child	
Hearing Impairment	84(19.5)	Mother	299(69.5)
Visual Impairment	4(0.9)	Father	49(11.4)
Physical Disability	17(4.0)	Grandparents	82(19.1)
Speech and Language Disorder	18(4.2)	Nanny	-
Emotional and Behavior Disorder	2(0.5)	Others	-
Autism Spectrum Disorder	59(13.7)	Age	
Multiple Disabilities	173(40.2)	Under 30 years	124(28.8)
Others	11(2.6)	31-40 years	189(44.0)
Whether have received professional diagnosis		41-50 years	42(9.8)
Yes	419(97.4)	Above 50 years	75(17.4)
No	11(2.6)	Education status	
Diagnosis Institutions		Primary school	94(21.9)
Hospital	370(71.3)	Secondary school	181(42.1)
Rehabilitation agency	139(26.8)	Undergraduate	150(34.9)
Education agency	9(1.7)	Graduate and above	5(1.2)
Others	1(0.2)	Family income	
Whether have received rehabilitation services		Below 20,000 Yuan	233(54.2)
Yes	410(95.3)	20,000-40,000 Yuan	121(28.1)
No	20(4.7)	Above 40,000 Yuan	76(17.7)
Rehabilitation institutions		Geographical location	
Hospital	89(18.1)	Guangxi	62(14.4)
Rehabilitation agency	386(78.6)	Ningxia	177(41.2)
Education agency	16(3.3)	Sichuan	65(15.1)
Others	-	Chongqing	126(29.3)

Note. The currency of family income is Chinese Yuan.

Family Needs

Perceived Needs of Chinese Families of Children with Disabilities

Family Needs Survey consists of 35 items in seven domains. Table 4 shows a descriptive statistical analysis of the perceived needs, including the percentage of responses for FNS items, Means and Standard Deviations. As the table indicates, the need for information gained the highest score (*M* = 2.91, *SD* = 0.23), followed by child care (*M* = 2.71, *SD* = 0.49), community services (*M* = 2.67, *SD* = 0.49), financial needs (*M* = 2.62, *SD* = 0.50), family and social support (*M* = 2.59, *SD* = 0.47), professional support (*M* = 2.57, *SD* = 0.54), and explaining to others (*M* = 2.35, *SD* = 0.63). With a further analysis of the perceived needs, it was found that parents had ten most priority needs as listed below.

(a) Information about present services for my child (*M* = 2.94, *SD* = 0.33);

(b) Information about future service for my child (*M* = 2.94, *SD* = 0.26);

(c) How to handle child's problem behavior (*M* = 2.92, *SD* = 0.38);

(d) How to parenting child (*M* = 2.92, *SD* = 0.37);

(e) Playing or talking with my child (*M* = 2.91, *SD* = 0.38);

(f) Information about child growth and development (*M* = 2.90, *SD* = 0.42);

(g) More time to talk to teacher or therapist (*M* = 2.89, *SD* = 0.43);

(h) Meeting and talking with other parents (*M* = 2.86, *SD* = 0.46).

(i) Information about child's condition or disability (*M* = 2.86, *SD* = 0.43);

(j) Locating a day care program or preschool for child (*M* = 2.82, *SD* = 0.53).

Furthermore, five least priority of family needs for these parents were: (a) Helping deciding on chores (*M* = 2.11, *SD* = 0.93); (b) Explaining to siblings (*M* = 2.17, *SD* = 0.95); (c) Explaining to parents or relatives (*M* = 2.23, *SD* = 0.92); (d) Explaining to other children (*M* = 2.30, *SD* = 0.88); (e) Responding when friends, neighbors, or strangers ask questions about child (*M* = 2.33, *SD* = 0.89).

The above data reveals that the perceived needs are mainly concentrated in need of information, and their need of explaining to others is relatively minimal.

Table 4

Descriptive Statistics of Perceived Needs by Items for Chinese Families of Children with Disabilities (N = 430)

Family Needs	**No %**	**No Sure %**	**Yes %**	***M***	***SD***
Information				**2.91**	**.23**
1.Child growth and development	2.1	4.7	93.3	2.90	.42
2. Playing/talking with child	3	3	94	2.91	.38
3. Parenting child	1.6	4.2	94.2	2.92	.37
4. Child's behavior	1.9	3.7	94.4	2.92	.38
5. Child's condition	1.2	10	88.8	2.86	.43
6. Present service for child	1.6	2.6	95.8	2.94	.33
7. Future service for child	0.7	4.4	94.9	2.94	.26
Family and social support				**2.59**	**.47**
8. Talking to some in family	6	9.5	84.4	2.77	.58
9. Talking to friends	18.1	13.5	68.4	2.48	.83
10. Having more time for self	12.8	11.6	75.6	2.61	.74
11. Helping spouse	17.7	8.8	73.5	2.54	.82
12. Helping discussing problems	5.6	6.5	87.9	2.82	.52
13. Supporting each other	6.3	5.8	87.9	2.81	.56
14. Helping deciding on chores	35.3	16	48.6	2.11	.93
15. Helping deciding on recreation	14.7	14.2	71.2	2.55	.76
Financial assistance				**2.62**	**.50**
16. Paying for basic expenses	8.8	8.8	82.3	2.73	.64
17. Paying for special equipment	12.6	6.5	80.9	2.67	.71
18. Paying for therapy/special services	7.2	7.9	84.9	2.77	.58
19. Helping getting a job	18.1	11.9	70	2.52	.78
20. Paying for child care	18.4	9.3	72.3	2.53	.80
21. Paying for toys	20	9.0	70.9	2.50	.82
Explaining to others				**2.35**	**.63**
22. Parents/relatives	33.3	10.2	56.5	2.23	.92
23. Siblings	34.2	12.1	53.7	2.17	.95
24. Responding other questions	24.7	15.8	59.5	2.33	.89
25. Other children	25.8	16.7	57.4	2.30	.88
26. Finding reading materials	8.6	10	81.4	2.72	.63
Child care				**2.71**	**.49**
27. Bay-sitter/respite care	17.4	14.4	68.1	2.50	.79
28. Day care/preschool	5.6	6.3	88.1	2.82	.53
29. Welfare care	6.3	6.3	87.4	2.81	.55
Professional support				**2.57**	**.54**
30. Meeting officer in government	19.8	23.7	56.5	2.36	.82
31. Talking to psychologist/counselor	18.4	14.4	67.2	2.47	.81
32. Talking to child's teacher/therapist	2.6	5.1	92.3	2.89	.43

Family Needs	**No** **%**	**No Sure** **%**	**Yes** **%**	***M***	***SD***
Community services				**2.67**	**.49**
33. Talking with other parents	2.3	8.4	89.3	2.86	.46
34. Locating a doctor	8.1	8.1	83.7	2.75	.61
35. Locating a dentist	23	13.3	63.7	2.39	.86

Note. All items were rated on a 3-point scale ranging from 1 = No, I do not need this; 2 = Not sure; and 3 = Yes, I need.

Family Needs Group Difference

In this study, the independent samples *t*-test was used to compare the difference of family needs between two groups of families with different conditions, such as different gender of child, whether the child is the only child, whether the child has a disability certificate, whether the child has received a professional diagnosis, whether the child has received rehabilitation and educational training. Besides, one-way analysis of variance (ANOVA) and the Fisher's Least Significant Difference (LSD) test were applied to compare the difference among groups of families with different conditions (i.e. children backgrounds, such as age, disability category; family backgrounds, such as family composition, parents' age, education status, household income, geographical location etc.). The level of statistical significance was set at $p < .05$ for all tests.

As indicated by *t*-test and ANOVA, the child's age, whether the child is the only child, whether the child has a disability certificate and the disability category had a significant effect on family needs, while the gender of child, whether the child has received a professional diagnosis and whether the child has received rehabilitation training had no significant effect on family needs. In terms of family background variables, parents' educational level, household income and geographical location had a significant effect on family needs, while parents' age, respondents' relationship with children, family type and family composition had no significant effect on family needs. The variables with significant effect on family needs are analysed separately as follows.

Family Needs Group Difference - Child Characteristics

In this study, the age of child was divided into three groups, namely 0-3 years old, 3-6 years old and over 6 years old. As indicated by ANOVA shown in

Table 5, in terms of need for information, child's age had a significant effect on family needs for information [*F* (2,427) = 3.151, *p* = .044]; the means was significantly different at *p* < .05. Multiple comparisons using the LSD test indicated that families of children with disabilities at the age of 3-6 had a higher need for information than families with children over 6 years of age.

Table 5
Analysis of Variance of Child's Age on Family Needs

FNS Subscales	**Child's age**						**ANOVA**		
	0-3 years		**3-6 years**		**>6 years**		***df***	***F***	***p***
	M	***SD***	***M***	***SD***	***M***	***SD***			
Information	2.88	.30	2.93	.15	2.88	.29	2,427	3.151	.044*
Family and social support	2.52	.53	2.61	.44	2.57	.49	2,427	1.132	.323
Financial	2.56	.57	2.63	.48	2.64	.49	2,426	0.549	.578
Explaining to others	2.21	.67	2.40	.60	2.31	.67	2,426	2.683	.070
Child care	2.64	.52	2.70	.51	2.76	.40	2,427	0.157	.209
Professional support	2.53	.58	2.59	.54	2.56	.54	2,427	0.406	.667
Community services	2.61	.55	2.65	.51	2.74	.40	2,427	2.021	.134
Total needs	2.56	.35	2.65	.31	2.64	.33	2,425	1.692	.185

Note. *p < .05

Table 6 presents the results of comparison of the perceived needs between families with only child and families with non-only child gained by the independent-samples *t*-test. This analysis revealed that in the area of *child care* there was a significant difference in the scores for only child families (*M* = 2.65, *SD* = 0.54) and non-only child families (*M* = 2.77, *SD* = 0.41), [*t* (414) = -2.672, *p* = .008]. As compared with families with only child, families with non-only child had a higher need for child care. However, there was no significant difference between them in other areas of needs and total needs.

Table 6

Comparisons of Family Needs between Only Child and Non-only Child Families

FNS Subscales	**Whether the only child**				***t*-test**		
	Only child		**Non-only child**				
	M	***SD***	***M***	***SD***	***t***	***df***	***Sig.*** **(2-tailed)**
Information	2.92	.22	2.90	.24	.684	428	.494
Family and social support	2.58	.46	2.59	.48	-.280	428	.779
Financial	2.61	.52	2.64	.48	-.492	427	.623
Explaining to others	2.31	.62	2.39	.64	-1.310	427	.191
Child care	2.65	.54	2.77	.41	-2.672	414	.008*
Professional support	2.58	.54	2.57	.55	.196	428	.845
Community services	2.67	.53	2.67	.45	-.065	428	.948
Total needs	2.62	.33	2.65	.32	-1.003	426	.316

Note. *$p < .05$

Table 7 shows the difference between families of children with disability certificate and those of children without disability certificate. Results of an independent-samples *t*-test revealed that whether the child has a disability certificate had significantly effect on their family needs of child care [t (213) = 2.182, p = .030], professional support [t (218) = 2.194, p = .029], community services [t (215) = 2.044, p = .042] and total needs [t (426) = 2.389, p = .017]. The sample means are displayed in Table 7, which shows that families of children with disability certificate scored significantly higher on needs of child care, professional support, community services than did families of children without disability certificate. In other words, families of children with disability certificate had higher needs than those of children without disability certificate in needs of child care, professional support, community services and total needs.

Table 7

Comparisons of Family Needs between Children with Disability Certificate and without Disability Certificate Families

FNS Subscales	Disability Certificate				*t*-test		
	Have		Not have		*t*	*df*	*Sig.* (2-tailed)
	M	*SD*	*M*	*SD*			
Information	2.91	.23	2.91	.21	.114	428	.909
Family and social support	2.60	.46	2.56	.49	.920	428	.358
Financial	2.65	.47	2.56	.56	1.825	427	.069
Explaining to others	2.37	.64	2.31	.61	.818	427	.414
Child care	2.75	.45	2.63	.56	2.182	213	.030*
Professional support	2.61	.51	2.48	.61	2.194	218	.029*
Community services	2.70	.46	2.59	.56	2.044	215	.042*
Total needs	2.66	.32	2.58	.33	2.389	426	.017*

Note. *$p < .05$

In this study, the type of disability was divided into eight categories, including Intellectual Disability (ID), Hearing Impairment (HI), Visual Impairment (VI), Physical Disability (PD), Speech and Language Disorder (SLD), Emotional and Behavior Disorder (EBD), Autism Spectrum Disorder (ASD), and Multiple Disabilities (MD).Table 8 presents the results of analysis of variance of disability category effect on family needs. Results revealed that the effect of disability category on need of child care was significant, [F (8,421) = 3.694, p = .000]. LSD multiple comparison indicated that the needs level of child care was as follows: ID > VI, HI > VI, PD > VI, SLD > VI, ASD > HI, ASD > VI, MD > HI, MD > VI. In short, families of children with Visual Impairment and Hearing Impairment had a lower need for child care, while families of children with Intellectual Disability, Physical Disabilities, Speech and Language Disorder, Autism Spectrum Disorder and Multiple Disabilities had a higher need for child care.

Table 8

Analysis of Variance of Child's Disability on Family Needs

FNS Subscales	**Child's Disability**								**ANOVA**		
	M/SD								***df***	***F***	***p***
	ID	**HI**	**VI**	**PD**	**SLD**	**EBD**	**ASD**	**MD**			
Information	2.91 .26	2.91 .18	2.86 .29	2.87 .32	2.88 .28	3.00 .00	2.95 .12	2.90 .25	8,421	.558	.812
Family and social support	2.52 .53	2.52 .52	2.50 .42	2.85 .37	2.58 .61	2.19 1.15	2.63 .40	2.60 .43	8,421	1.564	.133
Financial	2.64 .49	2.51 .50	2.38 .25	2.74 .56	2.54 .70	2.50 .71	2.58 .51	2.70 .44	8,420	1.801	.075
Explaining to others	2.23 .71	2.43 .62	1.90 .62	2.48 .70	2.46 .56	2.50 .71	2.30 .60	2.35 .61	8,420	.907	.511
Child care	2.69 .39	2.58 .57	1.92 .88	2.76 .61	2.78 .32	2.50 .71	2.81 .36	2.78 .42	8,421	3.694	.000*
Professional support	2.60 .58	2.48 .54	2.67 .47	2.55 .64	2.67 .47	2.83 .24	2.57 .48	2.60 .55	8,421	.480	.870
Community services	2.77 .35	2.55 .55	2.58 .32	2.82 .29	2.61 .56	2.83 .24	2.67 .41	2.68 .52	8,421	1.270	.257
Total needs	2.63 .32	2.57 .33	2.40 .29	2.72 .42	2.64 .36	2.62 .53	2.65 .29	2.66 .31	8,419	1.030	.412

Note. $*p < .05$.

ID = Intellectual Disability, HI = Hearing Impairment, VI = Visual Impairment, PD = Physical Disability, SLD = Speech and Language Disorder, EBD = Emotional and Behavior Disorders, ASD = Autism Spectrum Disorder, MD = Multiple Disabilities.

Family Needs Group Difference - Family Characteristics

In this study, the education levels of parents were divided into four groups, primary school, middle school, college and graduate school respectively. The results of ANOVA are shown in

Table 9. It was indicated that there were significant differences among families of parents with different educational status in area of financial needs [*F* (3.425) = 3.825, p = .010], at a significant level of $p < .05$. As indicated by the LSD multiple comparison, the financial needs of parents who had finished primary school and those who had finished middle school were higher than that of parents who had received college education.

Table 9

Analysis of Variance of Parent's Educational Status on Family Needs

FNS Subscales	**Parent's Educational Status**				**ANOVA**		
	Primary	**Secondary**	**College**	**Graduate**	***df***	***F***	***p***
	M/SD	***M/SD***	***M/SD***	***M/SD***			
Information	2.91/.18	2.89/.25	2.93/.22	3.00/.00	3,426	1.052	.370
Family and social support	2.65/.45	2.61/.44	2.52/.51	2.55/.19	3,426	1.860	.136
Financial	2.68/.43	2.68/.46	2.52/.56	2.37/.80	3,425	3.825	.010*
Explaining to others	2.45/.63	2.37/.60	2.27/.66	2.08/.69	3,425	1.867	.134
Child care	2.71/.54	2.74/.45	2.67/.49	2.73/.60	3,426	.488	.690
Professional support	2.58/.55	2.60/.53	2.54/.54	2.20/.69	3,426	1.121	.340
Community services	2.71/.44	2.67/.47	2.64/.55	2.60/.72	3,426	.479	.697
Total needs	2.67/.31	2.65/.31	2.58/.35	2.50/.26	3,424	2.049	.106

Note. *p < .05

Table 10 presents one-way ANOVA of the difference on the perceived needs of families by household income. Results indicated that annual per capita income was significantly related to the needs of family and social support [F (2,427) = 5.069, p = .007], financial support [F (2,426) = 10.492, p = .000], explaining to others [F (2,426) = 10.229, p = .000], professional support [F (2,427) = 11.391, p = .000] and the total needs [F (2,425) = 10.754, p = .000].

The results of LSD test comparisons indicated that families with low and middle-income levels perceived more needs than high-income families in needs of financial support, explaining to others, professional support and the total needs; in addition, families with low-income levels has more needs of family and social support than families with high-income levels.

Table 10

Analysis of Variance of Family Income on Family Needs

FNS Subscales	**Family Income**						**ANOVA**		
	< 20,000		**20,000-40,000**		**> 40,000**				
	M	***SD***	***M***	***SD***	***M***	***SD***	***df***	***F***	***p***
Information	2.91	.23	2.88	.25	2.95	.16	2,427	2.546	.080
Family and social support	2.64	.47	2.57	.45	2.45	.47	2,427	5.069	.007*
Financial	2.69	.45	2.63	.53	2.40	.54	2,426	10.492	.000*
Explaining to others	2.41	.61	2.41	.64	2.06	.62	2,426	10.229	.000*
Child care	2.74	.47	2.72	.50	2.61	.51	2,427	2.123	.121
Professional support	2.64	.51	2.60	.52	2.31	.60	2,427	11.391	.000*
Community services	2.69	.51	2.67	.46	2.58	.48	2,427	1.418	.243
Total needs	2.68	.32	2.64	.32	2.48	.30	2,425	10.754	.000*

Note. $*p < .05$

The currency of family income is the Chinese Yuan.

The Analysis of Variance of geographical location on family needs is shown in Table 11. Results indicated that there were significant differences among groups in needs of information [F (3,426) = 4.522, p = .004], family and social support [F (3,426) = 3.025, p = .029], explaining to others [F (3,425) = 4.383, p = .005], child care [F (3,426) = 3.005, p = .030], professional support [F (3,426) =3.689, p = .012], community services [F (3,426) =4.587, p = .004] and the total needs [F (3,424) = 5.495, p = .001]

As indicated by LSD test, families in Guangxi, Ningxia and Chongqing perceived more needs of information, family and social supports and community services than families in Sichuan; families in Ningxia has higher needs of explaining to others than families in Sichuan and Chongqing; families in Guangxi has more needs of child care than families in Ningxia, Sichuan and Chongqing; in the field of needs for professional support, families in Ningxia has higher needs than families in Sichuan and Chongqing; additionally, in the aspect of total needs, families in Ningxia perceived more needs than families in Sichuan and Chongqing.

Table 11

Analysis of Variance of Geographical Location on Family Needs

FNS Subscales	**Geographical Location**				**ANOVA**		
	Guangxi	**Ningxia**	**Sichuan**	**Chongqing**	***df***	***F***	***p***
	M/SD	***M/SD***	***M/SD***	***M/SD***			
Information	2.92/.18	2.94/.17	2.82/.31	2.91/.25	3,426	4.522	.004*
Family and social support	2.58/.52	2.64/.45	2.44/.47	2.58/.46	3,426	3.025	.029*
Financial	2.71/.48	2.62/.52	2.55/.48	2.63/.49	3,425	1.149	.329
Explaining to others	2.37/.62	2.47/.62	2.24/.61	2.23/.65	3,425	4.383	.005*
Child care	2.86/.34	2.71/.49	2.61/.48	2.69/.54	3,426	3.005	.030*
Professional support	2.61/.57	2.66/.47	2.44/.53	2.50/.61	3,426	3.689	.012*
Community services	2.70/.47	2.73/.42	2.48/.62	2.65/.50	3,426	4.587	.004*
Total needs	2.68/.32	2.68/.31	2.51/.32	2.60/.34	3,424	5.495	.001*

Note. $^*p < .05$

Family Supports

Perceived Supports of Chinese Families of Children with Disabilities

Family Support Survey consists of 21 items in three domains. Descriptive statistics, namely percentages, means and standard deviations were calculated to rank the level of family supports, the perceived supports were divided into three levels based on Means. A mean of 3.00-3.99 denotes a high level of support, a mean of 2.00-2.99 represents a medium level of support, and a mean of 1.00-1.99 is on behalf of a lower level of support. Table 12 presents a descriptive statistical analysis of perceived supports.

As the table indicates, the perceived support of 430 families generally belongs to the medium level. Emotional support (M = 2.53, SD = 0.58) is the No.1 support perceived by families, followed by informational support (M = 2.39, SD = 0.57) and instrumental support (M = 2.06, SD = 0.60).

Ratings of the 21 items on Family Support Survey were averaged and ranked to determine what supports the respondents found the most perceived. As shown by the statistical results, the priority items of support were mainly emotional and informational support, and those supports came from spouses, professionals or teachers. The higher scores of support perceived by families are as follows: (a) Knowledge, skills and precautions to bring up children provided by education and rehabilitation institutions or kindergarten teachers (*M* = 2.92, *SD* = 0.84); (b) Comfort and support from spouse (*M* = 2.90, *SD* = 0.96); (c) Spouse will seek medical institutions together (*M* = 2.86, *SD* = 0.96); (d) Comfort, support and encouragement from teachers (*M* = 2.84, *SD* = 0.83); (e) Spouse will discuss how to raise child together (*M* = 2.71, *SD* = 0.95).

Conversely, the perceived family supports with the lowest scores included: (a) Spiritual comfort and encouragement from religious groups (*M* = 1.52, *SD* = 0.83); (b) Welfares and related services available learned from social welfare agencies (*M* = 1.97, *SD* = 0.85); (c) Information provided by relatives or friends (*M* = 1.98, *SD* = 0.83); (d) Comfort and support from social workers (*M* = 1.99, *SD* = 0.84); (e) Assistance from relatives and friends in taking care of child (*M* = 2.00, *SD* = 0.84). Most of these supports were instrumental supports, and fewer supports came from religious groups, social welfare agencies, relatives and friends, and social workers.

Table 12

Descriptive Statistics of Family Supports by Items for Chinese Families of Children with Disabilities (N = 430)

Family supports	None %	Some %	Many %	A lot %	*M*	*SD*
Emotional Support					**2.53**	**.58**
1.Your spouse will comfort and support you	7.2	29.8	28.8	34.2	2.90	.96
2.Your spouse will discuss how to raise child.	8.6	37.2	28.4	25.8	2.71	.95
5.Your neighbor will take the initiative to express concern and care for the child.	17.4	53.5	20.0	9.1	2.21	.83
6.Your relatives or friends will give you comfort, support and encouragement.	7.9	45.6	30.0	16.5	2.55	.86
11.Social workers will give you comfort, support or encouragement on parenting your child.	29.8	46.7	17.9	5.6	1.99	.84
13.Teachers will give you comfort, support or encouragement on parenting your child.	3.7	32.8	39.5	24.0	2.84	.83
Informational Support					**2.39**	**.57**
3.Your spouse will find medical institutions.	9.3	26.5	33.5	30.7	2.86	.96
4.Your spouse will look for information on disabled children and discuss with you.	19.1	36.7	24.2	20.0	2.45	1.02
7.Your relatives or friends will offer information on taking care of child with disability.	28.4	51.4	13.7	6.5	1.98	.83
9.Medical staff will explain to you about the child's developmental disabilities or condition.	8.8	56.0	26.3	8.8	2.35	.76
10.Medical staff will guide you the knowledge, skills or precautions.	12.6	55.6	22.3	9.5	2.29	.81
12.Social workers will introduce you available social resources or rehabilitation agencies.	27.4	47.4	18.6	6.5	2.04	.85
14.Teachers will guide you the knowledge, skills or precaution on taking care of child.	2.6	31.9	36.3	29.3	2.92	.84
15.Special education experts will provide you with information about education.	19.5	43.0	23.7	13.7	2.32	.94
Instrumental Support					**2.06**	**.60**
8.Your relatives or friends will assist childcare.	28.8	49.3	15.3	6.5	2.00	.84
16.Other experienced parents will provide you with the experience of parenting.	6.3	54.9	27.4	11.4	2.44	.78
17.Parent group of disabled children will help, support and courage you parenting your child.	18.1	51.2	20.5	10.2	2.23	.86
18.Social welfare agencies help you know about available welfares and related services.	29.8	50.9	11.6	7.7	1.97	.85
19.Religious groups help you with spiritual	65.8	21.4	8.1	4.7	1.52	.83

Family supports	None %	Some %	Many %	A lot %	*M*	*SD*
comfort and encouragement.						
20.Internet resources or related books help solve problems you meet in parenting.	20.9	48.1	21.9	9.1	2.19	.87
21.Relevant organizations or groups will provide you with leisure or parent-child activities.	20.9	53.0	16.3	9.8	2.15	.86

Note. All items were scored on a 4-point scale ranging from 1 = none, 2 = some, 3 = many, 4 = a lot.

Family Supports Group Difference

Similarly, an independent-samples *t*-test was used to compare the difference of perceived supports between two groups of families with different conditions, such as different gender of the child, whether the child is the only child, whether the child has a disability certificate, whether the child has received professional diagnosis, whether the child has received rehabilitation and educational training etc. Besides, one-way ANOVA and LSD test were applied to compare the family supports group difference for families with different conditions (i.e. children backgrounds, such as age, disability category; family backgrounds, such as family composition, parents' age, education status, household income, geographical location etc.). The level of statistical significance was set at $p < .05$ for all tests.

As indicated by *t*-test and ANOVA, among the variables related to children backgrounds, whether the child has a disability certificate and the disability category had a significant effect on family supports, while child's gender, child's age, whether the child is the only child, whether the child has received professional diagnosis, and whether the child has received rehabilitation training had no significant effect on family supports. Besides, the difference of family supports among families with different characteristics was analyzed. Family income and geographical location had significant effect on family supports, while there was no significant effect of parents' age, educational level, respondent's relationship with the child, family type, and family composition on family supports. Variables with significant effect on family supports are analyzed below:

Family Supports Group Difference - Child Characteristics

Table 13 presents a comparison of the difference between families of children with disability certificate and those of children without disability certificate in terms of perceived supports. Results of an independent-samples *t*-test revealed a significant difference between these two groups in the emotional support domain [*t* (428) = 2.067, *p* = .039]. The sample means are displayed in Table 13, which shows that families of children with disability certificate scored significantly higher on emotional support than those of children without disability certificate (for children with disability certificate group, *M* = 2.57, *SD* = 0.57; for children without disability certificate group, *M* = 2.44, *SD* = 0.60). On the contrary, there was no significant difference between these two groups in the other two domains and the total supports.

Table 13

Comparisons of Family Supports between Child with Disability Certificate and without Disability Certificate Families

FSS Subscales	**Disability Certificate**				***t*-test**		
	Have		**Not have**		***t***	***df***	***Sig.* *(2-tailed)***
	M	***SD***	***M***	***SD***			
Emotional support	2.57	.57	2.44	.60	2.067	428	.039*
Informational support	2.42	.55	2.32	.61	1.709	428	.088
Instrumental support	2.07	.59	2.04	.62	.536	428	.592
Total supports	2.35	.50	2.27	.55	1.603	428	.110

Note. **p* < .05

As indicated by ANOVA results shown in Table 14, the effect of disability category on emotional support was significant, [*F* (8,421) = 2.416, *p* = .015]. The LSD multiple comparisons revealed that families of children with hearing impairment received more emotional supports than families of children with intellectual disabilities, speech and language disorder, autism spectrum disorder and multiple disabilities.

Table 14

Analysis of Variance of Child's Disability on Family Supports

FSS Subscales	**Child's Disability**								**ANOVA**		
	M/SD										
	ID	**HI**	**VI**	**PD**	**SLD**	**EBD**	**ASD**	**MD**	***df***	***F***	***p***
Emotional support	2.37	2.70	2.79	2.64	2.36	3.00	2.41	2.53	8,421	2.416	.015*
	.54	.55	.63	.58	.51	.24	.56	.60			
Informational support	2.26	2.49	2.50	2.47	2.26	3.00	2.36	2.40	8,421	1.210	.291
	.50	.53	.31	.47	.54	.71	.57	.60			
Instrumental support	1.97	2.09	1.68	2.09	1.94	2.50	2.04	2.08	8,421	1.022	.418
	.56	.59	.43	.55	.66	.51	.56	.62			
Total supports	2.20	2.43	2.32	2.40	2.19	2.83	2.27	2.33	8,421	1.495	.157
	.45	.48	.35	.47	.50	.15	.50	.54			

Note. *$p < .05$.

ID = Intellectual Disability, HI = Hearing Impairment, VI = Visual Impairment, PD = Physical Disability, SLD = Speech and Language Disorder, EBD = Emotional and Behavior Disorders, ASD = Autism Spectrum Disorder, MD = Multiple Disabilities.

Family Supports Group Difference - Family Characteristics

Table 15 presents one-way ANOVA of the difference on family supports of families by household income. Results indicated that annual per capita income was significantly related to the emotional support [*F* (2,427) = 3.687, *p* = .026], informational support [*F* (2,427) = 3.063, *p* = .048], instrumental support [*F* (2,427) = 4.043, *p* = .018] and the total supports [*F* (2,427) = 4.572, *p* = .011]. The results of LSD test comparisons indicated that families with low and middle-income levels received more supports than high-income families in terms of emotional, informational, instrumental and total supports.

Table 15

Analysis of Variance of Family Income on Family Supports

FSS Subscales	**Family Income**						**ANOVA**		
	< 20,000		**20,000-40,000**		**> 40,000**		***df***	***F***	***p***
	M	***SD***	***M***	***SD***	***M***	***SD***			
Emotional support	2.54	.61	2.59	.56	2.37	.51	2,427	3.687	.026*
Informational support	2.41	.60	2.44	.53	2.25	.49	2,427	3.063	.048*
Instrumental support	2.09	.64	2.12	.61	1.89	.41	2,427	4.043	.018*
Total supports	2.35	.55	2.38	.51	2.17	.39	2,427	4.572	.011*

Note. *$p < .05$

The currency of family income is the Chinese Yuan.

The ANOVA of geographical location on family supports are shown in Table 16. Results indicated that there were significant differences among groups in emotional support [*F* (3,426) = 7.729, *p* = .000], informational support [*F* (3,426) = 6.144, *p* = .000], instrumental support [*F* (3,426) = 4.152, *p* = .006] and the total supports [*F* (3,426) = 6.925, *p* = .000]

As indicated by LSD test, families in Ningxia and Sichuan perceived more emotional support than families in Guangxi and Chongqing; families in Ningxia received more informational support than families in Guangxi and Chongqing; in terms of instrumental support, families in Ningxia gained more supports than families in Guangxi, Chongqing and Sichuan. And in terms of total supports, families in Ningxia perceived more supports than those in Guangxi and Chongqing, and families in Sichuan received more supports than those in Chongqing.

Table 16

Analysis of Variance of Geographical Location on Family Supports

FSS Subscales	**Geographical Location**				**ANOVA**		
	Guangxi	**Ningxia**	**Sichuan**	**Chongqing**	***df***	***F***	***p***
	M/SD	***M/SD***	***M/SD***	***M/SD***			
Emotional support	2.40/.56	2.64/.58	2.65/.50	2.37/.59	3,426	7.729	.000*
Informational support	2.31/.55	2.52/.52	2.39/.53	2.25/.61	3,426	6.144	.000*
Instrumental support	2.00/.61	2.18/.60	2.00/.52	1.95/.62	3,426	4.152	.006*
Total supports	2.24/.52	2.44/.50	2.35/.44	2.19/.55	3,426	6.925	.000*

Note. *$p < .05$

CHAPTER 5 DISCUSSION

This study sought to examine the perceived needs and supports of Chinese families of children with disabilities in answering research questions on (a) characteristics of Chinese families of children with disabilities; (b) the perceived needs of these families; (c) group difference in family needs; (d) the perceived supports of these families; (e) group difference in family supports. This chapter summarizes key findings of the questionnaire survey, which is followed by a discussion of limitations of this study and the implications of the study for the future early intervention services at the policy and practical level respectively.

Summary of Key Findings

The results of data analysis indicate that families of children with disabilities in western China have their own unique features, with various needs and family supports. Moreover, due to the different characteristics of children and their families, there are significant differences in terms of perceived needs and family supports. The following section will discuss the key findings related to the research questions and previous researches.

Characteristics of Children and their Families in Western China

With the increasing attention to early intervention for children with disabilities, and the developing of national policies and legislations for early childhood education and rehabilitation services, more and more children have received early diagnosis and rehabilitation training. Early diagnosis is mainly provided by hospitals, followed by rehabilitation institutions. Nevertheless, rehabilitation institutions represented by the rehabilitation center of the Disabled Persons' Federation and private-operated institutions undertake more early intervention tasks as compared to hospitals and kindergartens.

It is noteworthy that children with disabilities who have received early intervention are mainly 3-6 years of age, followed by children over 6 years of age, while children under three years old take up a smaller proportion. Although early intervention is usually for children at the age of 0-6 in China, yet according to national conditions, considering regional differences and urban and rural differences, many early intervention services can be extended to poverty disabled children with rehabilitation needs under 7 years old. China still has a long way to go to improve the early screening, early diagnosis and early intervention services for infants and young children.

The results also indicate that the vast majority of families are two-parent families, while more than half are big families with three generations under one roof. This may originate from the traditional "family" culture in China where blood ties and marital relations form the core structure of the family. Although the size and structure of traditional Chinese family are changing with the social progress, the traditional families with three generations are still prevalent in the western region of China. The survey also finds that the primary caregivers of children are mothers, followed by grandparents who even undertake more child care tasks than the fathers. On the other hand, the parents generally have a relatively low educational level. The majority of them graduated from secondary school, followed by college, and those who only finished primary school account for 21.9%. The education background may have a direct impact on early intervention, access to information, and the mastering of knowledge and skills about education and rehabilitation, thereby influencing the outcomes of early intervention.

In addition, more than half of the families are in an unfavorable socioeconomic status, with the average annual income per capita being less than 20,000 Yuan (€ 2600). According to the sampling survey carried out by the National Bureau of Statistics among 160,000 urban and rural households, the annual per capita disposable income of national residents was 23,821 Yuan in 2016 (National Bureau of Statistics of the People's Republic of China, 2017). It can be found that the economic conditions of families of children with disabilities in western China are at a low level.

Current Situation about Family Needs and Available Supports

As indicated by the quantitative analyses, there is a remarkable higher family needs of families with children with disabilities, and the perceived supports are at a moderate level. Family needs ranked from the highest to the lowest are as follows: needs for information, child care, community services, financial support, family and social support, professional support, and explaining to others. Families have the highest need for information, indicating that parents expect to learn more information related to their children, such as information about rehabilitation services currently suitable for their children and services their children may need in the future as well as relevant information about child's growth and development, how to deal with child's problem behavior and how to raise a child. This is consistent with the findings indicated by some of the previous studies (J. Chen & Simeonsson, 1994; Gu et al., 2010; Y. Li, 2015; H. Liu & Zou, 2015; Luo & Lei, 1999; Wong et al., 2004).

It is important to note that although families of children with disabilities in western China are economically backward, yet this survey reveals that those families' needs of financial and professional support are not the most urgent and important, which is inconsistent with the results indicated by some previous studies. For example, some studies find that financial need is the highest need (X. Hu et al., 2015; X. Huang et al., 2009; J. Li et al., 2015), while some studies indicate that need of professional support is the most urgent (Y. Chen, 2007; Guo et al., 2014; Y. Li, 2015). The results may benefit from the implementation of central and local governments' policies and legislations about early intervention.

For instance, the central government arranged special subsidies from 2011 to 2015 to support the implementation of rescue rehabilitation programs for children with disabilities aged 0-6 years nationwide. According to the Colorful Dream Action

Plan, the central budget provides deaf children at the age of 1-6 with 12,000 Yuan per person as the artificial cochlea implant surgery cost subsidy, and provides them with a subsidy of 14,000 Yuan per person for one year (10 months) of rehabilitation training after surgery, including postoperative rehabilitation training, rehabilitation assessment, parents training, rehabilitation materials, accommodation, etc.; as for children with cerebral palsy under the age of 7, they are provided with an annual average subsidy of 13,200 Yuan for rehabilitation training and orthotics assembly; urban and rural autistic children with rehabilitation needs at the age of 3-6 are provided with a rehabilitation training subsidy of 12,000 Yuan per capita annually (State Council of the People's Republic of China, 2013). Thus, it is clear that the financial subsidy basically covers operation, assistive devices, rehabilitation training, parent training and accommodation. The rehabilitation programs strive to take the initiative to carry out medical treatment and rehabilitation so that children with disabilities can receive rescue rehabilitation.

From the perspective of the perceived supports, emotional support is the most priority, followed by informational support and instrumental support. And the sources of supports are mainly from professionals or teachers in education and rehabilitation institutions as well as spouses, which is consistent with the findings revealed by Cai et al. (2011). However, families rarely receive supports from religious groups, social welfare agencies, social workers, relatives or friends. Maybe parents are not interested in getting supports from them, or there is no channel for them to access relevant services; therefore, further investigation is needed.

Factors Influencing Family Needs and Supports

This study indicates that the predictor factors influencing family needs include child's age, whether the child is the only child, whether the child has a disability certificate, disability category, parents’ educational status, family income, geographical location and so on. Besides, the factors influencing family supports include whether the child has a disability certificate, disability category, family income, and geographical location. Some studies in the past consistent with this findings, for example, disability category (J. Chen & Simeonsson, 1994; Luo & Lei, 1999; P. Wang & Michaels, 2009), family income (Jia & Hu, 2016; Y. Li, 2015) and parents' educational status (Jia & Hu, 2016) have significant effect on family needs.

Limitations of this Study

In this study, questionnaire survey was applied to obtain quantitative information on the perceived needs and supports of Chinese families with children with disabilities. Although the attitudes of more families can be obtained, purposive sampling method used in this survey limits the ability to evaluate the distinctive characteristics of the participants. The samples were derived from families who have already received early intervention services in the western China, but failed to involve the families with severe disabilities who have never received regular early intervention services and those families who are reluctant to express their views through questionnaires, for example, those who receive early intervention services at home; and respondents with a lower education level may not be able to fully express their attitudes. In addition, children recruited from early intervention programs are overwhelming majority at the age of 0-6, children at the school age and other ages are not involved. Thus, this study cannot infer the overall needs and supports of Chinese families with children with disabilities.

Recommendations for Future Research

First, future researches should expand the scope of survey. The samples should cover Chinese families of children with disabilities in different regions, at different ages, with different disabilities and placements. Other sampling methods such as stratified sampling can be used to make the samples more representative.

Second, in terms of the research methods, questionnaire survey should be supplemented by qualitative methods so that the data collection can be sufficient both quantitative and qualitative, and the research results can be more closer to the actual circumstances. For instance, the items on family needs marked “not sure” maybe queried during the interview. Future studies can probe deeper into families with low socioeconomic status, especially families of children carried out rehabilitation at home and families in remote or rural areas.

Third, future research can further explore the difference between family needs and family supports, and the outcomes of the support and intervention services. In order to provide the corresponding support services according to the various needs of families with children with disabilities.

Implications for Early Intervention Services

Policy Level

Establishing Early Screening and Diagnosis System. At present, China has not yet established a relatively systematic screening system for children with disabilities, the existing neonatal screening and childcare service system of the health sectors does not explicitly include and standardize the disability screening, and there is no effective link between the maternal and child health care network of the health sectors and the rehabilitation service network under the China Disabled Persons’ Federation (Cao, Na, & Sun, 2012). As a consequence, newborns at high risk of disability and children with disabilities caused by various factors at different stages of growth cannot be timely found, diagnosed and transferred to professional early intervention agencies, and then miss the best time to recover and intervention. The early screening processes and technical specifications for 0-6 year-old children should be established, and a complete network with seamless link of early detection, early diagnosis, referral and early intervention remains to be set up, which will timely help the majority of children to receive early intervention services.

Establishing Rehabilitation Security System. In recent years, China has implemented rescue rehabilitation programs for poverty children with disabilities, such as Colorful Dream Action Plan, benefiting many urban and rural children with rehabilitation needs. But in the implementing of rehabilitation programs, China still faces the problem of decentralized relief and periodic relief. There is no sustained and stable system support in early intervention services. Developed countries have established special security systems for the disabled persons covering assistive devices and rehabilitation training based on the public social security system. However, though China has basically established the social security system for urban and rural residents, yet the special security system for children rehabilitation still remains to be improved (Cao et al., 2012).

In 2015, the State Council proposed to gradually expand the medical rehabilitation projects covered by the basic medical insurance, and in the next year, further incorporated 20 medical rehabilitation projects such as "comprehensive rehabilitation assessment" into the scope of medical insurance payment. The newly added rehabilitation projects give consideration to both functional assessment and treatment, covering disability categories like physical disability, mental disability, speech disorder, hearing impairment, and autism spectrum disorder (China Disabled Persons' Federation, 2016a). The implementation of these policies will significantly improve medical rehabilitation services, effectively reduce relevant medical expenses and reduce the economic pressure on families of children with disabilities. However, most education and rehabilitation programs for children with disabilities, such as rehabilitation training for children with hearing impairment, intellectual disability, and autism spectrum disorder, has not been included into urban and rural health care or medical assistance systems. As for the relevant expenses, families rely on periodic subsidy projects like rescue rehabilitation or Colorful Dream action plan. Rehabilitation costs that do not accord with the subsidy standard are borne by families themselves, while most of families suffer from economic difficulties and are unable to bear the costs. Therefore, it is particularly important to establish a long-term security mechanism of early intervention services for children with disabilities.

Due to the serious regional and urban-rural differences in mainland China, to guarantee the implementation of national macroeconomic policies, it is necessary to formulate corresponding local policies and make up safeguard measures for the shortage of resources and uneven distribution of early intervention services, and give priority to the middle and western regions. In addition, it is necessary to further strengthen the quality monitoring, outcomes management, and enhance the family involvement and cooperation strategies.

Practical Level

Informational supports. Most of disabled children live in rural, remote and poverty areas where there is limited access to information. These families usually lack of knowledge and skills about early intervention for their children, and are not fully aware of relevant policies and relief projects. Due to lack of publicity, some projects cannot find appropriate objects to rescue; on the other hand, children with disabilities cannot benefit from the rescue and preferential policies, resulting in waste of resources. This study also reveals that parents have the highest need for information, suggesting that early intervention agencies should provide families with sufficient information such as parenting skills, parent-child activities, and rehabilitation resources. It is necessary to increase the visibility and accessibility of information, and prevent parents of children with disabilities from missing the opportunities to apply for benefits.

Family-based Rehabilitation. According to the national conditions, the delivery of early intervention services should be diversified; institutional rehabilitation should be combined with community rehabilitation and family rehabilitation, and parents can play an important role in the early intervention.

Since family members interact with each other, early intervention services should regard family as a whole. The orientation of early intervention services for infants or severe disabilities should gradually be shifted from institutions to families.

Professionals should establish cooperative relationships with family members, respect the diverse family needs, and encourage family members to actively participate in early education and rehabilitation for their children, to jointly develop and implement individualized early intervention plans.

Furthermore, family supports mainly come from the spouse and professionals in education and rehabilitation institutions. Professionals need to provide family members with supports based on family needs and strengths. Thus, it is particularly important to increase professional human resources and enhancing their professional competence. Only by providing support services according to the diverse needs of children and their families, families can play a lager role in early intervention and benefit from early intervention.

Parent Training. Family is the main living environment for children; Whether parents have the awareness of early intervention and whether they master knowledge and skills about education and rehabilitation is extremely important, and it is also a key factor that determines the outcomes of early intervention services. Due to low educational status, backward ideas and few opportunities to receive parenting training, some parents are not fully aware of early intervention. As a result, family rehabilitation lacks professional support, and the effectiveness of early intervention services cannot be realized as well.

It is necessary to strengthen parents training, build a platform for parents to communicate with each other, help them update ideas about early intervention, learn and master knowledge and skills about special education and rehabilitation. Parent training might be an effective strategy to meet families' informational needs and provide parents with informational and instrumental supports. The considerable training topics include knowledge about the children development; strategies and skills to carry out daily care, interact with children and deal with problem behaviours; information about relief policies and support programs. In order to maximize the family functions, the primary caregivers should be encouraged to communicate with other family members and jointly make decisions in early intervention services plans. In addition, parent-to-parent groups can be established so that families with similar experiences can share experience with each other and work out solutions together.

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APPENDIX A. Survey Cover Letter

Dear parents,

You are invited to participate in a research study entitled *Family Needs and Family Supports of Chinese Families with Children with Disabilities*, which mainly explore the current situation of family needs and supports in parenting child.

The enclosed questionnaire is anonymous; your participation in this survey is strictly voluntary and your responses will be kept confidential. It should only take about 15 minutes of time; all responses will be compiled together and used only for statistical analysis as group. There is no standard answer to all the questions, please give your answer according to your own opinion and fact. Completing and returning the questionnaire indicates your consent to participate in this study.

The results will serve as a reference for professionals providing early intervention services. Your participation is very important; we hope this form will be helpful to you in identifying the services that you feel are important.

Thank you for your participation and contribution.

APPENDIX B. Demographic Information Form

Ⅰ. Child Information

A. Gender: ☐1. Boy ☐2. Girl

B. Age (chronological age): ☐1. 0-3 years ☐2. 3-6 years ☐3. Above 6 years

C. Whether the only child: ☐1.Yes ☐2.No

D. Whether the child has the disability certificate: ☐1.Yes ☐2.No

E. Type of disability

☐1. Intellectual Disability ☐2. Hearing Impairment ☐3. Visual Impairment

☐4.Physical Disability ☐5. Speech and Language Disorder

☐6.Emotional and Behavior Disorders ☐7. Autism Spectrum Disorder

☐8. Multiple Disabilities ☐9. Others

F. Whether have received professional diagnosis:

☐1.Yes ☐2.No

If once had, the place was:

☐1. Hospital ☐2. Rehabilitation agency ☐3. Education agency ☐4.Others___

G. Whether have received rehabilitation and educational training:

☐1.Yes ☐2.No

If once had, the place was:

☐1. Hospital ☐2. Rehabilitation agency ☐3. Education agency ☐4.Others___

Ⅱ. Family Information

A. Primary caregiver of child:

☐1.Mother ☐2.Father ☐3.Grandparents ☐4.Nanny ☐5.Others_____

B. Family type:

☐1.Two-parent ☐2.Single-parent ☐3.Others_____

C. Family composition:

☐1.Small-sized (Parents and child)

☐2.Large-sized (Three generations living under the same roof)

☐3.Others__________

D. Relationship between you and child:

☐1.Mother ☐2.Father ☐3.Grandparents ☐4.Nanny ☐5.Others_____

E. Your age:

☐1. Under 30 years ☐2. 31-40 years ☐3. 41-50 years ☐4. Above 50

F. Educational status:

☐1.Primary school ☐2.Secondary school ☐3.Junior college and undergraduate

☐4.Graduate and above

G. Family income (the annual per-capita income in Yuan)

☐1. Below 20,000 Yuan ☐2. 20,000-40,000 Yuan ☐3. Above 40,000 Yuan

H. Geographical location

☐1. Guangxi ☐2. Ningxia ☐3. Sichuan ☐4. Chongqing

APPENDIX C. Family Needs Survey

Listed below are some needs commonly expressed by families. It would be helpful to us to know about your family needs in the process of raising and educating your child.

If you don’t have this need at present, please circle ♊in the column of No.

If you feel it is necessary, please circle ♌in the column of Yes.

If you are not sure, please circle ♋in the column of Not Sure.

TOPICS	No	Not Sure	Yes
Information			
1. How children grow and develop	1	2	3
2. How to play or talk with my child	1	2	3
3. How to teach my child	1	2	3
4. How to handle my child’s behavior	1	2	3
5. Information about any condition or disability my child might have	1	2	3
6. Information about services that are presently available for my child	1	2	3
7. Information about the services my child might receive in the future	1	2	3
Family & Social Support			
8. Talking with someone in my family about concerns	1	2	3
9. Having friends to talk to	1	2	3
10. Finding more time for myself	1	2	3
11. Helping my spouse accept any condition our child might have	1	2	3
12. Helping our family discuss problems and reach solutions	1	2	3
13. Helping our family support each other during difficult times	1	2	3
14. Deciding who will do household chores, child care, and other family tasks	1	2	3
15. Deciding on and doing family recreational activities	1	2	3
Financial			
16. Paying for expenses such as food, housing, medical care, clothing, or transportation	1	2	3
17. Getting any special equipment my child needs	1	2	3
18. Paying for therapy, day care, or other services my child needs	1	2	3

TOPICS	**No**	**Not Sure**	**Yes**
19. Counseling or help in getting a job	1	2	3
20. Paying for babysitting or respite care	1	2	3
21. Paying for toys that my child needs	1	2	3
Explaining to Others 22. Explaining my child's condition to my parents or my spouse's parents	1	2	3
23. Explaining my child's condition to his or her siblings	1	2	3
24. Knowing how to respond when friends, neighbors, or strangers ask questions about my child	1	2	3
25. Explaining my child's condition to other children	1	2	3
26. Finding reading material about other families who have a child like mine	1	2	3
Child Care 27. Locating babysitters or respite care providers who are willing and able to care for my child.	1	2	3
28. Locating a day care program or preschool for my child	1	2	3
29. Getting appropriate welfare care for my child	1	2	3
Professional Support 30. Meeting with officer in government	1	2	3
31. Meeting with a counselor (psychologist, social worker, psychiatrist)	1	2	3
32. More time to talk to my child's teacher or therapist	1	2	3
Community Services 33. Meeting & talking with other parents who have a child like mine	1	2	3
34. Locating a doctor who understands me and my child's needs	1	2	3
35. Locating a dentist who will see my child	1	2	3

APPENDIX D. Family Support Survey

Please circle the answers that fit your situation. Thank you in advance for your time and assistance.

Supporting degree / **Family supports**	**None**	**Some**	**Many**	**A lot**
1.Your spouse will comfort and support while finding the child having developmental disorder.	1	2	3	4
2.Your spouse will discuss with you on how to raise child.	1	2	3	4
3.Your spouse will find medical institutions with you.	1	2	3	4
4.Your spouse will look for information on disabled children and discuss with you.	1	2	3	4
5.Your neighbor will take the initiative to express concern and care for the child.	1	2	3	4
6.Your relatives or friends will give you comfort, support and encouragement.	1	2	3	4
7.Your relatives or friends will offer you information on taking care of child with disability.	1	2	3	4
8.Your relatives or friends will assist you to take care of child.	1	2	3	4
9.Medical staff will explain to you about the child's developmental disabilities or condition.	1	2	3	4
10.Medical staff will guide you the knowledge, skills or precaution on taking care of disabled children.	1	2	3	4
11.Social workers will give you comfort, support or encouragement on parenting your child.	1	2	3	4
12.Social workers will introduce you available social resources or medical and rehabilitation agencies.	1	2	3	4
13.Education, rehabilitation agencies or kindergarten teachers will give you comfort, support or encouragement on parenting your child.	1	2	3	4
14.Education, rehabilitation agencies or kindergarten teachers will guide you the knowledge, skills or	1	2	3	4

Supporting degree / **Family supports**	**None**	**Some**	**Many**	**A lot**
precaution on taking care of child.				
15.Special education experts will provide you with information about education.	1	2	3	4
16.Other experienced parents will provide you with the experience of parenting.	1	2	3	4
17.Parent group of disabled children will help, support and courage you in parenting.	1	2	3	4
18.Social welfare agencies help you know about available welfares and related services.	1	2	3	4
19.Religious groups help you with spiritual comfort and encouragement.	1	2	3	4
20.Internet resources or related books help solve problems you meet in parenting child.	1	2	3	4
21.Relevant organizations or groups will provide you with leisure or parent-child activities.	1	2	3	4