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RESEARCH ON FAMILY QUALITY OF LIFE IN FAMILIES OF YOUNG CHILDREN WITH DISABILITIES IN CHINA

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By
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Declaration of Originality

I, Ling GUO (Student number D160488) declare that this dissertation entitled "Research on Family Quality of Life in Families of Young Children with Disabilities in China" submitted as partial requirement for Ph.D. study program of Special Education is my original work and all the sources in any form (e.g. ideas, figures, texts, tables, etc.) that I have used or quoted have been indicated and acknowledged in the text as well as in the list of reference.

Signature date

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ABSTRACT

With increasing emphasis on supporting children with disabilities in their home environment, the concept of family quality of life (FQOL) has been proposed on the basis of individual quality of life and has been considered as an important indicator for evaluating the effectiveness of supporting families of children with disabilities. FQOL has been defined as a dynamic sense of well-being of the family, and has been regarded as family members' perceived satisfaction for their family life in this study. The research on FQOL in families of children with disabilities has been highly valued internationally, especially research about families with children who have disabilities at young age. In early intervention area, FQOL has been increasingly recognized as an important concept, and furthermore been regarded as an important index to recognize the outcome of services delivery programs.

The purpose of this research is to investigate the current situation of FQOL in families of children with disabilities at young age and try to explore the potential improving strategies for better FQOL based on systematic analysis of the influencing parameters. A mixed method combining quantitative and qualitative approaches has been applied in this research, and both questionnaire survey and semi-structured interview have been used to collect data. For data analysis, SPSS 22.0 has been used to analyze the quantitative data from questionnaire survey, while NVivo11.0 Plus has been used to analyze the qualitative data from interview.

Based on analyzing the research data, the research findings have been summarized into four parts in terms of status of the objective family conditions, current situation of FQOL, influencing parameters, and improving strategies as research conclusions.

(1) The current status of objective family conditions in families of children with disabilities at young age is below average and need to be supported for improvements: families with balanced income and expenditure are less than half and more than 40% families with income far less than expenditure; families with disabled children at young age(199 responded families) have monthly average income 5155.28 Yuan in RMB (≈ 736$) for whole family and 1718 Yuan(≈ 245$) per person which is less than the province's average monthly disposable income 2059Yuan/ person(≈ 294$) in Sichuan province in 2019; average household expenditure on education and rehabilitation for

disabled children per month accounts for more than 40% of the average household income; the majority of the responded families have their own flats or houses as accommodation; more than half of the respondents are without job.

(2) The subjective FQOL in families of young children with disabilities is at medium level with mean of item score significantly higher than “neither dissatisfied nor satisfied”, but significantly lower than “satisfied”; the satisfaction level on the overall scale and five sub-scales rank as family interaction>parenting>overall scale>disability-related supports> material well-being>emotional well-being, which means families are most satisfied with family interaction and then parenting, while less satisfied with disability-related supports and material well-being and least satisfied with emotional well-being; main caregivers of young children with disabilities are generally with more negative emotional experience of FQOL and their “very negative” emotional experience is two times frequently mentioned than “very positive” emotional experience; huge psychological burden has been perceived by main caregivers and dissatisfaction also mentioned with family economy and leisure time

Besides, there are statistically significant differences of FQOL on child’s characteristics including child’s age, types and severity of special needs, health condition and behavior problem, with disability document or not, while no significant difference on disabled children’s gender, self-care ability and main placement; statistically significant differences of FQOL have also been witnessed on family’s characteristics including the age, education status, employment status of the main caregiver and marital status of parents, family location, household financial situation, parenting skill, whether parents join self-help organization and whether with child without special needs, while no significant differences on gender of main caregivers and their relationship to the disabled children.

(3) Six influencing parameters for FQOL in families with disabled children at young age have been recognized: difficulties related to child, economic factor, parental attitude, family preparation, family involvement and social support. These six parameters are not isolated from each other, and more complicated influences will be produced when these parameters are superimposed. Among them, difficulties related to child and economic factor are the most direct impact factors of satisfaction for their family life which build

the basic background for the family life. Then, parental attitude, family preparation and family involvement are shaped on the basis of the basic family background and further affect satisfaction for the family life. Meanwhile, social support as the resources from outside family can directly affect FQOL and also indirectly influence FQOL through other five parameters.

To be specific, difficulties related to child can negatively predict overall family quality of life (1.6%) and satisfaction for family interaction (4.5%) and economic pressure can negatively predict family satisfaction of material well-being (3.7%); while parental attitude has a strong positive prediction of total FQOL (53.1%) and also satisfaction for family interaction (15.3%), parenting (19.2%), emotional well-being (56.4%), material well-being (75.0%) and disability-related supports (25.4%); family involvement can predict overall family quality of life (5.3%) and satisfaction of parenting (1.4%), material well-being(1.3%); family preparation can positively predict overall family quality of life (1.3%) and family members' satisfaction for sub-dimensions of family life, including parenting (7.8%), emotional well-being (2.2%), and disability-related supports (7.3%); social support can positively predict family members' satisfaction for their family interaction (2.7%) to some extent.

(4) Four aspects of improving strategies have been discovered: family aspect, service aspect, government aspect and social environment aspect. These four aspects improving strategies build a progressive model of improving strategies of FQOL. Corresponding to family's ecological systems, family aspect strategies are in the family's microsystem, which are directly related to families with disabled children at young age and also most often mentioned by main caregivers and professionals; service aspect strategies are in family's mesosystem, which play critical role in building families' support system; government aspect strategies are in families' exosystem and are the external environmental conditions both directly and indirectly affected FQOL; social-environment aspect strategies are in family's macrosystem.

Based on the research findings, reflection of this research from the aspects of revelations and limitations has been done at the end.

Key words: family quality of life, children with disability, young children, China

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Chapter 1 Introduction

Disability is a long-standing and unavoidable social reality. In any country, individuals with disabilities are a component of the society that cannot be ignored. Inevitably, the emergence of individuals with disabilities affects the life in their family, especially at an early stage. With the emphasis on supporting families of members with disabilities, the concept of family quality of life (FQOL) has been proposed on the basis of individual quality of life and has been regarded as an important indicator for the effectiveness of family support. (Hu, 2012) This research is focused on FQOL in families of children with disabilities at young age. Five parts is included in this chapter, which starts with the introduction of the research background, and continues to the statement of the problem and purpose of this research. Then, the significance of this study and operational definition of the terms are presented in the last two parts of this chapter.

1.1 Research Background

The experience of family life in early ages has far-reaching impacts to individual’s development. For children with disabilities, on one hand they are more dependent on their families because of their ability restrictions and on the other hand, they will influence the life of the whole family. Hence, the functioning situation of family will be affected along with the emergence and existence of individual with disability, and vice versa. Along with the worldwide attention on individual’s quality of life, the functioning situation of families especially the FQOL in families with disabled children has also aroused the interest of researchers.

Child with disability affects the functioning of the whole family

According to the Family System Theory from Murray Bowen, family is a co-related dynamic system of emotional unit, in which the emotional state of each family member affects the emotion of all other members in the unit. (Cappuzzi et al., 2015) It is commonly accepted that the family unit constitutes a dynamic, interconnected, and self-regulating system and all family members share a set of unique contextual factors in their family (Gardiner & Grace,2012; Gardiner,2014; Christolini & Werstler,2014). It means family should be taken into consideration as a whole system and any change in the emotional functioning of one family member is predictably and automatically likely to bring about changes in the emotional functioning of other family members. Correspondingly, each family member can shape the functioning of the whole family. As a unique member of their family, children with disability also bring impacts to other family members, including parents, siblings and so on, which further affect the functioning conditions of the whole family.

Based on parents' view, caring for a disabled child is challenging and often deprives parents of their own basic personal needs as huge amount of time, effort and patience are needed to meet the high care demands of disabled children.(Richman,2009; Hoefman et al.,2014) These practical difficulties often result in various mental health problems, including more stress, higher level of anxiety, depression and even physical problems, among parents with disabled children compared to parents with typically developed children.(Fisman et al.1989; Bromley et al.,2004; Parish &Cloud, 2006; Li &Wang, 2015; Al-Farsi et al,2016) Furthermore, many families of children with disabilities have to face financial problems and underemployment and are more likely to live in poverty in consideration of the high-cost of child care including medical services, rehabilitation equipment and services, and difficulty in balancing parental employment and care-giving responsibilities.(Smith et al.,2001; Park et al., 2002; Parish &Cloud,2006) Moreover, according to the recent researches, misunderstandings of the causes of children' disabilities and considerable stress due to the behavior challenge of disabled children contribute to marital confrontation and dissatisfaction (Al-Farsi et al.,2016) and increases the chance of divorce among parents (Brombst et al., 2009; Kenny & korkin,2011). As a result, the challenges stemming from the presence of family member with disabilities can significantly affect family life and expose it to crises by affecting the physical or psychological well-being of other family members and their relationships. Hence, it is necessary to gain further understanding of the current situation of the quality of life in families of children with disabilities through empirical research.

Family is important for the development of child with disability

As the first environment for a person to gain life experience, family plays critical role in the development of individuals, especially in the early age period which is the time for rapid growth in motor, cognitive, linguistic and social-emotional areas. For young children with disabilities, they are more likely to be at higher dependence level than their typically developed correspondents or children with similar problems at other age ranges in consideration of their limits of abilities and age characteristics. Moreover, besides the impacts from children with disabilities to other family members, the family situation in return affects the development of disabled children. Therefore, recent disability-related research and policies have recognized the importance of building family capacity to support the development of children with disability among the world. (Turnbull et al, 2001; Chiu et al, 2013; Shen, 2016) Normally, family is the main environment for children with disability in the early age period and parents are individuals who spend the most time with them. Therefore, family and parents have been attached more and more importance in early intervention for children with disabilities. Family-centered practice has gradually replaced children-centered practice as the best practice of early intervention (Shen R., 2017) and has been proved to be effective in the early intervention practice for children with various kinds of special educational needs including hearing impairment, visual impairment, autism spectrum disorder and so on. (Shen R., 2017; Moeller M. P. et al, 2013) Therefore, it is necessary to know the practical situation of life in families with disabled children in order to provide the most effective rehabilitation for children as parents' involvement and abilities to assist rehabilitation directly affect the rehabilitation effect of children with special educational needs. (Ren L., & Zhang L., 2015)

Potential increase of young children with disability in China

As a developing country with the most population in the world, China has a huge number of people with disabilities. According to the second China national sample survey on disability in 2006, the number of populations with various kinds of disabilities is 82.96 million (China Disabled Persons' Federation, 2006), among which 1.678 million are children from 0 to 6 years old, accounting for 2.02% of the total (Cao Y., Na X.& Sun G.,2012). What's more, every year 199,000 new-born babies with disabilities will join to this age group. (China Disabled Persons' Federation) In recent years, along with the transformation in population structure in China, Chinese government fully opened the second child policy in 2015 after 30 years history of practicing one-child policy. Under one-child policy, one couple was only allowed to give birth to one child. During one-child policy period, the number of new-born babies had been efficiently controlled for several decades. With the opening of second child policy, a baby boom after long time of birth control could be expected in the whole country. Correspondingly, more new babies with disabilities can be expected in the following years. More babies with high risk of birth defects could also be supposed to be born, especially by mothers at high-risk age for child birth beyond 35 years old.

Based on the practical social background of potential new boom of babies at high-risk for disabilities, and the theoretical background of mutual influencing between children with disability and their family, it is necessary to recognize the functioning status of families with children of disability at young age through research in China.

1.2 Problem Statement

Along with the expansion of the connotation of health, well-being and quality of life (QOL) have been taken into consideration of individual's healthy level and attracted attention of researchers among the world. According to WHO, QOL is defined as an individual's perception of their position in life.(WHO,2018) Family quality of life(FQOL), as a natural extension of QOL research for individuals with intellectual and developmental disabilities, has emerged in the last 20 years as an important concept to influence policy making, guide service delivery, and enhance outcomes of individuals with disabilities and their families. (Brown & Brown, 2004; Turnbull, Brown, &Turnbull, 2004; Wang M. & Brown R., 2009) FQOL as a corresponding concept of individual's QOL, takes family as an overall system and focuses on family members' satisfaction of family life. Hence, FQOL is not only about family members' feelings of family life, but also an important index to show the functioning situation of family.

For families with disabled children, FQOL shows family outcomes (either positive or negative) experienced by family members as a result of interaction between the disabilities and supports & services for themselves and/or their children with disabilities. (Summers J. A, et al,2005) For families of children with disabilities at young age, because of misunderstandings of disorders, lack of experience for parenting and insufficient supports or services from the government and professionals, parents are likely to face with more stressful situation in daily life and be more vulnerable compared to families with typically developed children. Even though there are a considerable number of recent studies about FQOL in the special education area among the world, recent studies focus on FQOL in families with disabled children in China is comparatively less, and extremely limited studies involve families of children with disabilities at young age. Therefore, this research aims to explore the FQOL in families with disabled children at young age. These children are not included into the compulsive education system and their families are insufficiently provided with supports in mainland China.

1.3 Research Purpose

The purpose of this study is to examine the current situation of FQOL in families of children with disabilities at young age and try to explore the strategies for improving FQOL in these families based on systematic analysis of the influencing parameters. The study has been guided by the following aims:

I. Recognizing the current situation of FQOL in Chinese families of young children with disabilities;

II. Comparing the similarities and differences of FQOL among different family groups;

III. Exploring the influencing parameters of FQOL in families of young children with disabilities;

IV. Exploring possible strategies for improving FQOL in families of children with disabilities at young age.

1.4 Research Significance

The concept of QOL is often an important outcome in both research and applied settings. (Hoffman L. & Marquis J., 2006) As a concept involves the goodness of family life, FQOL shows overall family satisfaction with both internal and external dynamics, as well as support availability. (Gardiner E. & Iarocci G.2015) Therefore, for families with disabled children, on one hand FQOL indicates overall family outcomes with the impact of children' disabilities. On the other hand, FQOL can be taken as a comprehensive indicator to know the effectiveness of services or supports provided to families and children with disabilities. It also offers opportunities to compare program effects across different service models. (Hoffman L. & Marquis J., 2006) Hence, this research of FQOL is with important theoretical and practical significance.

Theoretical significance

Firstly, the outcome of this research is helpful to enrich the theoretical achievements of understanding of families with disabled children. Research on QOL has traditionally focused on individuals rather than families. (Hoffman L. & Marquis J., 2006) And there is lack of research about QOL in families with disabled children at young age in certain social background. Therefore, this research has the potential to gain more understanding of the family functioning and family members' satisfaction of family life when there is a child with disabilities in certain social and cultural background.

Secondly, the outcome of this research has potential to provide theoretical guide to the improvement of functioning in families with disabled children before school age. Based on the current situation of quality of life in families with disabled children at young age, this research has further explored the influencing factors of functioning of family life, which is helpful for coming up with target strategies for improving parents' satisfaction of family life.

Practical significance

Firstly, the outcome of this research is useful for modifying the early intervention services for children with disabilities and their families. On one hand, to know the current situation of FQQL in families with disabled children at young age helps to gain better understanding of the practical problems in the family life and corresponding needs for the whole family and the disabled children. On the other hand, for families with disabled children at the age of 0 to 6/7 years old, early intervention services are the main type of professional support for the children and their families. The current situation of FQOL can be taken as a useful indicator to know the effectiveness of early intervention services and to further modify the service providing model in early intervention.

Secondly, the outcome of this research is beneficial for improving the functioning of family life in families who have young age children with disabilities. To improve the FQOL is critical for the development of children with disabilities and should also be a valuable topic in special education area, especially in early intervention area in considering of the family-centered trend in the recent years. On one hand, exploration of FQOL's influencing parameters contributes to useful intervention strategies for parents' satisfaction of their family life. On the other hand, the research about how to improve the quality of life in families with disabled children at young age can provide reference to the practice of supporting families of children with disabilities.

1.5 Operational Definition of Terms

This study focuses on families of young children with disability and attempts to explore their FQOL in the background of mainland China. In order to avoid ambiguity, variation of meaning and understanding of terms, the meaning of following terms is defined according to usage in this study.

Early Intervention (EI): It is a kind of comprehensive services provided to children with disabilities or children with high-risk of developmental defects between 0 to 6 or 7 years old and their families. These professional services refer to early detection, early identification, early diagnosis and comprehensive supports including medical care, health care, rehabilitation, education, social services, parent parental guidance etc. (Zhang F. & Yang F., 2011)

Family Quality of Life (FQOL): There is still no worldwide recognized definition of family quality of life. Based on the literature analysis, in this research FQOL is regarded as an outcome and means “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 et al., 2011, P.262). In this research, FQOL has been regarded as family members’ perceived satisfaction on their family life.

Disability: Recently, countries among the world have given various legal definitions to disability as it is still an issue of much debate around the world. According to the definition from United Nations, disability means any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Compared to the definition in western countries, the definition of disability is relatively narrow in mainland China, which includes seven kinds: hearing impairment, visual impairment, speech disorder, physical disability, intellectual disability, mental disability and multiple disabilities. In this study, children with disability refer to children with diagnosis of any of the seven kinds of disorders or other kinds of diagnosis including autism spectrum disorder(ASD), attention deficit hyperactivity disorder (ADHD), developmental delay, learning disability and so on from professional institutions. In this study, children with special needs or disabled children has been used to refer to children with disabilities to avoid duplication.

Young children: In this study, young children refer to children from 0 to 8years old who are receiving or still have fresh experience of early intervention services. According to the social background in mainland China, young children (0-6/7-year old) are excluded from compulsive education and in the target period of early intervention.

Chapter 2 Literature review

This chapter aims at providing theoretical background and research foundation for this research. Firstly, family systems framework has been introduced to attain a holistic understanding of family as a system. Child with disability should be regarded as one family characteristic in the family system and it will affect family functions through the process of family interaction. Then, unified theory of family quality of life has been introduced to explain the theoretical framework of FQOL. This unified theory of FQOL provides theoretical foundation for exploring the influencing parameters and improving strategies of FQOL in families of children with disabilities at young age. Thereafter, literature review on FQOL related to children with disabilities, especially in Chinese families has been done in the following part.

2.1 Theoretical perspective

In describing family outcomes in families of children with disability, some theoretical frameworks have been developed to explain the effects between children with disability and their family. In consideration of the purpose of this research, family systems framework and unified theory of quality of life have been employed as theoretical frameworks for guiding this research.

2.1.1 Family systems framework

In 1960s to 1970s, Murray Bowen developed his family system theory based on his clinical experience with families of emotional illness. (Brown, 1999) Since then this theory has been attached significant importance in family therapy as it defines family as an emotional unit and uses systematic thinking to describe the complex interactions among family members in the family unit. According to family system theory, family has now been understood as an interconnected, self-regulating, dynamic and comprehensive system in which all family members are intensively connected emotionally, which means all family members have potential to influence each other and the whole family unit. In other words, mutual influence and interdependence are the basic features of relationship among family members. (Gardiner & Grace, 2012) Based on family system theory, Turnbull et al., (2015) developed family systems framework to address family systems in families of children with disabilities.

According to Turnbull et al., (2015, p.6), family is defined 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*” from a functional perspective. In practice, the definition of family limited family size and form. This shows difference on the impact of a child’s disability to the family. Usually, in large families, more people are available to provide supports and resources needed by children with disability.

In order to effectively understand (see Figure 2.1) the relationship of members in families of individual with disability, four key components in terms of family characteristics, family interactions, family functions, and family life cycle are included in this framework as shown in Figure1. The first component family characteristics include characteristics of the whole family, in terms of family size and form, cultural background, socioeconomic status, and geographic location; characteristics of individual members in terms of child’s disability, each family member’s skills in managing life, mental and physical health, communication, and motivation; unique circumstances refer to additional specific experiences in terms of homelessness, parents with a disability, teenage parents and so on. Regarding to families of member with disabilities, family characteristics mainly describe the variables of family characteristics related to disability, such as the type and degree of disability, number of kids, socioeconomic status of the family and so on. These variables are regarded as an input to affecting family functions through the process of family interaction. Family interaction refers to family members performing roles and interacting with each other. It describes the interaction between all family members, including partners, parents, siblings and other family members regarding to the four sub-parts of the family system in terms of marital, parental, sibling and extended family subsystems. Family functions refer to the types of individual needs satisfied by family, including daily care, affection, recreation, socialization and so on. The last component, family life cycle represents different developmental stages and transition periods which may result in changes in both family characteristics and family functions. The four components effect as a feedback loop to constitute the whole system.

According to family systems theory, there are three assumptions behind this framework. The first is the input-output assumption, in which family characteristics are inputs into the process of family interaction, and the output of this process are family functions. In other words, family characteristics interact with the system and produce outputs, and the outputs relate to how the family functions. Meanwhile, family functions also act as feedback to family interaction and thus bring changes to family characteristics along with family life cycle. The second assumption is that the family system is a whole and can't be understood through only one or more of its parts or subsystems. The third assumption is that boundaries exist among family members. As these boundaries result from the interaction among family members and from the interaction of the family unit with outside influences, different families vary in the degree to which their boundaries are open or closed to others non family members. (Zuna, et al, 2010, p.32)

According to family systems framework, individual with disability is regarded as one family characteristic in the family system and it will affect family functions through the process of family interaction along with other family characteristics. Meanwhile, family functions may also result in changes to family member with disability and other family characteristics through family interaction. These two-ways influencing could be negative and positive. Hence, family of children with disability should be understood as a whole system and understanding of their families is necessary for better understanding of them. In practice, professionals related to children with disability have shifted their focus from children or parental subsystems to a broader focus on the entire family system (McWilliam R., Snyder, Harbin, Porter, & Munn, 2000). Understanding and identifying the basic characteristics, interactions and functions of families can help provide valuable insight into how to deliver effective family-centered services in early intervention programs.

Based on its holistic understanding of family system, family systems theory provides a concrete framework for understanding the FQOL in families of children with disability. To be specific, the existence of family member with disability will affect other family members along with their related subsystems, and then affects the family functions and the QOL of the whole family. At the same time, family system as a system with homeostasis, it will adapt to the changes and reach a new balance. Hence, the QOL in families with disabled children is dynamic and changes in different family life cycle.

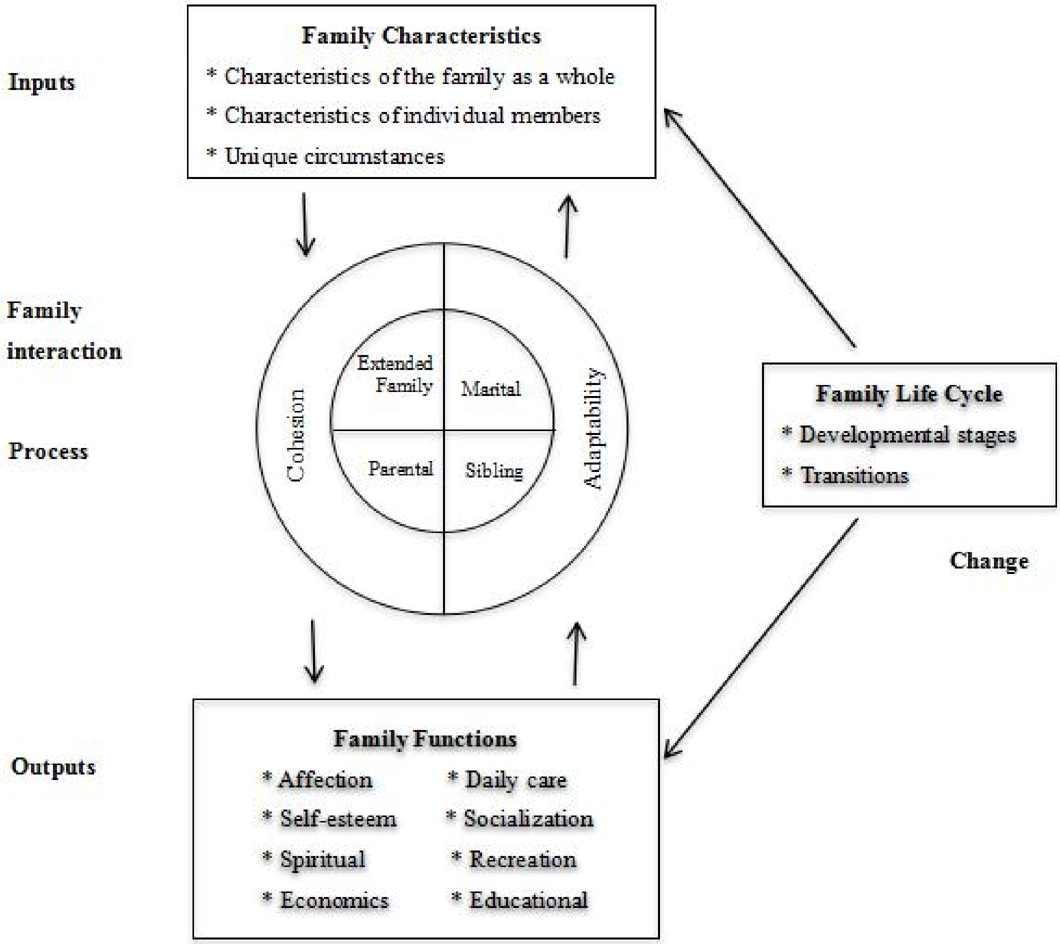

Figure 2.1 Family systems framework (Turnbull et al., 2015)

2.1.2 Unified theory of family quality of life

The attention on family quality of life has developed along with the change of service providing model in early intervention area over the past decades. Intervention programs for children with disabilities have been traditionally targeted at individual's special needs out of their family and other environmental context.(Samuel et al.,2012) However, with the influence of ecological systems theory developed by Bronfenbrenner, increasing emphasis on supporting individuals with disabilities in their home environment has been perceived in disability service provision, especially in early intervention area. Currently, unlikely the traditional child-centered service provision model only focuses on children with disabilities, new family-based early intervention programs increasingly emphasize on improving children's disabilities along with improving the functioning of their environmental context. (Samuel et al., 2012). Currently early intervention programs are aiming at helping child with disability and their family with one final target of improving outcomes of the child and also the whole family. Hence, FQOL has been increasingly recognized as an important concept in the field of early intervention, and furthermore, regarded as an important index to recognize the outcome of services delivery programs.

From early 2000s, researchers from the area of family research for individuals with disability, started to pay attention to conceptualization of FQOL and developing measurement instruments through qualitative research. (Poston et al., 2003; Samuel et al., 2012) Over past decades, the theoretical framework of family quality of life is gradually improved. Around a decade ago, Zuna et al., (2010, p.269) introduced the unified theory of FQOL to explain the internal and external factors contributing to changes of family outcomes. This theory is stated 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*" .

The unified theory of FQOL describes variations in FQOL and intends to explain why and how FQOL varies among families of children with disabilities. (Chiu et al.,2013) In this theory, various external environmental factors, together with internal family dynamics and characteristics that could influence FQOL have been introduced. According to Zuna et al., (2010, p.262-266), four domains of factors in terms of family-unit factor, individual family member concepts, performance concepts and systemic concepts are included in the unified theory of FQOL.

Societal values, policies, systems, and programs have been identified as systematic factor, while family members' characteristics (e.g., child's age, type of disability, parents education, employment status), demographics (e.g., child's behavior, parent depression, sibling's health status), and beliefs (e.g., attribution of meaning, expectation) have been regarded as individual-member factor. Besides, family unit factors refer to internal characteristics of the family (e.g., family cohesion and adaptability), while performance concepts refers to service (e.g., respite care[1], counseling, medical care, therapies), supports(less tangible resources, e.g., emotional support, knowledge and information, education and legal systems) and practice. (Zuna et al., 2010, p.262-265; Chiu et al., 2013) Moreover, the various influencing factors interact with family and individual support factors in a dynamic process and result in unique FQOL outcomes in actual family situation.

Meanwhile, as the main purpose of the unified theory is to describe and explain the potential interaction among these variables, the dynamic relationship between FQOL and its indirect and direct predictors is well summarized in the theory. (Chiu et al., 2013) To be specific, family characteristics and dynamic and individual demographics, characteristics and beliefs directly 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

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[1] Respite care is an example of external resource designed to give parents a ''short break'' from someone who has significant care requirements which provides family a chance to "relax", "refresh", and "recharge".(Harper et al., 2013)

predicts implementation of best practices, implementation of best practices impacts an individual child factor which in turn impacts FQOL (Zuna et al., 2010, p.267) Besides, FQOL outcome produces new family strengths, needs, and priorities which re-enter the model as new input. In practice, for families of children with disability, different individual demographics, characteristics and beliefs may include child's age, disability type and severity, educational level of parents, parents' expectation and so on. These factors together with the provision of services, supports, and practices lead them to make unique decisions about their life and their family's life and hence affect FQOL. The unified theory of family quality of life from Zuna et al. (2010, p.269) has been adapted by Chiu et al., (2013) as shown in Figure 2.2. In summary, this framework indicates that systems, policies, and programs indirectly impact FQOL through influencing individual and family-level supports, while services, practices, and individual family-unit characteristics act as direct predictors of FQOL.

The unified theory of family quality of life provides a comprehensive and systematic theoretical framework for this research. On the basis of this unified theory, various parameters including individual-level factor, family-unit factor, family and individual support, and systemic factors have been considered in the research process of exploring the influencing parameters and improving strategies of FQOL in families of children with disabilities at young age.

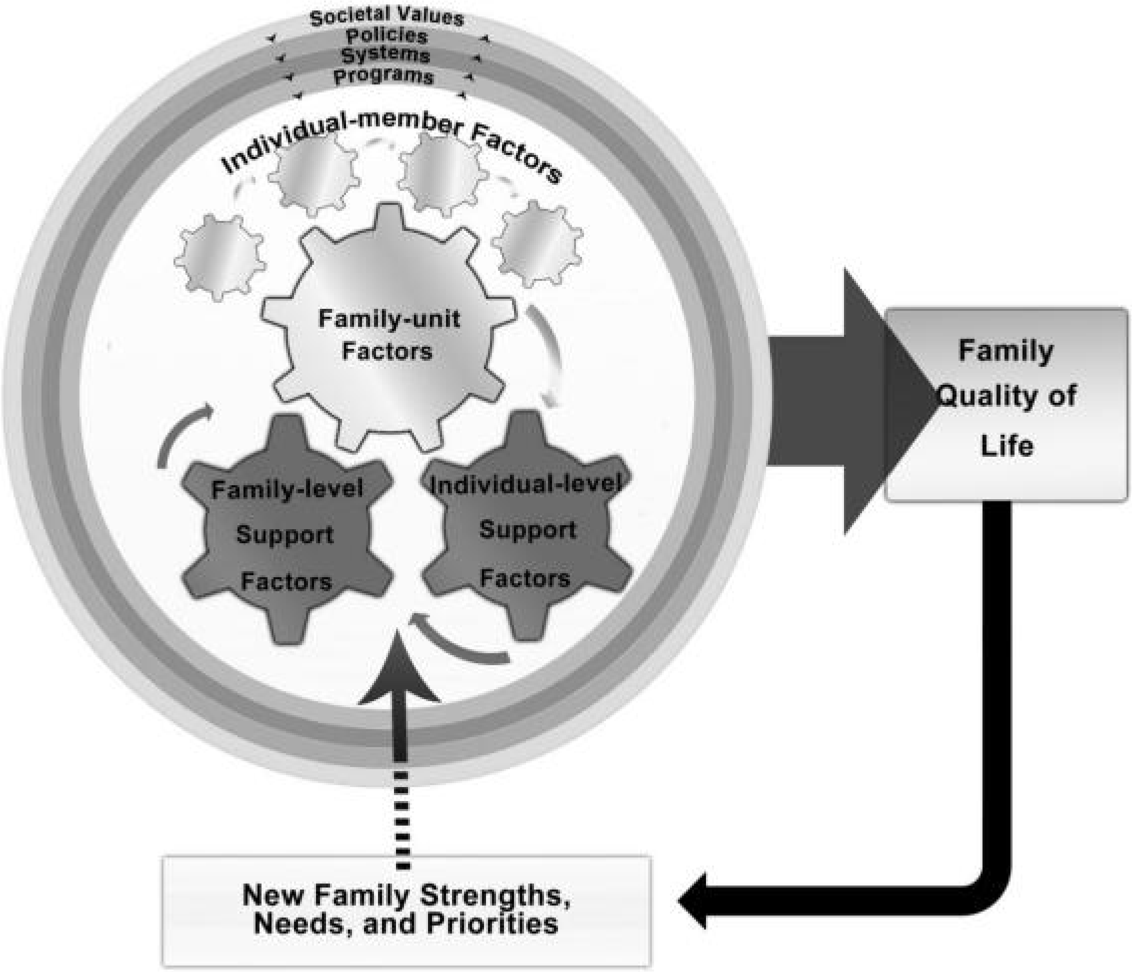

Figure 2.2 Unified theory of Family quality of life (Chiu et al., 2013)

2.2 Review on current research

During the last 20 years, along with the recognition of the importance of family, and service delivery model shift in early intervention, FQOL has attracted extensive attention from researchers all over the world. The research on FQOL focuses on three aspects: defining and elaborating FQOL's connotation, developing measurement instruments based on the theoretical framework of FQOL, investigating the current status of FQOL in families of children with disabilities, and exploring the predicting factors of FQOL.

2.2.1 Definition and connotation of FQOL

As mentioned before, there has been a shift of service delivery model from child-centered to family-centered over last decades. Since the end of 1980s, a growing recognition of the importance of family in terms of family priorities, family choices, family strengths and resources, and family as a support unit has been attached strong emphasis in early intervention for children with disability. In this family-centered service delivery model, FQOL has been regarded as an important policy/program outcome of service delivery for individuals with disabilities and their families. (Poston et al., 2003; Park et al, 2003; Summers, 2005; Samuel et al., 2012) Along with the shift of emphasis from individual-center to family-center service delivery, FQOL had been put forward as a natural extension from the concept of individual QOL together with the consideration of family (Poston et al., 2003; Samuel et al., 2012). From the beginning of 20c, researchers from different countries initiated some studies aiming at exploring the conceptual framework of FQOL based on their definition of FQOL. There are outcomes from two main research groups.

One group of researchers is from the Beach Center on Disability in USA. After a series of studies based on grounded theory qualitative methods, they described the definition of FQOL as "*Conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them*."(Park et al., 2002; Park et al., 2003, p.367) Moreover, a two-facet domain structure of FQOL was generated by their research findings. The six individual-oriented domains consist of advocacy, emotional well-being, health, physical environment, productivity, and social well-being while the four family-oriented domains are daily family life, family interaction, parenting, and financial well-being. Among the ten domains, nine of them are relevant for all families who have children with or without disabilities, while the 10th domain, advocacy, is only relevant for families of member with disability. (Poston et al., 2003; Wang & Brown, 2009)

An international research team including researchers mainly from Australia, Israel, and America has developed another holistic FQOL conceptual framework based on their previous work in individual QOL. They defined FQOL as "*Families experience satisfactory family quality of life when they (a) attain what families everywhere, and they in particular, strive for; (b) are satisfied with what families everywhere, and they in particular, have attained; and (c) feel empowered to live the lives they wish to live*"

(Wang & Brown,2009, p.32). Their conceptualization of FQOL focuses on six dimensions of individual QOL across nine major areas of family life, including health of family, financial well-being, family relationships, support from other people, support from disability-related services, spiritual and cultural beliefs, careers and preparing for careers, leisure and enjoyment of life, and community and civic involvement. (Isaacs et al., 2007; Wang & Brown, 2009).

Recently, according to the unified FQOL theory, the definition of FQOL as an outcome is described as "*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, et al., 2011, P.262; Ferrer et al.,2016).

To date, there is still no world-widely accepted definition and connotation of FQOL because of its complex structure. In research practice, researchers' understanding of FQOL varies according to the purpose of study, participants, researchers' personal experience and so on. However, consensus has been reached among researchers that FQOL is a multidimensional construct with multiple domains and FQOL refers to family members' subjective satisfactions of their family life. Hence, Zuna's definition has been used in this research as the definition of FQOL.

2.2.2 Measurement of FQOL

Along with the recognition of the importance of FQOL in affecting policy making, guiding service delivery, and enhancing outcomes of individuals with disabilities, there was a practical need to develop effective instrument for measuring FQOL. However, it turns out with challenges to measure FQOL regarding its multidimensional construct. Hence, most of the measures used to measure FQOL had been qualitative or designed for a specific population, while empirical measurement of FQOL had been only a few. (Wang & Brown, 2009; Samuel et al., 2012) In assessment of FQOL through well-organized qualitative method has the advantage of reflecting in-depth voices of family members. However, qualitative methods are usually time consuming and require sophisticated skills for data analyzing and results interpreting. Hence, it is urgent to develop a quantitative instrument with sound psychometric properties, which is necessary for large-scale research about FQOL. (Wang & Brown, 2009)

Among the a few empirical measurements of FQOL, the first attempt of systematic assessment was done by Olson & Barnes in 1982. The main task of their study was to assess the fit between the families of typically developing adolescents and their environment by assessing subjective life satisfaction of adolescents and their parents. Unfortunately, there has been no further evidence of using this measurement among families of members with disabilities. (Summers, 2005; Wang & Brown, 2009; Samuel et al., 2012)

Currently, there are two major systematical measurement instruments based on different connotations of FQOL. Both of them are with sound psychometric properties and widely used in FQOL studies around the world. One is the Beach Center FQOL Scale developed by researchers at the Beach Center for Disability in the USA, and the other one is the Family Quality of Life Survey (FQOLS-2006), developed by the international research team. Details about these two measures are described below.

The Beach Center FQOL Scale was developed through several phases of qualitative and quantitative studies on conceptualization and measurement the FQOL. (Park et al. 2003; Poston et al.2003; Turnbull et al. 2004b; Summers et al. 2005; Hoffman et al. 2006; Samuel et al. ,2012). The preliminary version of the scale included 112 items in ten domains. It came to be 41 items in 5 domains after test with representative group (n = 1197) (Park et al. 2003). After further field tests, it was reduced to a 25-items instrument (Beach Center FQOL Scale, version 2003) consisting of three sections: demographic questions about the family and the family member with disability, importance and satisfaction ratings grouped into five FQOL domains as shown in Table 2.1 (Park et al. 2003; Wang & Brown ,2009; Samuel et al. ,2012). Satisfactory psychometric properties in terms of the test-retest reliability, and convergent and construct validity have been reported and supported by studies. (Summers et al., 2005; Hoffman et al., 2006) The most current version of the Scale (version 2005) only includes satisfaction rating and is much shorter, allowing application together with other tools for evaluation. (Samuel et al., 2012)

The Family Quality of Life Survey (FQOLS-2006) was based on the connotation of FQOL of the international research team described in former section. The preliminary version of the survey was developed in 2000 with collected data from volunteers in several countries (Isaacs et al. 2007; Wang & Brown, 2009; Samuel et al., 2012). FQOLS-2006 is a comprehensive instrument for assessing multidimensional construct of FQOL through nine domains of family life (see Table2.1). Within each domain, six dimensions in terms of Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction are measured on a five-point Likert scale. Both quantitative and qualitative data are collected in the survey. (Werner et al., 2009) Currently, the FQOLS-2006 is available in two versions: general version and specific version for main caregivers of people with intellectual or developmental disabilities (FQOLS-2006, ID/DD version). To date, FQOL-2006 has been translated into at least 20 languages and has been used in more than 20 countries. (Wang & Brown, 2009; Samuel et al., 2012; Butler K., 2018)

Current studies suggest that FQOL could and also should become an ultimate goal for assisting and supporting families in need. Both of these two FQOL instruments can be used at the family level to measure family need and at the program level for assessment of service effectiveness and program evaluation.(Summers et al., 2005; Wang & Brown, 2009) For family level usage, both instruments are family friendly surveys in planning for and delivery family-centered services and supports collaboratively with families.(Zuna et al.,2014,;Butler K.,2018)

According to literature review, recently both of these two main measurement instruments have been translated and used in Chinese context. Comparatively speaking, Beach Center FQOL Scale has been more often used in Chinese families of children with disabilities. Hence, according to the research purpose and in consideration of the convenience for implementation and comparison with former studies, Beach Center FQOL Scale has been chosen to assess the current situation of FQOL in Chinese families of young children with disability.

Table 2.1 Comparing the domains and number of questions of two FQOL instruments (Samuel et al., 2012, p.8)

Domains of instruments	**Number of descriptive questions**	**Number of objective questions(psychometric measures)**
Beach center FQOL Scale domains	0	5
1.Physical and material well-being	0	4
2.Emotional well-being	0	6
3.Family interaction	0	6
4.Parenting	0	4
5.Disability-related support	0	
FQOLS-2006 domains*		
1.Health of the family	3	6
2.Financial well-being	6	6
3.Family relationships	3	6
4.Support from others	5	6
5.Support from disability-related service	3	6
6.Influence of Value	5	6
7.Careers and preparing for careers	6	6
8.Leisure and recreation	3	6
9.Community interaction	4	6

**There are 13 other questions in the introductory section, and seven in the final section on global FQOL (two questions of global FQOL are psycho-metrically testable)*

2.2.3 FQOL in families of children with disabilities

During the past two decades, studies about FQOL among families of children with disabilities have drawn continuous attention from researchers around the world. While there are many studies conducted in western countries to know the general situation of FQOL among families of children with different kinds of disabilities, FQOL related studies initiated relatively late in China and much of FQOL remains understudied.

2.2.3.1 Research on FQOL in families of children with disabilities outside China

As mentioned before, two major FQOL projects were initiated since the importance of FQOL had been recognized among the world. One project is the Beach Center at the University of Kansas and the other is the International Family Quality of Life Project. Along with these projects, many studies have been carried out to know the current situation of FQOL among families of children with various disabilities in different countries. Based on literature review, most studies have focused on children with intellectual disabilities and developmental disabilities, especially children with ASD, while just a few studies are about children with hearing impairment or visual impairment. Moreover, majority of studies are about FQOL in families of children at school age, while relatively fewer studies are targeted at FQOL of families of disabled children at young age or other life phases.

Elaine et al., (2013) conducted a survey among 189 Polish caregivers of individuals with intellectual or developmental disabilities and the results shows that the Polish caregivers were fairly satisfied with their FQOL despite having limited opportunities to improve their FQOL. Joana et al. (2016) also found out that emotional well-being of Spanish families of young children with disabilities was high, although they were concerned about health and financial well-being. And having two or more children with developmental delay has no major negative impact on families' QOL. (Patterson et al., 2018)

2.2.3.2 FQOL in Chinese families of children with disabilities

The researcher conducted a literature search for studies on FQOL in China National knowledge Infrastructure (CNKI), Wan fang Data and VIP database[2] and also EBSCO, Web of Science, and ERIC. The keywords included terms such as family quality of life, child with disability, children with disability and Chinese family. The search strategy was as follows: (a) TI=family quality of life; (b) AND AB= parent or caregiver or mother or father; (c) AND AB= disab* (to cover terms such as disability, disabled, disabilities) OR handicap OR impairment or special needs; (d) AND AB=children OR kid OR student or infant; (e) AND AB=Chinese OR China (not used

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[2] CNKI (China National Knowledge Infrastructure),Wan fang Data and VIP database are the three most important Chinese journal databases.

in CNKI,VIP or Wan fang Data) on the condition of full text and peer reviewed articles in Chinese or English. In order to obtain relevant literature as much as possible, the reference bibliography of key literature was also examined. Through searching, 22 related articles had been found and after re-check of the content, 2 articles about Chinese families in the USA and Malaysia were excluded from further analysis. Then, the other 20 studies were reviewed to know the research status of FQOL in Chinese families of children with disabilities. Among them, 5 articles are reviews while 15 are empirical studies (14in Chinese and 1 in English). 1 article is excluded because of unclear description of measurement instrument and participants and the 1 English and 2 another Chinese articles are also uncounted as they are the same studies of other articles from the same researchers. Then there are 11 articles left in the end. As shown in Table 2.2, these 11 studies are sorted chronologically, presenting the domains of the author, publication year, research design and main research instrument, information of children and main findings.

As shown in Table 2.2, there are not many studies of FQOL in China comparing to rich research from the world. Recent studies of FQOL in China are more focused on children during school age. The FQOL of families of children at young age is not much known. Meanwhile, recent studies are more focus on children with one type of disability, especially autism and intellectual disability. FQOL of families with other kinds of disabilities are not well-known. Moreover, most studies are about the current situation of FQOL by questionnaire survey, in-depth research about contributing factors and supporting strategies of FQOL are not involved. Hence, it is necessary to conduct comprehensive studies about FQOL in families of disabled children at young age using various research methods.

Table 2.2 Summary of reviewed studies on FQOL in Chinese families of children with disability

	Author (Year)	**Title**	**Children**	**Research Design**	**Main findings**
1	Huang Y., Wang H.& Yao L. (2003)	Study on Quality of Life in Families of Children with Cerebral Palsy	*N*=100(50CP,50 CG) Age :6m-3y	Survey *Hospital Anxiety and Depression Scale, self-complied questionnaire*	compared to parents of children with acute disease parents with CP children are in state of anxiety and depression; decreased FQOL
2	Hu X., Wang M.& Fei X. (2012)	Family quality of life of Chinese families of children with intellectual disabilities	*N*=442 (DD) Age:0-18y+ 2 below 6y	Survey *Beach Center FQOL Scale-CV*	medium level of FQOL and low economic situation and high unemployment
3	Luo L. (2014)	The Study of the Life Quality of Families with Autistic Children in Chengdu	*N*=90 (ASD) Age:6-17y	Mixed methods of Survey and interview *Self-complied Questionnaire about Life Quality of Family with Autistic Children*	satisfaction level of domains of FQOL: emotional>physical >leisure > obtained service related to disability
4	Han Y., Huang X.& Zh J. (2016)	Adequacy of Services for the Disabled Persons and Family Quality of Life-Family Caregivers of the Disabled Children in Shanghai	*N*=940(HI319, DD494, other 97) Age:7-12y	Survey *Beach Center FQOL Scale-CV*	medium level of FQOL; degree and category of children's disability, family annual income, et al., perceived adequacy of services is tested as a significant factor in predicting FQOL
5	Li L. (2016)	Research on Family Quality of Life of Families with the Autistic Children in Shanghai	*N*=216 (ASD) *Age:7-16y*	Mixed methods (survey and action research) *Beach Center FQOL Scale-CV* *The factors of FQOL questionnaire for the families with autistic children*	Family interaction>physical/material well-being>parenting >emotion well-being and disability-relative support
6	Hu X.; Feng Y., Chen T. (2016)	Research on the Life Quality of Families of Students with Intellectual Disabilities in Shanxi Province	*N*=333(ID) *Age:0-18y+* 2 below 6y	Survey *Beach Center FQOL Scale-CV*	Medium level general satisfaction of subjective FQOL; Satisfaction level: Family interaction >parenting>emotional well-being and physical / material well-being

7	Hu X., Yue X., Jia R. (2016)	The Status and Relationship Between Family Needs and Family Quality of Life of Children with Visual and Hearing Impairment in China	*N*=798(HI &VI) *Age:0-18y+* 25.3%below 6y	Survey *Beach Center FQOL Scale-CV*	Economic needs, leisure needs, and family resources are affecting factors of FQOL in families with HI and VI
8	Hu X. (2016)	Family Quality of Life and Family Support of Children with Disabilities in China	*N*=3198 Age:0-18+ 15.7%below 6	Mixed methods Survey and interview	FQOL correlated with professional support and support from relatives, social organizations, friends and spouse; Family centered support service to children with disabilities is lacking in China.
9	Huang R. (2017)	The Study of The Family Quality of Life of Families with Children of Intellectual Disabilities in Chongqing	*N*=785(ID) (n=353) *Age:1-18y* 43 below 6y	Mixed methods (Survey and interview) *Self-complied FQOL questionnaire for families of children with Intellectual Disability*	Self-complied questionnaire of FQOL is reported with good validity; High satisfaction of family communication and relatively low satisfaction of career development and financial well-being while worst satisfaction on dimensions of disability supports, support from others and leisure time; home address, children disorder degrees, schools, family structures, children's and parents' gender, children's and parents' ages, parents' identities predict factors of FQOL
10	Ren C., Shen R., Huang R., Liu C. (2018)	The Investigation of the Quality of Family Life in the Area of Southwest Where Minority People Live of China	*N*=162 Age: school age students	Survey *Self-complied FQOL questionnaire for families of children with Developmental Disability*	Children's disabilities， family economy and support， and family interaction have a certain influence on the FQOL; positive marriage indicates a higher FQOL

11	Liu W. (2019)	The Mediating Effect of Parenting Self-efficiency and Social Support on the Relationship between Parenting Stress and Family Quality of Life in Parents of Children with Autism spectrum disorder	*N*=1384(ASD) Age:0-12y 69.7%<6y	Survey	general satisfaction level of FQOL, clinically higher level of parenting stress, and low level of parenting self-efficacy and social support; parenting stress, parenting self-efficacy and social support are significantly associated with FQOL; Mediation analyses revealed that both parenting self-efficacy and social support partially mediated the relationship between parenting stress and FQOL at a significant level.

Note: CP=cerebral palsy, CG=control group, CV=Chinese version, DD=developmental disability, Hi=hearing impairment, VI=visual impairment, ID=intellectual disability, ASD=autistic spectrum disorder.

2.2.4 Predicting factors of FQOL in families of children with disabilities

According to the Unified Theory of FQOL and Family Systems Framework, multidimensional factors including systemic factors, family-unit factors, individual-level factors, family and individual support factors are contributing to the outcomes of family life.

Recent studies have found some impacting factors of FQOL in families of children with disabilities. Summers et al., (2007) found out that service adequacy ratings were a significant predictor of family quality of life. Li (2016) pointed out that for Chinese families of school age children with ASD, family atmosphere, parental attitude, problems of the children, social support were the main influencing factors of FQOL while economic pressure and parents' knowledge &skills played no significant role in predicting FQOL. Hu (2016) also pointed out that FQOL highly correlated with professional support and also correlated with support from relatives, social organization and spouse. Hsiao (2018) conducted a survey among parents of children with ASD and findings showed that parent's gender, marital status, education, family income, or perceived parental pressure were predictors of FQOL, and that family income and parental stress were two significant predictors when considering these variables together.

2.3 Summary of literature review

The literature review part provides theoretical background and research foundation for this study. On one hand, family systems theory and the unified theory of family quality of life build theoretical foundation for this research. As components in their family systems, children with disabilities are bound to have impacts on their family life in the interaction process with family members. Meanwhile, FQOL can be affected by various factors including individual-level factor, family-unit factor, family and individual support, and systemic factors according to the unified theory of family quality of life. Hence, multiple factors should be considered when exploring the influencing parameters of FQOL. On the other hand, through review on current research, the research design of this study gradually became clear. Firstly, well understanding of the definitions and connotations of FQOL ensured a reasonable operational definition of FQOL in this study. Secondly, by sorting out measurement tools of FQOL, as an effective research instrument, the Beach Center Family Quality of Life Scale (BC-FQOL) was chosen for investigation of the current situation of FQOL in families of young children with disabilities. Thirdly, based on review of the previous research, general understanding of the current situation of FQOL in families of children with disability and its predictor has been obtained. In one word, literature review builds basis for the further steps of this study.

Chapter 3 Methodology

The purpose of this research is to examine the current situation of quality of life in families of children with disabilities at young age and try to explore the improving strategies for better outcomes of their FQOL based on systematic analysis of the influencing parameters. This chapter describes the methodological approach employed in this study, which focuses on the research design, research questions and hypotheses, research methods, procedure for data collection. Additionally, this chapter also introduces the data analysis strategies in this study.

Exploratory mixed method combining quantitative and qualitative approaches has been applied in this research. Questionnaire survey and semi-structured interview have been used as main means for collecting research data. Questionnaire survey has been mainly used to know the current situation of FQOL in families of children with disabilities at young age in China, while Questionnaire survey and in-depth interview have been combined to explore the influencing parameters of their FQOL and potential improving strategies. Statistical analysis software SPSS 22.0 has been used to analyze the quantitative data from questionnaire survey, while Computer-Aided Qualitative Analysis Software (CAQDAS) NVivo11.0 Plus has been used to analyze the qualitative data from in-depth interview.

In particular, five parts are included in this chapter. Firstly, the research design is introduced through the research flow chart. The second part is about the research questions and hypotheses which run through and guide this research implementation. The third part introduces the research methods applied in this study. Literature review, questionnaire survey and semi-structured interview have been taken as the main research methods. The forth part presents the procedures of quantitative data collection and analysis, including the instruments, respondents of questionnaire, data collecting procedures and analysis strategies. The last part presents the procedures of qualitative data collection and analysis, which includes the participants, interview outline, qualitative data collecting and data analysis procedures.

3.1 Research design

Research designs also known as strategies of inquiry, are types of inquiry in terms of qualitative, quantitative, and mixed methods approach that provide specific direction for procedures in research conduction. (Creswell, 2014) It is a plan to show how one specific research will be carried out. Hence, research design should outline the process from writing hypothesis, collecting and analyzing data, to finally producing research outcomes. (Bhatta, 2013)

The most essential difference of quantitative approach and qualitative approach lies in their different research orientation. To be specific, under Quantitative research approach, the investigators primarily use positivist claims for developing knowledge and emphasize on testing research hypothesis and discovering connections between variables. Quantitative researchers usually employ strategies of inquiry such as experiments, surveys and collect data on predetermined instruments that yield statistical data. (Creswell, 2003) Different from quantitative approach, qualitative research method relies on extensive descriptions of real-life experiences and its interpretative meaning. Hence, qualitative method tends to be open-ended without predetermined responses while quantitative method usually includes closed-ended responses for example questions on questionnaires or psychological instruments (Creswell, 2014).

This research aims at examining the current situation of FQOL in families of children with disabilities at young age and exploring the influencing parameters and improving strategies of their FQOL. In consideration of the strengths of both approaches, a cross-sectional study based on mixed methods combining quantitative and qualitative approaches has been supposed to be the most appropriate approach for reaching the research purpose. Several research steps have been included in this research according to the research flowchart (see Figure 3.1).

As shown in Figure 3.1, the first step of this research is literature review of the recent studies about FQOL in special education area. The goal of this part is to gain clear understanding of the progress of related studies among the world, especially in

China. Through literature review, family system theory and unified theory of family quality of life provide solid theoretical foundation for this research. Meanwhile, through reviewing current related studies, the proposed research methods and instruments have become more and more clear. The second step is research design. A mixed method combining quantitative approach and qualitative approach has been adopted in this research. Quantitative approach has been mainly applied to know the current situation of FQOL in families of children with disabilities at young age, while qualitative approach has been mainly used to explore the improving strategies of their FQOL. Meanwhile, both quantitative and qualitative approaches have been applied to discovery the influencing parameters of the FQOL in families of children with disabilities at young age. The third step is data collecting. Quantitative data is collected through questionnaire survey in paper edition and electronic edition, while qualitative data is collected through semi-structured interview with recording and transcription. The forth step is data analysis. Descriptive and comparative analyses of quantitative data have been conducted through SPSS 22.0, while systematic coding and comparative analyses of qualitative data have been conducted through NVivo11.0 Plus. The fifth step is interpretation of the research results. In this step, the current situation of FQOL in families of children with disabilities at young age has been discussed and the influencing parameters and improving strategies of their FQOL have been explored on the basis of interpretation of quantitative and qualitative data. The last step is conclusion and reflection. Conclusions of FQOL in families of children with disabilities at young age have been drawn in this part and reflection of this research also has been done.

3.2 Research questions and hypotheses

In families of children with disabilities, child with disability is a family element that cannot be ignored. According to family system theory, the emergence of children with disabilities will inevitably affect their family outcomes. This research aims at investigating their family outcomes, and exploring the influencing parameters and improving strategies of their FQOL. This whole research is guided by the following research questions and the following research hypotheses have been tested through the quantitative research part.

Research questions

Ⅰ. What is the status of the objective family conditions in Chinese family with disabled children at young age?

Ⅱ. What is the current situation of subjective FQOL in Chinese families of young children with disabilities?

Ⅲ. Are there any significant differences of FQOL among different family groups?

Ⅳ. What influencing parameters contribute to the FQOL in Chinese families of young children with disabilities?

Ⅴ. What strategies can help improve the FQOL for Chinese families with disabled children at young age?

Research hypotheses

H_0 1.There is no statistically significant difference of satisfaction between domains of the FQOL in Chinese families of young children with disabilities.

H_1 1.There is statistically significant difference of satisfaction between domains of the FQOL in Chinese families of young children with disabilities.

H_0 2.There is no statistically significant difference of FQOL on child's characteristics.

H_1 2.There is statistically significant difference of FQOL on child's characteristics.

H_0 3.There is no statistically significant difference of FQOL on family's characteristics.

H_1 3.There is statistically significant difference of FQOL on family's characteristics.

H_0 4.Economic pressure does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 4.Economic pressure significantly predicts FQOL in Chinese families of young children with disabilities.

H_0 5.Difficulties related to child does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 5.Difficulties related to child significantly predicts FQOL in Chinese families of young children with disabilities.

H_0 6.Parental attitude does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 6.Parental attitude significantly predicts FQOL in Chinese families of young children with disabilities.

H_0 7.Family preparation does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 7.Family preparation significantly predicts FQOL in Chinese families of young children with disabilities.

H_0 8.Family involvement does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 8.Family involvement significantly predicts FQOL in Chinese families of young children with disabilities.

H_0 9.Social support does not significantly predict FQOL in Chinese families of young children with disabilities.

H_1 9.Social support significantly predicts FQOL in Chinese families of young children with disabilities.

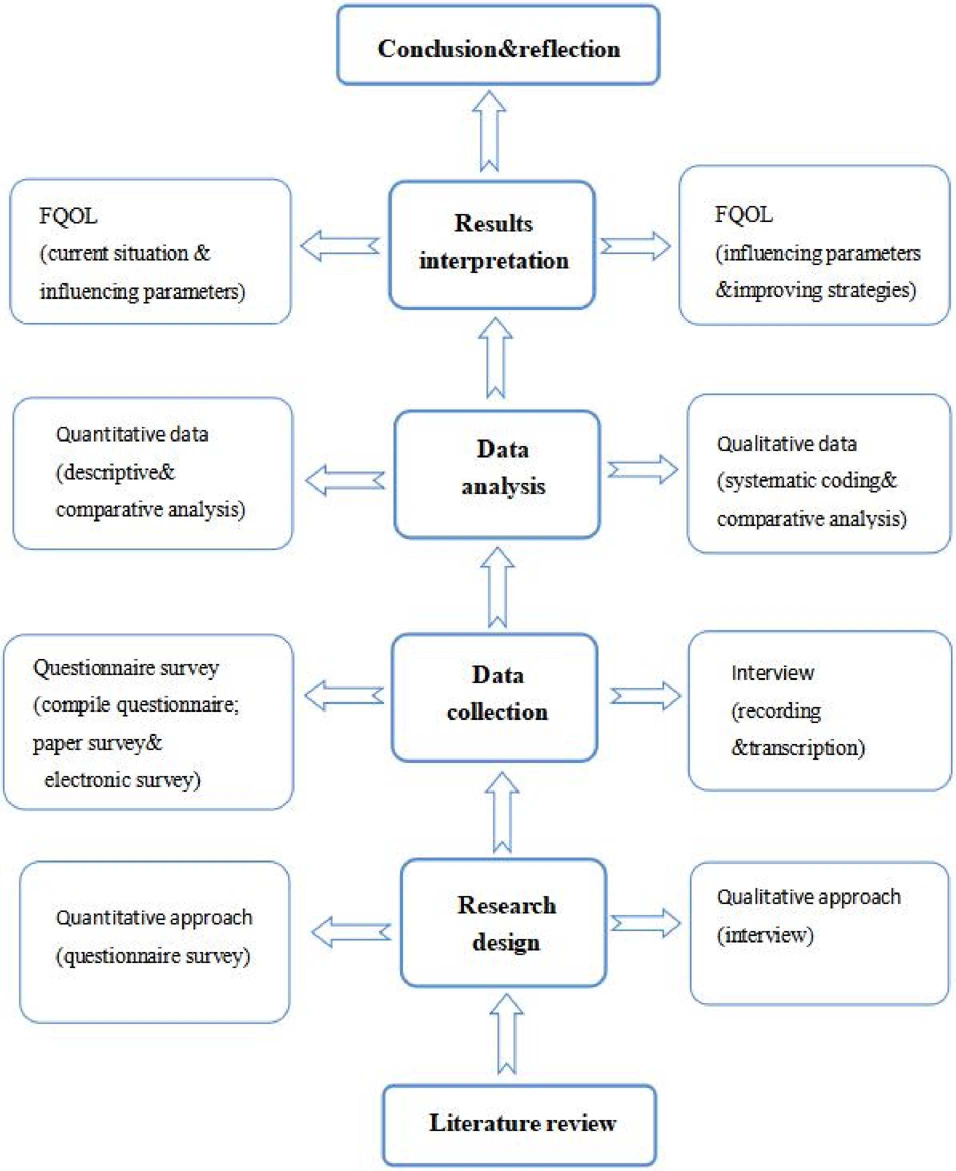

Figure 3.1 research structure of FQOL in Chinese families of young children with disabilities

3.3 Research methods

In this research, mixed methods including quantitative and qualitative approaches have been used to gain complete information of FQOL in families with disabled children at young age. In consideration of the strengths of these methods, literature review has been used to attain general understanding of the research status, while questionnaire survey and semi-structured in-depth interview have been used as the methods for data collection

Literature review

Literature method is a foundation for almost all research works and is one of the most common means to collect and analyze information for research purposes. It is often used to collect and analyze written and readily available materials which include academic papers, published and unpublished books, magazines, e-books etc. In this study, literature review has been applied to accumulate information related to theoretical background of FQOL and current research findings of FQOL in families of children with disabilities, especially in Chinese families with disabled children.

Questionnaire survey

Survey study is a good combination of qualitative and quantitative methods, as "*some surveys merely describe what people say, they think and do. Other survey studies attempt to find relationships between the characteristics of the respondents and their reported behaviors and opinions*" (Marcyzk et al., 2005, p.151). In this mixed study, both questionnaire survey and semi-structured interview have been used for collecting data.

Questionnaire survey is widely used in quantitative data collection. Anderson (2005) points out that, well- constructed questionnaire allows the collection of reliable and valid date from a large number of respondents about their behaviors, attitudes, and opinions in an efficient and timely way. In social science area, especially in psychology and education, it's very common to use questionnaire survey for capturing a wide variety of factors related to human experience through some established questionnaires. These established questionnaires have been tested by previous studies to be mature with reliability and validity. These mature questionnaires are attractive, but sometimes self-compiling questionnaire is necessary on the occasion of no established questionnaire available. (Anderson, 2005, p.179)

In consideration of the research needs, both mature scale with established reliability and validity and self-constructing questionnaire have been used to collect quantitative data in this study. To be specific, the established Beach Center FQOL Scale has been adopted to capture the current situation of FQOL in families with disabled children at young age and self-constructing FQOL influencing factors questionnaire has been used to explore its influencing factors. Both the BC-FQOL and the influencing factor questionnaire are 5-points Likert scale which will be further introduced in the next part. The questionnaire survey in this research is mainly conducted through paper questionnaires, supplemented by a small number of online questionnaires.

Semi-structured interview

Although it seems relatively simple compared with questionnaire survey, interview can cover wide range of content areas and allows the collection of deep data without formal testing. (Marcyzk et al., 2005, p.116) Interview is an essential component of most types of qualitative research as a flexible method for data collection with multi-sensory channels. (Marcyzk et al., 2005, p.117) Interviews enable participants to discuss their interpretations of the world in which they live, and to express how they regard situations from their own point of view. (Cohen et al, 2007, p.349) It is widely used in qualitative studies to get in-depth information from participant, including structured, semi-structured unstructured forms.

Semi-structured interview contains advantages of both structured and unstructured interviews. Under this method, the researcher prepares a set of similar questions to be answered by all the participants, but additional questions could be asked during the interview process for clarity and detailed explanation on specific issues related to the topic under investigation. (Boyce & Neale, 2006)

In this research, semi-structured interview has been conducted to collect viewpoints from parents and professionals of children with disabilities at young age about their satisfaction of family life, contributing factors, family difficulties and strengths, and suggested strategies for improvements.

“*Through verbal communication, individuals express their thoughts, and different individuals can achieve a certain mutual ‘understanding’. Through questions and conversations, people can surpass themselves and approach the fusion of the horizons between the subjects to build a new social reality that makes sense.*” (Chen, 2001, p.169)

Therefore, in-depth semi-structured interviews with open-ended questions have been adopted to collect qualitative data in this research. During the process, participants are encouraged to tell their inner true thoughts. The researcher maintains the posture of participants throughout the process and avoids preconceived guidance and tips. In order to ensure that important information is not omitted, the interview process was recorded throughout the interview process with the consent of the interviewee, which provided true original data for data analysis.

3.4 Quantitative data collection and analysis

As mentioned in the former part, both the established Beach Center FQOL Scale and self-constructing FQOL influencing factors questionnaire have been applied to collect quantitative date in this research. Hence, the quantitative data collection started from compiling of the influencing factors questionnaire of FQOL. Then, data collection in the pilot study of the influencing factors questionnaire is introduced in the following paragraphs. Thereafter, a description of data collection in the formal study of FQOL and its influencing factors is presented. In addition, data analysis strategies in the pilot study and formal study are described in the end.

3.4.1 Compiling the influencing factors questionnaire

In order to collect quantitative data of the contributing factors of FQOL in families of children with disabilities at young age, self-compiling measurement questionnaire must be constructed as there is no available instrument could be used. There are six recommended steps for constructing a questionnaire: determine the questions; draft the items; sequence the items; design the questionnaire; pilot-test the questionnaire; develop a strategy for data collection and analysis. (Anderson, 2005, p.179-190; Marcyzk et al., 2005, p.116) These six steps have been taken as guidelines for the compilation of the influencing factors questionnaire. The process of theoretical construction and the structure of the initial questionnaire will be presented in the following paragraphs.

Theoretical construction process

Theoretical construction process in questionnaire compilation is also the step to determine the question. The theoretical construction of the influencing factors questionnaire has been based on literature reviewing and informal interview. By searching from database such as EBSCO, ERIC, PubMed, CNKI, VIP and search engine Google scholar, relevant literature of FQOL in families of children with disabilities has been reviewed to explore the potential factors related to family quality of life. Some parameters which had been proved as predictors of FQOL in families with disabled children at young age have been taken into consideration to build the structure of the initial questionnaire. Meanwhile, related contributing factors of FQOL in families with disabled children at school age or of specific disability type (Li, 2016) were referred to build the basic structure of the questionnaire.

Besides, in order to attain comprehensive understanding of the influencing factors of FQOL in families with disabled children at young age, informal interviews with three parents, two special education teachers and two special education researchers were conducted by phone call or face-to-face communication. Repeatedly mentioned parameters and viewpoints on FQOL and its influencing factors were collected and had been taken into consideration to adjust the structure of the questionnaire.

Based on the literature review and informal interview, seven factors were selected to form the dimensions of the initial questionnaire, in terms of economic pressure, family atmosphere, parental attitude, difficulties related to child, social support, family preparation and family involvement. Corresponding to the seven dimensions, specific items were come up to constitute the preliminary draft of the initial "Influencing Factors Questionnaire of FQOL in Families of Children with Disabilities at Young Age".

In order to make sure that the expressions of the items are clear and understandable, necessary modification needs to be done based on experts validity. As Wu mentioned (2010, p.467),

"*Expert validity is one kind of content validity which is mainly evaluated by experts,* *scholars, and practitioners in the corresponding field on the suitability of the measurement items, including the meaning of item expressions, the fluency and completeness of the items, and the suitability of the potential features of the facets to be measured, etc.*"

Therefore, two researchers in special education area, two special education teachers and two parents who have children with disabilities were invited to form the experts group for validity testing. Member of experts group were asked to evaluate each item of the preliminary draft questionnaire and to give overall conclusion for the whole questionnaire on five-point-scale: very suitable, suitable, not sure, unsuitable, very unsuitable.(see Table 3.1) For each item, ambiguous statements had been revised and repeated items had been deleted. After modification based on suggestions from experts group, 44 items were retained to constitute the initial questionnaire which could be used in pilot study.

Table 3.1 Results of experts' validity testing

Conclusion	**Very suitable**	**Suitable**	**Not sure**	**Unsuitable**	**Very unsuitable**	**Total**
Number of people	1	4	1	0	0	6
Percentage	16.66%	66.66%	16.66%	0	0	100%

Structure of the initial questionnaire

As for the structure of the initial questionnaire, two parts are included. The first part is the background information of the questionnaire respondent, his/her family and information of the child with disability. Then the second part is the main body of the influencing factors questionnaire of FQOL. The background information part includes demographic information of the respondent such as the age, education level, and relationship with the disabled child and etc.; basic information of disabled child such as age, gender, disability type, severity of difficulties and etc.; and also basic information of the family, such as parental marital status, home location, monthly household income and so on.

The main body of the initial questionnaire consists of 44 items scattered across seven dimensions: economic pressure, family atmosphere, difficulties related to child, parental attitude, family preparation social support and family involvement. All of the 44 items in the main body of the questionnaire take the form of Likert five-point scale. Each item has one complete thought with a 5-point range of responses in terms of “totally inconsistent”, “inconsistent”, “not sure”, “consistent”, “totally consistent”, corresponding to 1 to 5 points. Among the 44 items, 5items are reversing items, and correspondingly responses from totally inconsistent to totally consistent are scored from 5 to 1 point.

3.4.2 Data collection in pilot study

After the initial questionnaire was completed, pilot study was conducted to test the validity and reliability of the self-compiling instrument. Introduction of the respondents in the pilot study and the description of questionnaire distribution and recall will be presents in the following part.

- **Respondents**

Based on convenience sampling principle, 60 main caregivers of children with disabilities from 0-8years old (including 8 years old) from 5 special schools in Sichuan province were selected to conduct the pilot study. Besides convenience of implementation, balance of administrative district and economic level was considered in the sampling process.

- **Questionnaire distribution and recall**

As main caregivers of children with disabilities are scattered in different institutions, indirect questionnaire distribution and recall by the teacher in the targeted school was adopted in the pilot study. Before the questionnaire distribution, principals or directors in selected schools were contacted by phone call, QQ or WeChat[3] to ask

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[3] QQ is an instant messaging software and WeChat is a Chinese multi-purpose messaging, social media and mobile payment app. Both are widely used social medias among Chinese people in work and personal life.

for the permission of conducting the pilot study. Thereafter the research description together with the initial questionnaire in PDF format was sent to the principals or directors for examination of the content. (Details see Appendix A) After obtaining the consent from the school, one head teacher who has directly contact with the targeted group of students had been recommended from the school. Then researcher got in touch with this head teacher and explained her or him how to distribute and recall questionnaire. Precautions during the process of questionnaire distribution and recall were sent to them in text format. Moreover, clear understanding of the precautions and the questionnaire was ensured before the distribution.

Questionnaires were printed by the head teachers or delivered to them from the researcher. After the questionnaire recall, the head teachers were asked to send the questionnaires back to the researcher by pre-paid delivery. In total, 65 questionnaires were distributed and 60 of them were valid and valid rate was 92.31%. After data collection of pilot study, the validity and reliability of the initial questionnaire were test to make modification of the initial questionnaire. In this modifying process, 17 items were deleted and the other 27 items were retained and re-codified to form the final Influencing Factors Questionnaire of FQOL in Families of Children with special needs at Young Age which has been used in the formal study.

3.4.3 Data collection in formal study

The formal study has two parts. One is the investigation of the current situation of FQOL in families of children with disabilities at young age, and the other is the investigation of the influencing factors of FQOL.

- **Respondents**

Based on the combination of random sampling and purposive sampling techniques, the formal research was carried out among 243 families of children with disabilities at the age of 0-8 years old(including 8 years old) from various institutions for children with special needs, including special school, rehabilitation center affiliated to China Disabled Persons' Federation(CDPF), private intervention center for children with disabilities, private kindergarten for children with special needs, NGO social work organization and department of pediatrics in hospital in Sichuan province of China.(see Table 3.2)

Table 3.2 Statistics of the sources of respondents

Type of institution	Number of institution	Number of respondents
rehabilitation centers affiliated to CDPF	2	25
private intervention centers	6	118
Kindergarten for children with special needs	1	32
NGO social work organization	1	15
Department of Pediatrics in hospital	1	30
special school	7	38
In total	18	243

Sichuan province is an important junction of southwest, northwest and central regions in China. Geographically, Sichuan province is located in the hinterland of southwest China and is the transitional zone where the first and second steps of China's terrain overlap; humanistically, Sichuan is the province with the biggest population (83.75 million permanent populations at the end of 2019) among the 31 provincial administrative regions in China, among which the main population is the Han nationality, and there are also many ethnic minorities such as Qiang, Tibetan, and Yi; economically, the total GDP is 461.66 billion Yuan in 2019, ranking 6th in the country, and the per capita GDP is 56,000 Yuan (US $ 8101)[4]/person, ranking 18th in the whole country. (Sichuan Statistics Bureau &National Bureau of statistics of China, 2019) Generally speaking, Sichuan province well represents the average level of China’s economic and social development.

As one big province in the southwest, Sichuan province governs 18 prefecture level cities and 3 autonomous prefectures. In order to obtain a more balanced sample, the formal research was conducted in 18 institutions for children with disabilities from 9

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[4] According to the exchange rate in May 2020, 1$≈7.09Yuan in RMB.

prefecture level cities and 1 autonomous county. The distribution of the 18 institutions is shown in Figure3.2. In the sampling process, the following points had been taken into consideration to increase the internal diversity of the research participants: institutions from the provincial capital city, prefecture level cities and also small towns were selected; institutions from the center and also the north, south, east and west parts of the province were included; both participants from the Han and minority areas were included. The specific information of the families with disabled children in the formal research is shown in Table 3.3.

Table 3.3 Demographic characteristics of respondents in formal study (N=243)

Child characteristics	**n (%)**	**Family characteristics**	**n (%)**
gender		Gender of main caregiver	
boy	150(61.73)	male	52(21.40)
girl	93(38.27)	female	191(78.60)
Age		Relationship to child	
0-2years old	20(8.23)	father	34(13.99)
3-4years old	80(32.92)	mother	137(56.38)
5-6years old	71(29.22)	grandfather	18(7.4)
7-8years old	72(29.63)	grandmother	47(19.3)
With disability document or not		other	7(2.9)
yes	170(69.96)	Age	
No	73(30.04)	under 25years old	8(3.29)
Type of special needs		26-35years old	97(29.92)
Hearing loss	46(18.93)	36-45years old	59(24.28)
Intellectual disability	64(26.34)	46-55years old	41(16.87)

Physical disability	16(7.82)	above 56 years old	38(15.64)
Speech and language disorder	7(2.88)	Education status	
Autism spectrum disorder	39(16.05)	primary school and below	44(18.11)
Multiple disabilities	35(14.40)	middle school	66(27.16)
Developmental delay	33(13.58)	high school or similar level	60(24.69)
Severity of special needs		bachelor or similar level	70(28.81)
mild	40(16.46)	master degree and above	3(1.23)
moderate	80(32.92)	Marital status of parents	
severe	82(33.74)	married and living together	196(80.66)
very severe	41(16.87)	married but living separately	23(9.47)
Health condition		divorced	23(9.47)
very good	77(31.69)	widowhood	1(0.41)
average	120(49.38)	Family location	
poor	46(18.93)	provincial capital city	35(14.40)
Self-care ability		prefecture level city	106(43.62)
completely independent	8(3.29)	town	39(16.05)
less dependence on others	57(23.46)	village	63(25.93)
most dependence on others	103(42.39)	Parenting skills of disabled child	
completely dependence	75(30.86)	serious shortage	72(29.63)
Impact on daily life		around average	152(62.55)
seriously	111(45.68)	very good	19(7.82)
slightly	99(40.74)	Whether with child without special needs	
no impact	33(13.6)	yes	116(47.74)

Main placement		no	127(52.26)
general kindergarten/school	36(14.81)	Whether parents join self-help organization	
special kindergarten/school	96(39.51)	yes	55(22.63)
private intervention center	60(24.69)	no	188(77.37)
center under CDPF	41(16.87)		
hospital	8(3.29)		
others	2(0.82)		

Note: CDPF refers to Chinese Disabled Persons' Federation.

Disability document: In China, with the medical document child with disability needs to get the disability document from CDPF, which is an official document for confirmation of disability. This disability document is necessary for receiving financial subsidy or free rehabilitation services from government.

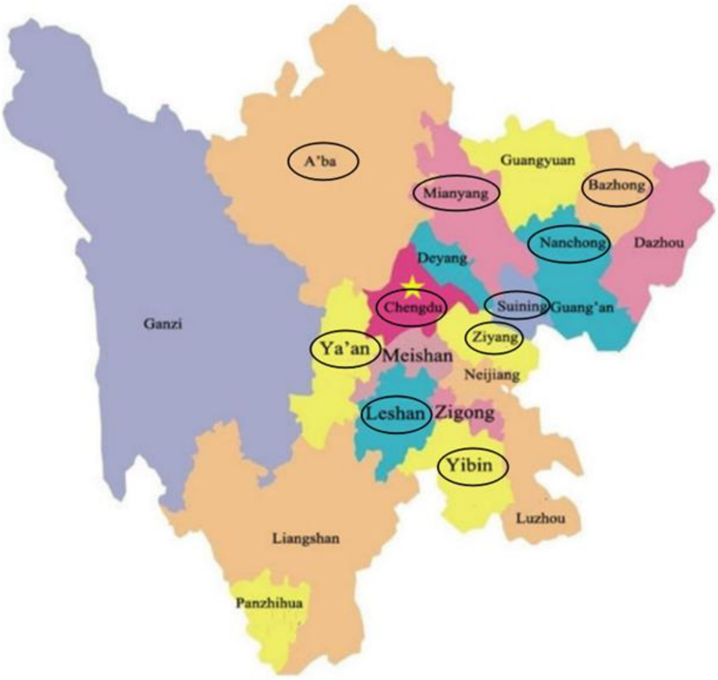


Figure 3.2 Sample selecting areas in Sichuan Province

● Instruments

In the formal research, three instruments were used to collect quantitative data. The first one is the self-compiled Demographic Information Form which was used to collect background information of the respondents, their families and children with disabilities. The second one is the established Beach Center Family Quality of Life Scale (BCFQOL), which was used to measure the current situation of FQOL. The last one is the self-complied Influencing Factors Questionnaire of FQOL in Families of Children with Disabilities at Young Age. (Details see Appendix B)

Demographic Information Form

The Demographic Information Form was designed for collecting background information of the respondents, their children and families. More specifically, child characteristics include child's gender, age, disability type and severity of special needs, impact on daily life, self-care ability, health condition, and main placement; family characteristics include respondent's relationship to child, gender, age, educational status, employment situation, marital status of parents, family financial situation, accommodation condition, average family income, average expenditure for disabled child's education and rehabilitation, parenting skills, whether join self-help organization for parents, whether with child without special needs and family location. A cover letter which introduces the study is included before the Demographic Information Form and completing and returning the questionnaires indicate respondents' consent to participate in this study.

Beach Center FQOL Scale

Beach Center FQOL Scale (BCFQOL) was adopted to measure the current situation of FQOL in families of children with disability. This scale was developed to assess family outcomes in families of children with developmental or intellectual disabilities, from birth to age 21 by Beach Center on Disability in Kansas University. Two investigation dimensions in terms of importance and satisfaction are included in the original scale. It is a 5-point (1=very unsatisfied, 2=unsatisfied, 3=neither unsatisfied nor satisfied, 4= satisfied, 5= very satisfied) Likert scale with 25-items which were extracted from 112 parameters based on group or individual interview with parents, service providers and administrative staff for persons with disabilities. The purpose of this scale is to measure families' perceived satisfaction in five aspects of family life: family Interaction, Parenting, Emotional Well-being, Physical/Material Well-being, and Disability-Related Support. (Beach center on disabilities, 2006) This scale has already been used to measure the quality of life in families with disabled children in western country and also China. (Gardiner E. & Iarocci G., 2015; Hu, X.& Wang M.,2012) And according to the recent researches, this scale has been reported with psychometric properties of internal reliability for the total and five subscales (α = 0.70–0.90) and been widely used for measuring FQOL in families with disabled children. (Hoffman et al. 2006)

Chinese version of BCFQOL (BCFQOL-CV) is used in this research with the permission of the researcher who had done the translation and confirmation factor analysis among Chinese students with developmental disabilities in Beijing. Hu's research shows that the Chinese version of BCFQOL is suitable for measuring the FQOL among Chinese families with disabled children with good model fit ($\chi^{2}_{(265, n=442)}$ =748.15, p=0.0, RMSEA =0.066, CFI=0.97, NNFI=0.96). (Hu, 2012) In consideration of the research needs, only the investigation dimension of satisfaction is used in this research.

Reliability test was conducted to test the reliability of the BCFQOL-CV. As shown in Table3.4, the internal consistency alpha coefficient of the total scale is 0.901, which means the reliability of the total scale of BCFQOL-CV is"very good" (see Table 3.5). The Cronbach's alpha coefficient of disability related supports sub-scale is 0.699, which means the reliability of this sub-scale is acceptable, while the alpha coefficient of other four sub-scales is between0.783-0.901, which means the reliability of these sub-scales is "good" or even better.

In general, the reliability test shows that the Chinese version of BCFQOL is reliable.

Table3.4 Reliability of total BCFQOL and its sub-scales (N=243)

	Number of items	**Cronbach’s α**
Family interaction	6	0.901
parenting	6	0.884
Emotional well-being	4	0.818
Physical well-being	5	0.783
Disability related supports	4	0.699
Total scale	25	0.930

Table 3.5 Evaluating criteria of the Cronbach’s α coefficient in reliability test

Cronbach’sα	**For dimensions**	**For the overall scale**
α≥0.900	Excellent	Very good
0.800≤α<0.900	Very good	Good
0.700≤α<0.800	Good	Acceptable
0.600≤α<0.700	Acceptable	Acceptable with modification
0.500≤α<0.600	Acceptable with modification	Unacceptable
<0.500	Unacceptable	

Influencing Factors Questionnaire of FQOL

In the formal study, the formal self-compiled Influencing Factors Questionnaire of FQOL was used to explore the contributing factors of FQOL in Chinese families with disabled children at young age. According to the results from pilot study, this questionnaire consists of 27 items allocated on six dimensions, including economic pressure, difficulties related to child, parental attitude, family preparation, social support, and family involvement. It is a 5-points (1=“totally inconsistent”, 2=”inconsistent”, 3=”neither”, 4=”consistent”, 5= “totally consistent”) Likert scale. Reliability test was conducted to test the reliability of the Influencing Factors Questionnaire of FQOL. The internal consistency alpha coefficient of the total scale is 0.845, which means the total scale of the Influencing Factors Questionnaire of FQOL in Families of Children with Disabilities at Young Age is with good reliability.

- **Questionnaire distribution and recall**

The questionnaire administration process in the formal study is similar to the pilot study. The obvious difference is that the researcher has visited the selected institutions. Introduction of the research and how to distribute and recall questionnaires was carefully explained to the related persons in the selected institutions face-to-face. Precautions during the process of questionnaire distribution and recall were sent to them in text format and clear understanding of the contents of the precautions and also the questionnaire was ensured before the distribution in order to give necessary explanation to participants.

In total, 300 questionnaires were distributed and 275 were returned, including 10 questionnaires of electronic version. Among them, 243 questionnaires were retained while 32 questionnaires were excluded because of incompleteness or filling with obvious regularity. The return rate of the questionnaire survey is 91.667% and the valid rate is 88.364%.

3.4.4 Quantitative data analysis

Statistical analysis software SPSS22.0 has been utilized to process the quantitative data. After data collection in pilot study, project analysis, factor analysis and reliability test were conducted to examine the validity and reliability of the initial influencing factors questionnaire of FQOL, and thereafter necessary modification has been made to form the formal influencing factors questionnaire; after data collection in the formal study, descriptive analysis, independent sample t-test and one-way ANOVA were conducted to know the general situation of FQOL in families of children with disabilities at young age, while correlation analysis and stepwise multiple regression were conducted to discovery the influencing factors of FQOL and its sub-dimensions. The detailed results of quantitative data analysis will be presented in next chapter.

3.5 Qualitative data collection and analysis

Qualitative data was collected through in-depth semi-structured interview in this research. Based on the combination of research purpose and convenience of research conduction, purposive sampling technique was used to select interview participants.

3.5.1 Interview participants

Interview participants in this study are main caregivers of children with disabilities at age of 0-8years old and professionals who directly work with these children and their families. In total, there are 24 participants in the in-depth interviews, including 16 parents and 8 professionals who directly work with disabled children or their families. Participants who are caregivers of children with disabilities are renamed as C1-C16, while participants who are professionals are renamed as P1-P8.

As shown in Table3.6, speaking of the roles of participants, there are 13 mothers,2 grandmothers, 1 father, 3 teachers, 2 heads of organization, 2 physical therapists,1 social worker; speaking of the gender of participants, 22 are females while 2 are males; speaking of the education status, 15 participants are with bachelor degree or above,4 with high school level education and 5 with middle school education; speaking of child's special needs, 9 participants have children with Autistic Spectrum Disorder(ASD) or mainly work with families of children with ASD, 6 participants have children with Developmental Disorder(DD) or mainly work with families of children with DD, 3 participants have children with Hearing Impairment(HI) or mainly work with families of children with HI,2 participants have children with Intellectual Disability(ID), 1 participant has child with Physical Disability and i participant mainly works with children of PD, while 1 participant has child with Visual Impairment (VI) and 1 participant has child with Multiple Disability(MD).

Table 3.6 Basic information of participants in interviews (N=24)

Participants	**Gender**	**Age**	**Education**	**Role**	**Child's**
C1	female	38	master	mother	PD
C2	female	28	middle school	mother	DD
C3	female	27	bachelor	mother	ID

C4	female	29	high school	mother	HI
C5	female	29	bachelor	mother	HI
C6	female	57	high school	grandmother	ASD
C7	female	39	high school	mother	ASD
C8	female	35	bachelor	mother	ASD
C9	female	45	middle school	mother	ASD
C10	female	40	bachelor	mother	VI
C11	female	38	high school	mother	ID
C12	female	37	bachelor	mother	ASD
C13	female	29	Middle school	mother	ASD
C14	female	65	Middle school	grandmother	DD
C15	female	34	Middle school	mother	MD
C16	male	36	bachelor	father	DD
P1	female	26	bachelor	teacher	ASD
P2	female	31	bachelor	social worker	/
P3	female	30	bachelor	Head of organization	HI
P4	male	30	bachelor	physical therapist	PD
P5	female	24	bachelor	teacher	ASD
P6	female	47	bachelor	head of organization	DD
P7	female	31	bachelor	physical therapist	ASD
P8	female	29	bachelor	teacher	DD

3.5.2 Instruments

Charmaz(2006, p.26) points out that, in the process of collecting qualitative data, a few broad, open-ended and non-judgmental questions can encourage stories to emerge.

Hence, semi-structured interview with a series of open-ended questions was used for collecting the real thoughts of the interviewees. The interview outline consists of four parts: basic information of the interviewee, current situation of satisfaction on family life, influencing factors of satisfaction on family life, suggestions for improving satisfaction on family life. The specific questions in the interview for caregivers and professionals are a little different. (Details see Appendix D)

After data collection through interview, the next critical problem is how to manage the complex and vast transcribed texts and obtain interviewees' core viewpoints behind their descriptions to find answer for the research questions. In qualitative research, coding is often applied to manage the transcripts, which is time-consuming and labor-intensive. Considering the amount of qualitative data in this study, the NVivo 11.0 Plus was utilized as a coding and analysis tool. NVivo is one of the most frequently used computer-aided qualitative analysis software and can process a variety of data forms (such as text, audio and video, pictures, images, webpages and etc.). In this study, the qualitative data coding and analysis process in the software was guided by the three steps qualitative data analysis procedure proposed by Strauss and Corbin (2015, p.220), in terms of open coding, axial coding, and selective coding. To be specific, data analysis in this study started from open coding of original texts into categories. Then data analysis proceeds to axial coding by assembling connections among categories and finishes with selective coding by refining core category upon relationship building to generate theoretical model. (Strauss & Corbin, 1990; Charmaz, 2006, p.46-60; Bryant & Charmaz, 2007, p.265)

3.5.3 Interview implementation

Along with the questionnaire survey, caregivers and professionals from the surveyed institutions were asked if they would like to participate in the following interview. Combined with their agreement and recommendation from the institutions, 24 interviewees were chosen and face-to-face semi-structured interviews were conducted to collect qualitative data. Each interview lasted 30 to 60 minutes, of which most of them were about 45 minutes. All the interviews were conducted in the institutions where their children got rehabilitation services or the professionals worked.

As interview is collaboration between the interviewee and researcher based on certain topic and selected questions, many factors could influence the interview results. Hence, language preferences and characteristics of the participants were considered in the interview implementation. Firstly, as the interviews were carried out in Sichuan province, language preference of participants was considered in the interview implementation. Most of the interviews were conducted in Sichuan dialect, while others were in Mandarin Chinese. Secondly, according to researcher's personal experience and advices from the professionals, families of children with disabilities are usually vigilant to strangers as they may worry about exposure of their family information to the public. Therefore, before starting the interview, a brief introduction of the study was given by the researcher to explain the research topic, interview procedure, and information confidentiality. Declaration of the interview purpose, description of the confidentiality of interview contents and written consent of participation from interviewee were done before starting the formal interview. (Details see Appendix C) Thirdly, in order to encourage the interviewee to express his/her inner thoughts as much as possible in good interview atmosphere, the researcher usually encouraged the interviewees to talk about their children with disabilities in the beginning part of the interviews. In addition, during the interview process, the researcher always gave oral or body feedback to encourage the interviewee fully express their ideas. Besides the "oral expression" of interviewees, their body language may also convey important information. Hence, field note was written by the researcher to record the non-spoken data in the interview. Meanwhile, specific questions and the order of questions in the formal interview might be adjusted according to the practical situation in the interview. Based on the agreement of interviewees, 23 interviews were voice recorded, while 1 interview was written down by the researcher because of disagreement of voice record from the interviewee.

3.5.4 Qualitative data analysis

The goal of data analysis is to provide a clear understanding of the thing being studied and to attain certain general principles which can be popularized to similar situations.(Denscombe, 2007, p.106) In qualitative research, data analysis is not only conducted after the data collection, but also during the process of data collection and collation. To ensure the accuracy of qualitative data, the basic information of the interviewees and the written notes were organized immediately after the interview, and the voice records were transcribed as soon as possible after the interview. In consideration of data confidentiality, the name of all interviewees, children with disabilities and related institutions were codified as well. Based on the transcriptions, contents that were not relevant to the research questions were eliminated. Then the valid contents from 19 interviewed participants (12 caregivers and 7 professionals) were codified, while the data of the other 5 interviewed participants (4 caregivers and 1 professional) were reserved for testing the theoretical saturation.

Constant comparative analysis

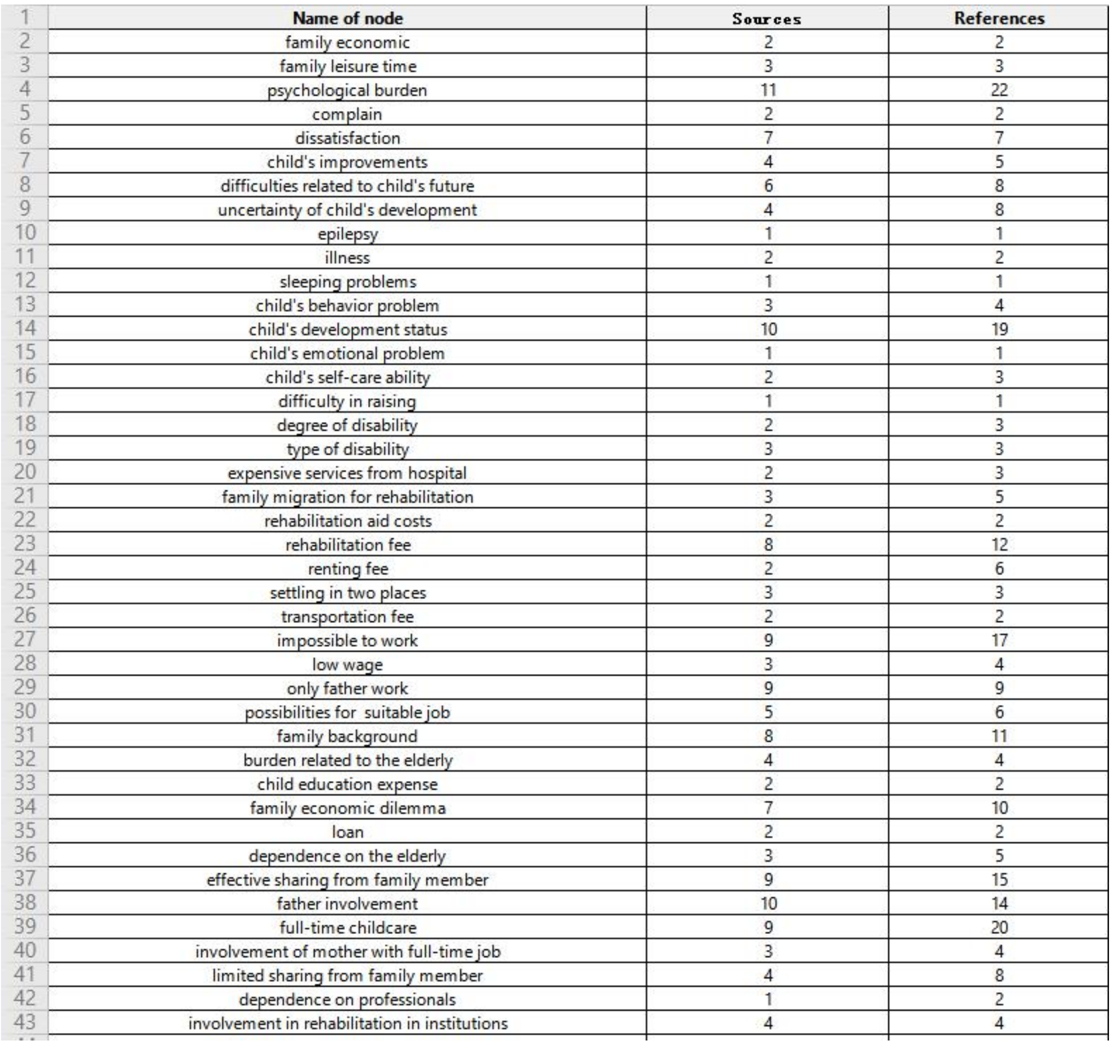
During the whole process of data analysis, constant comparative analysis method was applied to combine coding and analysis. The purpose of this method is to systematically generate a theory which is integrated, consistent, plausible and close to the original data by using explicit coding and analytic procedures (Glaser & Strauss, 1967, p.102-103). According to Glaser and Strauss, constant comparative method consists of four stages, including “comparing incidents applicable to each category; integrating categories and their properties; delimiting the theory, and writing the theory” (Glaser & Strauss, 1967, p.105). During open coding, incidents from original texts were constantly compared with previous labels in the same or different category. During axial coding, categories’ integrating was upon constant comparison of the similarities and differences of characteristics and properties of different categories. During selective coding, through constant comparison analysis, theory was generated based on comparison of relationship among categories to prioritize the core category. Besides, constant comparative analysis method was also used to test theoretical saturation.

Coding steps

In qualitative data analysis, coding is fundamental, which means to divide the corpus into segments and assign codes to these segments. (Singh & Estefan, 2018) The purpose of coding is to capture the essential nature behind the segments and assemble similar segments of corpus into categories. Before coding of the transcription, in order to be familiar with the raw data, the corpus from interviews was carefully read by the researcher for two times. And irrelevant contents were deleted from the corpus. During this process, the researcher firstly suspended her presets on FQOL in families of disabled children at young age from previous study or literature review, and then attempted to maximally understand the participants' viewpoints based on the original corpus.

Open coding is the first step of coding procedures. The purpose of open coding is to identify phenomena, define concepts, and discover categories, with the final goal of gradually conceptualizing and categorizing the obtained raw data. During the process of open coding, the raw data from 19 interviewees was examined sentence by sentence and labeled according to the essence of the phenomena or events. Thereafter, concepts were compared and classified into group categories. Sentence-by-sentence open coding minimizes the chance of missing important concepts and categories, largely avoids purposeful presenting of research data affected by subjective prejudice or presets, and increases the possibilities of building appropriate theory. (Singh & Estefan, 2018) Through constant comparative analysis, raw data with similar characteristic was labeled as same concepts and concepts with similar properties form one category by the process of conceptualizing. (Strauss &Corbin, 2008； Singh & Estefan, 2018).

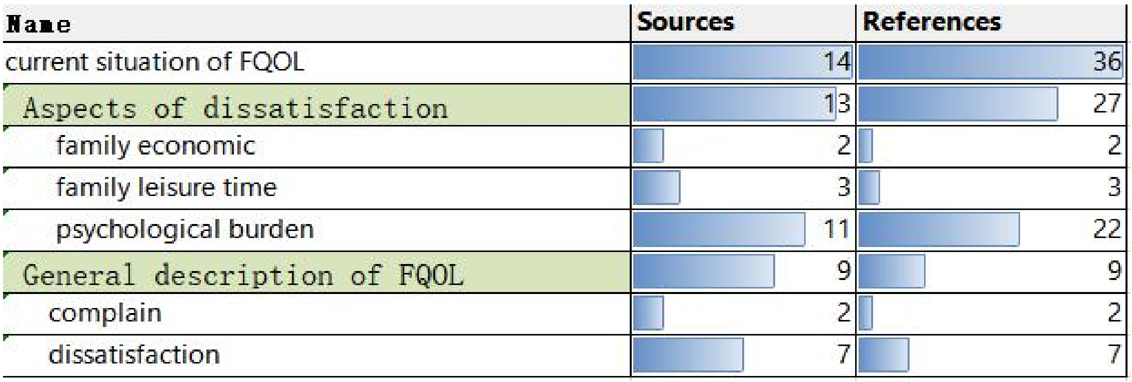
In NVivo11 Plus, the codes after coding is called "node", and if the same concept is mentioned several times by one interviewee or by different interviewees, the number of "references" and "sources" will increase accordingly. If a concept is rarely mentioned, it indicates that this concept is probably not an important factor, conversely, if a node has many references, reflecting the importance of this factor. As shown in the Figure3.3, 159 concepts were abstracted from the corpus of 19 interviews (C1-C12 &P1-P7). After further comparative analysis, the 159 concepts were classified into 33 categories.



1	Name of node	Sources	References
2	family economic	2	2
3	family leisure time	3	3
4	psychological burden	11	22
5	complain	2	2
6	dissatisfaction	7	7
7	child's improvements	4	5
8	difficulties related to child's future	6	8
9	uncertainty of child's development	4	8
10	epilepsy	1	1
11	illness	2	2
12	sleeping problems	1	1
13	child's behavior problem	3	4
14	child's development status	10	19
15	child's emotional problem	1	1
16	child's self-care ability	2	3
17	difficulty in raising	1	1
18	degree of disability	2	3
19	type of disability	3	3
20	expensive services from hospital	2	3
21	family migration for rehabilitation	3	5
22	rehabilitation aid costs	2	2
23	rehabilitation fee	8	12
24	renting fee	2	6
25	settling in two places	3	3
26	transportation fee	2	2
27	impossible to work	9	17
28	low wage	3	4
29	only father work	9	9
30	possibilities for suitable job	5	6
31	family background	8	11
32	burden related to the elderly	4	4
33	child education expense	2	2
34	family economic dilemma	7	10
35	loan	2	2
36	dependence on the elderly	3	5
37	effective sharing from family member	9	15
38	father involvement	10	14
39	full-time childcare	9	20
40	involvement of mother with full-time job	3	4
41	limited sharing from family member	4	8
42	dependence on professionals	1	2
43	involvement in rehabilitation in institutions	4	4

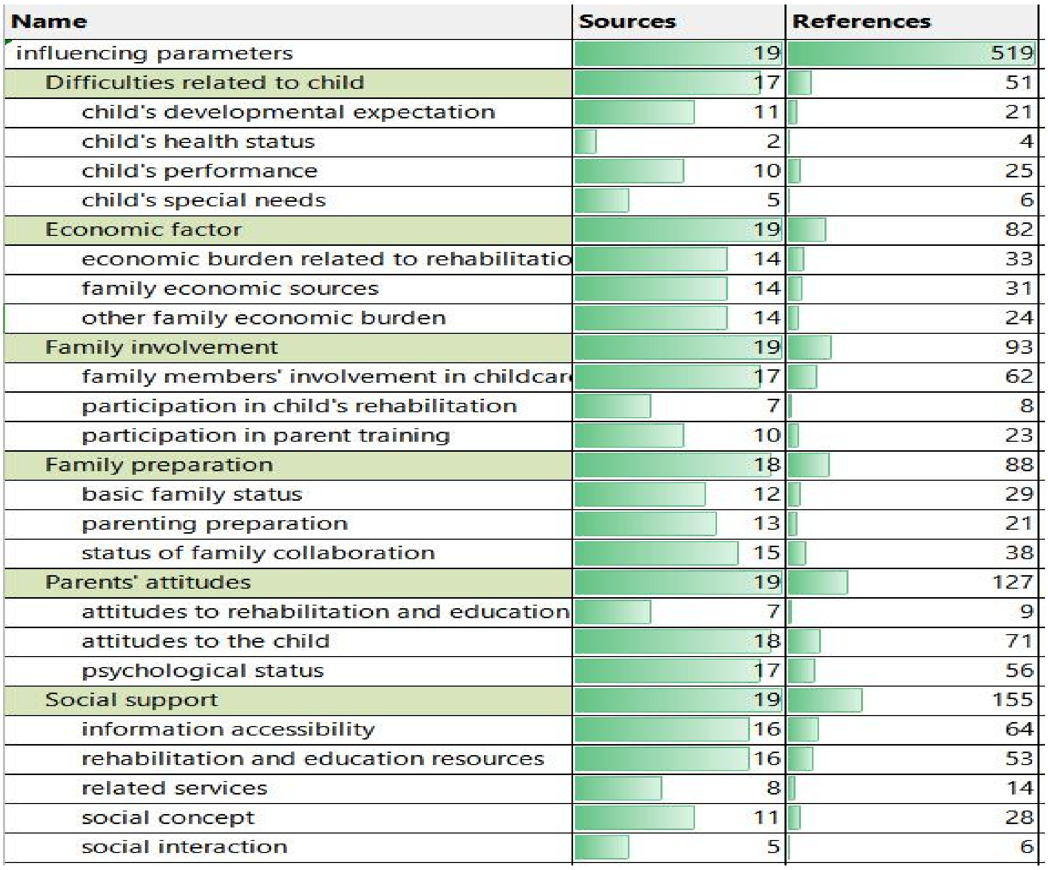
Figure 3.3 Partial nodes from open coding

Axial coding is “*a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories*” (Strauss & Corbin, 1990, p.96). The main goal of axial coding is to discover and establish links between categories which present the inner connections between different parts of the data. After open coding, axial coding was conducted to establish the connections among the 159 nodes and 33 categories. Main categories and sub-categories were developed through constant comparative analysis around core coding-Nodes. The results of axial coding were presented in Figure 3.4-6 and the structure diagrams of categories were presented in Figure 3.7-8.



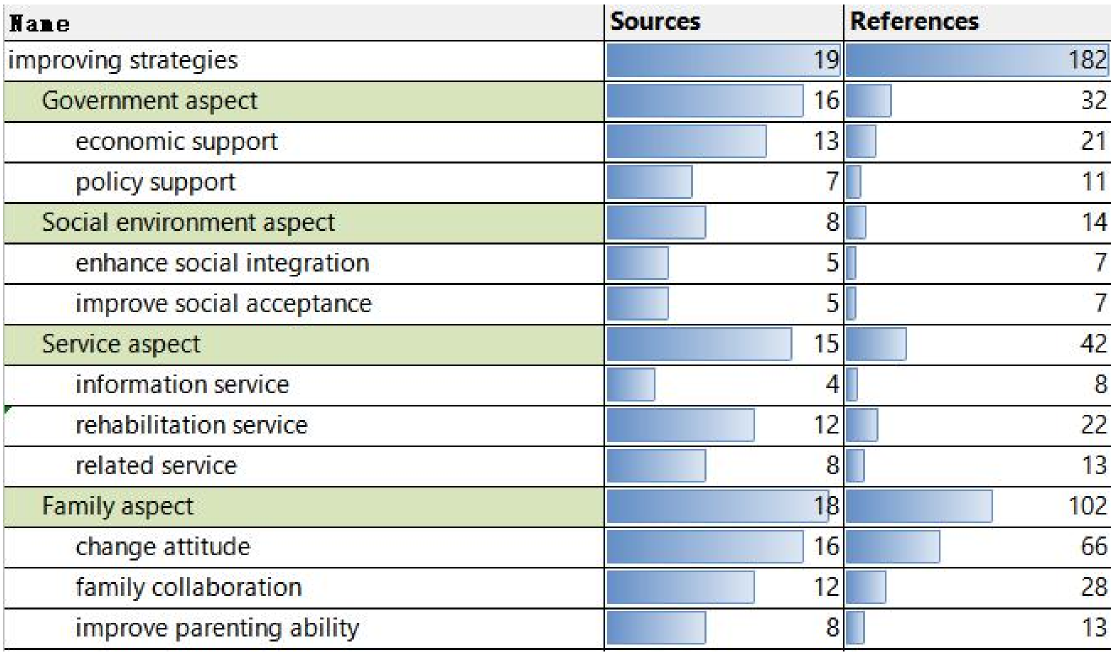
Name	Sources	References
current situation of FQOL	14	36
Aspects of dissatisfaction	13	27
family economic	2	2
family leisure time	3	3
psychological burden	11	22
General description of FQOL	9	9
complain	2	2
dissatisfaction	7	7

Figure3.4 Main Categories within the first part (current status of FQOL)



Name	Sources	References
influencing parameters	19	519
Difficulties related to child	17	51
child's developmental expectation	11	21
child's health status	2	4
child's performance	10	25
child's special needs	5	6
Economic factor	19	82
economic burden related to rehabilitatio	14	33
family economic sources	14	31
other family economic burden	14	24
Family involvement	19	93
family members' involvement in childcar	17	62
participation in child's rehabilitation	7	8
participation in parent training	10	23
Family preparation	18	88
basic family status	12	29
parenting preparation	13	21
status of family collaboration	15	38
Parents' attitudes	19	127
attitudes to rehabilitation and education	7	9
attitudes to the child	18	71
psychological status	17	56
Social support	19	155
information accessibility	16	64
rehabilitation and education resources	16	53
related services	8	14
social concept	11	28
social interaction	5	6

Figure3.5 Main Categories and sub-categories within the second part (influencing parameters)



Name	Sources	References
improving strategies	19	182
Government aspect	16	32
economic support	13	21
policy support	7	11
Social environment aspect	8	14
enhance social integration	5	7
improve social acceptance	5	7
Service aspect	15	42
information service	4	8
rehabilitation service	12	22
related service	8	13
Family aspect	18	102
change attitude	16	66
family collaboration	12	28
improve parenting ability	8	13

Figure3.6 Main Categories and sub-categories within the third part (improving strategies)

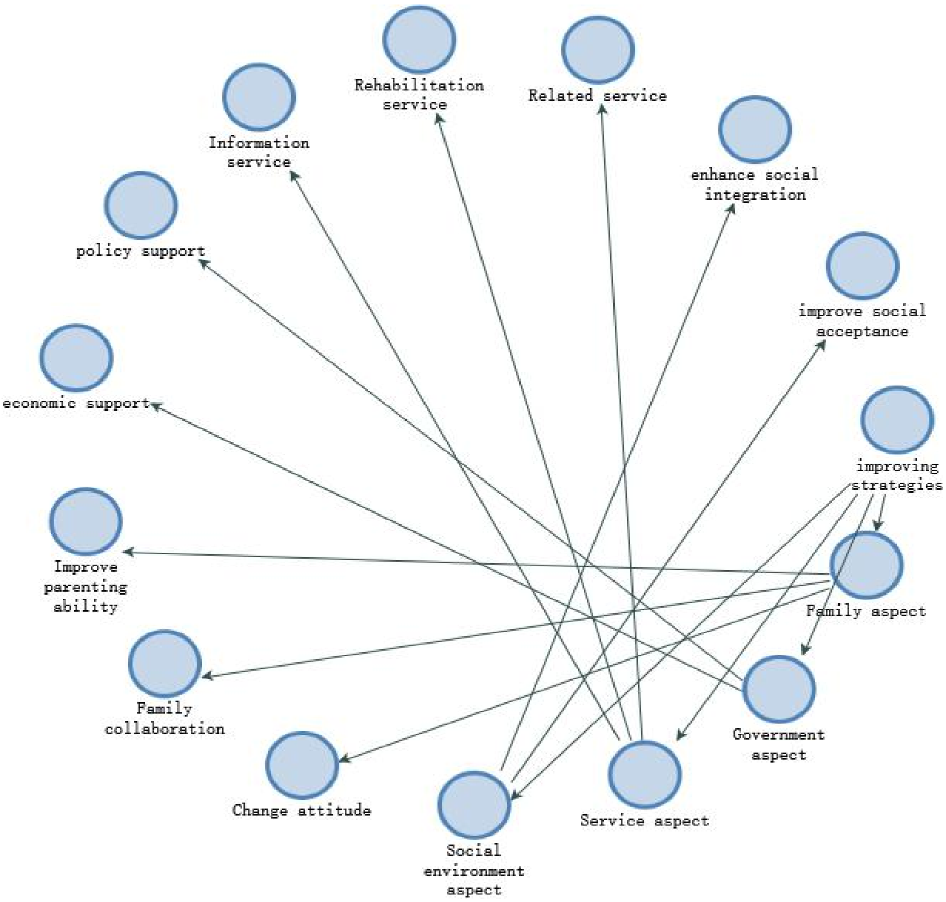


Figure3.8 Structure diagram of categories within the third part (improving strategies)

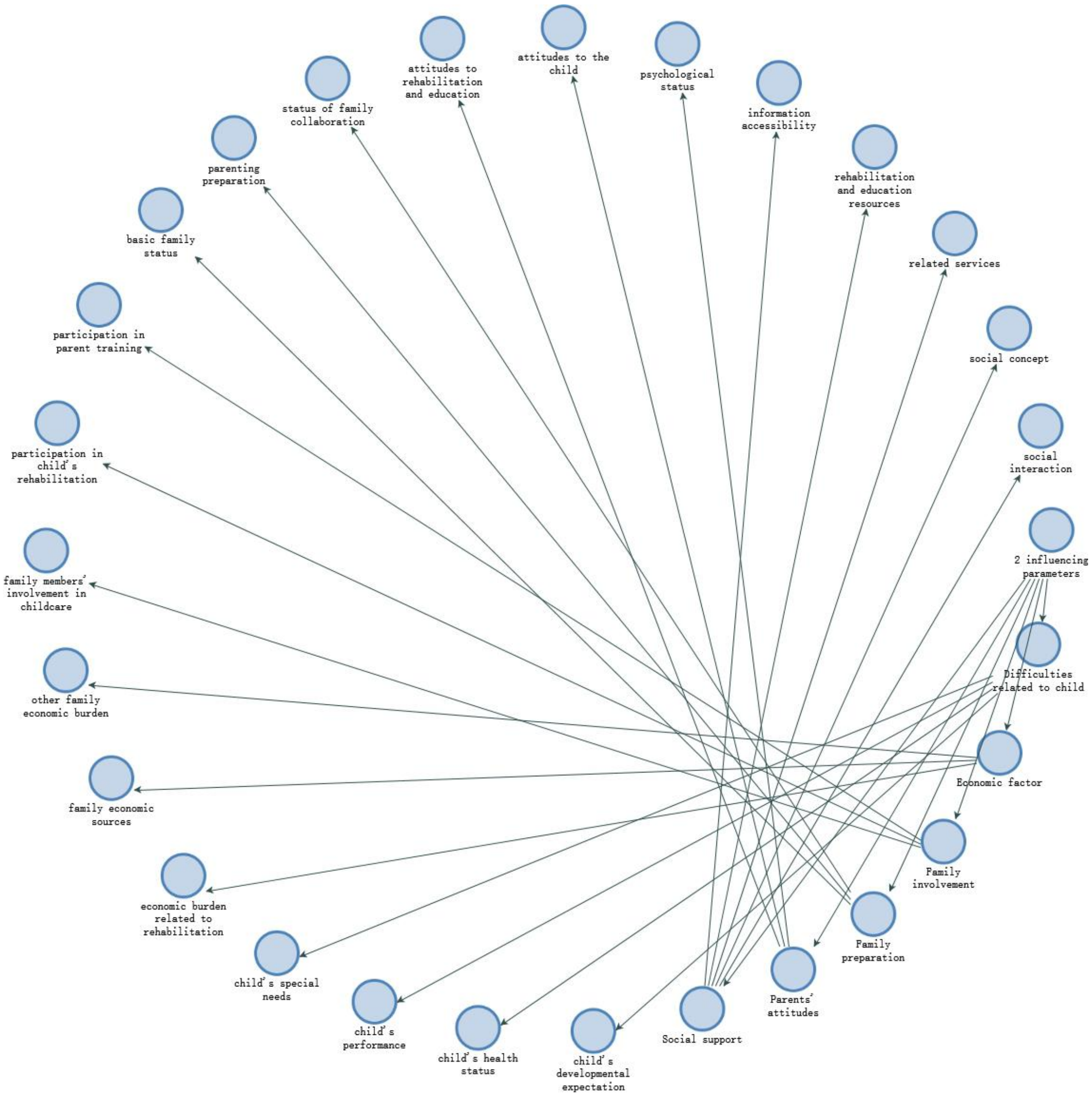


Figure3.7 Structure diagram of categories within the second part (influencing parameters)

As shown in Figure 3.4-6, two main categories were found within the current situation of FQOL: Aspects of dissatisfaction and General description of FQOL; six main categories were found within the influencing parameters part: Difficulties related to child, Economic factor, Family involvement, Family preparation, Parental attitude and Social support; four main categories were found within the part of improving strategies: Family aspect, Service aspect, Government aspect and Social environment aspect.

The data analysis process of coding is interrelated and systematical, especially from axial coding to selective coding, which is “hard to resist and happens automatically with ease" (Glaser, 2007, p.107). The task of selective coding is to identify the core category that connect all categories and concepts together and help to explain how they are organized. In the process of selective coding, all discovered concepts, categories and sub-categories were constantly questioned and compared (Hunter et al., 2011, p.10). During the process of identifying the core category, the researcher can gradually shape the story line of the study and refine the theoretical structure to generate grounded theory. Through in-depth analysis of the 12 main categories from axial coding, the overall structure diagram is presented in Figure 3.9.

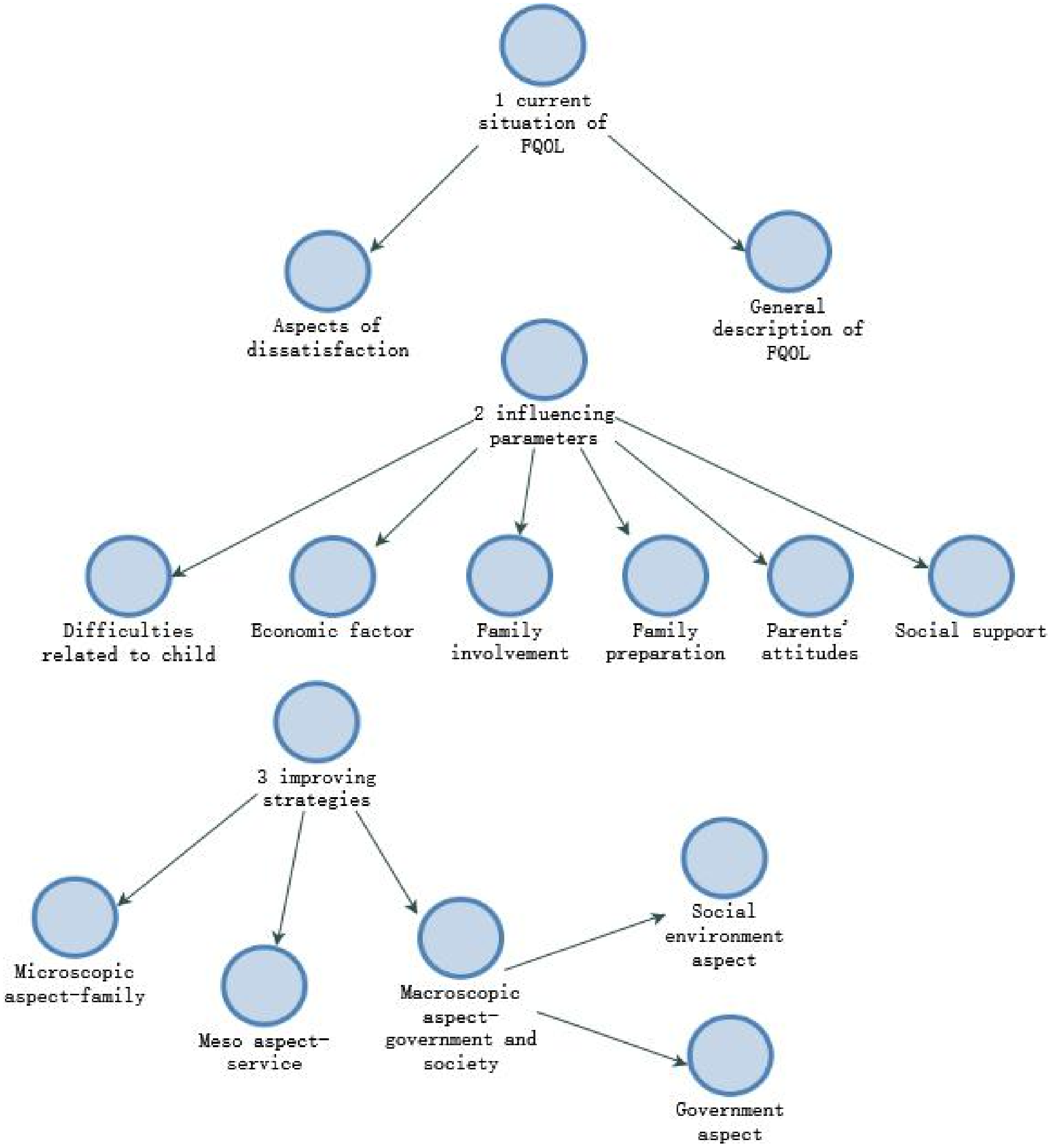


Figure3.9 Overall structure diagram

3.5.5 Trustworthiness

In qualitative research, trustworthiness aims to address how credible, transferable, confirmable, and dependable the findings are. In this study, the trustworthiness of findings is guaranteed through the method of triangulation, theoretical saturation test and appropriate sampling selection. Firstly, Triangulation method was adopted in data collection and analysis. Data from multiple sources including mother, father, grandmother, special educational teacher, therapist, social worker, and head of organization was collected and analyzed through computer assist qualitative analysis software and manual work to increase the internal validity.

Secondly, in this study, valid data of the other 5 interviewed samples (4 caregivers and 1 professional) was used to test the theoretical saturation. The transcribed texts from interviews with the other 5 participants (C13-C16&P8) were checked to see if there were any new initial concepts, sub-categories or main categories. The result shows that no extra initial concepts and categories has been found, which means the "model of influencing parameters" and the "model of improving strategies" of FQOL among families with disabled children at young age are theoretically saturated.

Besides, appropriate sample selection is vital to guarantee the validity of qualitative research. Cluster analysis according to coding similarity of the transcripts from 19 interviews was conducted to test the suitability of sample selection. No obvious central tendency has been found among the 19 participants. The Jaccard Coefficient of the coding is between 0.2 -0.539568 (See Appendix F), which means that low to medium correlation exists among the viewpoints of the interviewees. Combining with the result from theoretical saturation test, it indicates that the participants selected in this qualitative study is appropriate and is able to accurately reflect the perspectives of the research object.

Chapter 4 Quantitative Research results

As described in the former chapter, the purpose of this research is to know the current situation of FQOL in families of children with disabilities at young age, to discover the influencing parameters of their FQOL, and to explore the potential strategies for improving their family outcomes. Quantitative approach characterized with questionnaire survey has been applied to answer the following questions:

I. What is the status of the objective family conditions in Chinese family with disabled children at young age?

II. What is the current situation of subjective FQOL in Chinese families of young children with disabilities?

III. Are there any significant differences of FQOL among different family groups?

Research results from quantitative approach will be presented in this chapter in three parts. Specifically speaking, the first part introduce the analysis process and results from pilot study; while the second part presents the results of the current situation of FQOL in families of children with disabilities at young age and third part presents the relationship between FQOL and several influencing factors.

4.1 results from pilot study

In questionnaire compilation process, systematic analysis of the initial questionnaire to ensure reasonable validity and reliability of the measurement are necessary for selecting suitable items for the formal questionnaire.(Wu, 2010, p.158) Project analysis including critical ratio analysis and correlation analysis, factor analysis and reliability analysis are widely accepted analysis steps. For each step, certain criteria (see Table4.1) are recommended for evaluating the questionnaire items and items fail to reach the criteria need to be deleted to maintain acceptable validity and reliability of the questionnaire. For the step of critical ratio analysis, the common criterion for the critical value (CR) of the retained items must be≥3.00, and strict criterion is CR value≥3.50, while moderate correlation is necessary between the retained items and the total score, together with significant level ($p < 0.05$) of T-test results for both analysis; for the step of factor analysis, the factor loading of the items should be≥0.45, together with the communality≥0.20, while extracted factors can explain more than 50% of the variation; for the step of reliability test, the Cronbach's α value of the whole scale should be≥0.70, while the Cronbach's α value of each dimension is more than 0.50.(Wu, 2010, p.191-192,244)

Table 4.1 General criteria for evaluating items in initial analysis

item	**Extreme group comparison**	**Correlation between item and total score**	**Factor analysis**			**Reliability test**	
	CR value	Pearson correlation coefficient	Factor loading	communalities	Commulative explanatory variation	α of whole scale	α of sub-scale
criterion	≥3.00	≥0.40	≥0.45	≥0.20	≥3.00	≥0.70	≥0.50

4.1.1Project analysis

In measurement compiling research, project analysis is often used to evaluate the feasibility and relevance of the items in the initial questionnaire. Critical ratio analysis is the most frequently used method to know the discriminant index of each questionnaire item by calculating the decision value (CR). In order to get the decision value of each item, the total scores of the whole scale were calculated and ranked to find the upper and lower 27% cases which had been marked as two groups. Then the two groups were analyzed through an independent sample t-test to obtain the CR value which is the absolute value of "T". If CR value is less than 3.00, the discrimination of the item is poor and the item should be deleted. Item with higher CR value has better discrimination.

Through critical ratio analysis of the initial questionnaire, the results shows that: CR value of $Y7=1.762<3.00, P=0.088>0.05$; CR of $Y8=0.892, P=0.379>0.05$; CR of $Y9= 1.8059$, $P= 0.298>0.05$; CR of $Y10=1.000, P=0.325>0.05$; CR of $Y19=0.946$, $P=0.353>0.05$; CR of $Y20 = 2.727$, $P=0.011<0.05$; CR of $Y21=0.727$, $P=0.473>0.05$; CR of $Y22=0.690, P=0.495>0.05$; CR of $Y24=0.504, P=0.618>0.05$; CR of $Y2=1.255$, $P=0.219>0.05$; CR of $Y27=2.573, P=0.016<0.05$;CR of $Y33=0.642$, $P=0.526>0.05$;CR of $Y34=0.000, P=1.000>0.05$; CR of $Y36=2.521, P=0.017<0.05$; CR of $Y38=1.802$, $P=0.082>0.05$. The CR value of the other items are ≥ 3.00 together with significant difference between upper and lower groups ($P<0.05$). (See Table 4.2 in Appendix E for detailed information)

After critical ratio analysis, items Y7, Y8, Y9, Y10, Y19, Y20, Y21, Y22, Y24, Y26, Y27, Y33, Y34,Y36,Y38 were deleted because of poor discrimination.

Besides critical ratio analysis, homogeneity between specific item and the total score is another common used index for screening questionnaire items by calculating the correlation coefficient between the item and the total score. The higher the correlation coefficient is, the higher the homogeneity between specific item and the overall scale. If the correlation between one item and the total score fails to reach the significant level or the value of correlation coefficient is below 0.4, the item should be deleted because of its poor homogeneity to the overall scale. (Wu, 2010, p.181) Moreover, in the process of correlation analysis, if the structure of the scale has been determined from the beginning of the scale compiling based on specific theory or current research, it is recommended to perform the analysis on each dimension of the scale in order to minimize the potential underestimation. In this research, seven dimensions were designed for the structure of the initial questionnaire, but after the critical ratio analysis, all of the four items on the dimension of family atmosphere were deleted. Hence, the correlation analysis between the item and the total score had been separately performed on the other six dimensions. (See Table 4.3-8 in Appendix E for detailed information)

Regarding the correlation analysis on the dimension of economic pressure(D1), there are significant differences of the correlation between the items Y1-Y6 ($P<0.05$) and the total score of economic pressure, and the correlation coefficient are between 0.612 to 0.888, which are higher than the deletion criterion of 0.400. (See Table 4.3)Therefore, all of the six items Y1-Y6 were retained. Regarding the correlation analysis on the dimension of difficulties related to child(D2), there are significant differences of the correlation between the items Y11-Y15($P<0.05$) and the total score of difficulties related to child, and the correlation coefficient are between 0.811 to 0.899, which are higher than the deletion criterion of 0.400. (See Table 4.4) Therefore, all of the five items from Y11-Y15 were retained. Regarding the correlation analysis on the dimension of parental attitude(D3), there are significant differences of the correlation between the items Y16,Y17,Y18($P<0.05$) and the total score of parental attitude, and the correlation coefficient are between 0.696 to 0.861, which are higher than the deletion criterion of 0.400. (See Table 4.5) These three items were retained, while the item Y23 was deleted with a correlation coefficient of -0.040. Regarding the correlation analysis on the dimension of family preparation(D4), there are significant differences of the correlation between the items Y25,Y28,Y29,Y30,Y31($P<0.05$) and the total score of family preparation, and the correlation coefficient are between 0.692 to 0.874, which are higher than the deletion criterion of 0.400. (See Table

4.6)Therefore, these five items were retained. Regarding the correlation analysis on the dimension of social support, there are significant differences of the correlation between items Y32,Y35,Y37(P<0.05) and the total score of social support(D5), and the correlation coefficient are between 0.672 to 0.837, which are higher than the deletion criterion of 0.400. (See Table 4.7) Therefore, theses three items were retained. Regarding the correlation analysis on the dimension of family involvement(D6), there are significant differences of the correlation between items Y39-Y44 (P<0.05) and the total score of family involvement, and the correlation coefficient are between 0.630 to 0.841, which are higher than the deletion criterion of 0.400. (See Table 4.8) Therefore, these six items were retained.

Based on the correlation analysis, only item Y23 were deleted and the other 28 items were retained.

4.1.2 Factor analysis

After project analysis, exploratory factor analysis needs to be done to examine the construct validity, which shows to which degree the traits or concepts of the theory could be measured.(Wu, 2010, p.195) The main goal of exploratory factor analysis is to form a scale with smaller number of items but higher correlation between each other by exploring the potential factor structure of the scale and reducing the number of items.(Wu, 2010, p.194) Therefore, exploratory factor analysis was conducted to explore the factor structure of the initial questionnaire.

The first step of factor analysis is to check the KMO (Kaiser-Meyer-Olkin measure of sampling adequacy) value and the result from Bartlett's sphere test, which show whether the items are suitable for factor analysis with the criteria shown in Table 4.9. (Wu, 2010, p.208) Regarding the initial questionnaire, the KMO value is 0.760, together with significant difference of Bartlett's test of sphericity (Sig.= 0.000), which indicates that the items are suitable for factor analysis.

Table 4.9 Criteria for the determination of KMO indicators

Value of KMO	Description of determination	Factor analysis suitability
≥0.90	marvelous	Perfect
≥0.80	meritorious	Meritorious
≥0.70	middling	Middling
≥0.60	mediocre	Mediocre
≥0.50	miserable	Miserable
<0.50	unacceptable	Unacceptable

The second step for factor analysis is to check the communalities and factor loading of each item with the criteria shown in Table 4.10. Besides, the cumulative explanatory variance is another indicator to judge the factor extraction. If the cumulative explanatory variance could reach 60%, the factors after extraction are quite reasonable, and if the cumulative explanatory variance could reach 50%, the extracted factors are still acceptable. (Wu, 2010, p.232)

By performing the principal component analysis and maximum variance method, seven factors were extracted with eigenvalue greater than 1. Based on the scree plot, from the seventh factor, the plot tends to be relatively flat. Therefore, the first six factors were taken into consideration to form the structure of the initial questionnaire corresponding to the preset structure by the researcher. Then principal component analysis and maximum variance method were performed once again, six factors were extracted. Results are as follows: cumulative explanatory variance of the six factors is 72.390%, which is greater than 60% and indicates that the extracted factors are reasonable; for each item, the communality is greater than 0.200 and the factor loading of all retained items are greater than 0.450. (See Table 4.11-12 in Appendix E for detailed information) According to factor analysis, all of the items remaining after project analysis were retained.

Through the factor analysis, six factors were extracted to form the structure of the questionnaire, in terms of economic pressure (item Y1-Y6), difficulties related to child (Y11-15), parental attitude (Y16-Y18), family preparation (Y25, Y28-Y31), social support (Y32, Y35, Y37) and family involvement (Y39-44).

Table4.10 Criteria for factor loading and communalities

Factor loading	Communalities	Variable status
0.71	0.50	Excellent
0.63	0.40	Very good
0.55	0.30	Good
0.45	0.20	Fair
0.32	0.10	Poor
<0.32	<0.10	Deletion

4.1.3 Reliability analysis

Reliability is the stability and consistency of the results measured by measurement instrument or scale as the greater the reliability of the scale is, the smaller the standard error of the measurement instrument exists. (Wu, 2010, p.237) After factor analysis, reliability test should be done to test the reliability of the initial questionnaire and Cronbach's α coefficient is the most common used reliability indicator in compiling new scale or questionnaire. Cronbach's α coefficient is an internal consistency function which shows the inter-relatedness of the items.(Wu, 2010, p.238) As reliability indicates the measurement error in the real research, there is evaluating criteria for the reliability of the overall scale and the dimensions. For general attitude or psychological perception scale, the Cronbach's α coefficient of the overall scale is better to be greater than 0.800 for ensuring good reliability, if α is between 0.700 to 0.800, the scale could also be used with acceptable reliability; for each dimension of the scale, the Cronbach's α coefficient is better to be greater than 0.700, if α is between 0.600 to 0.700, it is also acceptable; If the α coefficient of the whole scale is below 0.800 or α coefficient of one dimension is below 0.600, statement modification of items or deletion of items or adding new items are recommended. (Wu, 2010, p.237-238)

Reliability test were conducted on the remaining 28 items and also the six dimensions. The internal consistency α coefficient of the 28 items is 0.913 and the α coefficient of the six dimensions are between 0.626 and 0.899 after deletion of item Y32, which indicates that the reliability of the initial questionnaire is very good.(See Table 4.13 in Appendix E for detailed information) Among the six dimensions, the reliability of "economic pressure ", "difficulties related to child" and "family preparation" is very good, and the reliability of "parental attitude" and "family involvement" is good, while the reliability of social support is acceptable after deletion of item Y32.

Through the reliability test, item Y32 was deleted and 27 items were retained to constitute the formal questionnaire.

Through project analysis, factor analysis and reliability analysis, 17 items were deleted (See Table 4.14 in Appendix E for detailed information) and the remaining 27 items were re-codified to form the final Influencing Factors Questionnaire of FQOL in Families of Children with Disabilities at Young Age. This formal questionnaire consists of six dimensions: economic pressure (y1-y6), difficulties related to child (y7-y11), family attitudes (y12-y14), family preparation (y15-19), social support (y20, y21) and family involvement(y 22-y27). Information of dimensions and corresponding items in detail is presented in Appendix B.

4.2 current situation of FQOL

Speaking of family quality of life, both objective and subjective parts should be considered. The objective part is mainly about the financial situation, accommodation condition and employment status of the respondents, while the subjective part is the subjective feelings of different dimensions of family life by family member.

4.2.1 Status of objective family conditions

In this research, the objective family conditions include general family financial situation, average monthly household income, average expenditure on disabled child's education and rehabilitation, family accommodation condition and employment status of respondents.

- General family financial situation

Family financial situation is one critical indicator of the objective family quality of life. Balance of family income and expenditure is a necessary condition for ensuring family life. As shown in Figure 4.1, less than half of the families are balanced in family income and expenditure and only 11.52% families have income far greater than expenditure, while more than 40% families get income far less than expenditure. It shows that near half of families with disabled children can hardly afford their daily life.

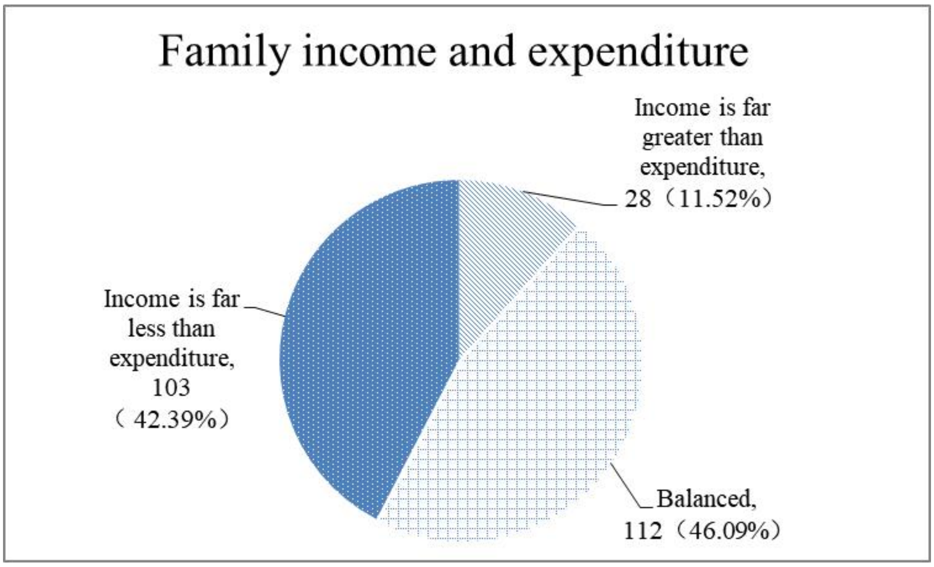


Figure4.1 Status of family income and expenditure of respondents (N=243)

- Average family household income for one month

Because income is a sensitive topic, some participants were not willing to reveal their household income. Therefore, 199 participants responded for the question of average household income for one month. The results are shown in Table4.15.

Table 4.15 Monthly average household income (N=199)

Monthly average household income(Yuan[5] in RMB)	**number**	**percentage**
≤ 1000	11	5.53
1001-2000	21	10.55

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[5] According to the exchange rate in May 2020, 1$≈7.09Yuan in RMB.

2001-3000	41	20.60
3001-4000	32	16.08
4001-5000	34	17.09
5001-6000	11	5.53
6001-7000	7	3.52
7001-8000	11	5.53
≥8001	31	15.58
Max=20000, Min=0, Mean=5155.28	χ^2=7648.00***	

*Note: *p<0.05, **p<0.01, ***p<0.001 (2-tailed), same as below.*

According to the table above, average monthly income for family of child with special needs is 5155.28 Yuan in RMB (≈736$), together with Max. value 20000(≈2857$) and Min. value 0. The distribution of average monthly household income concentrates in several intervals in terms of 2001-3000, following by 4001-5000 and 3001-4000. Besides these, more than 15% of families are with average monthly income less than 2000RMB (≈286$), while similar proportion families have monthly income more than 8000RMB (≈1143$). In general, the statistics show that there is significant difference of the average month income among families of children with special needs.

- Average household expenditure for disabled child's education and rehabilitation

In order to know the impact of children with disabilities on their family's economic status, average monthly household expenditure on disabled child's education and rehabilitation were investigated. The statistics from 192 participants shows in Table4.16. 28 families respond the average monthly household expenditure on education and rehabilitation for children with disabilities as 0 Yuan. Through further verification, the children with disabilities in these families are either at school age and receive free special education in local school district, or only receive early intervention and rehabilitation paid by government. Besides this, more than half of the families spend no more than 2000 Yuan (≈285$) on disabled children's education and rehabilitation, while more than 10% of families spend more than 4000Yuan (≈571$). The mean average monthly household expenditure on education and rehabilitation for children with disabilities is 2179.48Yuan (≈311$), which accounts for 42.28% of the average household income.

Table4.16 Average monthly household expenditure on disabled child's education and rehabilitation (N=192)

Monthly family expenditure(Yuan)	number	percentage
0	28	14.58
1-1000	48	25.00
1001-2000	36	18.75
2001-3000	46	23.96
3001-4000	12	6.25
4001-5000	8	4.17
5001-6000	5	2.60
6001-7000	5	2.60
7001-8000	2	1.04
⩾8001	2	1.04
Max=10000, Min=0, Mean=2179.48		

- Accommodation condition

As one necessary aspect in daily life, accommodation is closely related to individual's life quality. Hence, accommodation condition is another indicator for measuring the objective family life quality. In Chinese society, possession of own accommodation has long been regarded as basic guarantee of family life. According to Figure 4.2, more than 70% of families have their own accommodation. But there are still around 20% families without their own accommodation, among them, 18.11% families rely on long term renting, while 4.12% families stay with relatives or friends.

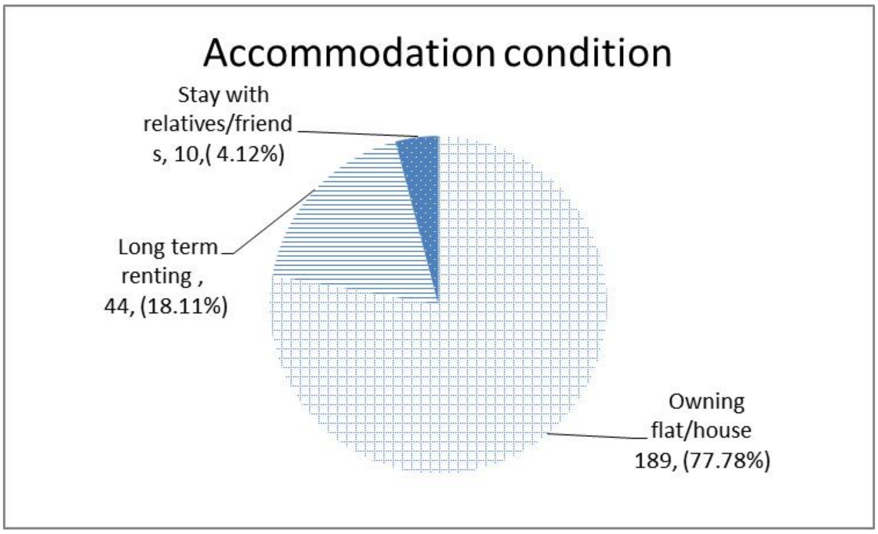


Figure 4.2 Accommodation condition of respondents (N=243)

- Employment status of respondents

Employment status reflects the family income situation from the side. In this research, according to the caregivers who responded to the questionnaire, 23.87% of respondents have full-time job and 12.76% have part-time job, while more than half of the respondents are without job. It reveals that the majority of main caregivers of children with special needs at young age are full-time caregivers and without job.

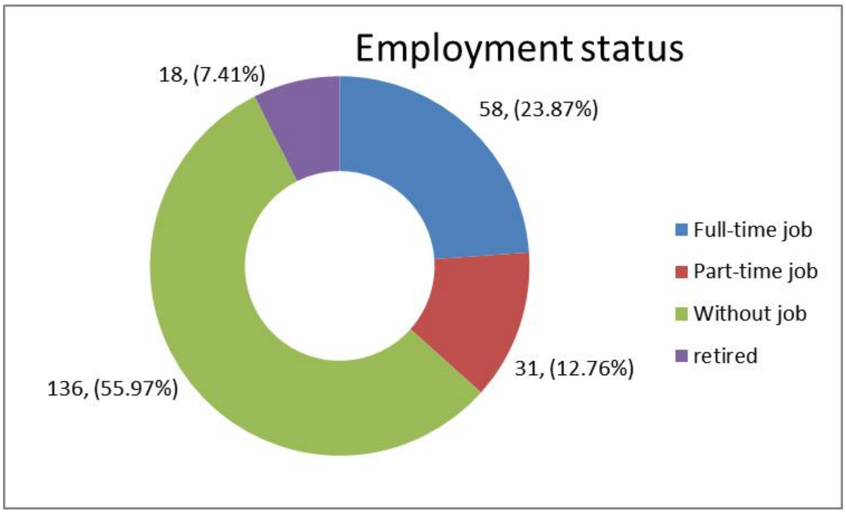


Figure 4.3 Employment status of respondents (N=243)

4.2.2 Current situation of Subjective FQOL

4.2.2.1General situation of subjective FQOL

The subjective FQOL is indicated by subjective satisfaction on the five dimensions of family quality of life in terms of family interaction, parenting, emotional well-being, material well-being and disability-related supports.

Distribution of the total score of FQOL

Frequency statistics of total satisfaction scores in different scoring ranges was conducted to reveal the distribution of the total score of FQOL. As the total score of BCFQOL is from 25-125 points, four scoring ranges were divided: 25-50, 51-75, 76-100, and 101-125. More than half of the families get total score of FQOL from 76-100 points, followed by 24.69% families with total scores from 51-75 points. 12.76% families get high total score more than 100 points, while only 1 family gets total score less than 50 points. These statistics show that the FQOL in the majority families of children with special needs stays around medium level.

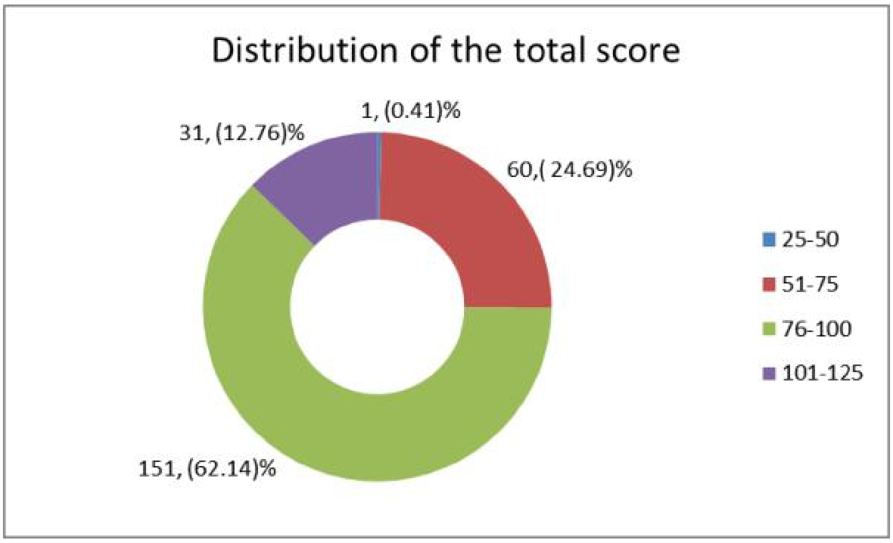


Figure 4.4 Distribution of the total score of FQOL (N=243)

Difference of FQOL on five dimensions

In order to know the satisfaction on different dimensions of BCQOL, average score per question of the overall scale and five sub-scales were calculated and ranked. As shown in Table4.17, there are differences of average score per question among the overall scale and five sub-scales. According to the average score per question, there is highest satisfaction on the sub-scale of family interaction with the mean of 3.648, while lowest satisfaction on the sub-scale of emotional well-being with mean of 3.116. The satisfaction level on the overall scale and five sub-scales rank as family interaction>parenting > overall scale >disability-related supports> material well-being> emotional well-being.

Further analysis has been done to know whether there are significant differences of satisfaction among them. On one hand, as the average score per question of the overall scale and five sub-scales are between 3-4 points, independent sample t-test has been done to test the average score per question of the overall scale and five sub-scales comparing to the criterion of 3 points and 4 points. The results show that the satisfaction of FQOL and its five dimensions is significantly higher than “neither dissatisfied nor satisfied”, but significantly lower than “satisfied”. On the other hand, paired sample t-test has been done to examine the internal differences among the overall scale and its five sub-scales. The results show that satisfaction on family interaction is significantly higher than satisfaction on parenting, satisfaction on parenting sub-scale is significantly higher than the satisfaction on the overall scale, satisfaction on overall scale is significantly higher than satisfaction in the sub-scale of disability-related supports, satisfaction on material well-being is significantly higher than satisfaction on emotional well-being, while no significant difference of satisfaction between sub-scales of disability-related supports and material well-being.(See Table 4.18)

In general, the subjective FQOL among families with disabled children at young age is at medium level and significantly below “satisfied”. Families with disabled children at young age are most satisfied with family interaction, while least satisfied with emotional well-being. There are significant differences of satisfaction among specific dimensions of family life with the trend of family interaction > parenting > disability-related supports/ material well-being> emotional well-being.

Table4.17 Average score per question of the overall scale and five sub-scales

	Mean	**SD**	**ranking**	**Comparing to 3 (T)**	**Comparing to 4 (T)**
Family interaction	3.648	0.788	1	12.809***	-6.975***
Parenting	3.534	0.724	2	11.491***	-10.044***
Emotional well-being	3.116	0.786	6	2.306***	-17.533***
Material well-being	3.242	0.725	5	5.203*	-16.298***
Disability-related supports	3.273	0.686	4	6.195***	-16.529***
Overall scale	3.394	0.583	3	10.530***	-16.191***

Table4.18 Paired sample T test of satisfaction among the overall scale and its five sub-scales

Paired sample of average score per question	**Mean difference**	**T**	**P**
Family interaction> parenting	0.114	2.835	0.005**
Parenting > overall scale	0.140	5.593	0.000***
Overall scale >disability-related supports	0.121	3.628	0.000***
Disability-related supports> material well-being	0.031	0.691	0.490
Material well-being> emotional well-being.	0.126	2.985	0.003**

4.2.2.2 Group differences of subjective FQOL

In order to know the differences of subjective FQOL between different family groups, independent samples t-test was conducted to compare the differences of perceived family quality of life between family groups with two kinds of conditions, such as gender of the disabled child, with disability document or not, whether with child without disability, gender of the main caregiver, whether join self-help organization for parents. Besides, one-way analysis of variance (ANOVA) was applied to compare the differences of perceived family quality of life among family groups with three or more kinds of conditions, such as child's characteristics in terms of age, type of disabilities, severity of disability, health condition, self-care ability, impact of behavioral problem on daily life, main placement, and family's characteristics in terms of the role of the main caregiver, age, education status of the main caregiver, marital status of parents, family location and parenting skills of child with special needs, household financial status, accommodation condition.

Group Differences of Subjective FQOL - Child Characteristics

- Difference on gender of child with special needs

Independent sample t-test was conducted to analyze the differences of the overall scale and five sub-scales between 150 boys and 93 girls with disabilities. As the following table shows, there are differences of overall FQOL and its sub-dimensions of family life, but the differences have not reached a significant level with P>0.05.

Table4.19 Difference of FQOL on gender of disabled child (N=243)

	Boy(n=150) (M+SD)	**Girl (n=93)** (M+SD)	**T**	**P**
Family interaction	21.860+4.715	21.925+4.774	-0.104	0.918
Parenting	21.287+4.123	21.065+4.697	0.387	0.699
Emotional well-being	12.553+3.062	12.323+3.281	0.555	0.579
Material well-being	16.473+3.399	15.785+3.945	1.442	0.151
Disability-related supports	12.993+2.674	13.247+2.862	-0.701	0.484
Total	85.167+14.346	84.344+15.025	0.427	0.670

- Difference on whether the disabled child has disability document

In China, after the child with disability gets documents describing his/her special needs from hospital, the family can apply disability document for the child from CDPF. With this document of disability from CDPF, the child can obtain government subsidies for free rehabilitation services and aids. Whether to apply for the disability certificate is based on voluntary principles. Among the 243 participants, disabled children from 170 families are with disability document and 73 are without disability document. Independent sample t-test was conducted to analyze the differences of FQOL on the overall scale and five sub-scales between the two family groups.

Table4.20 Difference of FQOL on whether the child has disability document (N=243)

	With (n=170) (M+SD)	**Without(n=73)** (M+SD)	**T**	**P**
Family interaction	21.624+4.559	22.493+5.080	-1.317	.189
Parenting	21.000+4.082	21.671+4.896	-1.105	.270
Emotional well-being	12.212+2.934	13.055+3.535	-1.790	.076
Material well-being	15.529+3.509	17.795+3.411	-4.652	.000***
Disability-related supports	12.929+2.499	13.466+3.232	-1.265	.209
Total	83.294+13.417	88.480+16.532	-2.366	.020*

As shown in Table 4.20, there is significant difference of satisfaction on total FQOL between family groups with and without disability document (P=0.020<0.05), together with extremely significant difference of satisfaction on material well-being (P=0.000<0.05). To be specific, families without disability document are significantly more satisfied for total FQOL and material well-being, comparing to families with disability documents.

- Difference on age of disabled child

This research is focused on families who have children with disabilities at young age. In this study, the age of disabled child was divided into three groups, namely 0-2 years old, 3-4 years old, 5-6 years old and over 7-8 years old. One-way analysis of variance (ANOVA) was conducted to analyze the satisfaction for family life among different age conditions of disabled child.

Table4.21 Difference of FQOL on different age conditions of disabled child (N=243)

	Child's age					
	0-2(n=20)	3-4(n=80)	5-6(n=71)	7-8(n=72)	F	P
			M			
Family interaction	23.350	22.388	20.817	21.972	2.189	.090
Parenting	22.600	21.638	20.690	20.833	1.469	.224
Emotional well-being	13.850	12.500	12.070	12.431	1.688	.170

Material well-being	17.350	16.575	16.099	15.597	1.651	.178
Disability-related supports	14.850	13.500	12.732	12.500	5.096	.002**
Total	92.000	86.600	82.409	83.333	2.980	.032*

As shown in the table above, there are significant differences of the total score of FQOL among different age conditions of disabled children (F=2.980，P=0.032<0.05) , which shows a downward trend with the age of disabled children from 0-6years old. It indicates that families with disabled children at young age, their satisfaction for family life decreases along with the disabled child getting older. According to ANOVA analysis, the significant differences mainly reveal on the sub-dimension of disability-related supports. (F=5.096， P=0.002<0.05)

Multiple comparisons by the method of LSD were applied to know the differences between specific age conditions. The results show that families with disabled children at the age of 0-2 years old perceive significantly higher quality of family life than families with disabled children at the age of 5-6years old (MD=9.59, P=0.009<0.05) and 7-8years old (MD=8.67, P= 0.018<0.05), while no significant difference comparing to families with disabled children at the age of 3-4 years old. On the sub-dimensions of family life, families with children at 0-2 years old are more satisfied with disability-related supports than families of older children with disabilities. Similar to this trend, families with children at the age of 3-4 years old are more satisfied with disability-related supports than families with children at the age of 7-8 years old (MD=1.00, P=0.022<0.05). Besides these, families with children at the age of 0-2 years old are more satisfied with family interaction and emotional well-being comparing to families with children at the age of 5-6 years old. Families with children at the age of 3-4 years old are also more satisfied with family interaction than families with children at the age of 5-6 years old. (See Table 4.22)

Table4.22 Multiple comparisons of the differences among different age conditions (N=243)

	Child's age									
	0-2/3-4		0-2/5-6		0-2/7-8		3-4/5-6		3-4/7-8	
	MD	P	MD	P	MD	P	MD	P	MD	P
Family interaction	/	/	2.53*	.034	/	/	1.57*	.041	/	/
Parenting	/	/			/	/	/	/	/	/
Emotional well-being	/	/	1.78*	.026	/	/	/	/	/	/
Material well-being	/	/	/	/	/	/	/	/	/	/
Disability-related supports	1.35*	.045	2.12*	.002	2.35*	.001	/	/	1.00*	.022
Total	/	/	9.59*	.009	8.67*	.018	/	/	/	/

Note: MD refers to mean differences.

- Difference on type of special needs

In china, disabilities are officially categorized into seven types, in terms of Hearing Impairment (HI), Visual Impairment (VI), Intellectual Disability (ID), Physical Disability (PD), Speech and Language Disorder (SLD), Mental Disability and Multiple Disabilities (MD). In this study, types of special needs are based on the official categories of disabilities, while Mental Disability is replaced by Autism Spectrum Disorder (ASD), and Developmental Delay (DD) is added.

One-way analysis of variance (ANOVA) was conducted to analyze the satisfaction for family life among families of children with different types of special needs. Among the 243 respondents, 64 families with Intellectual Disability children, 46 families have children with Hearing Impairment, 39 families have children with Autism Spectrum Disorder, 35 families have children with Multiple Disabilities, 33 families with Developmental Delay children, 19 families have children with Physical

Disability, and 7 families have children with Speech and Language Disorder, while no families has children with Visual Impairment. Therefore, families of children with Speech and Language Disorder or Visual Impairment have been excluded in the statistical analysis.

Table4.23 Difference of FQOL on different types of special needs of disabled child (N=236)

	Child's types of special needs							
	HI (n=46)	ID (n=64)	PD (n=19)	ASD (n=39)	MD (n=35)	DD (n=33)	F	P
	M							
Family interaction	23.22	19.92	22.16	22.15	23.09	22.30	3.109	.006**
Parenting	22.35	19.52	22.74	21.49	20.86	21.73	2.932	.009**
Emotional well-being	12.46	11.80	13.47	12.54	12.49	13.03	.997	.428
Material well-being	15.22	14.95	18.05	17.56	15.57	17.55	5.572	.000***
Disability-related supports	13.30	12.63	14.32	12.21	13.09	14.06	2.434	.027*
Total	86.54	78.81	90.74	85.95	85.09	88.67	3.055	.007*

As shown in Table4.23, types of special needs play significant effect on FQOL (F=3.055, P=0.007<0.05) and its sub-dimensions including family interaction (F=3.109, P=0.006<0.05), parenting(F=2.932,P=0.009<0.05),material well-being (F=5.572, P=0.000<0.05) and disability- related supports(F=2.434, P=0.027<0.05) among families with disabled children at young age, while there is no significant difference of satisfaction on emotional well-being (F=0.997, P=0.428> 0.05) among families with disabled children who have different types of special needs.

LSD multiple comparison was conducted to analyze the specific differences of quality of life between families of children with different types of special needs. The results show that perceived FQOL is as follows: on total scale ID<HI, ID<PD, ID<ASD,ID<MD,ID<DD; on sub-scale of family interaction, ID<HI, ID<ASD, ID<MD,ID<DD, on sub-scale of parenting, ID<HI, ID<PD, ID<ASD, ID<DD, on the sub-scale of material well-being, ID<PD, ID<ASD, ID<DD, HI<PD, HI<ASD, HI<DD, MD<PD, MD<ASD, MD<DD; on the sub-scale of disability-related supports, ID<PD,ID<DD, ASD<DD,ASD<PD.

According to the ANOVA analysis and multiple comparison, families of children with different types of special needs perceive different satisfaction for their family life. In general, families of children with intellectual disabilities are less satisfied with their overall family life and other sub-dimensions of family life, except for emotional well-being. Besides this, families of children with hearing impairment are less satisfied with material well-being comparing to families of children with autism or developmental delay. Families of children with autism are less satisfied with disability-related supports comparing to families of children with developmental delay or physical disability.

- Difference on severity of special needs

Taking severity of special needs as independent variable and FQOL as dependent variable, ANOVA analysis was conducted to analyze the difference of perceived family quality of life on disabled children's severity of special needs.

Table4.24 Difference of FQOL on severity of special needs (N=243)

	Severity of special needs					
	Mild (n=40)	Moderate (n=80)	Severe (n=82)	Very severe (n=41)	F	P
	M					
Family interaction	22.55	21.88	21.40	22.22	.614	.606
Parenting	21.48	21.11	21.23	21.05	.081	.970
Emotional	12.93	12.79	12.41	11.49	1.916	.128

well-being						
Material well-being	17.85	16.33	15.99	14.83	5.086	.002**
Disability-related supports	14.45	12.60	13.13	12.63	4.718	.003**
Total	89.25	84.70	84.17	82.22	1.736	.160

As shown in the table above, there are significant differences of perceived satisfaction on material well-being and disability-related supports among families of children with different severity of special needs. Further multiple comparisons were conducted to know the specific differences among four levels of severity of special needs. The results show that families of children with mild special needs perceived significantly higher satisfaction in material well-being and disability-related supports with P<0.05 than other family groups. Besides, family of children with very severity of special needs are less satisfied on overall family life or material well-being or emotional well-being compared to families of children with mild special needs.

Table4.25 Multiple comparisons of the differences among different age conditions (N=243)

	Child's severity of special needs							
	mild/moderate		mild/severity		mild/very severity		moderate/very severity	
	MD	P	MD	P	MD	P	MD	P
Family interaction	/	/	/	/	/	/	/	/
Parenting	/	/	/	/	/	/	/	/
Emotional well-being	/	/	/	/	1.44*	.040	1.30*	.031
Material well-being	1.53*	.027	1.86*	.007	3.02*	.000	1.50*	.029
Disability-related	1.85*	.000	1.32*	.012	1.82*	.003	/	/

supports								
Total	/	/	/	/	7.03*	.030	/	/

- Difference on health condition of disabled child

In order to know the difference of FQOL among families of disabled children with different health conditions, ANOVA analysis was conducted to examine the satisfaction for family life among 77 families of children with very good health, 120 families of children with average health and 46 families of children with poor health.

As shown in Table4.26, the effect of health condition is significant on the perceived quality of family life and the five sub-dimensions of family life among families of disabled children, which is extremely significant on the dimension of material well-being(F=12.319, P=0.000<0.001) and the overall FQOL(F=9.571, P=0.000<0.001). According to further multiple comparisons, families of children with poor health condition are less satisfied with the overall FQOL and its all sub-dimensions comparing to families of children with very good health condition. Similarly, families of children with average health condition are less satisfied with overall FQOL and its sub-dimensions except family interaction, comparing to families of children with very good health condition. (See Table4.27)

Table4.26 Difference of FQOL on health condition of disabled child (N=243)

	Health condition of disabled child				
	Very good(n=40)	Average(n=80)	Poor(n=82)	F	P
		M			
Family interaction	23.08	21.85	19.98	6.476	.002**
Parenting	22.29	20.79	20.46	3.690	.026*
Emotional well-being	13.30	12.20	11.76	4.411	.013*
Material well-being	17.68	15.88	14.61	12.319	.000***

Disability-related supports	13.88	12.77	12.61	4.911	.008**
Total	90.22	83.49	79.41	9.571	.000***

Table4.27 Multiple comparisons of the differences on different health conditions (N=243)

	Health condition of disabled child					
	poor/good		poor/average		average/ good	
	MD	P	MD	P	MD	P
Family interaction	-3.10*	.000	-1.87*	.020	/	/
Parenting	-1.83*	.023	/	/	-1.49*	.018
Emotional well-being	-1.54*	.008	/	/	-1.10*	.016
Material well-being	-3.07*	.000	-1.27*	.035	-1.79*	.000
Disability-related supports	-1.27*	.012	/	/	-1.12*	.005
Total	-10.81*	.000	/	/	-6.73*	.001

- Difference on self-care ability of disabled child

Taking self-care ability of disabled child as independent variable and FQOL as dependent variable, ANOVA analysis was conducted to analyze the difference of perceived FQOL on disabled children’s self-care ability.

Table4.28 Difference of FQOL on self-care ability of disabled child (N=235)

	Self-care ability child				
	Little dependence (n=57)	Most dependence (n=103)	Complete dependence (n=75)	F	P

		M			
Family interaction	22.46	21.91	21.25	1.144	.320
Parenting	20.82	21.43	21.05	.412	.663
Emotional well-being	12.60	12.57	12.12	.581	.560
Material well-being	16.14	16.38	15.81	.548	.579
Disability-related supports	12.46	12.99	13.35	1.849	.160
Total	84.48	85.28	83.59	.312	.732

Among the 243 respondents, there are 75 families of children with complete dependence on others, 103 families of children who mostly dependent on others and 57 families of children with little dependence, while 8 families have children who can take care of themselves. Because of limited samples, these 8 families were excluded from analysis in this study. Among other three groups with 235families, as shown in the table above, there is no significant difference of FQOL on the FQOL and its five sub-dimensions among families of disabled children with different self-care ability.

- Difference on behavior problem of disabled child

Taking disabled child's severity of behavior problem as independent variable and FQOL as dependent variable, ANOVA analysis was conducted to analyze the difference of perceived FQOL on disabled child's severity of behavior problem.

Table4.29 Difference of FQOL on severity of behavior problem of disabled child (N=243)

	Impact of behavior problem on daily life				
	Very serious (n=111)	Slight (n=99)	Almost no (n=33)	F	P
		M			
Family interaction	20.81	22.44	23.82	6.610	.002**
Parenting	20.70	21.40	22.27	1.856	.158
Emotional well-being	11.97	12.47	14.09	6.016	.003**
Material well-being	15.59	16.56	17.27	3.590	.029*

Disability-related supports	12.81	12.87	14.70	6.874	.001**
Total	81.88	85.75	92.15	6.945	.001**

As shown in Table4.29, there is significant difference of overall FQOL (F=6.945, P=.001<0.05) among families groups of children with different severity of behavior problem. Similarly, families' perceived satisfaction for sub-dimensions of family life including family interaction (F=6.610, P=.002<0.05), emotional well-being (F=6.016, P=.003<0.05), material well-being (F=3.590, P=.029<0.05) and disability-related supports (F=6.874, P=.001<0.05) varies significantly on disabled children's severity of behavior problem.

Table4.30 Multiple comparisons of the differences on severity of behavior problem (N=243)

	Impact of behavior problem on daily life					
	very serious/slight		very serious/almost no		slight/ almost no	
	MD	P	MD	P	MD	P
Family interaction	-1.63*	.011	-3.01**	.001		
Parenting						
Emotional well-being			-2.12**	.001	-1.62*	.010
Material well-being			-1.69*	.018		
Disability-related supports			-1.89***	.000	-1.83**	.001
Total			-10.27***	.000	-6.40*	.026

According to multiple comparisons, families of children with very serious behavior problem are significantly less satisfied with overall family life and its sub-dimensions of family interaction, emotional well-being, material well-being and disability-related supports, comparing to families of disabled children whose behavior problem has almost no impact on daily life. Besides, families of children with slight behavior problem also less satisfied with the overall family life and its sub-dimensions of emotional well-being and disability-related supports, comparing to families of disabled children whose behavior problem has almost no impact on daily life. (See Table4.30)

- Difference on main placement of disabled child

Main placement has been considered to be one independent variable in this study. The placement of disabled children from the 243 respondents fell into 6 categories, in terms of general kindergarten/ primary school, special kindergarten/ primary school, private intervention center, rehabilitation center under CDPF, hospital and others. The result based on ANOVA shows that there is no significant difference of FQOL and its sub-dimensions among family groups with disabled children who have different main placement. (See Table4.31)

Table 4.31 Difference of FQOL on main placement of disabled child (N=233)

	Main placement of disabled child					
	GK/PS (n=36)	SK/PS (n=96)	PIC (n=60)	RC under CDPF(n=41)	F	P
	M					
Family interaction	23.58	21.27	21.53	21.83	2.151	.095
Parenting	22.25	20.85	21.47	20.93	1.014	.387
Emotional well-being	12.92	12.29	12.68	12.20	.537	.657
Material well-being	16.67	15.69	17.00	15.90	1.915	.128
Disability-related supports	13.56	12.88	13.33	13.20	.682	.564

Total	88.97	82.98	86.02	84.05	1.646	.180

Note: Respondents of children with main placement of "hospital" (n=8) and "others"(n=2) were excluded in analysis because of limited sample.

GK/PS=general kindergarten/ primary school, SK/PS=special kindergarten/ primary school, PIC=private intervention center, RC under CDPF= rehabilitation center under CDPF.

Group Differences of Subjective FQOL - Family Characteristics

- Difference on gender of main caregiver

Independent sample t-test was conducted to analyze the differences of satisfaction for FQOL on the overall scale and five sub-scales between 52 males and 191 females. As the following table shows, there are differences of satisfaction for overall FQOL and its sub-dimensions, but the differences have not reached a significant level with P>0.05.

Table4.32 Difference of FQOL on gender of main caregiver (N=243)

	Male (n=52) (M+SD)	**Female (n=191)** (M+SD)	**T**	**P**
Family interaction	22.231+4.809	21.791+4.714	-0.594	0.553
Parenting	21.019+4.372	21.251+4.346	0.341	0.733
Emotional well-being	12.539+3.090	12.445+3.165	-0.190	0.850
Material well-being	16.865+3.799	16.031+3.566	-1.474	0.142
Disability-related supports	13.039+3.023	13.105+2.671	0.154	0.878
Total	85.692+15.625	84.623+14.323	-0.468	0.640

- Difference on main caregiver's relationship to the disabled child

Among the 243 respondents, 137 are mothers and 47 are grandmothers, while 34 are fathers and 18 are grandfathers. The other 7 respondents are relatives or full-time nanny of the disabled children. One way ANOVA analysis was conducted to know the difference of perceived satisfaction for family life from main caregivers who have different relationships to the disabled children. As shown in the table below, even though fathers perceive higher satisfaction for overall family life and also its sub-dimensions, there is no significant difference of FQOL among groups of mother, father, grandmother and grandfather. (See Table4.33)

Table4.33 Difference of FQOL on main caregiver's relationship to the disabled child (N=236)

	main caregiver's relationship to the disabled child					
	Mother (n=137)	Father (n=34)	grandfather (n=18)	Grandmother (n=47)	F	P
	M					
Family interaction	21.98	22.50	21.72	21.68	.231	.875
Parenting	20.95	21.06	20.94	22.57	1.777	.152
Emotional well-being	12.10	12.62	12.39	13.55	2.539	.057
Material well-being	15.80	17.29	16.06	16.85	2.086	.103
Disability-related supports	12.88	12.82	13.44	13.77	1.420	.238
Total	15.80	17.29	16.06	16.85	1.344	.261

Note: Respondents who has relationship type as "other" were excluded in analysis because of limited sample.

- Difference on age of main caregiver

In this study, the age of main caregiver is divided into five groups, in terms of under25 years old (8 respondents), 26-35years old (97 respondents), 36-45 years old (59 respondents), 46-55 years old (41 respondents) and more than 56 years old (38 respondents). Because of limited samples, respondents under 25years old were merged with respondents at the age of 36-45years old to be analyzed.

Table 4.34 Difference of FQOL on age of main caregivers (N=243)

	age of main caregiver					
	≤35y (n=105)	36-45y (n=59)	46-55y (n=41)	≥56 (n=38)	F	P
			M			
Family interaction	22.59	22.17	19.76	21.79	3.751	.012*
Parenting	21.58	20.73	20.07	22.11	1.995	.115
Emotional well-being	12.55	11.93	12.17	13.37	1.776	.152
Material well-being	16.42	16.02	15.46	16.74	1.020	.385
Disability-related supports	13.27	12.85	12.22	13.92	2.903	.036*
Total	86.41	83.69	79.68	87.92	2.865	.037*

Table 4.35 Multiple comparisons on age conditions of main caregiver (N=243)

	age conditions of main caregiver							
	46-55y/≤35y		46-55y/36-45y		46-55y/≥56y		36-45y/≥56y	
	MD	P	MD	P	MD	P	MD	P
Family interaction	-2.83*	.001	-2.41*	.011	/	/	/	/
Parenting	/	/	/	/	/	/	/	/
Emotional well-being	/	/	/	/	/	/	-1.44*	.028
Material well-being	/	/	/	/	/	/	/	/
Disability-related	-1.05*	.037			-1.70*	.006	/	/

supports							
Total	-6.73*	.012	/	/	-8.24*	.012	/	/

As shown in the Table 4.34 and Table4.35, there are significant differences of overall FQOL (F=2.865, P=0.037<0.05), family interaction (F=3.751, P=0.012<0.05) and disability-related supports (F=2.903, P=0.036<0.05) among main caregivers of different age conditions. Multiple comparisons were conducted to examine the specific difference of FQOL between different age conditions. The results show that main caregivers at the age of 46-55years old are less satisfied with overall family life and disability-related supports, comparing to main caregivers under 35 years old or above 56 years old. Besides, main caregivers at the age of 46-55years old are less satisfied with family interaction than caregivers under 35years old or at the age of 36-45years old. And main caregivers at the age of 36-45 years old are less satisfied with emotional well-being than caregivers above 56 years old. In general, main caregivers at the age of 46-55 years old are more vulnerable to family quality of life comparing to other age conditions.

- Difference on education status of main caregiver

Speaking of education status of the 243 respondents in this study, there are 44 of them with education of primary school level or below, 66 of middle school level, 60 of high school or similar level, 70 of bachelor or similar level and 3 of master level or above.

Table4.36 Difference of FQOL on education status of main caregivers (N=243)

	Education status of main caregiver					
	primary school (n=44)	middle school (n=66)	high school (n=60)	bachelor or above (n=73)	F	P
			M			
Family	20.39	21.50	21.30	23.62	5.478	.001**

interaction						
Parenting	20.14	21.50	20.57	22.10	2.490	.061
Emotional well-being	12.23	12.47	12.10	12.90	.827	.480
Material well-being	15.00	15.98	15.73	17.53	5.616	.001**
Disability-related supports	13.36	12.77	13.10	13.21	.480	.696
Total	81.11	84.23	82.80	89.36	3.852	.010*

Note: Respondents with education status of master level were counted as "bachelor or above" in the analysis.

According to Table4.36, education status of main caregiver has significant effect on overall FQOL (F=3.852, P=0.10<0.05) and its sub-dimensions of family interaction (F=5.478, P=0.001<0.05) and material well-being (F=5.616, P=0.001<0.05). Further multiple comparisons show that main caregivers who have higher education level are more satisfied with their family life, especially on the dimensions of family interaction and material well-being. To be specific, main caregivers with bachelor degree or above perceive significantly higher satisfaction of overall FQOL and its sub-dimensions of family interaction and material well-being, comparing to main caregivers with primary school, middle school or high school level education. (See Table4.37)

Table4.37 Multiple comparisons of the differences on education status of main caregiver (N=243)

	education status of main caregiver					
	bachelor or above /primary school		bachelor or above /middle school		bachelor or above / high school	
	MD	P	MD	P	MD	P
Family interaction	3.23*	.000	2.12*	.007	2.32*	.004

Parenting	1.96*	.018			1.53*	.043
Emotional well-being						
Material well-being	2.53*	.000	1.55*	.010	1.80*	.004
Disability-related supports						
Total	8.24*	.003	5.13*	.036	6.56*	.009

- Difference on employment status of main caregiver

One way ANOVA analysis was conducted to examine the difference of FQOL among family groups with different employment status of main caregiver. The results show that there is significant difference of satisfaction for material well-being. Further multiple comparison indicates that main caregivers with full-time job are more satisfied with family material well-being than caregivers with part-time job (MD=1.98, P=0.013<0.05) or without job (MD=1.67, P=0.003<0.05).

Table4.38 Difference of FQOL on employment status of main caregiver (N=243)

	employment status of main caregiver					
	full-time work (n=58) M	part time work(n=31)	without job(n=136)	retired (n=18)	F	P
Family interaction	22.55	21.19	21.83	21.33	.691	.559
Parenting	21.53	20.23	21.28	21.22	.647	.586
Emotional well-being	12.88	12.74	12.13	13.22	1.300	.275
Material well-being	17.43	15.45	15.76	17.00	3.762	.011*
Disability-rela	13.36	12.97	12.93	13.61	.571	.635

ted supports						
Total	87.76	82.58	83.93	86.39	1.272	.285

- Difference on marital status of parents

Speaking of marital status of parents, four situations were considered in this study, including married and living together, married but living separately, divorced and widowhood. Among the 243 respondents, one in widowhood was excluded from ANOVA analysis because of limited sample.

Table4.39 Difference of FQOL on marital status of parents (N=242)

	marital status of parents				
	married & living together (n=196)	married &living separately (n=23)	divorced (n=23)	F	P
		M			
Family interaction	22.31	19.96	20.30	4.087	.018*
Parenting	21.34	21.22	20.17	.735	.481
Emotional well-being	12.43	12.17	13.09	.558	.573
Material well-being	16.47	14.52	15.57	3.420	.034*
Disability-related supports	13.16	13.04	12.52	.562	.571
Total	85.71	80.91	81.65	1.735	.179

Note: One respondent with marital status of "widowhood" was excluded in the analysis.

As shown in the table above, significant effect of marital status of parents has been found on the sub-dimensions of family interaction and material well-being. Further multiple comparison shows that families with married parents living together perceive significantly higher satisfaction for family interaction (MD=2.35, $P=0.023<0.05$) and material well-being (MD=1.95, $P=0.015<0.05$), comparing to families with married parents living separately.

- Difference on family location

Speaking of family location, the 243 respondents were divided into four family groups, in terms of family from provincial capital city, family from prefecture level city, family from town and family from village. According to the ANOVA analysis, significant effect of family location exists on two sub-dimensions of family life: material well-being (F=5.349, P=0.001<0.05) and disability-related supports (F=3.463, P= 0.017<0.05).(See Table 4.40) Further multiple comparison shows that families from village are less satisfied with material well-being than families from provincial capital city (MD=-2.56, P=0.001<0.05) or prefecture level city (MD=-1.89, P=0.001<0.05). Moreover, families from village are also less satisfied with disability-related supports comparing to families from town (MD=-1.32, P=0.022<0.05) or provincial capital city (MD=-1.58, P=0.005<0.05). Besides, families from village also perceive less satisfaction for family interaction comparing to families from cities. (See Table 4.41)

Table4.40 Difference of FQOL on family location (N=243)

	Family location					
	provincial capital city (n=35)	prefecture level city (n=106)	town (n=39)	village (n=63)	F	P
	M					
Family interaction	23.06	22.24	21.92	20.62	2.462	.063
Parenting	21.86	21.05	21.39	20.98	.383	.765
Emotional well-being	12.80	12.39	12.77	12.22	.399	.754
Material well-being	17.40	16.74	15.92	14.84	5.349	.001**
Disability-rela	13.71	12.97	13.97	12.40	3.463	.017*

ted supports						
Total	88.83	85.38	85.97	81.06	2.450	.064

Table4.41 Multiple comparisons of the differences on family location (N=243)

	Family location					
	village /capital city		village/prefecture level city		village /town	
	MD	P	MD	P	MD	P
Family interaction	-2.44*	.014	-1.62*	.031		
Parenting						
Emotional well-being						
Material well-being	-2.56*	.001	-1.89*	.001		
Disability-related supports	-1.32*	.022			-1.58*	.005
Total	-7.77*	.011				

- Difference on household financial situation

Taking household financial situation as independent variable, FQOL and its sub-dimensions as dependent variables, one way ANOVA analysis was conducted to know the effect of household financial situation on family quality of life. As shown in Table 4.42, there is significant difference of overall FQOL (F=9.897, P=0.000<0.05) among families of different household financial situations. Moreover, significant difference of satisfaction also exist on the sub-dimensions of family life, including parenting (F=5.333, P=0.005<0.05), emotional well-being (F=4.717, P= 0.010<0.05), material well-being (F=20.852, P=0.000<0.05) and disability-related supports (F=3.915, P=0.021 <0.05). Further multiple comparison shows that families with income far less than expenditure are significantly less satisfied with parenting, emotional well-being, material well-being, disability-related supports and also the overall FQOL, comparing to families with almost balanced income and expenditure or far greater income than expenditure, while no significant difference of satisfaction for family life exists between families with balanced income and expenditure and families with far greater income than expenditure.(See Table 4.43)

Table 4.42 Difference of FQOL on household financial situation (N=243)

	household financial situation				
	income far greater than expenditure (n=28)	almost balanced income and expenditure (n=112)	income far less than expenditure (n=103)	F	P
		M			
Family interaction	22.64	22.44	21.08	2.663	.072
Parenting	22.46	21.82	20.18	5.333	.005**
Emotional well-being	13.14	12.95	11.76	4.717	.010*
Material well-being	17.12	17.47	14.59	20.852	.000***
Disability-related supports	14.04	13.32	12.58	3.915	.021*
Total	89.39	88.00	80.19	9.897	.000***

Table 4.43 Multiple comparisons of the differences on household financial situation (N=243)

	household financial situation					
	income far less than expenditure /income far greater than expenditure		income far less than expenditure /almost balanced income and expenditure		almost balanced income and expenditure/income far greater than expenditure	
	MD	P	MD	P	MD	P

Family interaction			-1.36*	.035
Parenting	-2.28*	.013	-1.64*	.005
Emotional well-being	-1.39*	.037	-1.19*	.005
Material well-being	-2.51*	.001	-2.88*	.000
Disability-related supports	-1.45*	.013	-.739*	.047
Total	-9.20*	.002	-7.81*	.000

- Difference on parenting skill

Taking parenting skill as independent variable, FQOL and its sub-dimensions as dependent variables, one way ANOVA analysis was conducted to know the effect of parenting skill on family quality of life. As shown in Table 4.44, there is significant difference of overall FQOL (F=20.760, P=0.000<0.05) among families of different parenting skill conditions. Moreover, significant differences of satisfaction also exist on all sub-dimensions of family life, for example, family interaction (F=12.402, P=0.000<0.05), parenting (F=16.808, P=0.000<0.05), emotional well -being (F=14.265, P=0.000<0.05), material well-being (F=6.393,P=0.002<0.05) and disability-related supports (F=15.941, P=0.000 <0.05).

Further multiple comparison shows that families which are in serious shortage of parenting skills are less satisfied with overall FQOL and all sub-dimensions of FQOL than families with around average parenting skills or families with very good parenting skills. Similarly, families with around average parenting skills are less satisfied with overall FQOL and sub-dimensions of family life including parenting, emotional well-being, material well-being and disability-related supports, while no significant difference on family interaction between these two family groups. In general, families with better parenting skills show higher perceived FQOL. (See Table

4.45)

Table4.44 Difference of FQOL on parenting skills (N=243)

	parenting skills				
	serious shortage(n=72)	around average(n=152)	very good(n=19)	F	P
		M			
Family interaction	19.75	22.61	24.16	12.402	.000***
Parenting	19.01	21.89	23.95	16.808	.000***
Emotional well-being	11.13	12.80	14.84	14.265	.000***
Material well-being	15.22	16.41	18.32	6.393	.002**
Disability-related supports	12.24	13.13	16.00	15.941	.000***
Total	77.35	86.86	97.26	20.760	.000***

Table4.45 Multiple comparisons of the differences on parenting skill (N=243)

	parenting skills					
	serious shortage / around average		serious shortage /very good		around average /very good	
	MD	P	MD	P	MD	P
Family interaction	-2.86*	.000	-4.41*	.000		
Parenting	-2.88*	.000	-4.93*	.000	-2.05*	.040
Emotional well-being	-1.68*	.000	-3.72*	.000	-2.04*	.005
Material well-being	-1.19*	.020	-3.09*	.001	-1.90*	.029
Disability-related supports	-.90*	.016	-3.76*	.000	-2.87*	.000

Total	-9.51*	.000	-19.92*	.000	-10.41*	.002

- Difference on whether parents join self-help organization

Parents' self-help organization is a good strategy to provide supports among parents. Among the 243 participants, only 55 families have joined self-help organizations for parents, while 188 families have not joined any self-help organization. Independent sample t-test was conducted to analyze the differences of FQOL on the overall scale and five sub-scales between these two family groups.

Table4.46 Difference of FQOL on whether parents join self-help organization (N=243)

	Yes (n=55) (M+SD)	**No(n=188)** (M+SD)	**T**	**P**
Family interaction	23.218+4.516	21.495+4.728	2.401	.017*
Parenting	22.382+3.644	20.856+4.478	2.312	.022*
Emotional well-being	13.164+3.431	12.261+3.033	1.884	.061
Material well-being	17.582+3.750	15.809+3.497	3.253	.001**
Disability-related supports	13.546+2.808	12.957+2.718	1.401	.163
Total	89.891+14.220	83.378+14.395	2.959	.003**

As shown in Table 4.46, there is significant difference of satisfaction on total FQOL between family groups whether parents join self-help organization (P=0.003<0.05), together with significant difference of satisfaction on family interaction (P=0.017<0.05), parenting (P=0.022<0.05) and material well-being (P=0.001<0.05). To be specific, families involved in self-help organization are significantly more satisfied with total FQOL and dimensions of family life in terms of family interaction, parenting and material well-being, comparing to families not involved in self-help organization.

- Difference on whether with child without special needs

In China, there is different fertility policy for family who has child with disability. When there was one-child policy, family with disabled child was allowed to have second baby. Till now, the second child policy has been practiced for several years. It is meaningful to know if there is any difference of FQOL between families with and without normal developmental child. Among the 243 participants, 116 families have child without special needs, while 127 families do not have normal developmental children. Independent sample t-test was conducted to analyze the differences of FQOL on the overall scale and five sub-scales between the two family groups.

Table 4.47 Difference of FQOL on whether with child without special needs (N=243)

	With (n=116) (M+SD)	**Without** (n=127) (M+SD)	**T**	**P**
Family interaction	22.509+4.654	21.315+4.740	1.978	.049*
Parenting	21.724+4.151	20.724+4.475	1.801	.073
Emotional well-being	12.733+3.207	12.221+3.076	1.271	.205
Material well-being	16.328+3.659	16.102+3.605	.483	.630
Disability-related supports	13.241+2.701	12.953+2.786	.818	.414
Total	86.535+14.452	83.315+14.592	1.726	.086

As the table above shows, families with normal developmental child are significantly more satisfied with family interaction than families without normal developmental child with P=0.049<0.05, while there is no significant difference on the total scale of FQOL or other sub-dimensions of family life with P>0.05.

4.3 influencing factors of FQOL

4.3.1 Correlation analysis between potential factors and FQOL

Pearson correlation analysis was conducted to examine the relevance between the six potential factors from the Influencing Factors Questionnaire and FQOL, together with its sub-dimensions. As shown in the table below, difficulties related to child, parental attitude, family preparation and family involvement are significantly correlated to FQOL and its all sub-dimensions with P<0.05. Besides, economic pressure is significantly correlated with FQOL ((P=0.000<0.05)) and its sub-dimensions including family interaction (P=0.009<0.05), emotional well-being

(P=0.000<0.05), material well-being (P= 0.000<0.05) and disability-related supports (P=0.001<0.05), while the correlation between economic pressure and parenting doesn't reach significant level (P=0.063>0.05). Social support is significantly correlated with FQOL(P=0.001<0.05) and its sub-dimensions including family interaction (P=0.001<0.05), parenting (P=0.004<0.05), emotional well-being (P=0.016<0.05), and disability- related supports (P=0.002<0.05), while the correlation between social support and material well-being doesn't reach significant level P=0.138>0.05) Moreover, according to the correlation coefficient, there are positive correlations between parental attitude, family preparation, social support, family involvement and FQOL, together with its sub-dimensions, while economic pressure, difficulties related to child are negatively related to FQOL and its sub-dimensions. It indicates that better situation of parental attitude, family preparation; social support and family involvement predict greater satisfaction for family life among families of children with disabilities, while more serious economic pressure and difficulties related to child predicts lower satisfaction for their family life.

Table4.48 Correlation analysis between influencing factors and FQOL and its sub-dimensions (N=243)

		FQOL	Family interaction	Parenting	Emotional well-being	Material well-being	Disability-related supports
Economic pressure	Pearson correlation	-.313**	-.167**	-.120	-.269**	-.505**	-.210**
	Sig.(2-tailed)	.000	.009	.063	.000	.000	.001
Child's difficulty	Pearson correlation	-.365**	-.323**	-.211**	-.270**	-.408**	-.202**
	Sig.(2-tailed)	.000	.000	.001	.000	.000	.002
Parental attitude	Pearson correlation	.729**	.391**	.438**	.751**	.866**	.504**
	Sig.(2-tailed)	.000	.000	.000	.000	.000	.000
Family preparation	Pearson correlation	.296**	.174**	.326**	.229**	.169**	.272**
	Sig.(2-tailed)	.000	.007	.000	.000	.008	.000
Social	Pearson correlation	.217**	.210**	.182**	.155*	.095	.199**

support	Sig.(2-tailed)	.001	.001	.004	.016	.138	.002
Family	Pearson correlation	$.357^{**}$	$.218^{**}$	$.332^{**}$	$.273^{**}$	$.250^{**}$	$.356^{**}$
involvement	Sig.(2-tailed)	.000	.001	.000	.000	.000	.000

4.3.2 Stepwise multiple regression of potential factors on FQOL

In order to examine to which degree these potential factors could influence FQOL and its sub-dimensions, stepwise multiple regressions were conducted to build suitable regression model. As the goal of regression analysis in this study is prediction, which means to find the most predictive independent variable for the calibration variables to build an optimal regression analysis model, stepwise multiple regressions were recommended for data process. Stepwise multiple regressions are also called as statistical regression analysis with the principle of selecting independent variables in order according to statistical criteria to enter the regression model. (Wu, 2010, p.393)

Before the regression analysis, correlation was done to check if there is collinearity problem among the six potential factors. As shown in the following table, the Spearman correlation coefficient between economic pressure and difficulties related to child is 0.554<0.75 and the correlation coefficient between family involvement and family preparation is 0.571<0.75, which means there is moderate correlation between these two pair factors. The Spearman correlation coefficient between other factors is all less than 0.5, which means there is low level correlation between these factors. As all the correlation coefficient is less than 0.75, it again indicates that there is no collinearity problem among these predictor variables and it is suitable for regression analysis.

Table 4.49 Spearman correlation coefficient between the potential factors (N=243)

	Economic pressure	Child's difficulty	Parental attitude	Family preparation	Social support	Family involvement
Economic pressure	1.000	.554	-.370	.136	.067	.018
Difficulties related to child	.554	1.000	-.306	-.014	-.091	-.154

Parental attitude	-.370	-.306	1.000	.123	.080	.191
Family preparation	.136	-.014	.123	1.000	.288	.571
Social support	.067	-.091	.080	.288	1.000	.408
Family involvement	.018	-.154	.191	.571	.408	1.000

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

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

4.3.2.1 Stepwise regression analysis of potential factors on total score of FQOL

Taking the six potential factors as independent variables and total score of FQOL as dependent variable, stepwise regression analysis was conducted. The result is showing in Table 4.50.

$Y_{\text{total score of FQOL}}=31.143+3.985X_{\text{Parental attitude}}+0.519X_{\text{Family involvement}}-.443X_{\text{Difficulties related to child}}+0.591X_{\text{family preparation}}$

As shown in Table 4.50, four factors among the six are selected into the optimal regression mode, which means that these factors in terms of parental attitude, family interaction, and child's difficult and family preparation have significant prediction to the total score of FQOL. The multivariate correlation coefficient(R) of these four factors to the total score of FQOL is 0.783 and the decisive coefficient (R2) is 0.613, which means that these four factors can effectively explain 61.3% of the total variation of FQOL. To be specific, parental attitude can positively predict 53.1% of total family quality of life (B=3.985,P=0.000<0.05), family involvement can positively predict 5.3% of total family quality of life (B=0.519,P=0.007<0.05), difficulties related to child can negatively predict 1.6% of total family quality of life (B= -0.443,P=0.001<0.05), family preparation can positively predict 1.3% of total family quality of life (B=0.591,P=0.005<0.05). This regression model indicates that better situation of parental attitude, family involvement and family preparation predict greater overall FQOL, while less severe of difficulties related to child predicts greater overall family quality of life. Among these four factors, parental attitude is with the most obvious effect on the prediction of FQOL. In addition, collinearity test shows that the tolerance value of these four factors is between 0.631-0.891>0, while the VIF is between 1.122-1.586<10. (Wu, 2010.p390) It again indicates that there is no collinearity problem among these four factors and it is suitable for regression analysis.

Table 4.50 Statistics from regression analysis on total score of FQOL

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test	
									Toler-ance	VIF
intercept						31.143		.000		
1.Parental attitude	.729	.531	.531	273.391	273.391	3.985	.645	.000	.886	1.129
2.Family involvement	.765	.585	.053	168.880	30.690	519	.138	.007	.631	1.586
3.Child's difficulty	.775	.600	.016	119.669	9.410	-.443	-.142	.001	.891	1.122
4.Family readiness	.783	.613	.013	94.325	7.912	.591	.141	.005	.650	1.539

4.3.2.2 Stepwise regression analysis of potential factors on family interaction

Taking the six potential factors as independent variables and family interaction as dependent variable, stepwise regression analysis was conducted. The result is showing in the following table.

Table 4.51 Statistics from regression analysis on family interaction

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test	
									Toler-ance	VIF
intercept						16.077				
1.Parental attitude	.391	.153	.153	43.440	43.440	.624	.312	.000	.902	1.109
2.Child's	.445	.198	.045	29.589	13.488	-.215	-.212	.001	.901	1.110

difficulty										
3.social support	.474	.225	.027	23.101	8.319	.484	.165	.004	.989	1.011

$Y_{\text{family interaction}}=16.077+0.624X_{\text{Parental attitude}}-0.215X_{\text{Difficulties related to child}}+0.484X_{\text{social support}}$

As shown in the table above, three factors are selected into the optimal regression mode $Y_{\text{family interaction}}=16.077+0.624X_{\text{Parental attitude}}-0.215X_{\text{Difficulties related to child}}+0.165X_{\text{social support}}$, which means that the three factors in terms of parental attitude, child's difficult and social support have significant prediction to the satisfaction for family interaction. The multivariate correlation coefficient(R) of these four factors to family interaction is 0.474 and the decisive coefficient (R^2) is 0.225, which means that these three factors can effectively explain 22.5% of the total variation of family interaction. To be specific, parental attitude can positively predict 15.3% of satisfaction for family interaction (B=0.624, P=0.000<0.05), difficulties related to child can negatively predict 4.5% of satisfaction for family interaction (B=-0.215, P=0.001<0.05), social support can positively predict 2.7% of satisfaction for family interaction (B=0.484, P=0.004<0.05). This regression model indicates that better situation of parental attitude and social support predict higher satisfaction for family interaction, while less severe of difficulties related to child predicts higher satisfaction for family interaction. Among these three factors, parental attitude is with the most obvious effect on the prediction of satisfaction for family interaction. In addition, collinearity test shows that the tolerance value of these four factors is between 0.901-0.989>0, while the VIF is between 1.011-1.110<10. It again indicates that there is no collinearity problem among these three factors and it is suitable for regression analysis.

4.3.2.3 Stepwise regression analysis of potential factors on parenting

Taking the six potential factors as independent variables and parenting as dependent variable, stepwise regression analysis was conducted. The result is showing in the following table.

Table 4.52 Statistics from regression analysis on parenting

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test Toler-ance	VIF
intercept						6.089				
1.Parental attitude	.438	.192	.192	57.299	57.299	.719	.391	.000	.968	1.033
2.family preparation	.520	.271	.078	44.508	25.817	.248	.198	.004	.654	1.530
3.family involvement	.533	.284	.014	31.608	4.507	.162	.145	.035	.640	1.562

$Y_{\text{parenting}}=6.089+0.719X_{\text{Parental attitude}}+0.248X_{\text{family preparation}}+0.162X_{\text{family involvement}}$

As shown in the table above, three factors are selected into the optimal regression mode $Y_{\text{parenting}}=6.089+0.719X_{\text{Parental attitude}}+0.248X_{\text{family preparation}}+0.162X_{\text{family involvement}}$, which means that the three factors in terms of parental attitude, family preparation and family involvement have significant prediction to the satisfaction for parenting. The multivariate correlation coefficient(R) of these four factors to parenting is 0.533 and the decisive coefficient (R^2) is 0.284, which means that these three factors can effectively explain 28.4% of the total variation of parenting. To be specific, parental attitude can positively predict 19.2% of satisfaction for parenting (B=0.719, $P=0.000<0.05$), family preparation can positively predict 7.8% of satisfaction for parenting (B=0.248, $P=0.004<0.05$), family involvement can positively predict 1.4% of satisfaction for parenting (B=0.162, $P=0.035<0.05$). This regression model indicates that better situation of parental attitude, family preparation and family involvement predict higher satisfaction for parenting of children with disabilities.

Among these three factors, parental attitude is with the most obvious effect on the prediction of satisfaction for parenting. In addition, collinearity test shows that the tolerance value of these four factors is between 0.640-0.968>0, while the VIF is between 1.033-1.562<10. It again indicates that there is no collinearity problem among these three factors and it is suitable for regression analysis.

4.3.2.4 Stepwise regression analysis of potential factors on emotional well-being

Taking the six potential factors as independent variables and emotional well-being as dependent variable, stepwise regression analysis was conducted. The result is showing in the following table.

Table 4.53 Statistics from regression analysis on emotional well-being

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test	
									Toler-ance	VIF
intercept						.364				
1.Parental attitude	.751	.564	.564	311.721	311.721	.978	.735	.000	.988	1.012
2.family preparation	.766	.586	.022	169.949	12.850	.136	.150	.000	.988	1.012

$Y_{\text{emotional well-being}}=0.364+0.978X_{\text{Parental attitude}}+0.136X_{\text{family preparation}}$

As shown in the table above, two factors are selected into the optimal regression mode $Y_{\text{emotional well-being}}=0.364+0.978X_{\text{Parental attitude}}+0.136X_{\text{family preparation}}$, which means that the two factors in terms of parental attitude and family preparation have significant prediction to the satisfaction for emotional well-being. The multivariate correlation coefficient(R) of these two factors to emotional well-being is 0.766 and the decisive coefficient (R^2) is 0.586, which means that these two factors can effectively explain 58.6% of the total variation of emotional well-being. To be specific, parental attitude can positively predict 56.4% of emotional well-being (B=0.978, P=0.000<0.05) and family preparation can positively predict 2.2% of emotional well-being (B= 0.136, P= 0.000 < 0.05). This regression model indicates that better situation of parental attitude and family preparation predict greater emotional well-being in families of disabled children. Besides, parental attitude is with greater effect on the prediction of emotional well-being than family preparation. In addition, collinearity test shows that the tolerance value of the two factors is 0.988>0, while the VIF is 1.012<10. It again indicates that there is no collinearity problem among the two factors and it is suitable for regression analysis.

4.3.2.5 Stepwise regression analysis of potential factors on material well-being

Taking the six potential factors as independent variables and material well-being as dependent variable, stepwise regression analysis was conducted. The result is showing in the following table.

Table 4.54 Statistics from regression analysis on material well-being

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test	
									Toler-ance	VIF
intercept						5.587				
1.Parental attitude	.866	.750	.750	722.551	722.551	1.170	.762	.000	.822	1.217
2.economic pressure	.887	.786	.037	442.029	41.145	-.163	-.218	.000	.849	1.178
3.family involvement	.894	.800	.013	317.946	15.685	.109	.117	.000	.960	1.042

$$Y_{\text{material well-being}}=5.587+1.170X_{\text{Parental attitude}}-0.163X_{\text{economic pressure}}+0.109X_{\text{family involvement}}$$

As shown in the table above, three factors are selected into the optimal regression mode $Y_{\text{material well-being}}=5.587+1.170X_{\text{Parental attitude}}-0.163X_{\text{economic pressure}}+0.109X_{\text{family involvement}}$, which means that the three factors in terms of parental attitude, economic pressure and family involvement have significant prediction to the satisfaction for material well-being. The multivariate correlation coefficient(R) of these four factors is 0.894 and the decisive coefficient (R^2) is 0.800, which means that these three factors can effectively explain 80.0% of the total variation of material well-being. To be specific, parental attitude can positively predict 75.0% of material well-being (B=1.170, P=0.000<0.05), economic pressure can negatively predict 3.7% of material well-being (B=-0.163, P=0.000<0.05), family involvement can positively predict 1.3% of material well-being (B=0.109, P=0.000<0.05). This regression model indicates that better situation of parental attitude and family involvement predict greater material well-being and less economic pressure predicts greater material well-being. Among these three factors, parental attitude is with the most obvious effect on the prediction of material well-being. In addition, collinearity test shows that the tolerance value of these four factors is between 0.822-0.960>0, while the VIF is between 1.042-1.217<10. It again indicates that there is no collinearity problem among these three factors and it is suitable for regression analysis.

4.3.2.6 Stepwise regression analysis of potential factors on disability-related support

Taking the six potential factors as independent variables and disability-related support as dependent variable, stepwise regression analysis was conducted. The result is showing in the following table.

Table 4.55 Statistics from regression analysis on disability-related support

Input variable order	R	R^2	ΔR^2	F	ΔF	B	(β)	P	Collinearity test Toler-ance	VIF
intercept						3.559				
1.Parental attitude	.504	.254	.254	81.901	81.901	.528	.454	.000	.968	1.033
2.family preparation	.571	.327	.073	58.191	25.988	.194	.274	.000	.968	1.033

$Y_{\text{disability-related support}}=3.559+0.528X_{\text{Parental attitude}}+0.194X_{\text{family preparation}}$

As shown in the table above, two factors are selected into the optimal regression mode $Y_{\text{disability-related support}}=3.559+0.528X_{\text{Parental attitude}}+0.194X_{\text{family preparation}}$, which means that the two factors in terms of parental attitude and family preparation have significant prediction to the satisfaction for disability-related supports. The multivariate correlation coefficient(R) of these two factors to disability-related supports is 0.571 and the decisive coefficient (R^2) is 0.327, which means that these two factors can effectively explain 32.7% of the total variation of disability-related supports. To be specific, parental attitude can positively predict 25.4% of satisfaction for disability-related supports (B=0.528, P=0.000<0.05) and family preparation can positively predict 7.3% of satisfaction for disability-related supports (B=0.194, P=0.000<0.05). This regression model indicates that better situation of parental attitude and family preparation predict higher satisfaction for disability-related supports. Besides, parental attitude is with greater effect on the prediction of satisfaction for disability-related supports than family preparation. In addition, collinearity test shows that the tolerance value of the two factors is 0.968>0, while the VIF is 1.033<10. It again indicates that there is no collinearity problem among the two factors and it is suitable for regression analysis.

Chapter 5 Qualitative Research results

Families of children with disabilities at young age interact with various aspects in their family life. The qualitative approach in this study dedicates to discovery the parameters that influence their family quality of life and the potential strategies that may improve their satisfaction for family life. Through investigating the viewpoints and experiences of caregivers and professionals of disabled children at young age, elements of influencing parameters and improving strategies are identified as concepts /nodes and classified into categories during the cyclical coding-recording process, which eventually leads to emergence of the prototypes of model. The model of influencing parameters aims at presenting the structure of the influencing parameters of FQOL among families of children with disabilities at young age, while the model of improving strategies targets at exploring the potential strategies of FQOL and the corresponding framework according to the findings based on systematically analysis with CAQDAS NVivo11 Plus.

Research results generating from constant comparative analysis of 19 semi-structured in-depth interview transcripts are presented in the following part. Based on the research results, the following three research questions have been responded to:

Ⅱ. What is the current status of FQOL (satisfaction with family life) in families with disabled children at young age?

Ⅳ. What influencing parameters contribute to the FQOL in Chinese families of young children with disabilities?

Ⅴ. What strategies can help improve the FQOL for Chinese families with disabled children at young age?

Research results from qualitative approach will be presented in this chapter.

As this research also aims at discovering the influencing parameters of FQOL in families of disabled children at young age, and exploring the potential strategies for improving their family outcomes, qualitative research characterized with semi-structured interview has been applied to attain this research purpose. The results will be presented in three parts: current situation of FQOL, influencing parameters of FQOL and improving strategies of FQOL.

5.1 Current status of FQOL

Before the exploration of influencing parameters and improving strategies of family quality of life, the current status of FQOL among families of young children with disabilities was investigated in this study. Results based on exploratory sentiment analysis and text analyses are presented as follows.

5.1.1 Exploratory sentiment analysis

Using automatic emotion recognition function in NVivo11, the content of the interview manuscript was codified and analyzed paragraph by paragraph according to the emotional tendency. Four emotion types were obtained: very negative, more negative, more positive, and very positive. As shown in Figure 5.1, 54% of references according to emotional tendency are “negative”, while 46% of references are “positive”. To be specific, 14% of references are “very negative”, while 7% are “very positive”. According to the statistics, “negative” emotion tendency accounts more than half of the proportion, occupying a dominant position in all data. The results indicate the participants are generally with more negative emotional experience of FQOL among families of disabled children at young age. “very negative” emotional experience is two times frequently mentioned than “very positive” emotional experience.

In order to know the differences of emotional tendency among participants, references of “very positive” and “very negative” according to participant were separately visualized and presented in Figure 5.2-3. All of the 19 participants expressed more times of “very negative” than “very positive” emotion in the interview transcripts. Among them, interviewee P3 expressed most times of “very negative” emotions with references of 25, while interviewee P2 expressed most times of “very positive” emotions with references of 6. Both interviewees are professionals. Among caregivers, interviewee C2 expressed most times of “very negative” emotions with references of 13, while interviewee C12 expressed most times of “very positive” emotions with references of 4.

It indicates that professional P3 and caregiver C2 are with more negative emotional experience of FQOL comparing to their counterparts, while professional P2 and caregiver C12 are on the contrary.

Interviewee P3 is a 31years old social worker in one social work organization in the provincial capital city of Sichuan Province. This institution is a non-profit, non-enterprise and non-governmental Organization (NGO). It provides early intervention, nursing care, education & rehabilitation and vocational training services for children and adolescents aged 3-6 and 16-59 with severe physical disability, intellectual disability, autism and so on. Hence, based on her personal working experience with families of children with severe disabilities, interviewee P3 holds more negative perspective to FQOL of these families.

Interviewee C2 is a 28 years old mother of one girl with pervasive developmental delay less than 2 years old. C2 is full-time taking care of her daughter as her husband comes back home once every two months, or even longer because of working in faraway place. C2 was an orphan without family member when she was young. Currently, the child has only one grandmother who is too old to help with taking care of the child. This family is from the suburbs of a county-level city. Besides, the question why her child was born with this developmental disability always bothers C2 as everything was fine during the pregnancy and delivery process.

Interviewee P2 is the head of special education department in one education technology company. This company was founded in 2015, specializing in Montessori early childhood education. Besides early education, this company also provides hearing rehabilitation and speech & language training for children with hearing impairment aged 0-6 years old. Generally, the rehabilitation cycle in this company is around 2 years and after that most of these children are able to study in general kindergarten or elementary school.

Interview C12 is a 37 years old mother who has a boy with autism around 3 years old. This boy is the second child of this family. After her son was diagnosed with autism, C12 has been full-time taking care of the child for one year. Her family owns a shop and her husband is responsible for taking care of their home business as they have their own shop. Her husband also helps her take care of the boy when he has free time. Besides, the grandparents of the boy help the family of housework and look after the school-age older daughter. After her son was suspected as child with autism, C12 has been active to learn the professional knowledge and rehabilitation skills from books, web-pages, online videos and so on. She prefers to focus more on providing child with appropriate intervention from parents and professionals than to doubt whether the child is with autism or not.

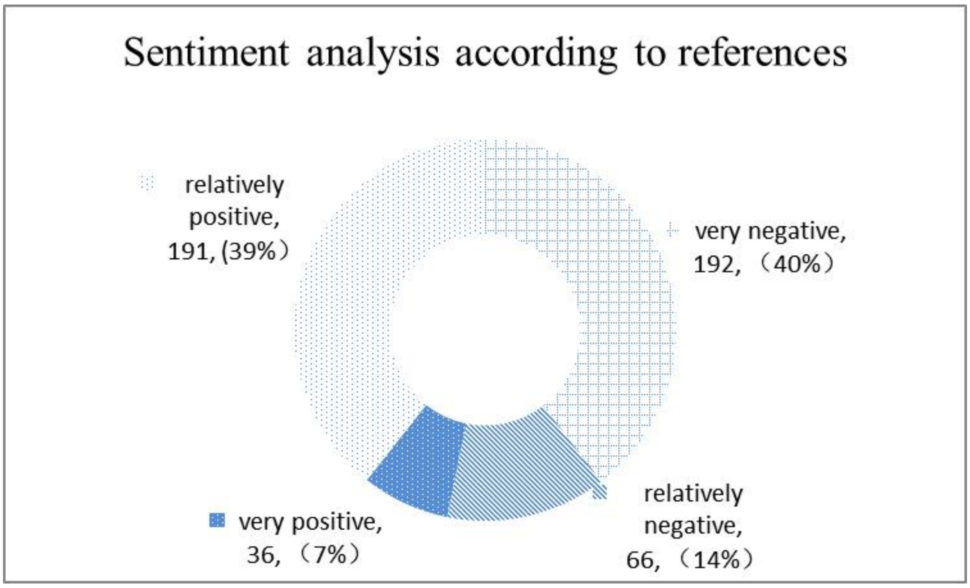


Figure 5.1 Result of exploratory sentiment analysis according to references (number, percentage)

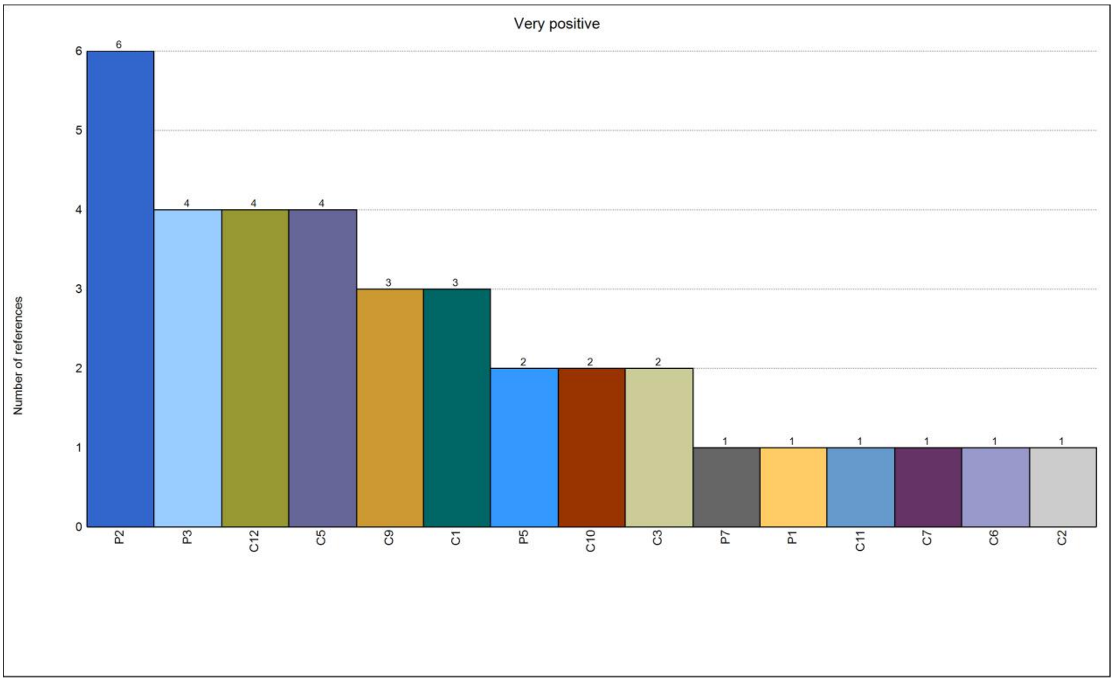


Figure 5.2 References of "very positive" according to participant

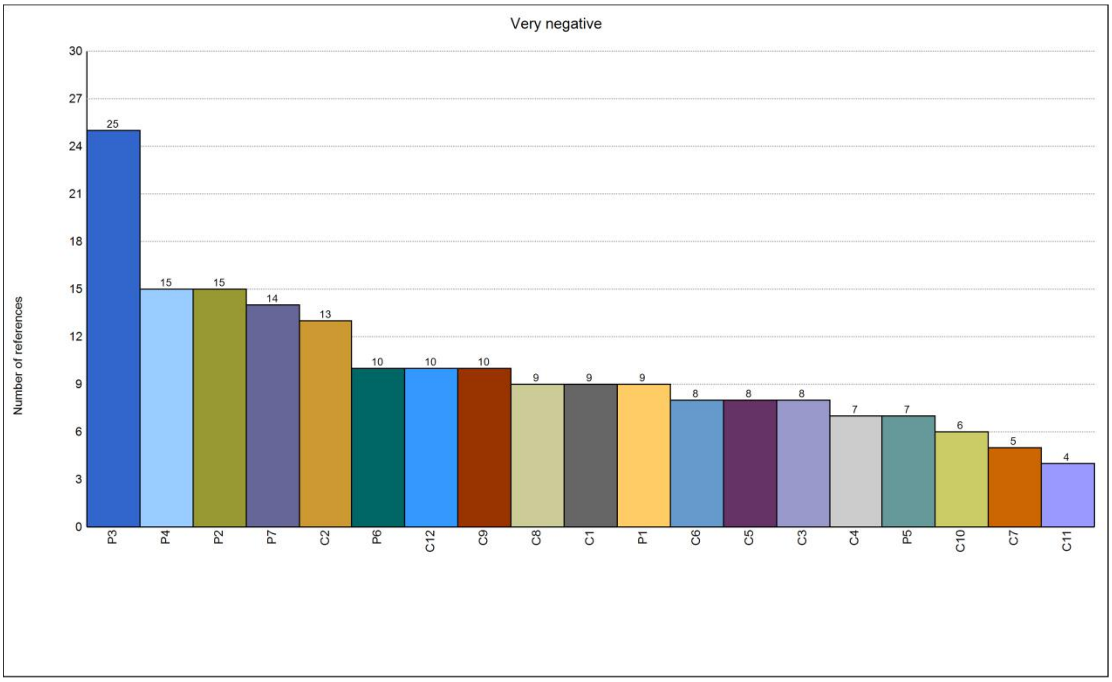


Figure 5.3 References of "very negative" according to participant

5.1.2 Coding analysis

Current status of FQOL represents interviewees' subjective feeling of FQOL among families with disabled children at young age. As shown in Table 5.1, the category of current situation of FQOL includes two subcategories: general description of FQOL and aspects of dissatisfaction.

Table 5.1 Coding information of current status of FQOL

Categories	**Subcategories**	**Concepts**	**Sources**	**References**
Current situation of FQOL	General description	dissatisfaction	7	7
		complain	2	2
	Aspects of dissatisfaction	psychological burden	11	22
		family leisure time	3	3
		family economic	2	2

Both of the concepts below the category of general description of FQOL are negative which has been named as complain and dissatisfaction. Speaking of the aspects of dissatisfaction in family life, psychological burden has been frequently mentioned. Besides, family economic and family leisure time have also been mentioned as dissatisfying aspects of family life, as participants said,

"*When I heard that my child is with disability, I was terrified; my mood at that time was simply beyond words. I' m definitely not satisfied with my current life situation, and there are many complaints in my family life. The main part is economic dissatisfaction, and the other is that I feel tired of taking care of my baby. My husband is not around. When I need help, my husband is not there. I feel very stressed and tired."* (C2)

"*Among this kind of families, 10 out of 10 families are dissatisfied, and we feel hopeless. There seems no future and the lives of adults and children are ruined.......if mothers take care of this kind of child, they are likely to have serious emotional problem. Most parents (with disabled children) i know are not in good psychological status. For example me, I was often lose control of my temper and hit my child when I was angry.* " (C8)

"The families I worked with, most of them often complain. Their family status is not good, and only small part of parents is in good state of life, often sharing positive

things every day. Several parents I have close relationship, even told me that they had thoughts of suicide.......Most families may lack awareness of leisure and entertainment. It seems the main activity in free time is to watch TV series on mobile phone. If go out during weekend, the activity is basically according to the child, for example, going to the playground."(P1).

Speaking of FQOL, the interviewees frequently responded with "dissatisfaction" and "complain" for satisfaction situation of their family life as they feel "hopeless". To be specific, poor family status and huge psychological burden have been perceived by parents who even result in thought of suicide, and dissatisfaction with the family economy and leisure time is also mentioned by parents. Parents often feel too tired for taking care of disabled child, which may result in serious emotional problems for main caregivers. Besides, these families usually lack the awareness of leisure and entertainment as they are too busy for coping with their children with disabilities.

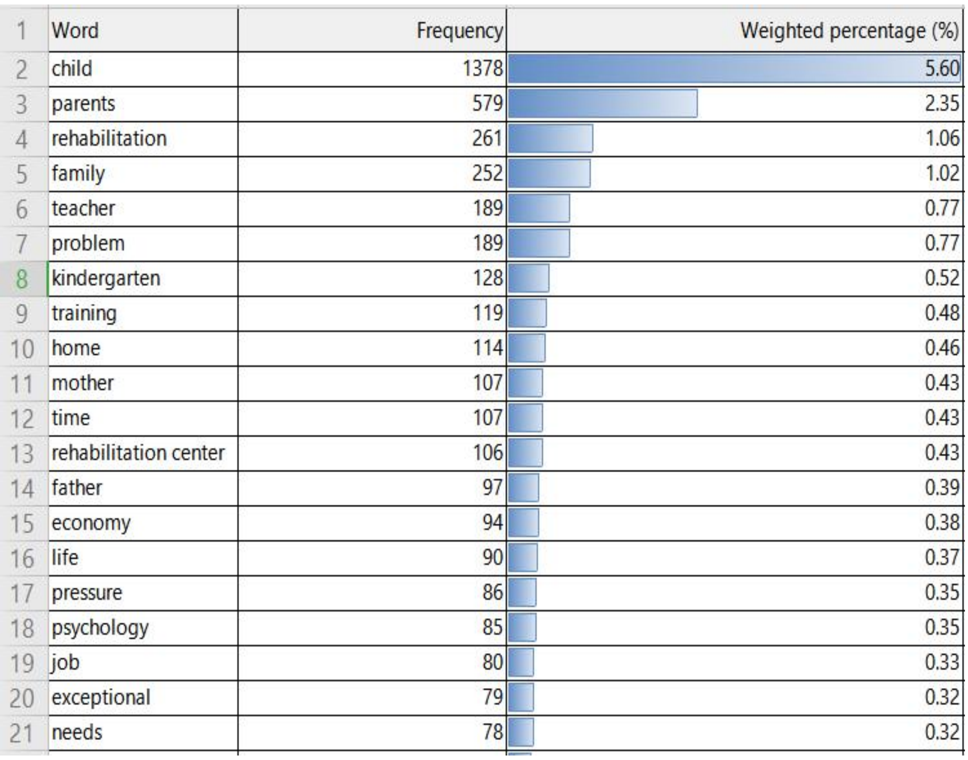
5.2 Influencing parameters of FQOL

In this study, the influencing parameters of FQOL among families with disabled children at young age were explored on the basis of systematical coding and constant comparative analysis of the transcripts from 19 interviews. Results from word frequency analysis, coding analysis, comparative analysis are presented in the following paragraphs. Thereafter, the exploratory model of influencing parameter of FQOL emerges on the basis of these analyses.

5.2.1 Word frequency analysis

Using word frequency query function in NVivo11, the word frequency of the transcripts was discovered. As the Figure 5.4 and 5.5 shows, "*child", "parents", "rehabilitation", "family", "teacher", "problem", "kindergarten", "training", "home", "mother", "time", "rehabilitation center", "father", "economy", "life", "pressure", "psychology", "job", "exceptional", "needs"* are the top 20 most frequently mentioned words by the interviewees on the topic of family quality of life. It reveals that child with disability, parents, rehabilitation and family are the most focused points on the topic of FQOL.

Figure 5.4 Word cloud according to word frequency analysis



1	Word	Frequency	Weighted percentage (%)
2	child	1378	5.60
3	parents	579	2.35
4	rehabilitation	261	1.06
5	family	252	1.02
6	teacher	189	0.77
7	problem	189	0.77
8	kindergarten	128	0.52
9	training	119	0.48
10	home	114	0.46
11	mother	107	0.43
12	time	107	0.43
13	rehabilitation center	106	0.43
14	father	97	0.39
15	economy	94	0.38
16	life	90	0.37
17	pressure	86	0.35
18	psychology	85	0.35
19	job	80	0.33
20	exceptional	79	0.32
21	needs	78	0.32

Figure 5.5 The top 20 most frequently mentioned words

5.2.2 Coding analysis

Based on systematical coding analysis, 24 subcategories were extracted from the 115 concepts in the transcripts of the 19 interview records, and thereafter six influencing factors were discovered in terms of: difficulties related to child, economic factor, family involvement, family preparation, parental attitude, and social support. The results from coding analysis will be presented separately in the following section.

- Parameter one: Difficulties related to child

This parameter refers to the child's difficulties perceived by caregivers and teachers which affect family quality of life. There are four subcategories: child's performance, child's developmental expectation, child's special needs, and child’s health status. Among them, child's performance and child's developmental expectation are the two main contributing factors with references of 25 and 21 respectively.

Table 5.2 Coding information of difficulties related to child

Subcategories	Number of Concepts	Sources	References
child's performance	5	10	25
child's developmental expectation	3	11	21
child's special needs	2	5	6
child's health status	3	2	4

(1) Child’s performance describes child’s developmental performance. To be specific, child's development status, child's behavior problem, emotional problem, self-care ability, difficulties in raising are included in this subcategory, as participants said，

“My son, his cognition development is far behind children at the same age. Now he is 7 years old, his cognition level is like child at 3-4 years old. But he behaves quite well, for example he is very obedient when he goes to other child’s home. When the trash can is full at home, he also knows to take the garbage to big trash bin outside. I'm very pleased for his behavior.” (C9)

"*My child has many serious problems, for example his emotional problems and nerve hyperactivity lead to a lot problem in our family life*."(C1).

According to participants' description, their children's performance affects their family life experience. Usually, parents from families of children with poor performance in terms of developmental status, serious behavior or emotional problems, low self-care ability and difficulties in raising up need to face more problems and may experience more dissatisfaction in their family life.

(2)Child's developmental expectation describes the potential or possibilities for child's development. To be specific, child's difficulties in future, uncertainty of child's development and child's improvements are included in this subcategory, as participants said,

"The main problem is that you can't know how the child will develop. When child is still small, you can see the current problem of the child, but you can't predict the development and rehabilitation possibilities. I feel my family is always crossing the river by feeling the stones. For example, i had no idea when my son could walk by himself. I was often asking the doctors this question, but they also can't answer me."(C1)

"An important aspect is the troubles related to child's rehabilitation training, because the progress of child's rehabilitation may be very slow, such as children's toilet problem, eating problem. If parents can't see obvious improvements of child's difficulties after spending 80 000 or 10 000 Yuan, they will feel huge psychological pressure and frustration. " (P2)

"When my son was 5 years old, i was told by doctor to be ready that my son may be impossible to be independent. My family is worrying that even we can prepare some money for him; he doesn't know how to take care of himself. I and his father both are more than 40 years old. We are worried about the self-care and survival of him in the future."(C9)

On the topic of child's developmental expectation, parents described their "huge psychological pressure and frustration" of their children development and rehabilitation possibilities. Child's difficulties in future, uncertainty of child's development and slow progress of child's improvements are perceived as "main problem" and "important aspect" for their family life by participants.

(3) Child's special needs in terms of type and degree of disability and child's health status also affect family's quality of life, as participants said,

"According to my experience, parents of children with cerebral palsy have better family status than that of parents of children with autism, maybe it is because the symptoms of children with cerebral palsy are obvious and clear, there is no doubt, and the reason is also clear." (P1)

"To be honest, I think my son is still lucky. Unfortunately, he has autism, but fortunately, he is relatively mild in autism, and his emotions are very peaceful." (C12)

"*My grandson is often ill, he doesn't eat much, often has a cold. Sometimes, he does not eat for whole day, and has convulsions from time to time. His problem bothers the family a lot.*"(C6)

According to participants' description, there are different family status between families of children with different types and severity of disabilities. For example, parents of child with cerebral palsy may have better family status than parents with autistic child because of "clear reason" and "obvious symptoms" of the special needs, and parents of child with mild autism feel "lucky" than parents of child with severe autism. Besides, families also suffer from child's poor health condition.

- Parameter two: Economic factor

Economic factor refers to the financial situation of the family. Three subcategories are included in this parameter: economic burden related to rehabilitation, family economic sources, and other family economic burden, all of which are frequently mentioned by participants with relatively more references. Among them, economic burden related to rehabilitation is the most important contributing factor to family's economic burden, followed by family economic sources.

Table 5.3 Coding information of economic factor

Subcategories	Number of Concepts	Sources	References
economic burden related to rehabilitation	8	14	33
family economic sources	4	14	31
other family economic burden	5	14	24

(1)Economic burden related to rehabilitation describes family economic pressure which related to child's rehabilitation directly or indirectly. For children with disabilities, young age, especially the age before 6 is the critical period for their development and rehabilitation. For families of disabled children at young age, economic burden from children's rehabilitation brings great pressure to the family life. To be specific, economic burden from children's rehabilitation includes cost for training program, family migration for rehabilitation, settling in two places, renting fee, transportation fee, rehabilitation aid costs, and expensive services from hospital, as participants said,

*"Generally, the families of these children (children with disabilities) always feel that money is not enough, unless the family is extremely rich. The rehabilitation training for child is very expensive, especially during the younger age. If you want your child's ability to be improved, all of it is investing with money. More than 100 Yuan per class, so you can count how much money is needed in one da*y." (P2)

"One child with special needs in Chengdu, even the child's special needs is just moderate, if the child takes 3-4 rehabilitation lessons a day, the expense in one year is generally more than 100,000 Yuan. Now intervention lessons are becoming more and more expensive. In many places, it is 100 or 120 Yuan for half an hour. A better one is 200 Yuan for 50 minutes, even higher. Then in one day it will be 600-700 Yuan." (C8)

"Now, the rehabilitation subsidy from government is 14,000 per year, but in fact, a

child's annual rehabilitation cost is on average 30,000-50,000 Yuan.......Besides, families sometimes migrate to other city for better rehabilitation services. For example, there are families from N, S ,G, D [6] *city come to Chengdu for rehabilitation. Sometimes, we even have families from other provinces.......Moreover, for many families; the child's cochlear implant is at family's own expense. Many of them are made by loans, so it is still a big burden on the family."* (P3)

"My family is from G city, not in Chengdu. The subsidy from our local government is 12,000 Yuan, which is even less than half of the rehabilitation expense here in Chengdu. "

The training fee here is around 70,000 to 80,000 Yuan a year, including the rent, living expenses, and transportation fee." (C4)

"The rehabilitation fee of my child, and we (only I and my child) live here. It is equivalent to have two families. The expenses must be large. " (C7)

"We come here for rehabilitation training, the lesson is free. But every time we come, we need take train, taxi and bus. it costs more than 100 Yuan for transportation, and more than 300 Yuan a week." (C9)

"Some parents take extra lessons for their children in hospital and some hospitals are more for profits. In these hospitals, it takes thousands Yuan to do an examination, more than ten rehabilitation items are arrange for a child per day, and various kinds of instruments and equipment. Then it will cost tens of thousands in a month." (P4)

According to participants' introduction, families of children with disabilities experience great economic pressure related to children's rehabilitation, because on one hand the rehabilitation service is quite expensive, on the other hand the annual rehabilitation subsidy from government is far from the actual rehabilitation expenditure. Moreover, in order to get better rehabilitation services, families may need to migrate to other places which results in extra expenditure for transportation

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[6] N,S,G,D, they are prefecture-level city in Sichuan province, while Chengdu is the provincial capital city.

and renting. Besides, rehabilitation aid costs and expensive services from hospital will increase economic pressure on families.

(2) Family economic sources describe the channels of household economic income. It is mainly about the employment situation of parents, including concepts such as impossible to work of caregiver, only father work, low wage, and possibilities for suitable job, as participants said,

"The biggest difficulty in my family is the financial difficulty. There are too many places to spend money. My child is still small and still eating milk powder. My husband's salary is not high and we have to repay the car loan. The main problem is that I can't work. In our case, it is not easy to find job. Half day work is basically not available. Even if the child goes to school in the future, it is still not easy to find work starting at 9 am and finishing at 4 pm."(C2)

"The main difficulty in my family life is the source of income. Because for a child like my daughter, there must be one person taking care of her all the time, so I can't go to work. Only dad works, and the salary is 3 000-4 000 a month. We need to rent a flat and have to pay tuition, etc." (C3)

In families of children with disabilities, usually one family member, often the mother needs to be the main caregiver who takes care of the children with disabilities for full-time. This main caregiver can't work because of time-consuming of taking care of child with disability. Then the father needs to be the main and even only economic source. Besides, the average salary of Sichuan province is comparatively low which even not enough for only the rehabilitation services. Besides, it is difficult to find job which can balance childcare and work.

(3)Except from child's rehabilitation and family economic source, family with disabled child also have to face other economic burden resulting from some family conditions. In this study, family background, family economic dilemma, burden related to the elderly, child education expense, and loan were mentioned as contributing factors, as participants said, *"We haven't been to big city for child's rehabilitation, because my family is just a middle class family in L city. We have another older child at school age. As we have both the elderly and the children to take care of, it is impossible to empty all their savings to treat the child's disease. To be practical, my son's disease can't be cured according to what I know. "* (C12)

"For the past few years, the living conditions in my family have been quite difficult. Last year, there were many sudden situations. The grandfather of the child got cancer, and I had surgery on my eyes. The younger son who is 3 years old now, was critically ill nearly to death at the end of last year. My family economy is very difficult." (C4)

"These two years, we had spent much money on my son's rehabilitation. I and my husband, both are from village without good family economic conditions. Currently, we still have loan for two flats in Chengdu. It's quite stressful for us. If the elderly are seriously ill, then we really can't afford rehabilitation for my son." (C8)

"I just have middle school education. People of my age neither have any skills nor high level education. What I can do is to grow food and vegetables by myself. And because of the green channel loan from government, my elder daughter could study in university." (C9)

In China, medical care and non-compulsory education including preschool education and education after middle school are not free. For families with disabled children at young age, child's preschool education, and other child's education, medical care for family members bring extra economic burden. Besides, other family conditions, such as parents' education status, parents' family background and so on also increase family economic burden.

- Parameter three: Parental attitude

Parental attitude refers to parents' attitude to the fact of having child with special needs and also their psychological situation. There are three subcategories included in this parameter: attitudes to the child, psychological status and attitudes to rehabilitation and education. Among them, attitude to the child is the most important subcategory with most references, following by psychological status.

Table 5.4 Coding information of parental attitude

Subcategories	Number of Concepts	Sources	References
attitude to the child	10	18	71
psychological status	10	17	56
attitude to rehabilitation and education	2	7	9

(1) Attitude to the child describes parents' attitudes to their child with special needs, which reflect parental understanding and acceptance of their children's special needs. In this study, incorrect understanding of children's disabilities, other family members' acceptance of child's special needs, unaware of the severity of child's difficulties, correct understanding of children's disabilities, deny for child's special needs, out of expectation, other family members doesn't accept child's special needs, excessive expectations of child, reasonable expectations of child's development, and suspecting child's diagnosis have been mentioned by participants as contributing factor to their family quality of life, as they said,

"I have no idea at all; even don't know the concept of autism. I thought the child could listen to the music, indicating that the hearing is okay. He can look and point with finger, indicating that the eyes are okay, and he can understand things, indicating his brain is also OK. But he gave no response when he was called by others, and he just walked away by himself as he wanted to go out. He also didn't have eye contact when saying hello to people. At the time, I didn't know that these were the manifestations of autism. I thought autism was introverted and did not like talking." (C12)

"At first, my family didn't believe the diagnosis and expected for good luck. We though the child would be normal later. In my family, only I am trying to know his special needs and characteristics. His father and sister dislike him. His sister refuses

to take him to public place as she feels ashamed of him. " (C9)

"Autism is unacceptable for ordinary families. If child with less arms or legs, parents could know it as soon as they were born, but these children, parents find out their problem during the time they grow up. If a child lacks arms and short legs, they will know it, but these children have grown up and found out that the child has a problem; I haven't fully accepted it until now, and I didn't want to intervene at first. I think my child is normal and there is no big problem. My family has always known the government subsidy policy. But we don't want to have a record of disability for our child if he could be recovered after intervention." (C8)

"There are some hidden problems, such as the lack of understanding of children's problems, and excessive expectations of children." (P4)

"Many parents still hope that through rehabilitation, their children will be recovered as soon as possible. They expect their children to be completely independent, to study in general schools, take college entrance examinations, work, get married, etc."(P7)

"My acceptance of daughter's visual impairment is also a slow process. Fortunately, everyone in my family is very supportive. My mother is a doctor. She suggested me to take examination for my daughter when she was 3 months old. After returning home from the operation, she suggested us to ask the community to see if we can get a disability certificate." (C10)

According to participants' description, on the topic of attitudes to the child, parents of disabled children are lack of or with incorrect understanding of their children' special needs; they tend to deny or suspect the diagnosis of their children's special needs and hope their children will "be normal later" on "good luck" or will "be recovered as soon as possible " through rehabilitation; they don't want to leave a "disability record" for their children and expect them to "be completely independent" which may be excessive expectations for their children with disabilities; it is likely to be a slow process for parents to accept their children's special needs and family members' acceptance of children with disabilities could be a supportive force for parents. The lack of or incorrect understanding of children's special needs among family members results in denial of children's special needs and excessive expectation for their children, which may bring high possibility of frustration to the family and even result in family conflicts.

(2) Psychological status describes family's psychological status facing with the fact of child's special needs. Bothered by the causes of disability, worried about falling behind normal children, family attitude change, pessimism and despair, worried about child's future, worried about child's safety, worried about child's mental health, understanding from family members, worried about child's education opportunity, worried about child's rehabilitation result were mentioned as contributing factors, as participants said,

"Because having a child with special needs, I often feel hopeless and worry about my child's future. I am worried about whether she can adapt to class in kindergarten like a normal child...I was told by doctor that there could be many reasons for my child's disability. It may be the genetic, the pregnancy, or the delivery process. But I still don't know the exact reason. I am always thinking why others can have healthy child, but my child is ..." (C2)

"As there is still no clear reason for autism, in family, the father may think it is mother's fault, while mother will suspects it may be the father's fault. It is common to attribute the cause to the partner or other family factor among families with autistic children." (P1)

"My family had one serious car accident and thereafter the child started to be different.... Sometimes, grandparents attribute the child's disability to mother's fault, but in fact, it is not necessary to worry about whether the child is autistic. Whether it is autistic or not, the child is lagging behind the normal child, and intervention is needed...If there is child with severe autism, mother's whole will be ruined and there

will be no hope for future. ” (C8)

“Parents in big cities care more about children’s social integration, while parents from small towns or villages are more focus on children’s rehabilitation training, and some parents give up immediately when they were told that their children with disabilities...Parents worry most about the effectiveness of their children’s rehabilitation, especially whether they can keep up with the results of general students.” (P7)

“Parents' anxiety about their children's rehabilitation and parenting is obvious. For children with special needs, the policy of Learning in Regular Class ensures them to study in general schools. The original intention is good, but there are some problems in the implementation process. For example, the test performance of special children is not included in the assessment, then parents and teachers may be confused. Should children with special needs be instructed when they are not studying in the class?” (P3)

On the topic of parents’ psychological status, because of limited understanding of children’s special needs, parents feel a lot of “hopeless” and “anxiety” as they are bothered by the reasons of their children’s special needs; sometimes mothers are vulnerable to be accused as the fault part of their children’s special needs by themselves or by family members; parents are constantly worried about children’s future, safety, mental health, education opportunity, rehabilitation effect and so on.

(3) Attitude to rehabilitation and education describes parents’ attitudes to child’s rehabilitation and education. To be specific, it includes two contributing factor: emphasis on parental responsibility and participation willingness in child's education and rehabilitation, as participants said,

“The situation in our family is that we don’t rely too much on the elderly. Whether or not to let the elderly help with taking care of children with special needs depends on the family practical situation. It’s okay if the elderly can help, but it doesn’t mean

that parents can get away...” (C1)

“In many families, grandparents are the main caregivers of children with special needs, but I still think it is better for parents to take care of the child by themselves.” (C5)

“Many parents have the mentality that the rehabilitation training is too professional for them to learn, so their willingness for learning professional skills is not strong. They think that it is enough to leave the child’s rehabilitation and education to therapists or teacher of the teachers in intervention institutions.” (P7)

Parental attitudes greatly influence their participation in child’s intervention practice. In family of child with special needs, due to family economic needs, parents need to work and the elderly are relied on for taking care of the child with special needs, which on one hand provide family with extra human resource for childcare or housework, on the other hand may cause parents to evade responsibility for taking caring of child with special needs. Besides, parents tend to think that rehabilitation for children with special needsren is too professional to learn and completely leave their child to professionals.

- Parameter four: family preparation

Family preparation refers to the preparation situation of families to cope with children’ special needs. Three subcategories are included in this parameter: basic family status, status of family collaboration and family parenting preparation. Among them, status of family collaboration has been mentioned most frequently by participants with references of 38, following by basic family status with 29 references and family parenting preparation with 21 references.

Table 5.5 Coding information of family preparation

Subcategories	Number of Concepts	Sources	References
basic family status	8	12	29
status of family collaboration	6	15	38

parenting preparation	6	12	21

(1) Basic family status describes some background information of family with disabled child. To be specific, it includes family conflicts, parents not living together, parents' education status, parents' marriage status, limited knowing of related information, more than one child, complicated family language environment, and young parents, as participants said,

"I and my husband often quarreled for a while, because the child is more excited, he couldn't sleep well before the age of 6, and he could be waked up by a little bit of sound. Because of this, i and my husband even reach the edge of divorce... The information that parents may have access to is limited, moreover it is very difficult and dangerous when there is no way to judge." (C1)

"Having a child like this, parents cannot be free for the whole life. Some families often quarreled and ended up with divorce because of this... if family has migrated to other place for rehabilitation, One this is that the husband and wife are separated from each other for a long time, and there is no home at all; the other is that the husband and wife cannot take care of each other; the third one is that the mother who takes care of the children every day is under great pressure and with no helper. As a result, the couple may often quarrel and end up with divorce....Besides; currently the parents are usually born in 1980s or 1990s, which means that they are likely to be under great pressure with young age. " (C8)

"Now my child comes to kindergarten here. We go back to hometown 2 or 3 times a week. We might be here 3-4 days a week, and be in hometown with my husband and daughter (9 years old) at other time. Sometimes it is really annoying as older child is not obedient, and neither is the younger one." (C7)

"I also know some parents with higher education status. Generally, they have a better awareness of their children's intervention. They are willing to spend more money and invest more energy to help their children develop better. They insist on

giving their children a longer time for intervention. ” (P1)

“If the parents have a high education level, they will strive to seek all resources during the entire rehabilitation process, but there is also a drawback that such parents often have higher requirements and expectations for their children, and their children will also be under great pressure” (P4)

Speaking of basic family status of families with disabled children, parents often quarrel and may end up with divorce because of child’s problems and parents’ high pressure from taking care of child’s special needs; moreover, families may migrate to other places for intervention service. The spouse relationship of these couples is vulnerable because of long-term separation of husband and wife; parents’ education level can either support parents’ participation in child’s rehabilitation or result in excessive expectations. Besides, with other child to care, limited knowing of related information, young parents generation and complicated family language environment also contributes to family quality of life.

(2) Status of family collaboration describes how family members work together to cope with the situation of having disabled children. To be specific, conflicts of parenting, without personal time, sharing psychological burden, family mentality, family members' reaction to emotional collapse, and family atmosphere are included, as participants said,

“Because the elderly in family spoil the child , I teach him some rules, but as long as the grandparents protect him, he will not follow the rules. ” (C11)

“In my family, other members think that since the child has special needs, then let it be, but as a mother, I don't think I can give up the child... ” (C4)

“If parents take care of the child , they have better acceptance and better energy. Most of grandparents' only care about ensuring that the child doesn’t run around, can eat enough and wear warm. They are not good at accepting new things and have no energy to practice intervention at home. ” (P6)

“Except for taking care of the disabled child, mother has very little time of her own.” (P4)

“(taking care of disabled child) It’s unusual energy-consuming. I must spend almost all the daytime on taking care of the child, and do housework after the child goes to sleep at night. I don’t have my own time at all. Before having the child, I used to have my own time to dress up, I don’t have such time at all. I even don’t have time to buy clothes as i have to take care of the child all the time...How can there be time to relax?” (C8)

“When I have psychological pressure, I don’t any friends, but I have brother and sister, and the child’ s grandparents, they will enlighten me...” (C9)

On the topic of family collaboration status, families of children with disabilities also experience parenting conflicts among parents or between parents and grandparents generation; comparing to parents, grandparents are more caring about children’s daily life than their rehabilitation and education, and are more likely to give up the disabled children; the main caregivers of children, usually the mothers have almost no personal time and also no time for relaxing; family members from extended family can provide support for parents to cope with their psychological pressure.

(3) Parenting preparation describes family preparation status for raising the child with special needs. To be specific, it includes lack of rehabilitation skills, lack of parenting skills, improper parenting, unknown of jargon, limited gain from parent training and seldom active learning according to the participants, as they said,

“Parents also have poor skills in caring for and raising these children...” (C8)

“After all, I have no experience in the education of disabled children, and I don’t have any professional knowledge in this area. All I know is from other parents’ sharing.” (C10)

“Sometimes I’m worried about being unprofessional. Although I have insisting on learning and growing, the situation of my child is changing and I may be not

professional enough." (C12)

"*Parents are not so active in family intervention. On the one hand, it may be that the parents don't have enough theoretical knowledge and the intervention practice at home lacks skills. Then the children don't follow at all, and parents may regard the method taught by teachers as useless things...*" (P1)

"*Many professional terms in the books are difficult for us to understand....There are a lot of professional terminology in the training for parents in the West China hospital*[7]*.*" (C9)

"*The grandmother was taking care of the child. She didn't want to go out and only watched TV at home every day. It can be said that the child had been watching TV all the time except sleeping from two months, so the children had no interaction with other people. At that time, the child likes to watch GG Bond*[8]*, and it is with sound but no language....Some training program for parents are relatively simple and not systematic.*" (C7)

"*Most parents in our center don' t take the initiative to learn, only a few parents consciously learn by themselves,*" (P4)

Speaking of parenting preparation, parents of disabled children are lack of professional knowledge, rehabilitation skills and parenting experience, and they are worried about these, but seldom initiate active learning; there may be parenting conflicts between parents and grandparents which lead to family conflicts and bad family atmosphere; some training programs for parents seem to be too simple and unsystematic and fail to meet parents' needs. All of these indicate that families are not well prepared for coping with children's special needs.

- Parameter five: family involvement

Family involvement refers to family members' participation in taking care of the disabled child, parent training program, and child's intervention. Correspondingly,

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[7] Huaxi, also known as West China hospital, is the biggest and best hospital in Sichuan province.

[8] GG Bond is a 3D cartoon series for child, which is with sound but without language.

three subcategories are included in this parameter: family members' involvement in childcare, family participation in parent training and family participation in child's rehabilitation. Among them, family members' involvement in childcare regarded as the most important subcategory with references of 62.

Table 5.6 Coding information of family involvement

Subcategories	Number of Concepts	Sources	References
family members' involvement in childcare	6	17	62
participation in parent training	4	10	23
participation in child's rehabilitation	3	7	8

(1) Family members' involvement in childcare describes family members' participation in taking care of disabled children. To be specific, full-time childcare, father involvement, effective sharing from family member, limited sharing from family member, dependence on the elderly, and involvement of mother with full-time job are mentioned by participants, as they said,

"From the child was born, I have been taking care of the child. I feel very tired for caring of the child all by myself...We go back to hometown every weekend and come back to the city on Monday for rehabilitation training."(C12)

"After my daughter was born, I have been taking care of her. No one has helped me. Every day of my life has been taking care of the child and I have to bring her whenever i go, even when i go to toilet. It can be said that the child is my complete life....My husband works in other province and comes back once per month. He has little time to be with or take care of the child.... Besides, I have no parents, only mother-in-law. She has little participation and basically no one can help me. Relatives from my family can help very little, and my husband is not around when I need help." (C2)

"Child's dad has to work and usually has very little participation in childcare."(C9)

“Grandparents in my family can help me with childcare and my family is also very supportive. Compared with other families, it is better and easier to accept children's problems in my family.” (C7)

“Father's participation in children's rehabilitation training and daily care is indeed relatively less, and usually fathers are less show up in the intervention centers.” (P2)

“Child’s mother works as a civil servant on the highway system. She has two day shifts and two night shifts every week, so she often comes back quite late from work and the child goes to sleep earlier. There isn’t much time for them to interact with each other.” (C6)

Speaking of family members' involvement in childcare in family with disabled child, mother is more likely to be the full-time caregiver of the child and there may be quite little help from other family members for childcare; usually father’s involvement in childcare is very less as he needs to make money to support family; mother with full-time job also has little time for childcare and the elderly have been relied on for childcare and housework.

(2) Participation in parent training describes family members’ participation in training programs for parents about parenting knowledge and skills. Below this subcategory, needs for parent training, participation willingness of parent training, no time for parent training, and no time for parents activities are included, as participants said,

“After certain problem appears, parents start to think about the solutions and to find information from the internet. As it is too far, it will be too difficult to carry out in practice. It may be better if there are professionals who can give more professional guidance for parents at home.” (C10)

“Speaking of parent training, the most important thing for child’s recovery is to rely on the parents, because the teacher has limited time and parents can teach the child at home . Then there is definitely a need for parent training. For example, how

to communicate with the child? children? How to help the child when he/she has emotional problems? How to teach physiological knowledge as the girls will have period later ?" (C3)

"We had two or three stages of systematical parent training before, but it didn't continue. We find that parents are in a contradictory state. On one hand, they are eager for relevant training, on the other hand, they are not willing to spare their time to participate in parent training. So now we stop to provide specific parent training, but do it together with the quarterly summary meeting which is combined with child's learning situation. Parents seems to have a stronger willingness to participate." (P3)

"I haven't participated in parent training, because my schedule of taking care of the child is too full. It seems that only weekends I can have time for parent training. I would like to join the training about children's language rehabilitation, fine motor skills rehabilitation training..." (C1)

"Parents' willingness to participate in the parent training is not high. On one hand, there is object reason as parents don't have spare time, on the other hand, it is also because of their mindset. Parent training is not well accepted by parents." (P4)

Speaking of participation in parent training, parents generally have needs for training, but they may have no time for participating the training in intervention centers or other places; hence, they prefer professional guidance at home; besides, parents' mindset of training and the content and implementation of parent training need to be considered for improving the training effectiveness.

(3) Participation in child's rehabilitation describes family's involvement in child's rehabilitation. To be specific, involvement in institutional rehabilitation, dependence on professionals and practice of family intervention are included, as participants said,

"In some places, there is closed-door training and parents are only allowed to watch the intervention through camera. Here, parents are suggested to enter the classroom. Teachers will tell parents about the intervention content and ask parents to

do something at home."(C8)

"Professionals in Huaxi Hospital use many terminologies in parent training, and we also don't have the professional equipment at home. Then I can't carry out family intervention by myself." (C9)

"Parents' willingness for learning professional skills is not strong. Most of parents think it is enough to leave their children to the therapists or teachers in institutions and put their hopes entirely in the institution." (P7)

"Parents' energy distribution is another question. During the day, parents have to bring their child to the institution and pick up after intervention. They put all their time and energy on the children during day time, and then they want to have time to relax after going home. Moreover, most mothers have to cook and do housework at home and they have no spare energy to do practice rehabilitation at home. " (P1)

According to participants' description, parents are not highly involved in child's rehabilitation. Speaking of the reasons, on one hand, parents' perspective is a problem as they may put full hope on the professionals in institution; on the other hand, institutional management is another obstacle as parents may be not allowed to participate in institutional rehabilitation. In addition, family intervention practice is not satisfying as parents usually have no time or are lack of skills and equipment.

- Parameter six: social support

Social support refers to various services and assistance from outside of the family that can help the family with disabled child to adjust and cope with difficulties. According to systematical coding, five subcategories are included in this parameter: information accessibility, rehabilitation and education resources, social concept, related services and social interaction. Among them, information accessibility is most frequent mentioned by participant with references of 64, following by rehabilitation and education resources with references of 53.

Table 5.7 Coding information of social support

Subcategories	Number of Concepts	Sources	References
information accessibility	9	16	64
rehabilitation and education resources	10	16	53
social concept	5	11	28
related services	5	8	14
social interaction	2	5	6

(1) Information accessibility describes family’s status of information obtaining, in terms of information source and information situation. To be specific, parents' access to information, parents share information, educational and rehabilitation institutions share information, related information from government, incorrect information about child's special needs, limited knowing of related information, problems of information from internet, importance of parents' communication, social media groups for parents are included, as participants said,

“In this aspect (information acquisition), I’m a bit behind. In the past few years, I really concentrated on training my child at home. Later when my child goes to school, I have been exposed to a lot of information from other parents and teachers...I think school and institution should be the center of information. All kinds of information, such as psychological counseling, medical and other information should be gathered in school and institution. Because parents have limited access to related information, and it is very dangerous when there is no way to judge as the information on the Internet is very complicated. It is very difficult to distinguish the true and false information, and once falling into a trap, it may cause irreparable losses because the most critical time for a child is a few years at the beginning. Once the family misses that critical period, there is no chance for recovery.” (C1)

“To obtain relevant information, I mainly search from the Internet or join some parent groups, but I still feel that the relevant information is not enough and lagging

behind. For the education of my child, I want to be able to keep up with the changing of the child's developments...In our place, the government's information channel is now available. Basically, if there are any questions, I can go to the community and get answers." (C10)

"There are basically no channels for information about government policies and subsidies, and I don't know where to ask. All I know is through listening to others. Someone told me that we can apply for minimum living allowance[9] *in this situation (child with disability). I have been to the local Civil Affairs Bureau for several times, but the reply is that we cannot have it because child's parents are still young and could make money by themselves..."* (C3)

"I usually learn knowledge about autism on my own. I buy books to read, and I also follow some related things online, such as online courses..." (C12)

"I buy books and watch videos, but I feel that reading books is slower. When I take the parent-child class, it is faster to watch a teacher's demonstration...After wearing hearing aids, the doctor didn't recommend rehabilitation training, only told us to talk more to my child. Then I also called the local rehabilitation institution and I was told that my child was too young for that institution and children for their institution should be at least 3 years old" (C4)

"For parents, 70-80% information is from buying books and watching videos online for self-study, but the information on the Internet is quite complicated. Parents need to judge by themselves...Because my husband doesn't talk much and he's a little introverted so from the beginning our family thought maybe my child is just like his dad." (C8)

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[9] The minimum living allowance (MLA) is a type of social security system in China. It means when family's household income per capita is lower than the local minimum living standard, the family can apply for allowance from government. The local minimum living standard is always the Poverty line. The MLA standard in Sichuan province is between RMB 540-700 Yuan/per month in city (including rural areas in Chengdu city) and 350-376.5 in rural area outside Chengdu. The amount of MLA per family is calculated based on number of family members.(Department of Civil Affairs in Sichuan Province,2019).Retrieved from https://mzt.sc.gov.cn/scmzt/zcfg/2019/12/23/b89c854cd3534e3bafecf313f8d2f558.shtml

"Some parents watched TV commercials to see that surgery could cure cerebral palsy. Many parents were tricked into performing that surgery on their children. There is also misleading information on the internet. If you search for cerebral palsy through Baidu[10], there will be a lot of advertisement for surgery." (P4)

"The doctor told my family, 'there is no need to spend energy on my daughter, and anyway, she cannot do anything later as she is a fool'. I got information from the doctor and also the internet that 'this kind of child can't live long, won't do anything and is stupid' which let me feel so hopeless." (C3)

"When we went to the Huaxi Hospital in Chengdu for examination, the old expert in neurology told us that there was no problem. He said that Einstein also started to speak when he was a few years old. He just suggested us to teach the child more by ourselves at home" (C7)

"It is necessary to organize some parents with effective rehabilitation to share their experiences and lessons with parents, so that parents can see hope and not be so desperate." (C5)

Speaking of information accessibility, families with disabled children mainly obtain information from internet, books, other parents and professionals in institution and hospital, government department (including CDPF) ; other parents' information sharing, especially from the Parent QQ group or WeChat group is the most effective way to obtain related information; it is worth noting that the misleading information from internet or from professionals may results in huge losses to family physically and also psychologically.

(2) Rehabilitation and education resources describes family's situation of access to rehabilitation and education resource. To be specific, negative experience in early intervention, difficulties in diagnosis process, lack of high quality rehabilitation services, poor qualifications of professionals,

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[10] Baidu is the 2nd largest internet searching engine after Google, which is mostly used in China.

accessibility of rehabilitation resources, distribution of rehabilitation resources, difficulty to be enrolled in public kindergarten, difficulty to be enrolled in general school, opportunity for inclusive education, and limitation from hukou[11](household registration) have been mentioned, as participants said,

" Before my child had hearing rehabilitation at a private institution in my hometown. To be honest, the training experiences there were painful for my child and also for me. The rehabilitation method used there was old-fashioned and the teacher was very strict, often scolding and even beating child. They put great emphasis on practicing pronunciation, and child will be beaten if he speaks not correctly...It was great pressure for me and my child to have intervention there...In addition, there is also the requirement of hukou for these kinds of children to attend school, and there may be without suitable school in the location of the household registration. " (C4)

"Parents struggling with pain are mostly from districts and counties. Generally, theses parents' rehabilitation perspectives are backward and past rehabilitation experiences may cause them some psychological pressure...Some parents have tried intervention in their local institutions, but the intervention effect was not good. They would rather spend more money to get intervention in Chengdu even though the intervention in local institutions within governmental subsidy program may be free. " (P3)

"We haven't had intervention from institutions, because I'm not satisfied with the institutions in my city. It's hard to find qualified professionals in third- and fourth-tier cities like our city. " (C12)

"In some places, the intervention fees are expensive, but because the teachers are

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[11] Hukou is a system of household registration used in mainland China. It officially identifies a person as a resident of an area and includes plenty of identifying information such as name, parents, spouse, and date of birth, marital status and so on. It often directly connects to social programs provided by the government.(Retrieved from https://en.wikipedia.org/wiki/Hukou)

good, there are still children who can't be arranged. This intervention industry for children with special needs started late, and Chengdu has had more institutions only in recent years. Many of them

are not qualified..." (C8)

"In our hometown, there is no institution for training in the local area, and there is no rehabilitation service from the CDPF. We don't live here and every time we come here for training from our hometown. It takes at least 2 hours to come here. Every time when we come here, we basically start at 8 am, and we will arrive at lunch time, and we will have intervention in the afternoon after eating..." (C9)

"Usually public kindergarten will not accept children with special needs, so it is not easy to be enrolled in public kindergarten. Moreover, there are too many kids[12] *in one class in public kindergarten, and the teachers can't take care of disabled children. If anything happens there because of the disabled child, parents will be asked to take the responsibility."* (C3)

Speaking of the rehabilitation and education resources, the distribution of resources is not balanced. High quality rehabilitation resources are usually located in big cities and families from districts and counties may have no access to rehabilitation services or get through painful intervention experiences in their local area which bring great psychological pressure and childcare burden to families of children with disabilities. Moreover, the requirement of household registration has limited family's free flow for better rehabilitation services and hindered the child's opportunity for getting education in public school system. In addition, large class size in public school and the current policy for inclusive education increases the difficulties for disabled

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[12] According to the regulation from Ministry of Education, Generally there should not be more than 30 students in one class in kindergarten, 45 students in primary school and 50 students in middle school. (from"Kindergarten Work Regulations"& "Compulsory Education School Standards", Retrieved from http://www.moe.gov.cn/srcsite/A02/s5911/moe_621/201602/t20160229_231184.html)
In practice, it often happens that the number of students exceeds these limits in public schools.

children to be educated in public school system.

(3) Social concept describes general perspectives of disabled children from the society. In this study, it includes low acceptance from the society, public awareness, exclusion of the child, teachers' acceptance, and acceptance from neighborhood according to the participants, as they said,

"The main concern for child's future is the strange vision of the child in the society and i am worrying about the psychological harm to the child..." (C3)

"Now the acceptance of these children in society is not high, which also makes mothers more stressed. If these children go to school, first the teacher must be able to accept them...At present, most of the integration education I know in general schools seems like this way: the teachers know that the child has problems, then they may not care about the child and attributes everything to the child's own problem. If teachers don't accept children with special needs, they may be rejected by peers...Another one is the society, families with disabled children have to face other people's strange vision in public place. It's another blow to parents. Then parents of disabled children wouldn't want to take them out anymore."(C8)

"It may be a problem of social recognition and acceptance. Many parents still have an inferiority complex and do not want to take their children out to contact the outside world." (P4)

"Many people still do not understand that this is a disease, and think that autism is because of child's failure in psychological adjustment."(C8)

"Children with special needs are not understood by the society. And there are some prejudices, which bother me a lot. For example, they think that disabled children are because of sick parents and they will treat the parents as monsters."(C1)

Speaking of social concept, generally children with disabilities and their families are not accepted by the society. Whether it is a "strange vision", or prejudices and misunderstandings will bring pressure and trouble to families with disabled children.

Parents are worried about teachers' and peers' acceptance of their children.

(4) Here related services describe various services that help the family function except information service and direct rehabilitation and education service. To be specific, self-help group among parents, barrier-free facilities at home, barrier-free facilities in public place, professional psychological service, and child care agency for young child have been mentioned by participants, as they said,

"There are few families with similar children in our local area, so I joined the WeChat group for parents here. However, the parent group here is not very active and parents usually have less online communication. Besides, the families here live scattered and some families live far away. Usually, parents have few opportunities to organize activities together." (C10)

"For example, there is Down Syndrome Association in Chengdu, which often organizes activities, such as reading clubs, parent training, etc. Parents share the expenses together, so if i have time on weekends, I will take my child to participate in activities there." (C3)

"I hope that society will pay more attention to these children, and if there can be such institutions or groups around, and parents can communicate with each other more..." (P6)

"Many of these families go to the park on weekends sometimes. Generally, these children (children with physical disability) can't go far, because they are inconvenient to move, and many need to use wheelchairs. However, the barrier-free facilities in the city are not well-built or well- maintained... The newly-built flats are usually with elevators, but many old buildings built in the past are without elevators, and it was inconvenient to go out. Someone had to carry them up and down when they go out. Then people with disabilities may not have good feeling. Their quality of life is not high...In addition, the hosting service for children with special needs, especially for young children, is in demand." (P4)

“ The family environment modification cannot keep up, and The family environment is not suitable for the daily life of children with disabilities. ” (P7)

“I also participated in psychological counseling activities. It is definitely helpful, but it is too short and the help is relatively small.” (C8)

According to participants’ description, there are spontaneous parents organization for a certain type of disability and also social media group for parents, for example Down Syndrome Association, WeChat group, QQ group and so on; usually, these organizations and groups work better in big cities; it’s worth noting that parents' communication channels are valued by parents; Besides, barrier-free facilities in public and at home are not satisfying, which affects the quality of life for children with disabilities and their family; professional psychological service for parents and hosting service for young children with special needs are in need.

(5) Social interaction describes the situation of family’s social network. Here, narrow social network and abandon social network are included in the category, as participants said,

“Because face is important for Chinese people. Having child with special needs has often been regarded as family ugliness and family don’t want other people to know it. Hence, many times they don’t want to ask help from relatives and friends. Parents of these children generally closed social circle. ” (P3)

“ Generally speaking, the social circle of these parents is relatively simple. It basically built around the needs of children, such as institutions, hospitals or other families of disabled children of the same kind. As the family circle becomes smaller and smaller, parents’ psychological pressure may be greater and greater. ” (P4)

“Most mothers with these kinds of children have closed their social circles and put all their energy and time on their children. Many parents say they have stopped contacting their friends because some of them will sympathize and show pity on them. Parents can't stand this. ” (P1)

“Because of the need to take care of children, there will be less chances for parents to interact with friends, and then the friends circle will also be narrowed. Besides, the behavior problems of disabled children, such as poor table manners, will also stop parents taking children out to meet friends, etc. In addition, parents' mindset, seeing the gap between their children and other people’s children will also cause parents to shrink back.” (P1)

Speaking of social interaction, families with disabled children are likely to have narrow social circle or simply give up social circle because of limited time for socialization, children’s behavior problem, mentality issues such as emphasis on face and mind of rivalry with other people. As parents’ social circles shrink, their psychological pressure may increase.

5.2.3 Comparative analysis

Based on coding analysis, further comparative analyses were conducted to know the differences among the six parameters and their differences on different participants’ characteristics. These comparative analyses are aiming at discovering the relative importance among the parameters and between different groups of participants.

5.2.3.1 General analysis

Firstly, the relative importance of each parameter to the participants was explored through the hierarchical chart in NVivo11. As Figure 5.6 shows, parameter social support and parents’ attitudes were attached higher importance with more mentioned times, following by parameters: family involvement, family preparation and economic factor. To be specific, social support is most often mentioned by participants with references of 155, which accounts for 26% of the proportion; the parameter on the second level is parental attitude with references of 127, which accounts for 21% of the proportion; parameters on the third level are family involvement, family preparation and economic factor, each of which accounts for about 15% of the proportion; while difficulties related to child is on the last level with references of 51. (See Figure 5.7)

Moreover, further comparative analyses were carried out among subcategories. The numbers of references of subcategories below each parameter is shown in Figure5.8. To be specific, below social support parameter, information accessibility and rehabilitation & education resources are relatively important subcategories for participants with 64 and 53 references respectively; below parental attitude parameter, attitudes to the child and parents' psychological status are the most important contributing factors with 71 and 56 references; family members' involvement in childcare is the most important contributing factor below family involvement parameter with 62 references; within family preparation parameter, the importance of subcategories is relatively balanced and only the subcategory of family collaboration with relatively more mentioned times; similar feature has also been found in the parameter of economic factor, below which economic burden related to rehabilitation is relatively more often mentioned by participants with 33 references; below the parameter of difficulties related to child, child's performance and child's developmental expectation are more frequently mentioned by participants with references of 25 and 21 respectively.

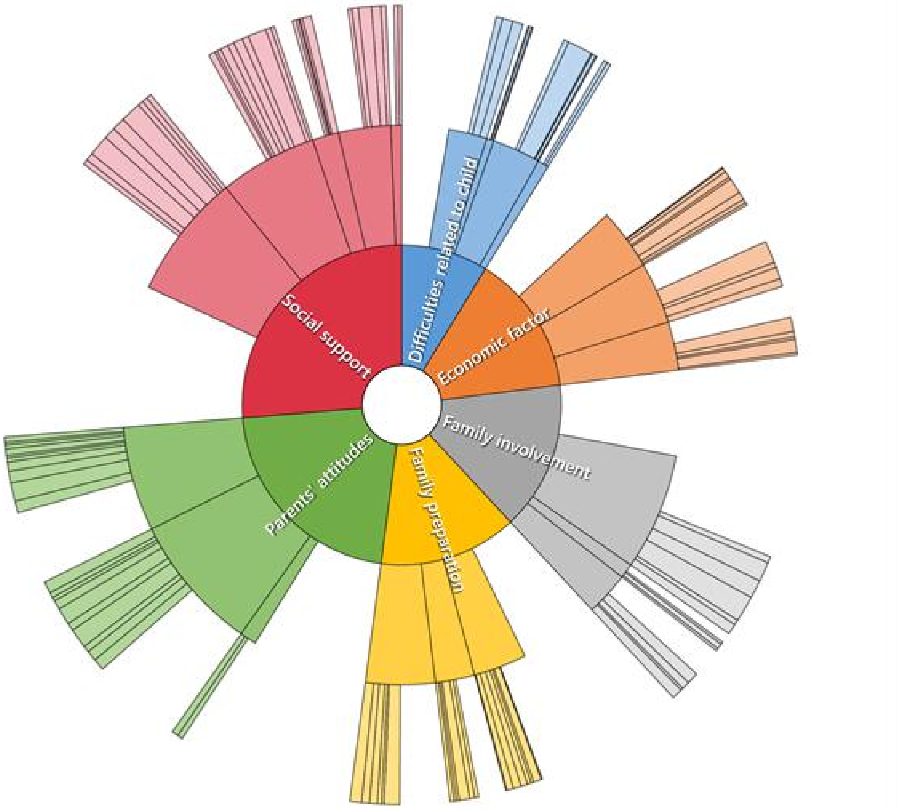

Figure 5.6 Hierarchical chart of the six influencing parameters

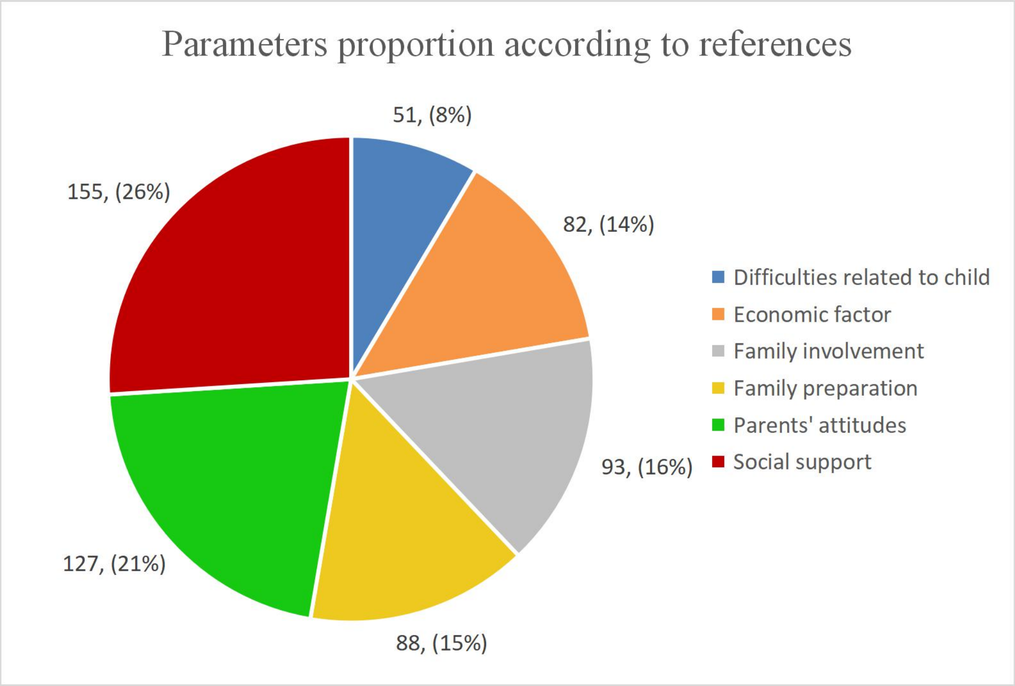

Figure 5.7 Parameters proportion according to references

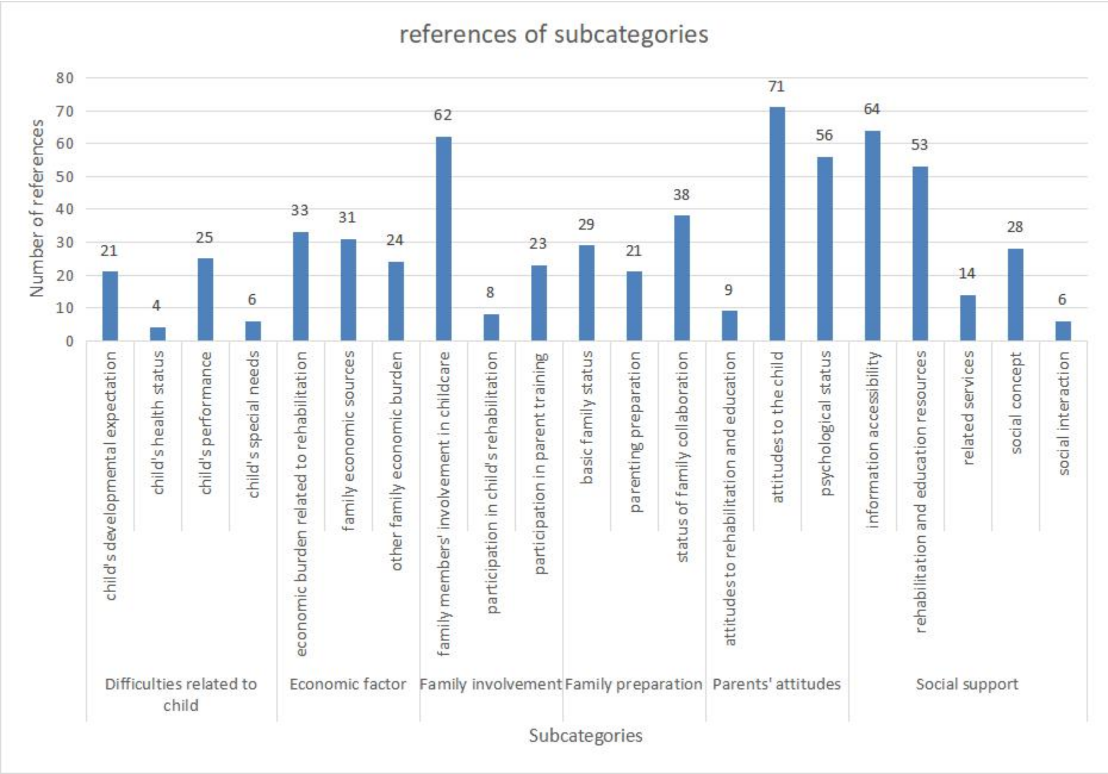

Figure 5.8 References of subcategories below each parameter

5.2.3.2 Comparative analysis between different participants groups

Comparative analyses according to the characteristic of participants were carried out to explore different viewpoints of influencing parameters of FQOL. Among the 19 participants, there are 12 caregivers and 7 professionals. As shown in Figure5.9, for both caregivers and professionals, social support and parental attitude are attributed as the most important two influencing parameters with number of references 106 &90 and 49&37, respectively, as one participant said,

"The most important thing is parents' attitudes. Parents' acceptance of children's problems is a long-term issue. If you look at these parents on the surface, they may also look very happy. It seems that they have already understood the children' problems, but from their behavior you will find that they don't really accept their children' special needs..." (P1)

Speaking of the age difference, 19 participants were categorized into three age groups: <30 years old, 30-44 years old and >44 years old. There are 6 participants below 30 years old, 10 participants between 30-44 years old and 3 participants >44 years old. As shown in Figure 5.10, participants below 30 years old attach most importance to parental attitude and then to social support, while participants of other two age groups attach most importance to social support, following by parental attitude. Besides, compared with participants below 30years old, participants more than 44years old attribute FQOL more to economic factor and difficulties related to child, even in consideration of the difference of participants' quantity in different age groups. The results show that parental attitude as a influencing parameter of FQOL, its contributing effect has more been emphasized by parents at younger age(below 30 years old in this study) among families of children with disabilities, while objective factor such as economic factor and difficulties related to child have been more emphasized by parents at older age or grandparents.

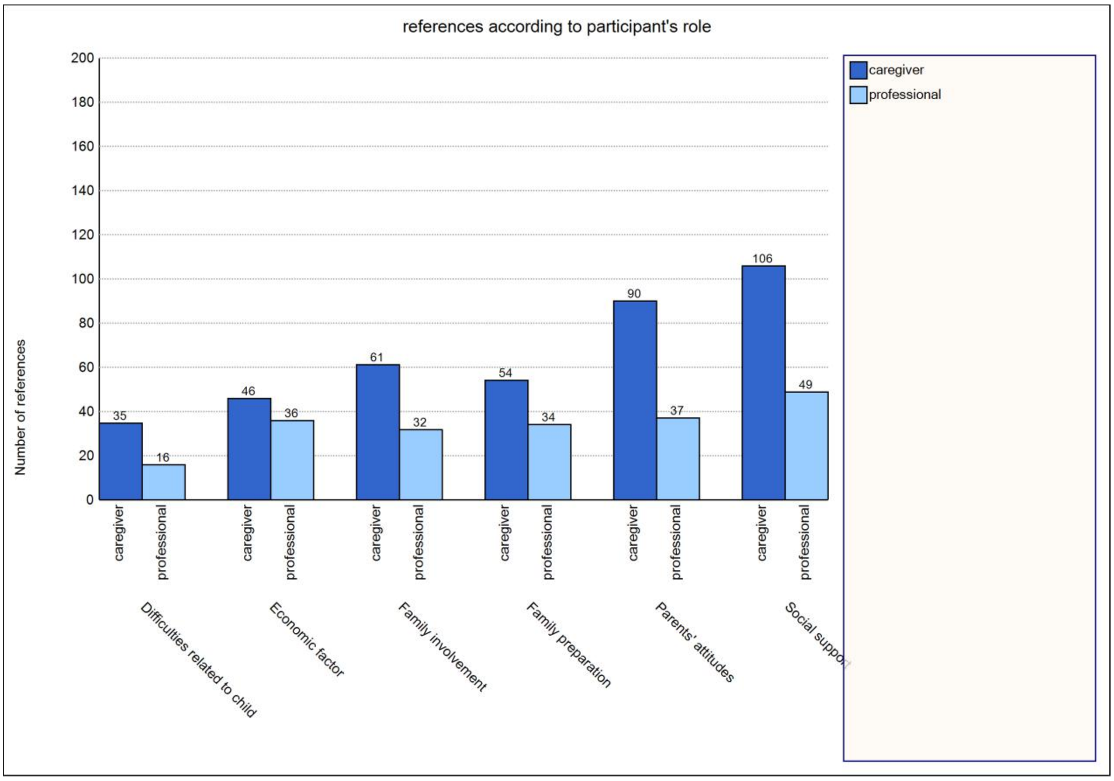

Figure 5.9 Number of references according to participant's role (influencing parameters)

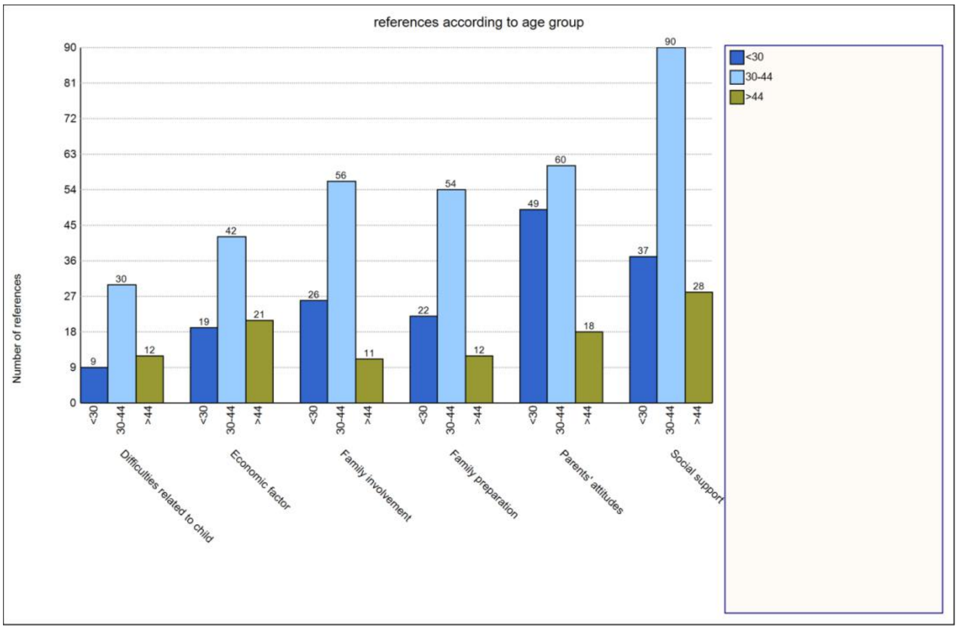

Figure 5.10 Number of references according to participant's age group (influencing parameters)

5.2.4 Exploratory model of FQOL influencing parameters

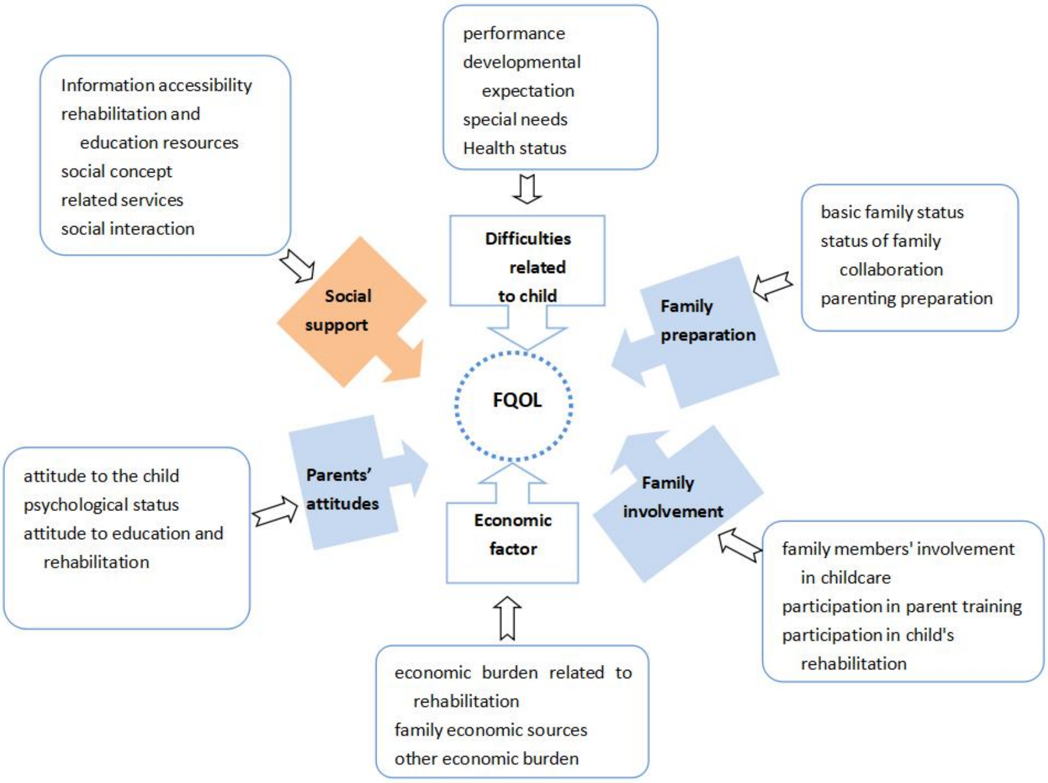

Figure 5.11 Exploratory model of FQOL influencing parameters

Based on systematic coding analysis and constant comparative analysis of the 115 concepts from19 interview transcripts, six influencing parameters of FQOL in families of children with disabilities at young age were discovered in terms of: social support, parental attitude, family involvement, family preparation, economic factor, and difficulties related to child and below each parameter, there are specific contents directly affect FQOL. The exploratory model of FQOL's influencing parameters is shown in Figure 5.11. According to this study, all of the six parameters can influence the FQOL in families of children with disabilities at young age, but the six parameters are not isolated from each other. When the influence parameters are superimposed, their influence to the FQOL in families of children with disabilities at young age is more complicated. For families with disabled children, difficulties related to child and economic factor are the most direct impact factors of satisfaction for their family life and build the basic background for their family life. Then, on the basis of the basic family background, parental attitude, family preparation and family involvement further affect satisfaction for their family life. Meanwhile, social support as the resources from outside family can directly affect FQOL and also indirectly influence FQOL through other five parameters.

5.3 Improving strategies

Similar to the influencing parameters, the improving strategies of FQOL among families with disabled children at young age were explored on the basis of systematical coding and constant comparative analysis of the transcripts from 19 interviews. Results from coding analysis and comparative analysis are presented in the following paragraphs, following by the exploratory model of improving strategies of FQOL.

5.3.1 Coding analysis

Based on systematical coding analysis, 10 subcategories were extracted from the 39 concepts in the transcripts of the 19 interview records, and thereafter four aspects of improving strategies were discovered: family aspect, service aspect, government aspect and social environment aspect. The results from coding analysis will be presented separately in the following section.

- Family aspect

Family aspect strategies refer to strategies from family side which benefit family function and help to improve FQOL. To be specific, three subcategories are mentioned by participants in this aspect: change attitude, optimize family collaboration and improve parenting ability. Among them, change attitude has been attached most importance by participants with references of 66, following by family collaboration and improve parenting ability. (See Table 5.8)

Table 5.8 Coding information of family aspect

Subcategories	**Number of Concepts**	**Sources**	References
change attitude	7	16	66
family collaboration	9	12	28
improve parenting ability	3	8	13

(1) Change attitude describes in what ways parents change their attitudes and thus help improve the quality of their family life. To be specific, self-adjustment, emphasis on family and parents, emphasis on early intervention, optimistic attitude, rational thinking, psychological preparation, and plan for child's future have been mentioned by participants, as they said,

"It is a process for parents to accept this (child with special needs). Parents should do more self-adjustment. This problem requires long-term intervention and it is calculated on a yearly basis, not on a daily or monthly basis... Parents should be mentally prepared, the child may have new problems at any time and be prepared to fight at any time." (C8)

"Parents have to come out first. If parents can't go out, the child certainly will not make much progress. If the community does not know the situation, the family may miss a lot of things." (C10)

"Parents' emotions directly affect children's emotions. It's not necessary to worry too much about whether the child is autistic. The point is that he is behind the peers

and needs intervention. He also needs to live like a normal child. First of all, they must be regarded as normal children who needs a little special support...In addition, I think that all institutions, as well as special education teachers, are less important than parents' intervention based on family life. Professionals are with magic power and their time with child is also very limited." (C12)

"*I know that many parents often cry because of their children's problems, but I think we should always be optimistic...My mentality is to do your best on everything you have to do. Everyone has pressure, but we need to try to make it into motivation. With effort, you will find that the pressure is getting smaller and smaller...On the other hand, I may be more concerned about how to solve children's problem. Crying does not help at all and the best way is to be good at observation, to see what kind of state the child is in...Whether it is a hospital or an institution, it can only serve as a model for the rehabilitation of children. It can never replace a large amount of family training and rehabilitation. It is also impossible to put all hope on professionals as each child may in a completely different state... In this process, a better way out can be formulated for the child. This way out is not only a question of making money, but also an identity, because everyone needs to have his own identity, and there must be a cut to interact with society and integrate into society." (C1)*

"*Parents are required to participate in rehabilitation training, because for a child, most of the time is still at home. The combination of institutional rehabilitation and home rehabilitation has always been emphasized.*" (P7)

"*For children with special needs, early intervention is very important. If you persevere in this way, the children will always give you a lot of surprises later. Early detection and early intervention are the most important, don't go detours.*" (C5)

According to the participants, families with disabled children are suggested to do more self-adjustment and accept their children's special needs as earlier as possible on the basis of optimistic attitude and rational thinking; parents are suggested to be prepared for long term intervention and make a plan for children's future in terms of social identity and social integration; Besides, the importance of family, home rehabilitation and early intervention have been recognized.

(2) Family collaboration describes strategies for optimizing family collaboration to cope with child's special needs. To be specific, balance of work and child care, division and cooperation among family members, work opportunities, engagement in things giving sense of accomplishment, work releases pressure, adjustment of family relationship, social interaction of family, time management of caregiver, economic preparation are included in this subcategory, as participants said,

"In my family, there is a clear division of labor. Father works outside to make money and I mainly take care of the child. At present, I have a job for 2-3 months and i can balance the work and taking care of my child. Of course it is difficult to find such kind of job, but it is still very important." (C5)

"For improving the quality of family life, I want to find something(a job) to do while looking after my child. On one hand, it can improve the economic status of the family, on the other hand, it will also help me relieve pressure by letting me away from the child for a while and diverting my attention..." (C9)

" Some parents want to go to work. Then it is necessary to create some employment opportunities suitable for these parents. Because the average job requires 8 hours in work, but most of these parents can only work for half a day." (P7)

"I have to give half of the day to take care of the children, but I also need to have some time for myself. For example, when I am translating, I am releasing my pressure. No matter what to do, the key is to do something to make you feel fulfilled. This is like a process of absorbing energy and transferring energy. So for me, doing translation work allows me to keep in touch with the outside world and keep myself confident." (C1)

"It is not so easy to improve family life quality... The second thing is to advise

parents how to reasonably arrange or allocate their own time. These arrangements include leisure time activities for families and parents." (P1)

"*The family itself is the main aspect. First of all, there must be enough support and harmony within the family. Parents' concept and ability are a foundation.*" (P4)

In order to optimize family collaboration, clear division of labor in family is recommended by participants. In families of children with disabilities, division of labor usually seems to be that fathers are the persons to work outside and mothers take the role of full-time childcare. However, more important than division of labor in family is the family members' collaboration in childcare and other family duties. Meanwhile, although mothers are usually the primary caregivers of their children, they are still advised to balance work and childcare. It's important for caregiver to release pressure and gain sense of accomplishment in the work. In addition, it is also important for parents to plan and allocate time better.

(3) Improve parenting ability describes strategies for improving family's parenting ability. To be specific, know the child, learn professional knowledge, and learn parenting skills are included in this subcategory, as participants said,

"*Adjust the intervention measures according to the child's performance, for example, if I want to train the child, I need to observe how the child feels today, how his body is, and also find out what the child needs most according to my judgment.*" (C1)

"*Besides, you must choose the method that suits your child. There is no method that is suitable for all children. Parents must choose by themselves, because parents know their children best. Parents really need to accompany their children and be involved in their children's life by acting as playmates for their children.*" (C12)

"*Parents should learn some basic parenting knowledge and skills, even parents of with normal developmental children need learn parenting skills.*" (P1)

Speaking of parenting ability, parents with disabled children are advised to know their children by continuous careful observation and choose suitable intervention methods based on their judgments; meanwhile, families are also advised to improve their professional knowledge and parenting skills.

- Service aspect

Service aspect strategies refer to strategies for improving various services which are beneficial for supporting family quality of life. In this aspect, three subcategories including rehabilitation service, related service and information service are mentioned by participants. Among them, rehabilitation service has been attached most importance with references of 22, following by related service and information service. (See Table 5.9)

Table 5.9 Coding information of service aspect

Subcategories	**Number of Concepts**	**Sources**	**References**
rehabilitation service	2	12	22
related service	5	8	13
information service	3	4	8

(1) Rehabilitation service describes strategies for improving rehabilitation services. To be specific, improving rehabilitation effect and family rehabilitation instruction have been mentioned in this subcategory, as participants said,

"I heard that in the United States, there is a center for family guidance. Every day, professionals are sent to the family for about half an hour to an hour to tell parents how to carry out intervention for their children at home. If the professional can go to the family to give some professional guidance, especially when the child is young, the psychological burden of parents will be much smaller." (C10)

"My family came here for intervention after being introduced by my friend. After consultation, I found that it was free. I was relieved at that time and I felt hopeful. The teachers here are very professional and the rehabilitation effect for my child is very good." (C2)

"I feel that the psychological state of parents is ups and downs with the progress of the child. If any problems related to the child emerge, the mother is under pressure. Then, it is easy to bring family quarrel and go into vicious circle." (C8)

" After making a cochlear implant, through training, family members have changed their minds, thinking that it is necessary to do cochlear implants for the child... " (C4)

According to participants, family rehabilitation guidance is needed by parents and improving rehabilitation effect is important as parents' psychological status goes with child's progress.

(2) Related service describes strategies related to various services from outside which helps parents increase their satisfaction with family life, except information service and directly rehabilitation service. To be specific, psychological support for parents, family parenting instruction, parents mutual assistance platform, Parent-child interaction, and respite service are mentioned, as participants said,

"Thinking about the previous process, the person who plays a very important role in giving me psychological counseling is the child's surgeon. He didn't communicate with me from the perspective of a doctor, but from the perspective of a third party who saw a lot of parents. He helped me adjust my emotions and answered my concerns...Therefore, it is necessary to give parents some psychological counseling and psychological lectures."(C5)

"Some parents may chat with their children's therapists when they have emotional breakdown, but most of them will not. More likely, they will communicate between parents to seek comfort. Therefore, the promotion strategy can consider regular psychological counseling. From the perspective of professionals, it is more about carrying out some parent-child activities to promote harmonious family relations." (P7)

"Especially for families, such as how to arrange the family, how to make the blind

children familiar with the family environment and the adjustment of the living environment at school, etc. These contents are very useful to us." (C10)

"In addition, the hosting service for children with special needs, especially for young children, is in demand." (P4)

"*It will be good if we, parents build a group and share experiences with each other. If there is any problem, I can ask for help in the group. Other experienced parents will also be willing to share the experience in the group."*(C4)

According to participants' description, professional psychological support including psychological lectures and regular psychological counseling services can help parents comfort emotional pressure and cope with their emotional breakdown; family parenting instruction, especially about how to "arrange family environment" and " adjustment of the living environment at school" are necessary for parents; Besides, parents mutual assistance platform is expected by parents to share experiences and ask for help from other parents; In addition, respite service such as hosting service for young children is in a need to free parents from the burdensome tasks of caring for disabled children.

(3) Information service describes strategies for enhancing parents understanding of information related to children with disabilities, especially the policy information regarding to special education and social welfare. To be specific, information channel, positive examples, and information need have been mentioned by participant, as they said,

"Government's information channel is now available. Basically, if there are any questions, I can go to the community and get answers. At first, we didn't know what to do. I went to the community, and the community told me how to do it. Then I went to get the child's disability certificate, and then started rehabilitation...but I think a lot of information is still not enough, mainly related to children's education." (C10)

"There is the local branch of the disabled federation, and let us pay attention to

their WeChat Official Account[13]*, but there is no specific explanation for policies that should be given to children like mine."*(C3)

"As a parent, I care more about information from professionals and authoritative ones, such as doctors. I may believe something they say more, so I hope professional staff, doctors, and professional institutions can give parents relevant information."(C5)

About information service, more information related to children's education, and clear introduction and explanation of policy information from government, together with smooth information channels are needed by parent; for parents, information from professionals and authoritative ones including doctors, experts in this area, and professional institutions are expected by parents; in addition, community can play important role in providing information service for parents.

- Government aspect

Government aspects strategies refer to strategies from government which help improve the quality of family life among families of disabled children at young age. As shown in Table 5.10, two subcategories in terms of economic support and policy support are included in this aspect with references of 21 and 11, respectively.

Table 5.10 Coding information of government aspect

Subcategories	Number of Concepts	Sources	References
economic support	2	13	21
policy support	4	7	11

(1) In this study, economic support, in terms of financial aid and free rehabilitation program have been mentioned by mentioned by participants as strategies to improve family quality of life among families with disabled children, as they said,

"It would be better if the government could help a little more. Now the financial

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[13] WeChat Official Account is an application account that a developer or a merchant applies for on the WeChat platform, through which the merchant can realize comprehensive communication with specific groups by using text, pictures, voice, and video.

subsidies are different in each locality. The local finance in my hometown is not good, so the subsidy is too less and far from enough. I hope the government will have better policy support."(C4)

"Speaking of the strategies to improve their family quality of life, first starting from economic aspect, If there will be more subsidies from government, family's economic pressure will be lower, and they will have money to travel, relax or study... " (P2)

"For child's rehabilitation, the government has provided subsidies. We only need to pay for the transportation and food & drink...but it may be difficult if we need to replace the equipment (Cochlear implant) later."(C5)

"To get rehabilitation from here, it depends on whether you meet the government subsidy conditions. Only if you meet the conditions can you receive the policy subsidies from the Disabled Persons' Federation. After training here, the economic pressure of rehabilitation training has been reduced a lot...I want to apply a minimum living allowance for my child and hope that the government and society will pay more attention to this kinds of children, and provide more supports from economics and policies."(C2)

According to participant's description, economic support has contributed to decreasing family economic pressure and strong economic support will provide families with disabled children more chances to increase their family quality of life. Meanwhile, it is worth noting that there is obvious regional difference of financial subsidies from government, which restricts family access to rehabilitation services elsewhere. Besides, at present, government financial aid is more focus on providing rehabilitation training to children with disabilities, while not much consideration on assistive technology and aids. Generally speaking, more financial aids and free rehabilitation programs are expected by families with disabled children.

(2) Policy support describes policies from government which help families with disabled children improve their quality of family life. To be specific, appropriate

educational placement, improve the qualification of professionals, improve government service efficiency, support professional rehabilitation resources are included in this subcategory, as participants said,

"However, school enrollment is still restricted by hukou because policy subsidies are involved. Only families with local hukou can enjoy local policy subsidies" (C10)

"At present, government policies are not practiced very well. As I know, children with disabilities at the first and second levels can enjoy minimum living allowance, but in my hometown local government doesn't support it. Last year, my daughter has one big surgery, then we handed in the documents for applying the medical assistance. After one year, there is still no answer. From Monday to Friday, i need to take my daughter to school so I still haven't time to ask about it."(C3)

"In rehabilitation institutions, not all teachers are from special education area. Some graduated from preschool education major and some worked in marketing or administration before. And many teachers are very young girls, having no child and little experience with children. There are few good teachers in this industry...That is, the industry should be more regulated, and the intervention teachers should be more qualified."(C8)

"Currently, the government treats the private rehabilitation institutions with no regard for them, no support, and even makes us feel that our institution is doing the dirty work. It should be said that the government haven't seen the importance of professions at all."(P4)

Speaking of policy support, reducing policy restrictions in order to let families receive rehabilitation and education services flexibly and promoting local implementation of policies are mentioned by participants. In addition, policies for regulating and supporting the intervention industry are expected by parents and institutions.

- Social environment aspect

Social environment aspect refers to strategies aiming at building better social atmosphere for families with disabled children. Improving social acceptance and enhancing social integration are included in this aspect.

Table 5.11 Coding information of social environment aspect

Subcategories	Number of Concepts	Sources	References
improve social acceptance	2	5	7
enhance social integration	4	5	7

Social acceptance and social integration are important for families with disabled children to be involved in the society. In this aspect, public awareness of children's special needs, acceptance by teachers and peers, social participation and barrier-free environment have been mentioned, as participants said,

"It is necessary to carry out more public welfare propaganda, for example, there are many promotional activities about autism and deafness, but very few about children with cerebral palsy. These children are just suffering from a disease, not lunatics or freaks..." (C1)

"If the public will know more about autism, they can be more tolerant of these children and their families...Only when teachers in general schools can accept disabled children, other children in the class will accept them, and then these children can study in general school."(C8)

"For example, we often take children out to public places in the community, such as large supermarkets and other places to have lessons. In general, the surrounding residents are basically accustomed to our existence and are relatively friendly."(P2)

"These children have poor mobility, and many of them need to use wheelchairs. If the barrier-free facilities in the city are not well-built, it's not easy for their families to go out. " (P4)

In order to promote disabled children's social integration, more publicity of children with disabilities is advised for increasing public awareness and social acceptance; acceptances by teachers and peers, especially acceptance by general teachers are vital for disabled children to receive integration education; improvements of barrier-free facilities benefit the social integration of disabled children and their families, thereby helping to improve their family quality of life.

5.3.2 Comparative analysis

Based on coding analysis, further comparative analyses were conducted to know the differences among the four aspects of improving strategies and their differences on different participants' characteristics. These comparative analyses are aiming at discovering the perceived importance differences among the strategies and between different groups of participants.

5.3.2.1 General analysis

Firstly, the relative importance of each aspect of strategy to the participants was explored through the hierarchical chart in NVivo11. As Figure 5.12 shows, family aspect is attached the highest importance following by service aspect and government aspect, while strategies below social environment aspect are less mentioned than strategies of the other three aspects. To be specific, family aspect strategies are most often mentioned by participants with references of 102; service aspect strategies are on the second level with references of 42, following by government aspect strategies with reference of 32; social environment aspect strategies are relatively less mentioned by participants with references of 14. (See Figure 5.13)

Moreover, further comparative analyses were carried out among subcategories. The numbers of references of subcategories below each aspect of improving strategies are shown in Figure5.14. To be specific, change attitudes has been perceived as the most important family aspect strategy with references of 66, following by family collaboration with references of 28 and improving parenting ability with references of 13; rehabilitation service has been attached most importance among service aspect strategies with references of 22, following by related service with references of 13 and information service with references of 8; below government aspect strategies, economic support has been most often mentioned by participants with references of 21, following by policy support with references of 11; below social environment aspect, improve social acceptance and enhance social integration have been attached similar importance by participants with references of 7.

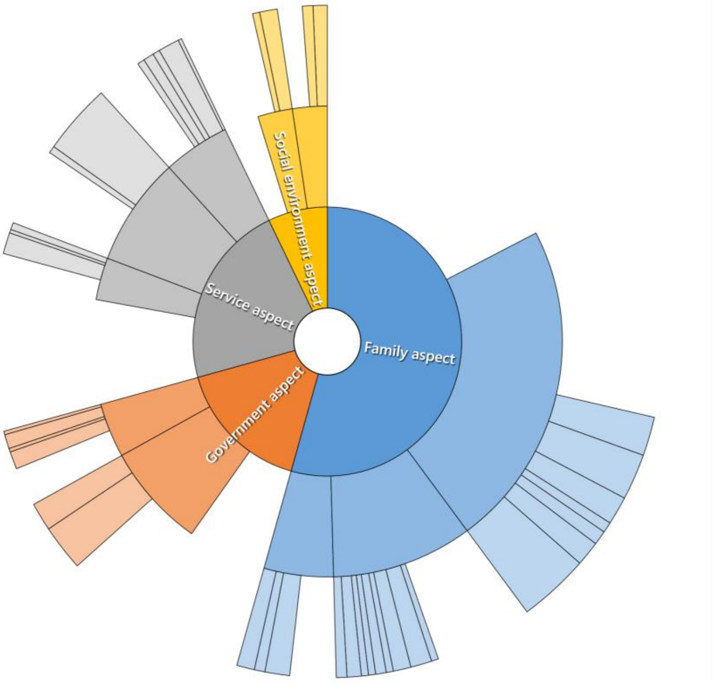

Figure 5.12 Hierarchical chart of the four aspects of improving strategies

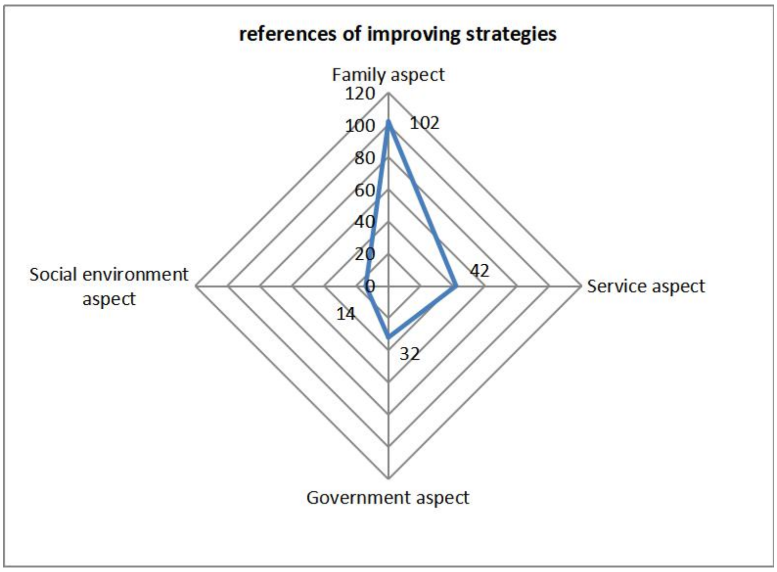

Figure 5.13 References of four aspects of improving strategies

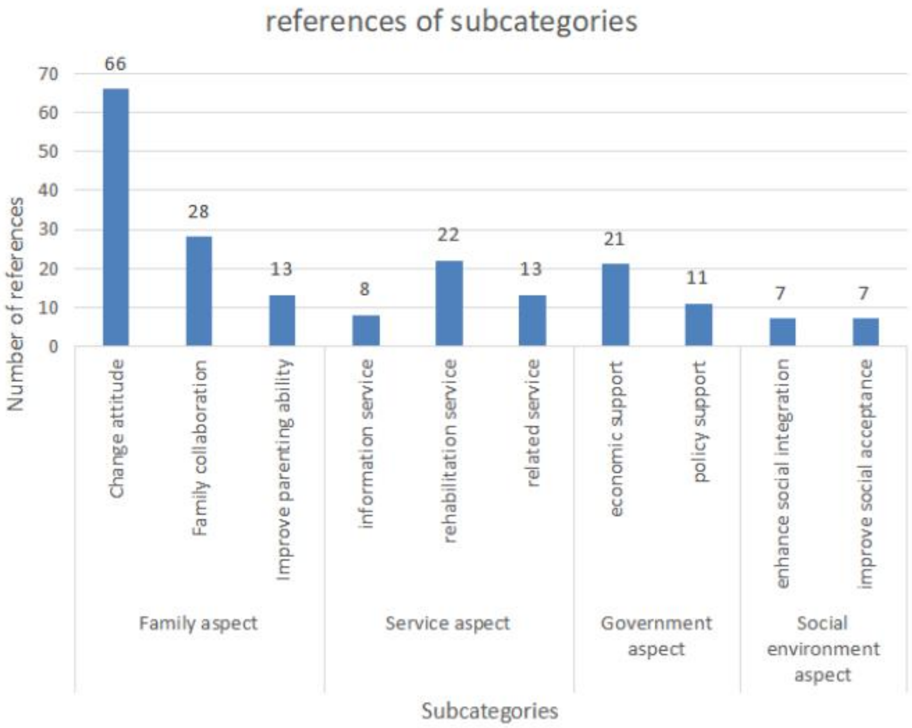

Figure 5.14 References of subcategories below each aspect of improving strategies

5.3.2.2Comparative analysis between different participants groups

Comparative analyses according to the characteristic of participants were carried out to explore different viewpoints of improving strategies of FQOL. As shown in Figure5.15, for both caregivers and professionals, family aspect strategies have been attached with greatest importance for improving family quality of life among families with disabled children at young age. According to the mentioned frequency, the importance of family aspect strategies is more valued by caregivers even considering the differences in the quantity of participants. It indicates that both caregivers and professionals of children with disabilities, especially the caregivers, have recognized the importance of family in improving FQOL, as participants said,

"Parents have to come out (from poor family status) first. If parents can't go out, the child certainly will not make much progress." (C10)

"To improve the quality of life among families with disabled children, the family, government, and society all need to do something. The family itself is the main aspect.

First of all, there must be sufficient support within the family, harmony within the family, and the concept and ability of parents are a foundation...” (P4).

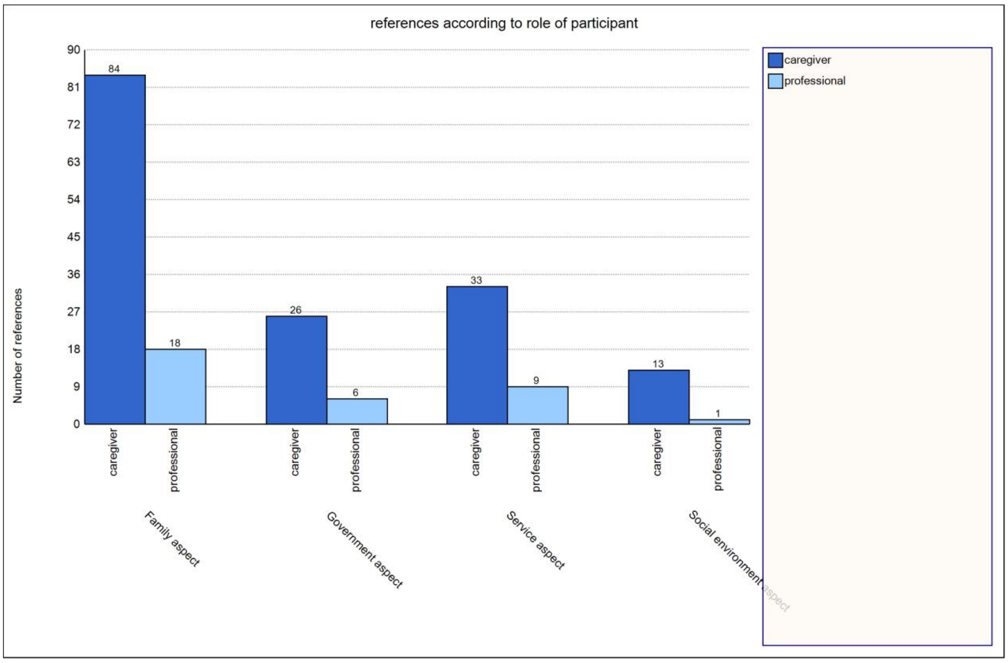

Figure 5.15 Number of references according to participant’s role (improving strategies)

Speaking of the participants’ age differences on improving strategies, among the 6 participants below 30 years old, 10 participants between 30-44 years old and 3 participants >44 years old, participants at all age groups attach most importance to family aspect strategies, especially participants at the age between 30-44 years old. Besides, participants >44 years old and participants below 30 years old attach relatively more emphasize on government aspect strategies comparing to participants between 30-44 years old in consideration of the difference of participants’ quantity in different age groups. It indicates that caregivers and professionals at younger age (<30 years old) or older age (>44 years old) emphasize more on government aspect of strategies to improve FQOL among families of disabled children at young age. (See Figure 5.16)

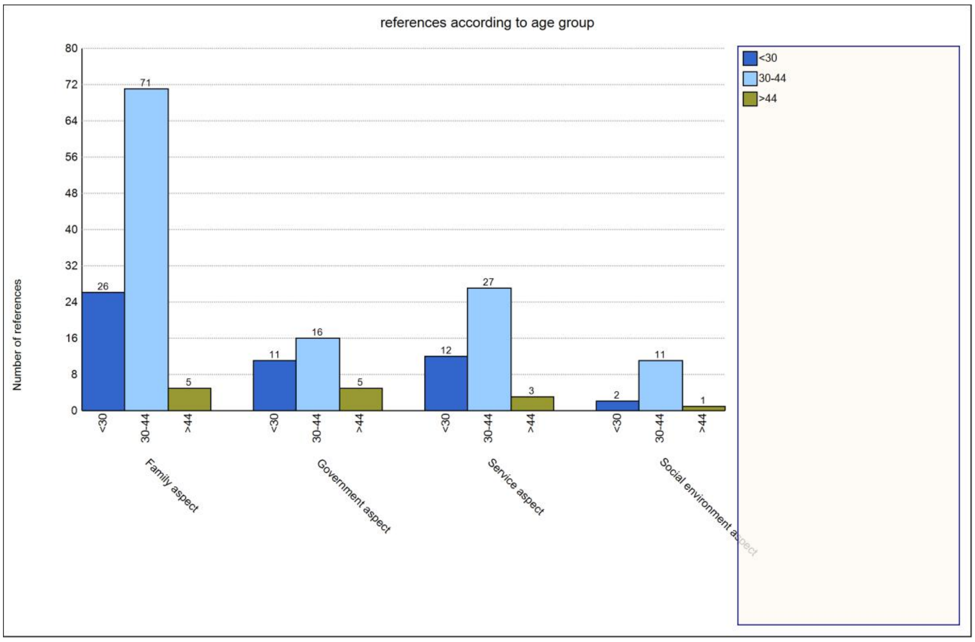

Figure 5.16 Number of references according to participant's age group (improving strategies)

5.3.3 Exploratory model of FQOL improving strategies

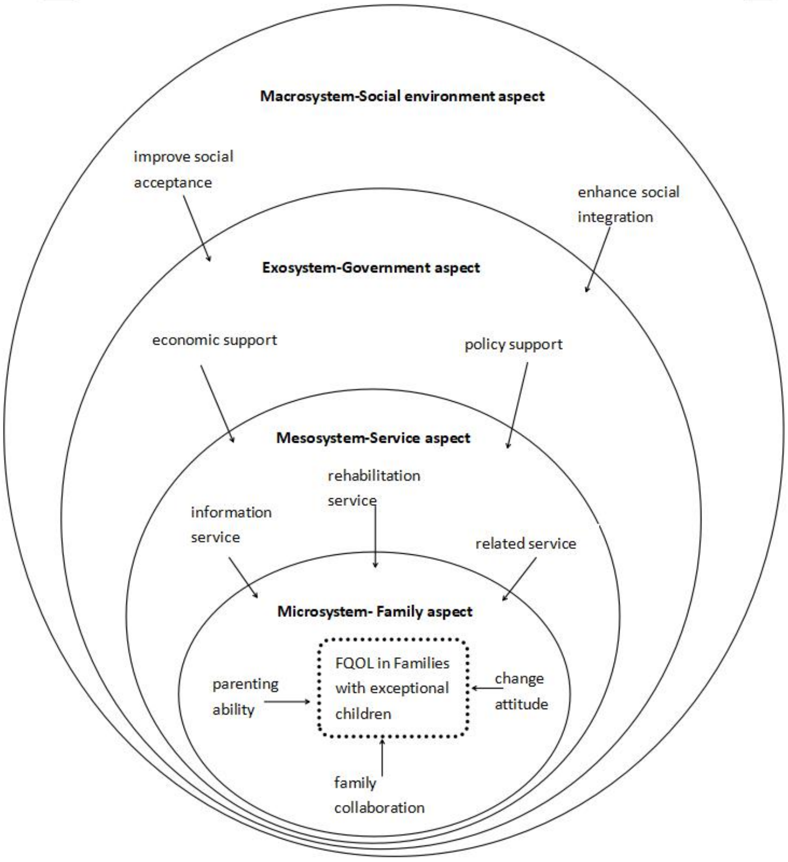

Figure 5.17 Exploratory model of improving strategies of FQOL

Based on systematic coding analysis and constant comparative analysis of the 115 concepts from 19 interview transcripts, four aspects improving strategies of FQOL in families of children with disabilities at young age were discovered in terms of: family aspect, service aspect, government aspect and social-environment aspect. Corresponding to the Ecological Systems Theory, these four aspects improving strategies build a progressive model of improving strategies of FQOL. As shown in Figure 5.17, family aspect strategies are in the family's microsystem, which are directly related to families with disabled children at young age and also most often mentioned by main caregivers and professionals; service aspect strategies are in family's mesosystem, which play critical role in building families' support system; government aspect strategies are in families' exosystem and are the external environmental conditions both directly and indirectly affected FQOL; social-environment aspect strategies are in the macrosystem, which is relatively far from family members, but the improvement of the social environment also helps to improve the quality of family life.

Chapter 6 Discussion

In this chapter, the research results from both the quantitative and qualitative approaches have been further discussed. To be specific, four parts are included in this chapter. The first part is the current situation of FQOL in families of disabled children at young age, which describes the status of objective family conditions and the current situation of perceived satisfaction for their family life. The second part is about the influencing parameters of FQOL in families with disabled children at young age. Six influencing parameters, in terms of difficulties related to child, economic factor, parental attitude, family preparation, family involvement and social support have been introduced specifically. The third part introduces the improving strategies of FQOL in families with disabled children at young age. In particular, family aspect, service aspect, government aspect and social environment aspect strategies have been discussed in this part. Further reflection of the implication and limitations of this study has been done in the last part.

6.1 Current situation of FQOL

6.1.1 Status of objective family conditions

By revealing the situation of family income and expenditure, household financial status is one of the main indicators for family material well-being and objective family quality of life. (Feng, 2000) Among the 243 families in this study, families with balanced income and expenditure are less than half and for more than 40% families, their income is far less than expenditure, while only small proportion families are with far greater income than expenditure. This is consistent with the research results of the families with autistic children in Shanghai (Li, 2016). It reveals that in China there is still big proportion of families with disabled children at young age in poor family financial situation which are struggling for affording their daily life. Specific to household monthly income, the 199 responded families with disabled children have monthly average income 5155.28 Yuan in RMB (≈736$) for whole family. If only 3 persons are counted in one family, the monthly average income per person is 1718 Yuan(≈245$), which is less than the average monthly disposable income 2059Yuan/ person(≈294$) in Sichuan province in 2019. (Sichuan Statistics Bureau, 2019) Moreover, there are most families with monthly average income between 2001 to 3000 Yuan, which is consistent with the findings from the investigation for families of children with autism in Chengdu. (Luo, 2014) Besides, there are also a proportion of families with average income of more than 8000 Yuan(≈1143$) which reveals a large income gap among families with disabled children at young age. Except for family income, household expenditure on education and rehabilitation for children with disabilities is also considered in this study. Average household expenditure on education and rehabilitation for disabled children per month accounts for more than 40% of the average household income, which makes the family financial situation even worse. This is similar to the finding in families of children with autism in Chengdu in 2014. (Luo, 2014)

In this study, the majority of the 243 families have their own flats or houses as accommodation, while still more than 1/5 families rely on long term renting or staying with relatives or friends. These findings are consistent with the research results from investigation for families of children with autism in Shanghai and Chengdu. (Luo, 2014; Li, 2016) In addition, employment status of the respondents has also been taken into consideration. The statistics show that less than a quarter of the respondents have full time job, while more than half are without job, which is consistent with the findings from previous studies in families of children with disabilities in South Korea, Canada, Australia and Chinese families of children with developmental disability in Beijing, with intellectual disability in Shanxi and with autism in Chengdu and Shanghai. (Brown et al., 2010; Hu & Wang, 2012; Hu et al., 2014; Luo, 2014; Li, 2016) The reason is that children with disabilities at young age need intensive childcare. Hence at least one family member must be responsible for full-time childcare. Usually mothers are the main caregivers who are taking care of young children with disabilities and they cannot participate in work. The employment status of main caregivers exacerbates the financial difficulties of the family to some extent.

6.1.2 Subjective FQOL in families with disabled children at young age

6.1.2.1 Subjective FQOL as a whole

Subjective FQOL refers to family members' satisfaction for their family life. The research results show that satisfaction for family life in families with disabled children at young age is significantly higher than “ neither dissatisfied nor satisfied ” , but significantly lower than “ satisfied”, which means that the subjective FQOL is at medium level and necessary for improvement. This finding is consistent with the investigation for families of children with developmental disabilities in Taiwan and Beijing, and families of autistic children in Chengdu. (Hong, 1999; Hu &Wang, 2012; Luo, 2014)

From the distribution of satisfaction scores, more than half of families are with medium level satisfaction score for their family life from 76-100, while still around 1/4 of families are with lower satisfaction score for their family life between 51 and 75; from the ranking of average satisfaction score per question, the satisfaction level on the overall scale and five sub-scales rank as family interaction >parenting > overall scale >disability-related supports> material well-being> emotional well-being. It means that the sample families are most satisfied with family interaction and then parenting, while less satisfied with disability-related supports and material well-being and least satisfied with emotional well-being. This finding is partially consistent with the previous research that families with disabled children are most satisfied with their family interaction. (Hu, 2012; Chiu, 2013; Meral, et al., 2013; Li, 2016), while less satisfied with disability-related supports, material well-being and emotional well-being. (Summers et al., 2007; Hu, 2012; Hsiao, 2018) Based on the findings from the qualitative approach, main caregivers of disabled children at young age are generally with more negative emotion experience of their FQOL. Most families of children with disabilities are not satisfied with their family life and most of them often complain as they feel “hopeless”. Their “very negative” emotional experience is two times frequently mentioned than “very positive” emotional experience. Speaking of the aspects of dissatisfaction, huge psychological burden has been perceived by main caregivers of disabled children at young age and dissatisfaction with the family economy and leisure time has also been mentioned. (Hoefman, 2014) They often feel too tired for taking care of disabled child, which may result in serious emotional problems for main caregivers. Besides, these families usually lack the awareness of leisure and entertainment as they are too busy for coping with their children with disabilities. (Luo, 2014)

6.1.2.2 Group difference of subjective FQOL

Group difference of subjective FQOL-based on child's characteristics

Independent sample *t*-test and one way ANOVA analysis together with multiple comparisons were conducted to examine the differences of satisfaction for family life among different family groups. The results show that there is a statistically significant downward trend of perceived satisfaction for family life along with the increase of disabled children's age, which is partially consistent with the previous study among parents with disabled children at 0-6 years old in Spain, but inconsistent with the previous study among parents of children with autism at the age 3-10 years old in France (Mas et al., 2016; Cyrielle et al., 2018) To be specific, in this study the significant differences mainly reveal on the sub-dimension of disability-related supports. Families with disabled children at the age of 0-2 years old perceive significantly higher quality of family life than families with disabled children at the age of 5-6years old or 7-8years old. It may be because those families with disabled children at the age of 0-2 years old have comparatively more positive attitude to disability-related supports and future expectation for child's rehabilitation as it is the preliminary stage for facing the child's difficulties and related supports.

In this study, the results show that families of children with different types of special needs have different perceived satisfaction for their family life. (Ren et al., 2018) To be specific, families of children with intellectual disabilities are less satisfied with their overall family life and other sub-dimensions of family life, except for emotional well-being; families of children with hearing impairment are less satisfied with material well-being comparing to families of children with autism or developmental delay; families of children with autism are less satisfied with disability-related supports comparing to families of children with developmental delay or physical disability. As this study is focused on families with disabled children at young age, families of children with intellectual disability in this study are either families of children who have intellectual disability at moderate or severity or very severity level in early intervention programs or in first grade of special school. Hence, their families are more possible to be less satisfied with their family life. In China, not all children with hearing impairment could have free cochlear implant from government, hence some families of children with hearing impairment at young age have big economic pressure of hearing aids and following speech and language rehabilitation. This may be the reason that families of children with hearing impairment are less satisfied with material well-being comparing to families of children with autism or developmental delay.

According to this study, there is also significant difference of FQOL on disabled child's characteristics including severity of child's special need, health condition and behavior problem. To be specific, family of children with very severity of special needs are less satisfied on overall family life or material well-being or emotional well-being compared to families of children with mild special needs, while families of children with mild special needs perceived significantly higher satisfaction in material well-being and disability-related supports than family groups of children with serious special needs; families of children with excellent health condition are significantly more satisfied with the overall FQOL and its sub-dimensions except family interaction, comparing to families of children with poor or average health condition; families of disabled children whose behavior problem has almost no impact on daily life are significantly more satisfied with overall family life and its sub-dimensions of family interaction, emotional well-being, material well-being and disability-related supports, comparing to families of children with very serious behavior problem.(Emily.& Grace,2015) In general, there is negative correlation between severity of children's special needs, disabled children's behavior problem and their family quality of life, while positive correlation between disabled children's health condition and their families' satisfaction for family life. These finding are consistent with the previous studies in families with disabled children (Wang et al., 2004; Chiu., 2013; Mas et al., 2016 ; Cyrielle, et al.,2018) and among families with autistic children in Shanghai. (Li, 2016) The reason may be that families of children with very severity of special needs or with very serious behavior problem or with poor health condition experience greater dissatisfaction because of more difficulties and disappointments in the process of raising children.

In addition, the results show that there is significant difference of satisfaction on total FQOL and material well-being between family groups with and without disability document. To be specific, families without disability document are significantly more satisfied for total family quality of life and material well-being, comparing to families with disability document. In China, families which chose not to apply for disability document for their disabled children are usually two kinds. The first kind are families of disabled children with mild special needs, which often have more positive attitude and expectation for children's future development. The second kind is families with quite good economic situation which chose to avoid the risk of discrimination, rather than to apply for the financial help from government. Both these two groups may be more satisfied with their family life. Besides these, results show that there is no significant difference on disabled children's gender, self-care ability and main placement.

Group difference of subjective FQOL-based on family's characteristics

Speaking of the family characteristics, some previous studies have explored the connections between FQOL and family characteristics, such as parents' gender, marital status, education level, household income, parents' stress and parenting skills. (Park et al., 2002; Glinac,2013; Emily.& Grace,2015; Mas,2016; Li,2016; Patton, 2016; Aldersey et al.,2017; Cyrielle, et al.,2018; Hsiao, 2018; Ren et al., 2018) According to the results in this research, there are significant differences of family quality of life on the age, education status, employment status of the main caregiver and marital status of parents, family location, household financial situation, parenting skill, whether parents join self-help organization and whether with child without special needs, while no significant differences on gender of main caregivers and their relationship to the disabled children (Wang et al., 2006).

In this study, significant differences of satisfaction on overall FQOL, family interaction and disability-related supports have been revealed among main caregivers of different age conditions. The results show that main caregivers at the age of 46-55 years old are more vulnerable to family quality of life comparing to other age conditions. Main caregivers at the age of 46-55 years old are usually young grandparents with first grandchild or senior parents with second child after the second-child policy. On one hand, because of their age, they may not so well informed of information related to children with disabilities comparing to younger caregivers who can obtain related information through internet, smart phone, television and so on. On the other hand, it might be difficult for them to accept the first grandchild or second child with special needs.

The research results show that education status of main caregiver has significant effect on total FQOL and its sub-dimensions of family interaction and material well-being. Main caregivers who have higher education level are more satisfied with their family life, especially on the dimensions of family interaction and material well-being. To be specific, main caregivers with bachelor degree or above perceive significantly higher satisfaction for family quality of life than main caregivers of other education status. The reason may be that main caregivers with higher education status are usually with better family financial situation and in advantage of searching for suitable supports for children with disabilities, which are helpful for improving their satisfaction for family life, especially for their family interaction and material well-being. In addition, main caregivers with full-time job are more satisfied with family material well-being than caregivers with part-time job. It is also mainly because of better family financial situation.

In this study, marital status of parents is also an indicator for FQOL among families of children with disabilities. Families with married parents living together perceive significantly higher satisfaction of family interaction and material well-being than families with married parents living separately. It is obvious that families with married parents living together have more chance and time for family interaction, while families with married parents living separately have less chance for direct family interaction and extra household expenditure for accommodation, transportation and so on.

According to this study, there is significant difference of satisfaction on total FQOL and its sub-dimensions of parenting, emotional well-being, material well-being and disability-related supports among families of different household financial situation, which is consistent with the findings from previous studies.(Cho& Hong, 2013; Dardas, et al.,2014;Mas, 2016) To be specific, families with balanced income and expenditure or far greater income than expenditure are significantly more satisfied with parenting, emotional well-being, material well-being and disability-related supports than families with income far less than expenditure. It may be because that family with better financial status can obtain more resources and supports for their families to cope with children's special needs. In addition, no significant difference of satisfaction for family life exists between families with balanced income and expenditure and families with far greater income than expenditure in this research. This indicates that when family has enough money to cover the expenditure, the impact of money on family life satisfaction will become smaller.

In this study, family location is another indicator for satisfaction of family life in terms of material well-being and disability-related supports. To be specific, families from village are less satisfied with material well-being than families from city and less satisfied with disability-related supports comparing to families from town or capital city. The reason may be that in China professional rehabilitation or intervention organizations are usually located in the city or town with higher population density. Besides, families from village are more probably in disadvantage of family financial status comparing to families from city.

According to previous research, parenting skill is one indicator for FQOL among Chinese families of children with autism. (Li., 2016) In this study, significant difference of FQOL has been revealed on all sub-dimensions of family life. To be specific, families those are in serious shortage of parenting skills are less satisfied with all sub-dimensions of FQOL than families with around average parenting skills or families with very good parenting skills. Similarly, families with around average parenting skills are less satisfied with sub-dimensions of family life including parenting, emotional well-being, material well-being and disability-related supports. Generally speaking, families with better parenting skills show higher satisfaction for perceived FQOL. This finding is consistent with the result from investigation among families with autistic children in Shanghai.((Li., 2016)) Families with better parenting skills are more capable to deal with disabled children's difficulties and decrease the negative influence of children's special needs to their family life. Therefore, they are relatively more satisfied with their family life.

According to Patton (2016), families participated in parent-to-parent peer mentoring programs show increased FQOL scores, but the difference doesn't reach statistical significance. Inconsistent Patton's finding, significant difference of satisfaction for family life has been recognized between family groups whether parents join self-help organization or not in this study. To be specific, families involved in self-help organization are significantly more satisfied for total family quality of life and dimensions of family life in terms of family interaction, parenting and material well-being, comparing to families not involved in self-help organization. It indicates that self-help organization for parents plays positive role in increasing satisfaction for family life by enhancing family interaction and improving parenting skills. In addition, whether with normal developmental child also indicates family quality of life. Families with normal developmental child are significantly more satisfied with family interaction than families without normal developmental child.

6.2 Influencing parameters of FQOL in families with disabled children at young age

On the basis of the research results through both the quantitative approach and qualitative approach, six influencing parameters have been recognized for FQOL in families with disabled children at young age: difficulties related to child, economic factor, parental attitude, family preparation, family involvement and social support. In addition, child's characteristics including child's age, types and severity of disability, health condition and behavior problem, with disability document or not, and family's characteristics including the age, education status, employment status of the main caregiver and marital status of parents, family location, household financial situation, parenting skill, whether parents join self-help organization and whether with child without special needs, could also be taken as predictor of FQOL in families of children with disabilities at young age. Among them, child's age, types and severity of disability, health condition and behavior problem, with disability document or not, could be integrated in the factor of difficulties related to child; the age, education status, employment status of the main caregiver and marital status of parents, parenting skill, and whether with child without special needs, could be integrated in the factor of family preparation; family location, and household financial situation could be integrated in the factor of economic factor; and whether parents join self-help organization could be integrated in the factor of social support. Hence, they will not be discussed separately in the following discussion part.

Corresponding to the unified theory of family quality of life, difficulties related to child, together with child's age, types and severity of disability, health condition and behavior problem, with disability document or not, and parental attitude, together with the age, education status, employment status of the main caregiver are individual-member factors; while economic factor, family preparation, family involvement, together with marital status of parents, family location, household financial situation, parenting skill, whether parents join self-help organization and whether with child without special needs, are family-unit factor; social support is belong to systematic factor.(See Figure 2.2 in Chapter 2)

The six influencing parameters are not isolated from each other, and when these parameters are superimposed, their influence to the FQOL in families of children with disabilities at young age is more complicated. Among them, difficulties related to child and economic factor are the most direct impact factors of satisfaction for their family life which build the basic background for the family life. Then, parental attitude, family preparation and family involvement are shaped on the basis of the basic family background and further affect satisfaction for the family life. Meanwhile, social support as the resources from outside family can directly affect FQOL and also indirectly influence FQOL through other five parameters. In addition, combining the quantitative and qualitative research results, parental attitude and social support have been regarded as the most important influencing parameters of FQOL in families of young children with disabilities. Meanwhile, the importance of parental attitude in impacting FQOL is more recognized by caregivers and professionals at younger age(below 30 years in this study); while the objective factor such as economic factor and difficulties related to child have been more emphasized by parents at older age or grandparents.

6.2.1 Difficulties related to child

For families of disabled children at young age, difficulties related to child is the most direct influencing parameter of their FQOL. (Dardas, et al., 2014) To be specific, child's performance, especially child’s behavioral or emotional problems; child's developmental expectation; child's special needs, including the type of disability and severity of special needs; and child's health status affect family members’ perceived satisfaction for their family life. Based on the regression analysis, difficulties related to child can negatively predict overall family quality of life (1.6%) and satisfaction for family interaction (4.5%). It indicates that families of children with more severe difficulties perceive less satisfaction for family interaction and their overall family life.

6.2.2 Economic factor

Economic factor reveals families' general socioeconomic status. For families with disabled children at young age, family economic status, in terms of household financial situation, parents' employment, economic burden related to children's rehabilitation and other family economic burden influence family members' satisfaction for their family life. According to the regression analysis, economic pressure can negatively predict family satisfaction of material well-being (3.7%). It indicates that families with disabled children at young age are dissatisfied with their family material well-being because of great economic pressure, especially the economic burden related to children's rehabilitation. In addition, for families with disabled children at young age, one family member usually the mother must be full-time caregiver and cannot work. This makes the family financial situation even worse as the whole family is often relied on father's income. In this study, families with worse household financial situation are significantly less satisfied with material well-being, parenting and disability-related supports. (Dardas, et al., 2014; Aldersey, 2017) The reason may be that family with greater economic pressure doesn't have enough money to deal with various family difficulties, especially when the child's special needs are money consuming and not enough financial assistance is available. (Park, 2002) As a result, their satisfaction for material well-being will be relatively lower.

6.2.3 Parental attitude

In this study, parental attitude refers to parents' attitude to the fact of having child with special needs which reveals parent's acceptance of child's special needs, parents' psychological status and their attitude to child's rehabilitation and education. According to the regression analysis, for families of disabled children at young age, parental attitude has a strong positive prediction of total FQOL (53.1%) and also satisfaction for family interaction (15.3%), parenting (19.2%), emotional well-being (56.4%), material well-being (75.0%) and disability-related supports (25.4%). Parents with positive attitude to child's special needs, tend to be more objective to child's difficulties, more sensitive to child’s special needs and more active in seeking for help, which would lead to higher satisfaction of emotional well-being, material well-being, disability-related supports, parenting and also family interaction. (Ferrer, et al., 2016; Aldersey et al., 2017) Unfortunately, in practice parents of children with disabilities often have negative attitude, especially when children are at young age as the acceptance of children’s special needs is a time-taking process. The lack of or incorrect understanding of children’s special needs among family members results in denial of children’s special needs and excessive expectation for their children, which may bring high possibility of frustration and conflicts to the family. Moreover, because of limited understanding of children’s special needs, parents feel a lot of “hopeless” and “anxiety” which may greatly influence their participation in child’s intervention practice.

6.2.4 Family preparation

In this study, family preparation means how family is prepared for parenting children with disabilities. It includes basic family status, status of family collaboration and family parenting preparation, in terms of family members’ understanding of the child’s special needs, family’s parenting efficiency, and also their information readiness for seeking supports. According to the regression analysis, family preparation can positively predict overall family quality of life (1.3%) and family members’ satisfaction for sub-dimensions of family life, including parenting (7.8%), emotional well-being (2.2%), and disability-related supports (7.3%). It indicates that greater FQOL will be perceived among families those are more familiar with children’s difficulties and more effective in responding to children’s special needs and seeking for suitable supports. In practice, families with disabled children at young age are not well prepared for coping with children’s special needs. These parents are probably lack of professional knowledge, rehabilitation skills and parenting experience, which results in quarrels among family members and may end up with divorce because of parenting conflicts and high pressure from childcare.

6.2.5 Family involvement

Family involvement refers to family members' participation in taking care of the disabled child, parent training program, and child's intervention. Specifically, family involvement, on one hand, includes family members' participation in childcare and training program for parents, in child's rehabilitation in terms of designing the rehabilitation plan and participating in rehabilitation practice, and on the other hand includes the relationship between family members and professionals, and family's power for making decision related to child's intervention. According to the regression analysis, family involvement can predict overall family quality of life (5.3%) and satisfaction of parenting (1.4%), material well-being (1.3%) among families of children with disabilities at young age. It indicates that to some extent, higher family involvement in disabled children's intervention predicts greater family quality of life and higher satisfaction for parenting and material well-being. It may be because families those are highly involved in disabled children's early intervention are likely with closer family interaction, higher parenting efficiency and close connection with professionals.(Cyrielle et al, 2018)) In return, it might be more likely for them to be satisfied with parenting and family material conditions. In practice, for families with disabled children at young age, mother is more often to be the full-time caregiver and there may be quite less help from other family members; usually father is seldom involved in childcare as he needs to make money to support family; it often happens that the elderly are relied on for childcare and housework; parents are not highly involved in child's rehabilitation, because of their inappropriate perspective and restrictions from institutional management; parents generally have needs for training program but seldom have time to participate.

6.2.6 Social support

Social support refers to various services and assistances from different sources including government, community, society, other parents with disabled children and so on. In this study, information accessibility, rehabilitation and education resources, social concept, related services and family's social interaction are included in this parameter. Research results in this study show that families participated in self-help organization for parents are significantly more satisfied for family interaction, parenting and material well-being, and social support can positively predict family members' satisfaction for their family interaction (2.7%) to some extent. It indicates that better situation of social support predicts higher satisfaction of family interaction among families of children with disabilities. (Summers et al., 2007; Kyzar,et al., 2012; Cho& Hong, 2013; Meral, et al., 2013; Lu et al., 2015; Hu, 2016;Marsack, 2017; Ren et al., 2018;Balcells-Balcells et al., 2019) Besides, previous research reveals that social support can positively predict satisfaction of disability-related support among families with autistic children. In practice, families with disabled children at young age mainly obtain information from internet, books, other parents and professionals in institution and hospital, government department (including CDPF); the distribution of rehabilitation and education resources is not balanced which means families from districts and counties may have no access to rehabilitation resources; requirement of household registration has restricted access for better rehabilitation and education services; generally children with disabilities and their parents are not well-accepted by the society; communication channels among parents, professional psychological support for parents and barrier-free facilities in public and at home are in need for improvements; vulnerable families' social interaction may result in psychological pressure. (Hsiao, 2018)

6.3 Strategies for improving FQOL in families with disabled children at young age

On the basis of the in-depth interview with main caregivers and professionals, four aspects of strategies have been raised for improving FQOL in families with disabled children at young age: family aspect, service aspect, government aspect and social environment aspect. These four aspects improving strategies build a progressive model of improving strategies of FQOL. Corresponding to family's ecological system, family aspect strategies are in the family's microsystem, which are directly related to families with disabled children at young age and also most often mentioned by main caregivers and professionals; service aspect strategies are in family's mesosystem, which play critical role in building families' support system; government aspect strategies are in families' exosystem and are the external environmental conditions both directly and indirectly affected FQOL; social-environment aspect strategies are in the macrosystem, which is relatively far from family members, but the improvement of the social environment also helps to improve the quality of family life.

6.3.1 Family aspect strategies

According to the discussion above, parental attitude, family preparation and family involvement are influencing parameters of FQOL from family itself, which can positively predict family members' satisfaction on total family life and also all sub-dimensions. Moreover, family characteristics such as age, education status, employment status of the main caregiver and marital status of parents, family location, parenting skill have been discovered as predictors for FQOL in families of children with disabilities at young age. Hence, family aspect improving strategies, in terms of changing attitude, optimizing family collaboration and improving parenting ability have been regarded as the most important improving strategies for FQOL in families of disabled children at young age.

Among them, changing attitude has been attached most importance by caregivers and professionals, as positive family perceptions could act as a mechanism for coping with burden and stress from taking care of disabled children. Positive attitude towards children with disabilities is helpful for family members in the adaptation and accommodation process. (Folkman & Moskowitz, 2000; Lloyd & Hastings, 2008; Paczkowski & Baker, 2008; Ferrer et al., 2016; Ferrer et al., 2017) Specifically, on one hand, positive perceptions and acceptance of children with disabilities can protect families from some negative influence from disabilities or circumstances; on the other hand, positive perceptions and increase of parents' knowledge about children's disabilities could reduce mothers' feelings of guilt (Kuhn & Carter, 2006; Ferrer et al., 2016; Cyrielle,2018) Therefore, family aspects improving strategies emphasize the importance to build on family's strengths which enable family to make decision and have more control over child's present improvements and future developments. (Ferrer et al., 2017; Huang, 2018)

According to this research, families with disabled children at young age are suggested to do more self-adjustment and accept their children's special needs as earlier as possible on the basis of optimistic attitude and rational thinking. Moreover, clear division of labor in family and family members' collaboration in childcare and other family duties are recommended to optimize family collaboration. Child's main caregivers are suggested to balance childcare and work, and to release pressure and gain sense of accomplishment in the work. Besides, parents with disabled children are advised to know their children by continuous careful observation and to improve their parenting skills and professional knowledge. In addition, the importance of family, home rehabilitation and early intervention have been recognized and parents are advised to actively participate and highly involved in child's rehabilitation and education.

6.3.2 Service aspect strategies

According to the discussion above, on one hand, social support is one important influencing parameter of FQOL in families of disabled children at young age; on the other hand, there are significant differences of satisfaction for family life between families join self-help organization or not. Besides, both individual level support and family level support have been regarded as enhancing strengths for family outcomes in the unified theory of FQOL. Hence, support-based service framework including rehabilitation service, related service and information service has been suggested for encouraging family members' strengths and promoting their FQOL. (Hu &Wang, 2012; Zuna et al., 2014; Hsiao, 2016; Li, 2016; Ferrer et al., 2017; Li, 2017)

As discussed in the above, families with disabled children at young age have to face numerous difficulties related to their children's special needs, including diminished job opportunities, increased financial costs and transportation problems, little spare time or energy for leisure activities. (Harris, 2008). It indicates that families with disabled children require additional resources and also need to know how to use the formal and informal resources available around to solve their difficulties and to build social support networks. (Tétreault et al., 2014; Mas et al., 2016) Previous studies show that not sufficient supports are available for Chinese family and there is significant gap between the status quo of services to parents and their own expectations (Han, 2005; Hu, 2012; Hu & Wang, 2012; Hu, 2016) Hence, family-centered support services program are needed for families with disabled children at young age, including family rehabilitation guidance, professional psychological support, parents' education, respite care etc.(Luo, 2014; Tétreault et al., 2014; Bearss et al., 2105; Hu, 2016; Hu et al., 2016) These family support services contribute to reduce parents' psychological distress, enable them to care effectively for children's special needs and have global beneficial effects on their health and well-being. (Tétreault et al., 2014; Hu, 2016)

For families of disabled children, it has been reported to have difficulty accessing information about their children's special needs. (Summers et al., 2007) Hence, more information about children's education and clear explanation of policy information from government, together with smooth information channels are needed by parents with disabled children at young age. Information from authority, including doctors, research experts in this area, and professionals is highly recognized by these families. Besides, effective family–professional partnerships have been recognized as recommended practices in early childhood programs. (Summers et al., 2007; Hu, 2012; Huang, 2017) In addition, parents mutual assistance platform is expected by parents to share experiences and get help from other parents in managing day-to-day stress and challenges. (Iscoe & Bordelon, 1985; Wiley et al., 2014; Patton, 2016)

6.3.3 Government aspect strategies

Government plays an indispensable role in improving disabled children's rehabilitation conditions and promoting their families' outcomes. Government aspects strategies in terms of economic support and policy support have been recommended by caregivers and professionals for improving the FQOL in families of children with disabilities. (Hu, 2012; Luo, 2014; Hu, et al., 2016; Li, 2016), especially for families with disabled children at young age.(Huang, 2017)

Economic factor is one important influencing parameter of FQOL in families of disabled children at young age. Moreover, there are significant differences of FQOL on different household income. In China, there is rehabilitation rescue project from government for families with disabled children. For example, in Sichuan province, disabled children from 0-6 years old with disability document can get rehabilitation subsidy from government. Speaking of the requirements of the rehabilitation rescue project, there are obvious regional differences, as the rescue project of Sichuan province[14] describes,

"*Rescue objects are eligible children with visual impairment, hearing impairment, speech and language disorder, intellectual disability, physical disability etc. from 0 to 6 years old and children with autism. The age of children with cerebral palsy is extended to 12 years old; children with hearing impairment studying in general schools can apply for cochlear implantation to 12 years old; children with physical disabilities can apply for corrective surgery till 14 years old...* The subsidy for *rehabilitation surgery shall not exceed RMB 30,000Yuan/year, rehabilitation training less than 20,000 Yuan / year, basic assistive device not more than 5,000 Yuan / person, cochlear implant is not more than 60,000 Yuan / person, hearing aid less than 10,000 Yuan / person,* and *universal prosthetic limb installation does not exceed 10,000 Yuan/ person.*"

Correspondingly, rescue project in Chengdu[15] describes,

"*Rescue objects are eligible children with visual impairment, hearing impairment, speech and language disorder, intellectual disability, physical disability etc. from 0 to*

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[14] China association of the blind. 关于印发《四川省 0-6 岁残疾儿童康复救助项目实施方案》的通知 [Notice on Issuing the Implementation Plan for the Rehabilitation and Relief Project for Children with Disabilities of 0-6 Years in Sichuan Province]. (2016, March 20). Retrieved May 8, 2020, from: http://www.zgmx.org.cn/newsdetail/d-69254-0.html

[15] Chengdu Municipal People's Government. 关于完善残疾儿童康复救助制度的实施意见 [Implementation Opinions on Improving the Rehabilitation and Assistance System for Children with Disabilities]. (2019, August 30). Retrieved May 8, 2020, from: http://gk.chengdu.gov.cn/govInfoPub/detail.action?id=110867&tn=6

15years old and children with autism, who have Hukou(household registration) in Chengdu…The subsidy for rehabilitation surgery shall not exceed RMB 30,000Yuan/year, rehabilitation training less than 30,000 Yuan / year, basic assistive device not more than 10,000 Yuan / person, cochlear implant is not more than 80,000 Yuan / person, hearing aid less than 15,000 Yuan / person, and universal prosthetic limb installation does not exceed 10,000 Yuan/ person."

According to the interviewees' description, usually one child with disability below 6 years old can get 12000 -14000Yuan(≈1714-2000$) rehabilitation subsidy per year, but the annual rehabilitation cost for disabled child at young age is on average 30,000-50,000Yuan(≈4286-7143$). The subsidy from government is less than half of the rehabilitation expense. Therefore, more economic support from government has been frequently mentioned by caregivers and professionals for promoting FQOL.

Meanwhile, the obvious regional differences of governmental financial subsidies and policy regulations restrict family access to rehabilitation services elsewhere. Children with disabilities can get free nine years compulsive education in the schools within household registration, but extra money should be paid if they want to have education in schools outside their household registration. For example, only the special education center in Qingyang district (one district in Chengdu city) accepts disabled children outside the Chengdu area, but 30,000 Yuan/ year(≈4286$) must be paid for each student without local household registration as tuition fee, while it is free for local children with disabilities. (Luo, 2014) Hence, in order to let families receive rehabilitation and education services sufficiently and flexibly, more financial aids and reducing policy restrictions are expected by families with disabled children at young age. In addition, policies for regulating and supporting the intervention industry are also expected by families and institutions.

6.3.4 Social environment aspect strategies

According to the unified theory of FQOL, systematic factors can directly influence supports and services gained by children with disabilities and their families, which includes societal values, policies, systems, and programs. (Wehmeyer et al., 2013) In this study, social environment aspect strategies refer to strategies aiming at building better social atmosphere which for families with disabled children. Improving social acceptance and enhancing social integration are proposed by caregivers and professionals. (Li, 2016) According to the interviewees, there are still many misunderstandings among public, for example attributing child’s special needs to parents’ faults or bad family upbringing, connecting disabled children with aggressive behaviors, or equating autism with introvert, supposing children with intellectual disabilities as useless people. Therefore, in order to promote disabled children’s social integration, more publicity of children with disabilities is advised for increasing public awareness and social acceptance, especially about the kinds of special needs not well-known by public, such as autistic spectrum disorder, physical disabilities, ADHD, developmental disabilities and so on. Meanwhile, acceptance of disabled children by teachers and peers, especially acceptance by general teachers is vital for disabled children to receive inclusive education. In addition, improvements of barrier-free facilities benefit the social integration of disabled children and their families, thereby helping to improve their family quality of life.

6.4 Reflection on the study

Through combination of quantitative and qualitative approaches, a relatively comprehensive understanding of FQOL in families of children with disabilities at young age has been obtained in this research on the basis of these meaningful results discussed above. Firstly, both objective and subjective FQOL in families of disabled children at young age are not satisfying and need to be supported for improvements. Main caregivers of these children experience great child care burdens, limited household income, high rehabilitation expenses and huge psychological pressure. These families are most satisfied for their family interaction, while least satisfied for family emotional well-being. Secondly, parental attitude, social support, family preparation, family involvement, economic factor, difficulties related to child have been discovered as influencing parameter for FQOL in these families. The six influencing parameters and some family and child characteristics can predict the satisfaction for family life in families with disabled children at young age. Thirdly, four aspects of strategies in terms of family, service, government and social environment have been proposed for improving of FQOL in these families. These research findings have enriched the understanding of FQOL in families of young children with disabilities, and triggered the following revelation about this topic:

- Generally, family life dilemma in families of children with disabilities is an intensified version of that in families without disabled children.

Nowadays in China, there are various family problems in the process of social transformation and development, such as skipped generation families, absent father, only-child parents' family education ability etc. (Zhu, 2019; Wen & Zhai, 2019; Jin & Xu, 2020; Nie, 2020) These problems are also presented in families of children with disabilities. The difference is that these problems interact with the difficulties related to children with disabilities, and the dilemma of family life in families with disabled children becomes more prominent. Hence, it’s necessary to consider these problems as well when trying to improve the FQOL in families with disabled children at young age.

- Family and family’s needs should be seen and responded in early intervention.

As it is mentioned in the first chapter, supporting family should be and has been emphasized in early intervention area in the world. However, in the early intervention practice in China, the focus on family support and family needs has not been implemented. Parents and sometimes even the professionals are more inclined to rely on institutional rehabilitation training to solve their children's problems. Family and family’s support needs are undervalued. Hence, it is advocated to improving services delivery in early intervention to emphasize on family strengths and promote the family outcomes in these families. In order to reach this goal, FQOL should be taken as a priority issue along with the rehabilitation progress of child in early intervention by identifying and prioritizing needed supports within a family-centered service delivery model. (Zuna et al., 2014)

- The misalignment between influencing factors and improving strategies reflects the understanding of disability in Chinese society.

In this research, regarding the influencing parameters of FQOL in families of disabled children at young age, external social support parameter was most frequently mentioned by caregivers and professionals. However, in terms of the improving strategies, both caregivers and professionals pay more attention to families' self-regulation. On one hand, this misalignment reveals that special education professionals, parents of children with disabilities and even the entire society more believe that individuals with disabilities are the responsibility of their family itself rather than the common responsibility of the society. This may be related to the long-standing social value orientation in Chinese society, that is, more emphasis on collective interests rather than individual rights and interests. On the other hand, this misalignment also reflects that Chinese parents of children with disabilities are helpless in advocating for children and family rights. Some families with disabled children even have no idea what kinds of support they could seek from government and society. Hence, alliance of parents with disabled children should be valued and become a key force for mutual parent assistance and advocacy for disabled children's rights in China. Meanwhile, families of children with disabilities need comprehensive support system rather than just financial assistance.

- Rebuilt the supporting system for families of young children with disabilities.

According to this study, the support system of families with disabled children in China is vulnerable. The main caregivers usually experience huge childcare burden and psychological stress, while there may be limited sharing from other family members and seldom support from relatives or friends. Families' perceived supports from professional institutions are not stable in certain but received by chance, so families often feel hopeless. Hence, it is urgent to rebuilt comprehensive support system for families with disabled children in China.

Although, this study provides abundant research results and meaningful enlightenments, inevitably there are still some limitations. Firstly, perspectives of

FQOL from other family members haven’t been obtained as the main caregivers are the respondents of questionnaire survey and main participants of interviews in this study. FQOL is a holistic concept of family members’ satisfaction for their family life. Different family members may have different feelings and viewpoints. Although previous studies on FQOL often used parents or primary caregivers as respondents, and there was no significant difference of views on FQOL between father and mother (Wang et al., 2006), other family members such as siblings and grandparents may have different experience and understanding of their family life. Hence, it is necessary to expand the range of respondents and take into account of other family members. Secondly, because of limited time and realistic conditions of the research, only a small number of families with disabled children at young age from minority groups have been reached in this study, while the majority of families are from Han area. Therefore, the research findings more present the situation of FQOL in the Han area, while only limited application is possible in minority areas. Thirdly, the instrument used for measuring influencing factors of FQOL in this research is a self-compiling questionnaire, which hasn’t been verified by other studies. Knowledge and experience limitations of the researcher may affect the validity of the questionnaire to a certain extent. For example, the scope of social support dimension is relatively restricted because of small amount of items. Fourthly, there is lack of consideration of the dynamic process in family life. This study is a static study on the quality of family life, in terms of current situation, influencing factors and improving strategies of FQOL. However, family members’ satisfaction on their family life may change dynamically in the process of family interaction. Hence, further research about FQOL based on family interaction could be done in the future.

Chapter 7 Conclusions

Through this mixed design combining quantitative and qualitative methods, this research has examined the current status of objective family conditions and perceived FQOL in families of disabled children at young age, and further explored its influencing factors and improving strategies. Conclusions based on the research results and discussions in the former part will be presented in the following paragraphs.

7.1 Status of the objective family conditions

The current status of objective family conditions in families of disabled children at young age is below average and needs to be supported for improvements: families with balanced income and expenditure are less than half and more than 40% families with income far less than expenditure, while only small proportion families are with far greater income than expenditure; families with disabled children at young age (199 responded families) have monthly average income 5155.28 Yuan in RMB (≈736$) for whole family and 1718 Yuan(≈245$) per person, which is less than the province's average monthly disposable income 2059Yuan/ person(≈294$) in Sichuan province in 2019; there are also a proportion of families with average income more than 8000 Yuan(≈1143$) which reveals a large income gap among families with disabled children at young age; average household expenditure on education and rehabilitation for disabled children per month accounts for more than 40% of the average household income; the majority of the responded families have their own flats or houses as accommodation, while still more than 1/5 families rely on long term renting or staying with relatives or friends; less than a quarter of the respondents have full time job, while more than half are without job.

7.2 Current situation of the FQOL

The subjective FQOL in families of young children with disabilities is at medium level with mean of item score significantly higher than "neither dissatisfied nor satisfied", but significantly lower than "satisfied"; the satisfaction level on the overall scale and five sub-scales rank as family interaction >parenting > overall scale >disability-related supports> material well-being> emotional well-being, which means families are most satisfied with family interaction and then parenting, while less satisfied with disability-related supports and material well-being and least satisfied with emotional well-being; main caregivers of young children with disabilities are generally with more negative emotional experience of FQOL and their "very negative" emotion experience is two times frequently mentioned than "very positive" emotional experience; huge psychological burden has been perceived by main caregivers of disabled children at young age and dissatisfaction with the family economy and leisure time has also been mentioned.

Regarding to group differences of subjective FQOL in families of children with disabilities at young age, there are statistically significant differences of FQOL on child's characteristics including child's age, types and severity of special needs, health condition and behavior problem, with disability document or not, while no significant difference on disabled children's gender, self-care ability and main placement; statistically significant differences of subjective FQOL have also been witnessed on family's characteristics including the age, education status, employment status of the main caregiver and marital status of parents, family location, household financial situation, parenting skill, whether parents join self-help organization and whether with child without special needs, while no significant differences on gender of main caregivers and their relationship to the disabled children.

7.3 The influencing parameters of FQOL

Combining the research findings from both the quantitative and qualitative methods, six influencing parameters for FQOL in families with disabled children at young age have been recognized: difficulties related to child, economic factor, parental attitude, family preparation, family involvement and social support. These six parameters are not isolated from each other, and when these parameters are superimposed, their influence on the FQOL in families of children with disabilities at young age is more complicated. Among them, difficulties related to child and economic factor are the most direct impact factors of satisfaction for their family life which build the basic background for the family life. Then, parental attitude, family preparation and family involvement are shaped on the basis of the basic family background and further affect satisfaction for the family life. Meanwhile, social support as the resources from outside family can directly affect FQOL and also indirectly influence FQOL through other five parameters.

To be specific, difficulties related to child can negatively predict overall family quality of life (1.6%) and satisfaction for family interaction (4.5%) and economic pressure can negatively predict family satisfaction of material well-being (3.7%); while parental attitude has a strong positive prediction of total FQOL (53.1%) and also satisfaction for family interaction (15.3%), parenting (19.2%), emotional well-being (56.4%), material well-being (75.0%) and disability-related supports (25.4%); family involvement can predict overall family quality of life (5.3%) and satisfaction of parenting (1.4%), material well-being(1.3%); family preparation can positively predict overall family quality of life (1.3%) and family members' satisfaction for sub-dimensions of family life, including parenting (7.8%), emotional well-being (2.2%), and disability-related supports (7.3%); social support can positively predict family members' satisfaction for their family interaction (2.7%) to some extent.

In addition, combining the quantitative and qualitative research results, parental attitude and social support have been regarded as the most important influencing parameters of FQOL in families of young children with disabilities. Meanwhile, the importance of parental attitude in impacting FQOL is more recognized by caregivers and professionals at younger age(below 30 years in this study); while the objective factor such as economic factor and difficulties related to child have been more emphasized by parents at older age or grandparents.

7.4 The improving strategies of FQOL

On the basis of the in-depth interview with main caregivers and professionals, four aspects of strategies have been raised for improving of FQOL in families with disabled children at young age: family aspect, service aspect, government aspect and social environment aspect. These four aspects improving strategies build a progressive model of improving strategies of FQOL. Corresponding to family's ecological system, family aspect strategies are in the family's microsystem, which are directly related to families with disabled children at young age and also most often mentioned by main caregivers and professionals; service aspect strategies are in family's mesosystem, which play critical role in building families' support system; government aspect strategies are in families' exosystem and are the external environmental conditions both directly and indirectly affected FQOL; social-environment aspect strategies are in the macrosystem, which is relatively far from family members, but the improvement of the social environment still helps to improve the quality of family life.

Summary of the research conclusions and main research findings are presented in Table 7.1 on the following page.

Table7.1 Summary of the research conclusions and main findings

Domain	Conclusions	Main research findings
Current status of FQOL	Objective family conditions are below average.	1.40% families with income far less than expenditure; 2.monthly average income per person less than the provincial average monthly disposable income; 3.high expenditure on education & rehabilitation; 4.more than half main caregivers without job.
	Subjective FQOL is at medium level.	1.Mean of item score significantly lower than “satisfied”; 2.satisfaction level: family interaction>parenting> overall scale>disability-related supports> material well-being> emotional well-being; 3.more negative emotion experience of FQOL; 4. statistically significant differences of FQOL on certain child’s characteristics; 5. Statistically significant differences of FQOL on certain family’s characteristics.
Influencing parameters	difficulties related to child	negatively predicts overall FQOL and satisfaction for family interaction
	economic factor	negatively predicts family satisfaction of material well-being
	parental attitude	strong positive prediction of total FQOL and satisfaction for family interaction, parenting, emotional well-being, material well-being and disability-related supports
	family preparation	positively predicts overall FQOL and satisfaction for parenting, emotional well-being, and disability-related supports
	family involvement	positively predicts overall FQOL and satisfaction of parenting, material well-being
	social support	positively predicts satisfaction for family interaction
Improving strategies	family aspect strategies	changing attitude, optimizing family collaboration and improving parenting ability
	service aspect strategies	rehabilitation service, related service and information service, eg. family support services, more information about children’s education, clear explanation of policy information from government, smooth information channels, parents mutual assistance platform and so on
	government aspect strategies	more financial aids, reducing policy restrictions, policies for regulating and supporting the intervention industry
	social environment aspect strategies	more publicity of children with disabilities, acceptance of disabled children by teachers and peers, improvements of barrier-free facilities

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Appendix

Appendix A Description of the research project

Dear person in charge of rehabilitation center, institution, school and kindergarten for children with special needs:

Hello！

First of all, thank you very much for taking the time to read this introduction of the research project entitled Family Quality of Life(FQOL) in Families of Young Children with Special Needs, which mainly explores the current situation of the family life satisfaction in families of children with special needs at young age and its potential influencing factors. The research participants of this project are the parents (or main caregivers) of children with special needs at young age and the professionals engaged in rehabilitation and education for these children. Two parts are included in this project: questionnaire survey and in-depth interview. (See the following table) In this research, the children with special needs at young age refer to children with special needs aged 8 years and below, and the types of children's disabilities are not limited.

Research form	**Required participants**	**Content description**
Questionnaire survey	Parents/main caregivers of children with special needs	demographic information, current situation of FQOL, and potential influencing factors
Interview	Parents/main caregivers of children with special needs and relevant professionals	The status quo, satisfaction, dilemma of family life and the need to improve family life quality

This research is aiming at finding possible strategies for improving the FQOL in these families and providing references for institutions and schools related to children with special needs at young age to better understand the actual difficulties and needs in their families. I sincerely invite you and your institution to provide strong support and help to this research, and jointly contribute to the promotion of better FQOL in families of children with special needs at young age. Your support and cooperation are highly appreciated. For any questions and suggestions for this research, please feel free to contact the researcher (QQ: 1956788365, 1956788365@qq.com).

The researcher：Guo Ling

2019/12

Appendix B Questionnaires

Research on FQOL in families of young children with special needs

Dear parent：

Hello! You are invited to participate in the study entitled Family Quality of Life (FQOL) in Families of Young Children with Special Needs, which mainly explores the current situation of your satisfaction for your family life and relevant influencing factors. This study is aiming at finding appropriate strategies for supporting families of children with special needs at young age. Please tick ”√” the option that most matches your family’s real situation, or fill in the relevant information on "___" based on the actual situation of your family and your real thoughts in the past 12 months.

Tips for filling the questionnaire:

1. Please let the child’s main caregiver to fill in the questionnaires, and if the main caregiver c cannot fill it out for objective reasons, it can be filled in by other nuclear family members according to the main caregiver's viewpoints.
2. If you have any questions during the filling process, feel free to ask the questionnaire issuer or contact the researcher (Guo, QQ: 1956788365).
3. Please check again after filling in to make sure there are no omissions.

There is no right or wrong answer, only for academic research; the information you fill out will not be used for other purposes, please feel free to answer; participation in this research is based on voluntary principles, if you agree to participate, please fill out the following questionnaires; thank you for your support and cooperation!

Part 1 Demographic Information Form

1.You are the child’s: ①mother ②father ③grandfather ④grandmother ⑤other

2.Your gender: ①female ②male

3.Your age: ①under 25y ②26-35y ③36-45y ④46-55y ⑤above 56y

4.Your education level: ①primary school and below ②middle school ③high school or similar level ④bachelor or similar level ⑤master degree and above

5.Employment status: ①full-time job ②part-time job ③without job ④retired

6. Information about your child: (if there are two children with special needs, please fill in the information according to the child who has a greater impact on your family life)

(**1**)child’s age: ① 0-2y ② 3-4y ③ 5-6y ④ 7-8y (**2**)gender: ① boy ② girl；

(**3**)whether with disability document:①yes ②no

(**4**)type of special needs: ①visual impairment ②hearing loss ③intellectual disability(includes down syndrome) ④physical disability(includes cerebral palsy) ⑤speech and language disorder ⑥autism spectrum disorder ⑦multiple disabilities ⑧developmental delay ⑨other_________

(**5**)severity of special needs: ①mild ②moderate ③severe ④very severe

(**6**)self-care ability：①completely independent ②less dependence on others

③most dependence on others ④completely dependent

(8)impact of problem behavior on daily life：①seriously ②slightly ③no impact

(9)current main placement：①general kindergarten/school ②special kindergarten/school private intervention center ④center under CDPF ⑥hospital ⑦other ⑧______

7.Marital status of child's parents:①married and living together ②married but living separately ③divorced ④in widowhood

8.Family location：①provincial capital city ②prefecture level city ③town ④village；

9.Monthly average household income______Yuan in RMB， monthly expenditure for child's rehabilitation and education_______Yuan in RMB

10.Family income and expenditure status：①income is far greater than expenditure ②balanced ③income is far less than expenditure

11.Accommodation condition: ① owning flat/house ② long term renting ③ stay with relatives/friends

12.Family members' parenting skills：①serious shortage ②around average ③very good

13.whether with child without special needs：①yes ②no

14. Whether parents join self-help organization：①yes ②no

Part 2 Beach Center FQOL Scale

Please think about your family life over the past 12 months and chose how satisfied you are with these things in your family：(1=very dissatisfied; 2=dissatisfied; 3=neither;4=satisfied;5=very satisfied),in the questionnaire the "child" refers to the child with special needs in your family.

Description of the family life (1=very dissatisfied; 2=dissatisfied;3=neither;4=satisfied;5=very satisfied)	**Satisfaction**				
	1	**2**	**3**	**4**	**5**
1. My family enjoys spending time together.					
2.My family members talk openly with each other					
3. My family solves problems together.					
4. My family members support each other to accomplish goals.					
5. My family members show that they love and care for each other.					
6. My family is able to handle life's ups and downs.					
7. My family members help the child learn to be independent.					
8. My family members help the child with schoolwork and activities.					
9. My family members teach the child how to get along with others.					
10. Adults in our family teach the child to make good decisions.					
11. Adults in my family know other people in the child's lives (friends, teachers, etc.).					
12. Adults in my family have time to take care of the individual needs of every child.					
13. My family has the support we need to relieve stress.					
14. My family members have friends or others who provide support.					
15. My family members have some time to pursue our own interests.					
16. My family has outside help available to us to take care of special needs of all family members.					
17. Family members have needed transportation.					
18. My family gets medical care when needed.					
19. My family feels safe at home, work, school, and in our neighborhood.					
20. My family can get necessary regular medical examination					
21. My family has a way to take care of our expenses.					
22. My family member with a disability has support to accomplish goals at school or at workplace.					
23. My child has support to accomplish goals at home.					
24. My child has support to make friends.					
25. My family has good relationships with professionals who provide services and support to my child.					

Influencing Factors Questionnaire of FQOL

How consistent are the following descriptions with your family life:

Descriptions (1=very inconsistent; 2=inconsistent;3=not sure;4=very consistent;5=very consistent)	**Consistency**				
	1	2	3	4	5
1. My family household income is not enough to cover daily expenses.					
2. The material living conditions of my family are very poor.					
3.Child's rehabilitation has caused great financial pressure on my family.					
4. My family has a heavy financial burden.					
5. One of the parents had to quit the job because of childcare.					
6. Purchasing assistive devices (hearing aids, cochlear implants, wheelchairs, etc.) needed by children puts great financial pressure on families.					
7. The child's disability has brought our entire family into a difficult situation.					
8. Child’s problem behaviors disrupt our normal family life.					
9. Child's communication difficulties cause great distress to my family.					
10. Child's emotional problems affect the normal life of the whole family.					
11. Poor self-care ability of the child brings a great burden to my families.					
12. My family is often worried about the child’s safety.					
13. My family is always worried about the child’s future.					
14. We are afraid of being looked down upon by others because of my child’s disability.					
15. We well-understand the types and characteristics of child’s disability.					
16. We try not to miss any lectures and training for parents about children with special needs.					
17. We often read books related to the type of our child's special needs.					
18. We study hard about special education knowledge to help our child.					
19. We are able to use the special education knowledge we have learned to improve our child’s development.					
20. The assistance from government is very helpful to my family.					
21. Mutual help and information sharing among parents has greatly					

helped my family.					
22. We often participate in assessments related to child rehabilitation.					
23. We often participate in the development of my child’s rehabilitation training plans.					
24. We often act as teachers' assistants to assist teachers in my child’s teaching and rehabilitation training.					
25. My child’s teachers or therapists often communicate with us about the child’s difficulties and improvements.					
26. My family can decide where our child will receive rehabilitation training and education.					
27. We can give advice to the professionals about my child’s teaching and rehabilitation.					

This is the end of the questionnaire; please check all the questions again to ensure that there are no omissions, thank you again for your participation and contribution to this research!

Appendix C Informed consent of interview participation

Dear parent/teacher, hello! Thank you very much for your participation in the interview part of the research project entitled Family Quality of Life (FQOL) in Families of Young Children with Special Needs. The purpose of this study is to know the status quo and potential influencing factors of the family life quality in families of children with special needs at young age, to reflect on the implementation of early intervention for children with special needs, and to explore possible strategies to improve their family outcomes. Your participation and contribution in this research are highly appreciated.

Your participation in this study is to do a one-to-one, semi-structured interview with the researcher. It will take about 30-60 minutes. During the interview, you are encouraged to freely express your opinions according to your actual situation. Your identity and the content of your conversation will be kept strictly confidential. You can also terminate the interview at any time. In order to ensure the completeness of the data collection, the conversation content will be recorded during the interview. Besides, the researcher will also take notes during the interview. The collected data will only be used for research after your consent, while the original recording will be destroyed.

I promise not to disclose any information of the interviewee, the interview materials will be used anonymously, and the original recording will be destroyed after the transcription.

________（signature of researcher）

________ (date)

I agree to participate in this interview. I fully understand that the interview will be recorded or taken notes, and I know that the recordings will be destroyed after the notes are sorted out, and personal information will be kept strictly confidential.

________（signature of interviewee）

________ (date)

Appendix D Interview outline

For parents/caregivers

Part one Before the formal interview

- Briefly introduce the research topic and ask for consent
- Ask the basic information of the interviewee(role, age, education level, family location)
- Build atmosphere by asking the participant to introduce his/her child and family

Part two Status quo of the FQOL

- How do you feel about your family life? How satisfied are you for your family life?
- Which aspects are you dissatisfied for? Why?
- Which aspects are you satisfied for? Why?

Part two Influencing parameters of FQOL

- What factors has affected your family life? What bothers you in your family life?
- Does the emergence of child with special needs change your family life? What are the changes? How do you feel about it?
- How is your child's development status? How does it affect your family life?
- How is the relationship of your family members? How is your family members' cooperation?
- What is your family's attitude to your child with special needs?
- How do your family members know about your child's special needs?
- How are the parenting skills of the child with special needs in your family? Your family's mastery of special education knowledge and rehabilitation skills?
- Do you have normal developmental child? How does it affect your family life?
- How is your family financial status? How does it influence your family life?
- How do you family participate in your child's education and rehabilitation? What is the impact to your family life?
- How is the relationship between your family and professionals who work with your child? What is the influence to your family life?
- How is the relationship between your family and relatives/friends/neighbors? How do they help your family? What is the influence to your family life?
- How do you get the relevant information about your child's education and rehabilitation?
- How do you think about the influence of government assistance to your family?
- How do you think about the social atmosphere for individuals with disabilities? What is the influence to your family?

Part three Improving strategies for FQOL

- On which aspects of parenting the child with special needs does your family feel obvious pressure and frustration?
- At present, what are the main difficulties and needs in your family?
- What often bothers you and your family members? What could be done to help your family?
- What could be done to improve your FQOL or increase your satisfaction for your family life?(from aspects of family itself, the child with special needs, professionals, rehabilitation institution, school, government, relatives/friends/community, social environment and so on...)

For professionals

Part one Before the formal interview

- Briefly introduce the research topic and ask for consent
- Ask the basic information of the interviewee(role, age, education level,)
- Build atmosphere by asking the participant to introduce his/her working experience with families of children with special needs

Part two Status quo of the FQOL

- What is the general status of FQOL in families of young children with special needs? (satisfaction of family needs, family member's relationship)
- Which aspects are they usually dissatisfied with? Why?
- Which aspects are they usually satisfied with? Why?

Part three Influencing parameters of FQOL

- What are the main factors affecting their satisfaction for family life? What often bothers these families?
- What are the influences of the child with special needs to his/her family?
- How is the relationship among family members in these families?
- How is the family structure and family cooperation in these families?
- How is the family attitude to the child with special needs?(understanding and acceptance of the child's special needs, expectation for the child, worries and concern related to the child, and so on)
- How are the parenting skills of child with special needs in these families? Their willingness to learn the related knowledge and skills?
- How is these families' recreation time?
- How is these families' financial status? How does it influence their family life?
- How do they participate in child's education and rehabilitation? What is the impact to their family life?
- How is the relationship between these family and professionals? How does it influence their family life?
- How is the relationship between them and their relatives/friends/neighbors? What is the influence to their family life?
- How do they get the relevant information about child's education and rehabilitation?
- How do you think about the influence of government assistance to these families?
- How do you think about the social atmosphere for individuals with disabilities? What is the influence to these families?

Part four Improving strategies for FQOL

- What are the main difficulties and needs in these families? How to help with?
- What could be done to improve the FQOL or increase their satisfaction for family life?(from aspects of family itself, the child with special needs, professionals, rehabilitation institution, school, government, relatives/friends/community, social environment and so on...)

Appendix E Statistics from revision process of the influencing factors questionnaire

Table 4.2 Critical ratio analysis (initial questionnaire)

	Levene's Test for Equality of Variance		t-test for Equality of Means						
	F	Sig.	t	df	Sig.(2-tailed)	Mean Difference	Std.Error Difference	95% Confidence Interval of the Difference	
								Lower	Upper
Y1	.020	.889	3.000	30	.005	1.125	.375	.359	1.891
Y2	1.000	.325	4.392	30	.000	1.500	.342	.802	2.198
Y3	1.097	.303	4.919	30	.000	1.750	.356	1.023	2.477
Y4	7.676	.010	4.105	26.065	.000	1.438	.350	.718	2.157
Y5	2.124	.155	4.376	30	.000	1.750	.400	.933	2.567
Y6	6.930	.013	3.614	27.154	.001	1.375	.381	.594	2.156
Y7	.603	.444	1.762	30	.088	.375	.213	-.060	.810
Y8	.001	.977	.892	30	.379	.313	.350	-.403	1.028
Y9	2.924	.098	1.059	30	.298	.250	.236	-.232	.732
Y10	.712	.406	1.000	30	.325	.250	.250	-.261	.761
Y11	3.284	.080	6.408	30	.000	1.938	.302	1.320	2.555
Y12	.432	.516	6.452	30	.000	1.813	.281	1.239	2.386
Y13	1.622	.213	4.044	30	.000	1.375	.340	.681	2.069
Y14	.221	.642	6.682	30	.000	2.000	.299	1.389	2.611
Y15	2.043	.163	4.105	30	.000	1.438	.350	.722	2.153
Y16	12.318	.001	3.370	18.730	.003	1.125	.334	.426	1.824
Y17	3.378	.076	3.312	30	.002	.875	.264	.335	1.415
Y18	6.922	.013	3.764	27.023	.001	1.313	.349	.597	2.028
Y19	9.199	.005	.946	26.486	.353	.375	.397	-.439	1.189
Y20	5.000	.033	2.727	27.725	.011	1.063	.390	.264	1.861
Y21	.320	.576	-.727	30	.473	-.250	.344	-.952	.452
Y22	.000	1.000	-.690	30	.495	-.125	.181	-.495	.245
Y23	6.618	.015	-3.997	24.254	.000	-1.188	.297	-1.800	-.575
Y24	.727	.400	.504	30	.618	.188	.372	-.572	.947
Y25	13.270	.001	5.811	22.059	.000	1.438	.247	.925	1.950
Y26	.476	.496	1.255	30	.219	.438	.349	-.275	1.150
Y27	8.373	.007	2.573	25.495	.015	.813	.316	.163	1.462
Y28	17.614	.000	3.770	18.798	.001	1.125	.298	.500	1.750
Y29	6.410	.017	3.835	26.001	.001	1.250	.326	.580	1.920
Y30	17.752	.000	4.038	21.048	.000	1.250	.310	.606	1.894

Y31	14.595	.001	5.882	21.029	.000	1.563	.266	1.010	2.115
Y32	17.433	.000	4.160	19.892	.000	.938	.225	.467	1.408
Y33	.639	.430	.642	30	.526	.250	.389	-.545	1.045
Y34	6.752	.014	.000	24.290	1.000	.000	.347	-.715	.715
Y35	5.444	.027	3.576	23.696	.001	1.125	.315	.475	1.775
Y36	2.209	.148	-2.521	30	.017	-.813	.322	-1.471	-.154
Y37	3.805	.060	3.066	30	.005	.938	.306	.313	1.562
Y38	3.561	.069	1.802	30	.082	.625	.347	-.083	1.333
Y39	2.394	.132	3.732	30	.001	1.313	.352	.594	2.031
Y40	2.106	.157	4.726	30	.000	1.625	.344	.923	2.327
Y41	10.052	.003	6.764	22.091	.000	1.688	.249	1.170	2.205
Y42	34.286	.000	4.568	21.434	.000	1.375	.301	.750	2.000
Y43	1.114	.300	3.143	30	.004	1.125	.358	.394	1.856
Y44	6.261	.018	4.109	26.975	.000	1.375	.335	.688	2.062

Table 4.3 Correlation analysis on dimension of economic pressure (D1) (initial questionnaire)

		Y1	Y2	Y3	Y4	Y5	Y6	Total score of D1
Y1	Pearson correlation	1	.709**	.543**	.612**	.213	.360**	.723**
	Sig.(2-tailed)		.000	.000	.000	.101	.005	.000
Y2	Pearson correlation	.709**	1	.757**	.741**	.331**	.484**	.856**
	Sig.(2-tailed)	.000		.000	.000	.010	.000	.000
Y3	Pearson correlation	.543**	.757**	1	.802**	.361**	.559**	.862**
	Sig.(2-tailed)	.000	.000		.000	.005	.000	.000
Y4	Pearson correlation	.612**	.741**	.802**	1	.464**	.534**	.888**
	Sig.(2-tailed)	.000	.000	.000		.000	.000	.000
Y5	Pearson correlation	.213	.331**	.361**	.464**	1	.388**	.612**
	Sig.(2-tailed)	.101	.010	.005	.000		.002	.000
Y6	Pearson correlation	.360**	.484**	.559**	.534**	.388**	1	.716**
	Sig.(2-tailed)	.005	.000	.000	.000	.002		.000
Total score of D1	Pearson correlation	.723**	.856**	.862**	.888**	.612**	.716**	1
	Sig.(2-tailed)	.000	.000	.000	.000	.000	.000	

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

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

Table 4.4 Correlation analysis on dimension of child's difficulties (D2) (initial questionnaire)

		Y11	Y12	Y13	Y14	Y15	Total score of D2
Y11	Pearson correlation	1	.656**	.610**	.575**	.612**	.811**
	Sig.(2-tailed)		.000	.000	.000	.000	.000
Y12	Pearson correlation	.656**	1	.724**	.780**	.641**	.899**
	Sig.(2-tailed)	.000		.000	.000	.000	.000
Y13	Pearson correlation	.610**	.724**	1	.567**	.651**	.837**
	Sig.(2-tailed)	.000	.000		.000	.000	.000
Y14	Pearson correlation	.575**	.780**	.567**	1	.614**	.843**
	Sig.(2-tailed)	.000	.000	.000		.000	.000
Y15	Pearson correlation	.612**	.641**	.651**	.614**	1	.835**
	Sig.(2-tailed)	.000	.000	.000	.000		.000
Total score of D2	Pearson correlation	.811**	.899**	.837**	.843**	.835**	1
	Sig.(2-tailed)	.000	.000	.000	.000	.000	

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

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

Table 4.5 Correlation analysis on dimension of parental attitude (D3) (initial questionnaire)

		Y16	Y17	Y18	Y23	Total score of D3
Y16	Pearson correlation	1	.773**	.543**	-.335**	.861**
	Sig.(2-tailed)		.000	.000	.009	.000
Y17	Pearson correlation	.773**	1	.365**	-.361**	.731**
	Sig.(2-tailed)	.000		.004	.005	.000
Y18	Pearson correlation	.543**	.365**	1	-.434**	.696**
	Sig.(2-tailed)	.000	.004		.001	.000
Y23	Pearson correlation	-.335**	-.361**	-.434**	1	-.040
	Sig.(2-tailed)	.009	.005	.001		.763
Total score of D3	Pearson correlation	.861**	.731**	.696**	-.040	1
	Sig.(2-tailed)	.000	.000	.000	.763	

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

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

Table 4.6 Correlation analysis on dimension of family preparation (D4) (initial questionnaire)

		Y25	Y28	Y29	Y30	Y31	Total score of D4
Y25	Pearson correlation	1	.363**	.418**	.471**	.593**	.725**
	Sig.(2-tailed)		.004	.001	.000	.000	.000
Y28	Pearson correlation	.363**	1	.499**	.456**	.502**	.692**
	Sig.(2-tailed)	.004		.000	.000	.000	.000
Y29	Pearson correlation	.418**	.499**	1	.731**	.625**	.828**
	Sig.(2-tailed)	.001	.000		.000	.000	.000
Y30	Pearson correlation	.471**	.456**	.731**	1	.743**	.855**
	Sig.(2-tailed)	.000	.000	.000		.000	.000
Y31	Pearson correlation	.593**	.502**	.625**	.743**	1	.874**
	Sig.(2-tailed)	.000	.000	.000	.000		.000
Total score of D4	Pearson correlation	.725**	.692**	.828**	.855**	.874**	1
	Sig.(2-tailed)	.000	.000	.000	.000	.000	

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

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

Table 4.7 Correlation analysis on dimension of social support (D5) (initial questionnaire)

		Y32	Y35	Y37	Total score of D5
Y32	Pearson correlation	1	.344**	.160	.672**
	Sig.(2-tailed)		.007	.223	.000
Y35	Pearson correlation	.344**	1	.464**	.837**
	Sig.(2-tailed)	.007		.000	.000
Y37	Pearson correlation	.160	.464**	1	.710**
	Sig.(2-tailed)	.223	.000		.000
Total score of D5	Pearson correlation	.672**	.837**	.710**	1
	Sig.(2-tailed)	.000	.000	.000	

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

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

Table 4.8 Correlation analysis on dimension of family involvement (D6) (initial questionnaire)

		Y39	Y40	Y41	Y42	Y43	Y44	Total score of D6
Y39	Pearson correlation	1	.923**	.581**	.499**	.168	.387**	.780**
	Sig.(2-tailed)		.000	.000	.000	.201	.002	.000

Y40	Pearson correlation	.923**	1	.637**	.499**	.327*	.451**	.841**
	Sig.(2-tailed)	.000		.000	.000	.011	.000	.000
Y41	Pearson correlation	.581**	.637**	1	.604**	.319*	.483**	.783**
	Sig.(2-tailed)	.000	.000		.000	.013	.000	.000
Y42	Pearson correlation	.499**	.499**	.604**	1	.441**	.690**	.796**
	Sig.(2-tailed)	.000	.000	.000		.000	.000	.000
Y43	Pearson correlation	.168	.327*	.319*	.441**	1	.693**	.630**
	Sig.(2-tailed)	.201	.011	.013	.000		.000	.000
Y44	Pearson correlation	.387**	.451**	.483**	.690**	.693**	1	.794**
	Sig.(2-tailed)	.002	.000	.000	.000	.000		.000
Total score of D6	Pearson correlation	.780**	.841**	.783**	.796**	.630**	.794**	1
	Sig.(2-tailed)	.000	.000	.000	.000	.000	.000	

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

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

Table4.11 Cumulative explanatory variance of the six extracted factors

	Initial eigenvalue			Extraction sums of squared loading			Rotation sums of squared loading		
component	eigenvalue	Variance (%)	Cumulative(%)	eigenvalue	Variance (%)	Cumulative(%)	eigenvalue	Variance (%)	Cumulative(%)
1	8.726	31.164	31.164	8.726	31.164	31.164	4.641	16.576	16.576
2	4.744	16.943	48.107	4.744	16.943	48.107	4.159	14.854	31.430
3	2.153	7.690	55.798	2.153	7.690	55.798	3.531	12.610	44.040
4	1.821	6.504	62.302	1.821	6.504	62.302	3.145	11.231	55.271
5	1.508	5.386	67.688	1.508	5.386	67.688	2.587	9.240	64.511
6	1.317	4.704	72.392	1.317	4.704	72.392	2.207	7.881	72.392
7	1.015	3.626	76.019						
8	.925	3.302	79.321						
9	.806	2.880	82.201						
10	.703	2.509	84.711						
11	.560	1.998	86.709						
12	.541	1.931	88.640						
13	.472	1.687	90.326						
14	.383	1.367	91.694						
15	.356	1.270	92.963						
16	.311	1.111	94.075						
17	.254	.907	94.982						
18	.237	.847	95.829						
19	.208	.744	96.573						

20	.196	.701	97.273						
21	.162	.578	97.851						
22	.132	.471	98.322						
23	.122	.436	98.758						
24	.104	.371	99.129						
25	.083	.296	99.425						
26	.073	.261	99.686						
27	.063	.227	99.912						
28	.025	.088	100.000						
Extracting method: principal component analysis.									

Table 4.12 Communality and factor loading of the items in initial questionnaire

Factor	item	Communality	Factor loading	Note
Economic pressure	Y1	0.575	0.688	retained
	Y2	0.803	0.828	retained
	Y3	0.837	0.838	retained
	Y4	0.807	0.855	retained
	Y5	0.547	0.520	retained
	Y6	0.621	0.698	retained
Difficulties Related to child	Y11	0.690	0.658	retained
	Y12	0.792	0.611	retained
	Y13	0.786	0.816	retained
	Y14	0.773	0.504	retained
	Y15	0.689	0.761	retained
Parental attitude	Y16	0.728	0.837	retained
	Y17	0.756	0.832	retained
	Y18	0.562	0.573	retained
Family preparation	Y25	0.607	0.587	retained
	Y28	0.692	0.717	retained
	Y29	0.865	0.848	retained
	Y30	0.832	0.841	retained
	Y31	0.765	0.668	retained
Social support	Y32	0.588	0.723	retained

	Y35	0.729	0.782	retained
	Y37	0.452	0.452	retained
Family involvement	Y39	0.807	0.608	retained
	Y40	0.873	0.604	retained
	Y41	0.741	0.552	retained
	Y42	0.788	0.804	retained
	Y43	0.741	0.689	retained
	Y44	0.823	0.869	retained

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Table 4.13 Summary of reliability test results of the initial questionnaire

	Cronbach's α	Reliability level	Note
Economic pressure	0.864	Very good	
child's difficulties	0.899	Very good	
Parental attitude	0.773	Good	
Family preparation	0.854	Very good	
Social support	0.626	Acceptable	After deletion of Y32
Family involvement	0.726	Good	
Overall questionnaire	0.913	Very good	

Table 4.14 Summary of evaluation indicators of the initial questionnaire

Item in initial scale	Critical value	Correlation	Communalities	Factor loading	Retained/ deleted	Item in formal scale
Y1	3.000	$.723^{**}$	0.575	0.688	retained	y1
Y2	4.392	$.856^{**}$	0.803	0.828	retained	y2
Y3	4.919	$.862^{**}$	0.837	0.838	retained	y3
Y4	4.105	$.888^{**}$	0.807	0.855	retained	y4
Y5	4.376	$.612^{**}$	0.547	0.520	retained	y5
Y6	3.614	$.716^{**}$	0.621	0.698	retained	y6
Y7	1.762	/	/	/	deleted	/
Y8	0.892	/	/	/	deleted	/
Y9	1.059	/	/	/	deleted	/

Y10	1.000	/	/	/	deleted	/
Y11	6.408	.811**	0.690	0.658	retained	y7
Y12	6.452	.899**	0.792	0.611	retained	y8
Y13	4.044	.837**	0.786	0.816	retained	y9
Y14	6.682	.843**	0.773	0.504	retained	y10
Y15	4.105	.835**	0.689	0.761	retained	y11
Y16	3.370	.861**	0.728	0.837	retained	y12
Y17	3.312	.731**	0.756	0.832	retained	y13
Y18	3.764	.696**	0.562	0.573	retained	y14
Y19	0.946	/	/	/	deleted	/
Y20	2.727	/	/	/	deleted	/
Y21	0.727	/	/	/	deleted	/
Y22	0.690	/	/		deleted	/
Y23	3.997	-.040	/	/	deleted	/
Y24	.0504	/	/	/	deleted	/
Y25	5.811	.725**	0.607	0.587	retained	y15
Y26	1.255	/	/	/	deleted	/
Y27	2.573	/	/	/	deleted	/
Y28	3.770	.692**	0.692	0.717	retained	y16
Y29	3.835	.828**	0.865	0.848	retained	y17
Y30	4.038	.855**	0.832	0.841	retained	y18
Y31	5.882	.874**	0.765	0.668	retained	y19
Y32	4.160	.672**	0.723	0.723	deleted	/
Y33	0.642	/	/	/	deleted	/
Y34	0.000	/	/	/	deleted	/
Y35	3.576	.837**	0.782	0.782	retained	y20
Y36	2.521	/	/	/	deleted	/
Y37	3.066	.710**	0.452	0.452	retained	y21
Y38	1.802	/	/	/	deleted	/
Y39	3.732	.780**	0.807	0.608	retained	y22
Y40	4.726	.841**	0.873	0.604	retained	y23
Y41	6.764	.783**	0.741	0.552	retained	y24

Y42	4.568	.796**	0.788	0.804	retained	y25
Y43	3.143	.630**	0.741	0.689	retained	y26
Y44	4.109	.794**	0.823	0.869	retained	y27
Criteria	⩾3.000	⩾.400	≥0.200	≥0.450		

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

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

“Cronbach’s α of economic pressure : 0.864”

“Cronbach’s α of difficulties related to child: 0.899”

“Cronbach’s α of parental attitude: 0.773”

“Cronbach’s α of family preparation : 0.854”

“Cronbach’s α of social support: 0.626(after deletion of Y23)”

“Cronbach’s α of family involvement: 0.726”

“Cronbach’s α of the overall questionnaire : 0.913”

Appendix F Cluster analysis based on coding similarity -jaccard coefficient

Source **A**	Source **B**	Jaccard Coefficient
Internals\\C9	Internals\\C8	0.539568
Internals\\C9	Internals\\C4	0.47541
Internals\\C8	Internals\\C2	0.470149
Internals\\C9	Internals\\C7	0.462121
Internals\\C7	Internals\\C4	0.458333
Internals\\P2	Internals\\C8	0.455128
Internals\\C7	Internals\\C5	0.448819
Internals\\C9	Internals\\C2	0.436508
Internals\\C7	Internals\\C2	0.430894
Internals\\C4	Internals\\C2	0.429825
Internals\\P2	Internals\\P1	0.428571
Internals\\C5	Internals\\C4	0.425
Internals\\P7	Internals\\P6	0.424
Internals\\C9	Internals\\C5	0.421053
Internals\\P7	Internals\\P2	0.417808
Internals\\P6	Internals\\P5	0.415842
Internals\\P6	Internals\\C8	0.414286
Internals\\P2	Internals\\C5	0.412587
Internals\\C8	Internals\\C4	0.410072
Internals\\P4	Internals\\P2	0.409722
Internals\\P3	Internals\\C5	0.408333
Internals\\C3	Internals\\C10	0.403226
Internals\\C4	Internals\\C10	0.401639
Internals\\C7	Internals\\C6	0.4
Internals\\C9	Internals\\C10	0.4
Internals\\P6	Internals\\P1	0.4
Internals\\C4	Internals\\C3	0.398305
Internals\\P7	Internals\\C4	0.396825
Internals\\P5	Internals\\C4	0.39604
Internals\\P7	Internals\\C8	0.390728
Internals\\P6	Internals\\C9	0.389313
Internals\\P2	Internals\\C1	0.388535
Internals\\P2	Internals\\C4	0.388489
Internals\\P5	Internals\\C7	0.387387
Internals\\P7	Internals\\C9	0.385714
Internals\\C5	Internals\\C10	0.384615
Internals\\P7	Internals\\P5	0.383929
Internals\\P6	Internals\\P2	0.382979

Internals\\P6	Internals\\C7	0.382812
Internals\\P2	Internals\\C7	0.38255
Internals\\P2	Internals\\C9	0.379085
Internals\\P5	Internals\\C2	0.378641
Internals\\P1	Internals\\C7	0.376
Internals\\C8	Internals\\C5	0.375839
Internals\\C8	Internals\\C7	0.375
Internals\\P3	Internals\\C10	0.373984
Internals\\P7	Internals\\P1	0.373016
Internals\\P5	Internals\\C9	0.37069
Internals\\C5	Internals\\C1	0.370629
Internals\\P7	Internals\\C5	0.37037
Internals\\P6	Internals\\C4	0.366667
Internals\\P1	Internals\\C6	0.366337
Internals\\P1	Internals\\C12	0.366071
Internals\\C6	Internals\\C2	0.365385
Internals\\P3	Internals\\P2	0.364286
Internals\\P6	Internals\\C2	0.363636
Internals\\P6	Internals\\C10	0.362205
Internals\\P6	Internals\\C6	0.361905
Internals\\P7	Internals\\C10	0.360294
Internals\\C9	Internals\\C6	0.358974
Internals\\C7	Internals\\C3	0.358779
Internals\\C8	Internals\\C10	0.357616
Internals\\C8	Internals\\C12	0.357143
Internals\\P2	Internals\\C2	0.356643
Internals\\C4	Internals\\C12	0.356522
Internals\\P4	Internals\\C8	0.355263
Internals\\C5	Internals\\C2	0.354331
Internals\\C7	Internals\\C10	0.352941
Internals\\P5	Internals\\P1	0.352941
Internals\\C5	Internals\\C12	0.352459
Internals\\P6	Internals\\C5	0.351562
Internals\\C7	Internals\\C1	0.351351
Internals\\P5	Internals\\C5	0.351351
Internals\\P1	Internals\\C8	0.34965
Internals\\C9	Internals\\C1	0.348684
Internals\\P5	Internals\\C6	0.348315
Internals\\P5	Internals\\C11	0.346154
Internals\\P5	Internals\\C8	0.346154
Internals\\P2	Internals\\C12	0.345324

Internals\\P1	Internals\\C10	0.344
Internals\\P1	Internals\\C5	0.344
Internals\\C2	Internals\\C1	0.342857
Internals\\P2	Internals\\C3	0.342466
Internals\\P4	Internals\\C2	0.341085
Internals\\P1	Internals\\C9	0.340909
Internals\\P7	Internals\\C7	0.340426
Internals\\P2	Internals\\C10	0.337748
Internals\\P4	Internals\\C7	0.330935
Internals\\P4	Internals\\P1	0.330709
Internals\\C12	Internals\\C10	0.330645
Internals\\P3	Internals\\C8	0.328767
Internals\\P7	Internals\\P4	0.328571
Internals\\C5	Internals\\C3	0.328244
Internals\\C9	Internals\\C12	0.328244
Internals\\P6	Internals\\P4	0.328244
Internals\\P7	Internals\\P3	0.328244
Internals\\P6	Internals\\P3	0.327869
Internals\\P6	Internals\\C12	0.327731
Internals\\C4	Internals\\C1	0.326241
Internals\\P3	Internals\\C3	0.325203
Internals\\P1	Internals\\C4	0.325
Internals\\P5	Internals\\P3	0.32381
Internals\\C8	Internals\\C1	0.323353
Internals\\P2	Internals\\C6	0.323077
Internals\\P3	Internals\\C4	0.322314
Internals\\C7	Internals\\C12	0.320312
Internals\\C3	Internals\\C1	0.319444
Internals\\P3	Internals\\C9	0.318519
Internals\\C6	Internals\\C4	0.317757
Internals\\P3	Internals\\C12	0.316239
Internals\\C6	Internals\\C5	0.315789
Internals\\C3	Internals\\C12	0.31405
Internals\\P5	Internals\\P2	0.312977
Internals\\C7	Internals\\C11	0.311321
Internals\\P7	Internals\\C2	0.311111
Internals\\P3	Internals\\C7	0.310606
Internals\\P1	Internals\\C11	0.308511
Internals\\C9	Internals\\C3	0.307143
Internals\\P3	Internals\\C11	0.305263
Internals\\C12	Internals\\C11	0.304348

Internals\\C12	Internals\\C1	0.302158
Internals\\P5	Internals\\P4	0.301724
Internals\\P1	Internals\\C2	0.300813
Internals\\P5	Internals\\C12	0.298077
Internals\\C8	Internals\\C6	0.296296
Internals\\C2	Internals\\C10	0.293233
Internals\\P4	Internals\\C9	0.292517
Internals\\P4	Internals\\C6	0.290598
Internals\\P7	Internals\\C1	0.288462
Internals\\P3	Internals\\P1	0.286885
Internals\\P5	Internals\\C1	0.286822
Internals\\C6	Internals\\C12	0.285714
Internals\\P4	Internals\\C4	0.283582
Internals\\C10	Internals\\C1	0.281046
Internals\\P6	Internals\\C11	0.28
Internals\\P4	Internals\\C1	0.279221
Internals\\P7	Internals\\C3	0.278571
Internals\\P1	Internals\\C1	0.277778
Internals\\P6	Internals\\C1	0.277027
Internals\\C2	Internals\\C12	0.276423
Internals\\P4	Internals\\C5	0.274648
Internals\\C9	Internals\\C11	0.274336
Internals\\C4	Internals\\C11	0.272727
Internals\\P4	Internals\\C3	0.268116
Internals\\C8	Internals\\C3	0.267516
Internals\\P6	Internals\\C3	0.265152
Internals\\C3	Internals\\C11	0.264706
Internals\\P5	Internals\\C10	0.260504
Internals\\P3	Internals\\C2	0.257812
Internals\\C3	Internals\\C2	0.257576
Internals\\P4	Internals\\C10	0.256944
Internals\\P1	Internals\\C3	0.255814
Internals\\C6	Internals\\C11	0.25
Internals\\P7	Internals\\C6	0.25
Internals\\C2	Internals\\C11	0.245098
Internals\\P4	Internals\\P3	0.240876
Internals\\C11	Internals\\C10	0.238532
Internals\\C5	Internals\\C11	0.238532
Internals\\P4	Internals\\C11	0.236364
Internals\\P3	Internals\\C1	0.233333
Internals\\P5	Internals\\C3	0.230769

Internals\\P4	Internals\\C12	0.22963
Internals\\C11	Internals\\C1	0.227642
Internals\\P2	Internals\\C11	0.226562
Internals\\P7	Internals\\C12	0.223022
Internals\\C8	Internals\\C11	0.221374
Internals\\C6	Internals\\C1	0.220588
Internals\\C6	Internals\\C10	0.219512
Internals\\P3	Internals\\C6	0.219298
Internals\\P7	Internals\\C11	0.217391
Internals\\C6	Internals\\C3	0.2